A pilot cross-sectional study of colorectal cancer survivors examining their nutritional beliefs, behaviours, and access to dietary care

A thesis presented in partial fulfilment of the requirement for the degree of

Master of Science

in

Nutrition and Dietetics

at Massey University, Auckland, New Zealand

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2024

ABSTRACT

Main Study:

Background: In New Zealand, colorectal cancer (CRC) ranks as the second most common cancer. Over the past three decades, the survival rate of CRC patients in New Zealand has steadily increased. Diet and lifestyle advice affects cancer recovery and the prevention of cancer recurrence. Understanding CRC survivors' current dietary and lifestyle beliefs, behaviours, and advice and support from health services and other sources will identify gaps in service provision.

Aim: To gather preliminary evidence on the sources and quality of dietary and lifestyle advice delivered in community settings according to CRC survivors.

Methods: This study is a pilot cross-sectional study. Participants were sought through convenience sampling. Survivors aged 18 years and older who had been diagnosed with colorectal cancer, received clinical treatment in New Zealand, completed treatment 6 months to 30 months before registration, and resided in the New Zealand community were invited to complete an online questionnaire. Data was collected using the online Qualtrics software. Descriptive statistics were used to examine quantitative data.

Results: In total, six valid responses were received (83.3% female, mean age 50 years). CRC survivors believed in the important role diet and lifestyle changes played in aiding cancer recovery and preventing cancer recurrence. Five major findings were identified: 1) CRC survivors received insufficient dietary and lifestyle advice and ongoing support from healthcare professionals (HCPs), 2) CRC survivors prefer to receive individualised dietary information specific to their health status and symptoms, 3) current practice did not meet the National Institute for Health and Care Excellence (NICE) guidelines recommended for CRC by HCPs, 4) despite awareness of World Cancer Research Fund

International/American Institute for Cancer Research (WCRF/AICR) dietary guidelines among CRC survivors, for some, this did not lead to change in dietary habits, 5) CRC survivors achieved the physical activity levels recommended in guidelines proposed by the U.S Physical Activity Guidelines Advisory Committee.

Conclusion: A structured and systematic approach should be developed to provide dietary and lifestyle information for CRC survivors throughout their cancer trajectory so that they will have a better quality of life and a reduced CRC recurrence.

Sub-study

Please note: Chapter 5 provides a separate stand-alone chapter on a sub-study.

Aim: To gain preliminary insights into the role and resources of HCPs in dietary and lifestyle advice provision and support to CRC survivors in New Zealand.

Method: This study design is a pilot descriptive cross-sectional survey. HCPs aged 18 and older with experience providing care to CRC survivors in the community or government-funded health services were sampled through convenience sampling. Participants were invited to complete an online questionnaire, and data was collected using the online Qualtrics software. Descriptive statistics were used to examine quantitative data.

Results: Six responses (100% female, nurse practitioners, and a cancer support worker) were included in this study. Five major findings were identified: 1) HCPs reported many CRC survivors suffered from complex nutritional problems, 2) all HCPs viewed diet as important for CRC recovery, though their attitudes towards the role of diet in CRC recurrence varied, 3) there is a lack of dietitian access for CRC survivors, 4) there is a variation in providing dietary advice to CRC survivors between HCPs, 5) barriers to information provision include limited access to dietitians, lack of funds, insufficient

educational resources, time constraints, the cost to patients, limited knowledge or training, and absence of dietitian services within the organisations.

Conclusion: The sub-study recognised a potential gap in CRC survivor care and accessibility to dietetic support. These findings highlight a gap in service provision for CRC survivors in advice, support and information on diet and lifestyle.

Acknowledgements

This endeavour would not have been possible without my supervisors, Associate Professor Hugh Senior and Dr Judy Thomas, for their constructive criticism, patience, and guidance throughout this journey. You have shown me a high level of expertise and knowledge, and I learned so much from both of you. I want to express my deepest gratitude for the weekend meetings and the time that you spent with me to help me achieve my greatest potential and complete the thesis.

I am also grateful to the participants (CRC survivors, HCPs, and participants in the evaluation test) who spent time completing the questionnaires to make this research journey smoother. Without your support and help, I would not have completed my thesis.

I'd like to acknowledge my parents (Zhiyong and Yiping), who were there for me every day and supported me mentally all the way from China. I would not have completed this research journey without your constant encouragement. To Kyle, thank you for supporting me during the endless nights, constantly reminding me that I can do this, and taking me to the weekend adventures so that I feel less stressed about the thesis.

Thanks should also go to my fellow dietetic classmates who have supported me and heard all my complaints over the past two years. I wish you all the best with your future career.

I will dedicate the below section to Mum and Dad, hence writing in Chinese.

妈妈、爸爸，我能专心的完成这篇论文，你们给了我很大的帮助，让我可以不用为生计烦恼。妈妈，谢谢你总是聆听我的烦恼，给我尽可能的提供情绪价值。如果没有那些视频电话排解我的心情，我的论文不可能那么顺利。爸爸，谢谢你总是尽你所能的给我提出解决办法，让我可以在不知所措的情况下找到方法应对困难。最后，谢谢你们对我一如既往的支持。没有你们，我不可能取得今天的成就。我爱你们。

TABLE OF CONTENTS

CHAPTER 1. INTRODUCTION 12

1.1 BACKGROUND 12

1.2 CONTRIBUTORS OF THIS STUDY 14

1.3 AIMS AND OBJECTIVES 15

1.3.1 Aim 15

1.3.1 Objectives 15

1.4 THESIS STRUCTURE 15

CHAPTER 2. LITERATURE REVIEW 16

2.1 CLINICAL DEFINITION AND CHARACTERISTICS OF COLORECTAL CANCER 16

2.1.1 Definition of Colorectal Cancer 16

2.1.2 Staging of Colorectal Cancer 16

2.1.3 Screening of Colorectal Cancer 17

2.2 CONSEQUENCES OF COLORECTAL CANCER FOR SURVIVORS 18

2.2.1 Physical Consequences 18

2.2.2 Psychosocial Consequences 19

2.2.3 Economic Consequences 19

2.2.4 Health-Related Quality of Life Consequences 20

2.3 EPIDEMIOLOGY OF COLORECTAL CANCER 20

2.3.1 Prevalence of Colorectal Cancer 20

2.3.2 Global and National Trends in the Incidence Rates of colorectal cancer 21

2.4 RISK FACTORS OF COLORECTAL CANCER 22

2.4.1 Dietary Fibre 22

2.4.2 Red and Processed Meat 23

2.4.3 Obesity (High BMI) 23

2.4.4 Alcohol 24

2.4.5 Smoking 25

2.4.6 Physical activity 25

2.5 GUIDELINE RECOMMENDATIONS 26

2.5.1 Guideline Recommendations on Diet for Cancer Survivors 26

2.5.2 Body Mass Index 27

2.5.3 Physical Activity 28

2.6 CANCER SURVIVORSHIP AND SUPPORTIVE CARE 28

2.6.1 Cancer Survivorship 28

2.7 ROLE OF HEALTH PROFESSIONALS AND NGOS IN CANCER SURVIVORSHIP 29

2.8 BELIEFS AND BEHAVIOURS OF COLORECTAL CANCER SURVIVORS 30

2.8.1 Nutritional Beliefs of Colorectal Cancer Survivors *30*
2.8.2 Lifestyle Behaviours of Cancer Survivors *31*
2.9 INFORMATION NEEDS AND INFORMATION SOURCES 34
2.9.1 Colorectal Cancer Survivors' Information Needs *34*
2.9.2 Health Communication and Promotion *35*
2.9.3 Sources of Information *35*
2.10 INFORMATION SEEKING BEHAVIOURS 38
2.10.1 Barriers to information provision *39*
2.11 IMPORTANCE OF THE STUDY AND THE GAPS IN RESEARCH IN NEW ZEALAND 40

CHAPTER 3. RESEARCH MANUSCRIPT 43

3.1 ABSTRACT 43
3.2 INTRODUCTION 44
3.3 METHODS 47
3.4 RESULTS 50
3.4.1 Participant Demographic Characteristics *50*
3.4.2 Health Status and Medical History *51*
3.4.3 Nutrition problems in the last 6 months *55*
3.4.4 Nutritional Advice and Support *55*
3.4.5 Dietary Information Needs and Beliefs *58*
3.4.6 Knowledge of WCRF/AICR Dietary Recommendations *59*
3.4.7 Dietary Habits and Changes Post-treatment *59*
3.4.8 Provision of Advice on Physical Activity *62*
3.5 DISCUSSION 64
3.6 CONCLUSION 70

CHAPTER 4. CONCLUSION AND RECOMMENDATIONS 71

4.1 STUDY SUMMARY 71
4.2 STUDY STRENGTHS AND LIMITATIONS 73
4.3 RECOMMENDATIONS FOR CLINICAL PRACTICE 74
4.4 RECOMMENDATIONS FOR FUTURE RESEARCH 75

CHAPTER 5. A PILOT CROSS-SECTIONAL STUDY EXAMINING THE DIETARY AND LIFESTYLE GUIDANCE PROVIDED BY NURSE PRACTITIONERS AND CANCER SUPPORT WORKERS IN NEW ZEALAND 76

5.1 INTRODUCTION 76
5.2 METHODS 77
5.3 RESULTS 79
5.4 DISCUSSION 92

5.5 CONCLUSION 96

CHAPTER 6. APPENDICES 107

6.1 Appendix A.1: Advertisement to recruit colorectal cancer survivors 107

6.2 Appendix A.2: Advertisement to recruit healthcare professionals 108

6.3 Appendix A.3: Author instructions NZMJ 109

6.4 Appendix C.1 Registration Form and Informed Consent Form of Colorectal Cancer Survivor Survey 112

6.5 Appendix C.2 Colorectal Cancer Survivor Questionnaire 119

6.6 Appendix C.3 Healthcare Professional Questionnaire 136

List of Tables

Table 2.1 TNM staging system 17

Table 3.1 Summary of the demographic characteristics of the respondents to the survey 51

Table 3.2 Health status and medical history of the respondents 53

Table 3.3 Nutritional information provision during and after treatment 56

Table 3.4 Nutritional information provision from healthcare professionals 57

Table 3.5 Dietary information needs and beliefs on the importance of diet in recovery and recurrent 58

Table 3.6 Post-treatment dietary habits 60

Table 3.7 Post-treatment Dietary Changes 61

Table 3.8 Physical activity information provision and information needs 63

Table 3.9 Physical activity status and sedentary behaviours of colorectal cancer survivors 63

Table 5.1 Summary of the demographic characteristics of the healthcare professionals 79

Table 5.2 Nutrition assessment by healthcare professionals 80

Table 5.3 Healthcare professionals' beliefs about the role of nutrition on colorectal cancer recovery and recurrence 81

Table 5.4 Management strategies by healthcare professionals 82

Table 5.5 Healthcare professionals' recommended timing to dietary and physical activity information provision during cancer trajectory 84

Table 5.6 Information provision and patient needs 85

Table 5.7 Confidence in providing dietary advice and training 86

Table 5.8 Dietary resources provided to CRC patients by organisations 87

Table 5.9 Provision of WCRF/AICR recommendations to colorectal cancer survivors 89

Table 5.10 Healthcare professionals perceived barriers to information provision, screening needs, and improvement in the referral process to a dietitian 90

Table 5.11 Primary role in providing nutritional advice to a colorectal survivor 92

List of Figures

Figure 2.1 Recommendations of the World Cancer Research Fund International guideline 27

Figure 3.1 Nutrition issue in last 6 months 55

Figure 5.1 Nutrition issues that colorectal cancer survivors experience 84

Figure 5.2 Perceived barriers to information provision 91

List of Abbreviations

Abbreviation	Definition
ACS	American Cancer Society
ADL	Activities of daily living
BMI	Body mass index
CI	Confidence incidence
CRC	Colorectal cancer
DALY	Disability-adjusted life year
DHB	District health board
FIT	Faecal immunochemical test
GLOBOCAN	Global Cancer Observatory
GP	General practitioner
HCP	Healthcare professional
HRQoL	Health-related quality of life
ICD-10	International Statistical Classification of Diseases 10th version Code
IL-1	Interleukin-1
IL-6	Interleukin-6
IL-7	Interleukin-7
IL-8	Interleukin-8
IOM	Institute of Medicine
IPAQ	International Physical Activity Questionnaire
IRAC	International Agency for Research on Cancer
MUST	Malnutrition Universal Screening Tool
NBSP	New Zealand Bowel Screening Programme
NGO	Non-governmental organisation
NICE	National Institute for Health and Care Excellence
NZNO	New Zealand Nursing Organisation
PA	Physical activity
PAF	Population attributable fraction
RD	Registered dietitian

RR	Relative ratio
TNF-α	Tumour necrosis factor
TNM	Tumour, node, metastasis classification
UICC	Union for International Cancer Control
USA	United States of America
WC	Waist circumference
WCRF/AICR	World Cancer Research Fund International/American Institute for Cancer Research
WHO	World Health Organisation
WHR	Waist to hip ratio
YLD	Years lived with disability
YLL	Years of life lost

CHAPTER 1. INTRODUCTION

1.1 BACKGROUND

In New Zealand, CRC is the second most prevalent cancer (1, 2). According to Te Whatu Ora Health New Zealand, in 2021, there were 27,867 new cancer registrations. Of these, over 3300 were new CRC cases (11.8%) (3). More CRC patients have survived in recent decades due to early cancer detection through screening programmes, which has allowed cancer to be detected at earlier stages facilitating earlier treatment and survival (4). Additionally, improvements in cancer treatment, such as chemotherapy, surgery, and radiation therapy, have increased CRC patient survival rate (5).

Although many CRC patients survive after a diagnosis, they experience significant physical impacts from the disease and the treatment, including changes in bowel movements, intestinal cramps, reduced appetite, and unintentional weight gain or loss (6, 7, 8), all of which impact CRC survivors well-being and quality of life. Further, preventing cancer recurrence is important for CRC survivors to increase survival. Diet and lifestyle play a critical role in aiding cancer recovery and preventing cancer recurrence. The World Cancer Research Fund and the American Institute for Cancer Research (WCRF/AICR) guidelines recommend maintaining a healthy weight, being physically active, consuming whole grains, consuming dairy products, consuming high-fibre-containing foods, reducing intake of red meat, processed meat, and alcohol (9). A randomised controlled trial (n=223) conducted in Hong Kong found that adherence to a diet that reduced red and processed meat intake and limited refined grains intake promoted generic and CRC-specific health-related quality of life (10). A Netherlands cross-sectional study (n=155) found a higher adherence to WCRF/AICR recommendations was associated with better physical functioning and less fatigue in CRC survivors (11).

In order to change behaviour for the adoption of the WCRF/AICR guideline recommendations in daily life, quality dietary and lifestyle education and information needs to be provided by healthcare professionals and organisations to influence beliefs and guide behavioural changes (12). CRC survivors seek health information from trustworthy sources (13, 14, 15). The common trusted sources of dietary and lifestyle advice and information are from general practitioners (GPs), nurses, dietitians, allied HCPs, oncologists and cancer-related non-governmental organisations (NGOs).

In a recent New Zealand study, Peniamina et al. (2021) identified that CRC patients had a gap in knowledge of the importance of nutrition for recovery and to prevent cancer recurrence, and that this impacted their beliefs on the role of diet and lifestyle changes (12). In another New Zealand hospital-based cross-sectional study, CRC patients reported they were prepared to make dietary changes following diagnosis and treatment (16). Yet, they reported their information needs were unmet to provide them with the tools to make the change (16). It is essential that these unmet advisory and informational needs are addressed to allow CRC survivors to be equipped with the knowledge and skills to make healthy changes in behaviour.

Currently, there is a scarcity of well-conducted research into the dietary and lifestyle information that CRC survivors receive from HCPs in New Zealand. This pilot cross-sectional study will gather preliminary evidence on the sources and quality of dietary and lifestyle advice delivered in community settings according to CRC survivors, and the level of compliance with the WCRF/AICR recommendations. In addition, this pilot will test recruitment and data collection methods for a proposed representative cross-sectional study.

Please note: Chapter 5 provides a **separate stand-alone chapter** with its own aims and objectives on a sub-study that explores the role of HCPs, the ideal and actual dietary and lifestyle information provision, and identifies the gaps and barriers to information provision and support.

1.2 CONTRIBUTORS OF THIS STUDY

Researcher	Contributions
Danlu Cao	Student researcher: Researched and prepared literature review, recruited participants, designed questionnaire and its evaluation, set up Qualtrics software, data analysis, developed healthcare professionals' sub-study, interpreted results, authored research manuscripts and thesis manuscript.
Assoc. Prof. Hugh Senior	Academic supervisor: Designed study, assisted with the structure of literature review and research manuscripts, interpretation of results, revised and approved thesis manuscript.
Dr Judy Thomas	Academic co-supervisor: Designed study, interpretation of results, revised and approved research and thesis manuscripts.

1.3 AIMS AND OBJECTIVES

1.3.1 Aim

This study aims to gather preliminary results on the nutritional beliefs, behaviours, and access to dietary and lifestyle information of CRC survivors in New Zealand, as well as to inform a larger study.

1.3.1 Objectives

1. To explore information provision provided by HCPs to CRC survivors
2. To explore the perceived role of diet and physical activity in cancer recovery and recurrence among CRC survivors
3. To explore dietary habits and changes in diet and lifestyle after CRC diagnosis and treatment
4. To explore the physical activity status in CRC survivors

1.4 THESIS STRUCTURE

This research is divided into five chapters. **Chapter 1** outlines an overview of this study and the significance of conducting it, and the aims and objectives. **Chapter 2** provides a comprehensive literature review on clinical definitions and characteristics of CRC, consequences of having CRC, epidemiology and risk factors of CRC, guidelines for CRC survival and prevention, cancer survivorship, beliefs and behaviours of CRC survivors, information needs and sources, information seeking behaviours, and study rationale and gaps in research. **Chapter 3** consists of a research manuscript including an abstract, introduction, methods, results, discussion, and conclusion. The research manuscript is targeted for publication in the New Zealand Medical Journal. See **Appendix A.3** for author guidelines. **Chapter 4** outlines a summary of the main study, including strengths, limitations, and suggested recommendations. **Chapter 5** provides a ***separate stand-alone*** chapter on a quantitative sub-study that assesses the quality and the content of dietary and lifestyle information advised by HCPs in New Zealand for CRC survivors.

CHAPTER 2. LITERATURE REVIEW

This literature review is divided into seven sections. Section 1 discusses a clinical definition and characteristics of CRC. Section 2 describes the consequences of CRC for survivors, including the impact on physical and psychosocial, economic, and health-related quality of life. Section 3 outlines the current epidemiology and risk factors of CRC. Section 4 discusses current guideline recommendations on cancer prevention and lifestyle management. Section 5 discusses cancer survivorship, and the specific roles of healthcare professionals and non-governmental organisations. Section 6 explores the beliefs and behaviours of CRC survivors. Section 7 discusses the information needs and sources for CRC survivors. Section 8 outlines information seeking behaviours, including barriers to sourcing quality information. Finally, section 9 outlines a rationale for this study.

2.1 CLINICAL DEFINITION AND CHARACTERISTICS OF COLORECTAL CANCER

2.1.1 Definition of Colorectal Cancer

The International Statistical Classification of Diseases 10th version code (ICD-10) classifies CRC as malignant cancers that develop in the colon (C18), the rectosigmoid junction (C19), and the rectum (C20) (17, 18). CRC is also known as bowel cancer.

2.1.2 Staging of Colorectal Cancer

Staging is a means of classifying malignant tumour growth and metastases in an individual's colon/rectum. This informs HCPs about the severity of the CRC and is instrumental in the development of a treatment plan.

The American Joint Cancer Committee and Union for International Cancer Control (UICC) created a tumour, node, metastasis (TNM) classification system to define the staging of CRC. The size of the primary tumour in its initial stage is depicted by T, N describes the

level of involvement of the regional lymph nodes, and M denotes whether distant metastasis is present or absent (19, 20). Additionally, the numbers indicate the size of the primary tumour and the extent of metastasis (21). Table 2.1 illustrates TNM clinical classification.

Table 2.1 TNM staging system

T – Primary Tumour	
Tx	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Tis	Carcinoma in situ
T1-T4	Increasing size and/or local extent of the primary tumour
N – Reginal Lymph Nodes	
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1-N3	Increasing involvement of regional lymph nodes
M – Distant Metastasis	
M0	No distant metastasis
M1	Distant metastasis

Source: Sobin 2011

2.1.3 Screening of Colorectal Cancer

Screening has contributed significantly to lowering the risk of mortality and increasing survivorship in comparison to patients who are not screened (22, 23). Preventative polypectomy lowers the risk of CRC, or the detection of CRC at an earlier stage, which increases the chance of curative treatment and survivorship (22, 23).

A publicly funded New Zealand National Bowel Screening Programme (NBSP) is offered every two years to individuals aged 60 to 74 years. To address health inequities, Māori and Pasifika peoples are invited to participate in the programme at the age of 50 years (24). The faecal immunochemical test (FIT) detects occult blood in stools that may be sourced from pre-cancerous polyps or malignant tumours of the gut (25). A referral for a colonoscopy occurs in the event of a positive FIT test (25). Colonoscopy is used for

diagnosis and the polypectomy of pre-cancerous polyps to reduce the risk of colorectal cancer (26, 27, 28).

2.2 CONSEQUENCES OF COLORECTAL CANCER FOR SURVIVORS

Colorectal cancer patients experience significant physical, psychosocial, economic and health-related quality of life (HRQoL) consequences from both the disease and treatment. These may include a deterioration in physical condition, depression, anxiety, fear of recurrence, sexual dysfunction, loss of income and medical costs, and impacts on overall HRQoL. These impacts are described in detail below.

2.2.1 Physical Consequences

Colorectal cancer treatment includes chemotherapy, radiotherapy and surgery. CRC survivors suffer from significant deterioration in overall physical health after these treatments. Bodily pain, sleep disturbance, fatigue, nausea, vomiting and inactivity are side effects correlated with surgery (29). Additionally, anorexia, fatigue, lethargy, nausea, pain and peripheral neuropathy are prevalent post-chemotherapy and post-radiotherapy treatment (29). A population-based case-control study on older adults with CRC (stage III and IV) in the USA showed a reduction in activities of daily living (ADL) occurred within six months post-treatment (30). Quach et al. (2015) also reported that CRC patients had a higher number of ADL impairments at two-years post-treatment compared to controls (1.25 vs 1.06; P = .02). ADL assessment is a measurement of an individual's functional status, and it includes showering, dressing, eating, toileting, walking and transferring (31). A systematic review with 11,817 patients reported similar findings that physical and functional declines are seen in CRC patients within six-month post-treatment (29).

The overall disease burden of CRC is measured using the disability-adjusted life year (DALY). DALY is a time-bound measure combining years of life lost due to premature mortality (YLLs) and years lived with disability (YLDs) (32). Concerningly, the Global Burden of Disease study found that CRC was responsible for 19 million (18.5 – 19.5) DALYs in 2017, with an age-standardised rate of 235.7 DALYs per 100,000 person-years

(33). In New Zealand, a prospective study identified that the proportion of estimated DALY burden for CRC compared to all cancers was 12.9% for females and 13.5% for males. Māori people had lower DALY age-standardised rates for CRC when compared with non-Māori for both sexes (34).

2.2.2 Psychosocial Consequences

Colorectal cancer survivors suffer from changes in psychosocial well-being. A greater proportion of CRC patients are at risk of major depressive disorder compared with a propensity-scores matched control group (30). Additionally, Cotrim & Pereira (2008) in a cross-sectional survey reported that CRC survivors with stoma often experienced greater psychological morbidity than survivors without stoma. Stoma impacted social life, sexuality, quality of life, body image, and led to higher levels of depression and anxiety which affect their emotional and mental health (35).

2.2.3 Economic Consequences

Financial strain and stress post-diagnosis are common in CRC survivors. A cross-sectional study conducted in Ireland reported that 41% of CRC survivors experienced cancer-related financial stress, 39% had cancer-related financial strain, and 32% suffered from both (36). Cancer-related financial expenses included travel and parking for hospital appointments, costs of treatment and surgery, increased household bills, and costs of new clothes (36). Cancer treatment impacts both individual and family income due to the patient's inability to work or caregivers' need to forgo or reduce employment to provide care (37). Furthermore, the emotional impacts on CRC survivors and their families are usually associated with economic consequences. A narrative qualitative study found that the financial burden experienced by CRC survivors influences emotional well-being (37).

2.2.4 Health-Related Quality of Life Consequences

Health-related quality of life (HRQoL) is the impact of disease and treatment on overall function and the physical, psychological, and social domains of well-being (38, 39). The impact of CRC on physical functioning and ADLs, and psychosocial functioning including the ability to engage in social participation and employment directly impacts HRQoL in survivors (36, 40). A prospective observational cohort study (n= 2531) in Spain found that CRC survivors were more likely to have a lower HRQoL if their quality of life was lower before treatment, were female, had co-morbidities, had experienced complications, had a family history of CRC, and had received chemotherapy (41).

2.3 EPIDEMIOLOGY OF COLORECTAL CANCER

This section will describe the prevalence, trends and risk factors of colorectal cancer.

2.3.1 Prevalence of Colorectal Cancer

The International Agency for Research on Cancer (IRAC) and the World Health Organisation (WHO) published the updated Global Cancer Observatory (GLOBOCAN) estimates of global incidence and mortality in 2022 (42). Colorectal cancer is the third most frequent cancer and the second leading cause of cancer deaths for both sexes (42). The estimated five-year prevalence of CRC, namely the number of patients diagnosed and alive over five years, is over 5.7 million people worldwide (42). Overall, an estimated 1.9 million new cases of CRC and over 900,000 deaths occurred globally (42). Further, age-standardised incidence rates of CRC are 12.4% for colon cancer and 9.1% for rectal cancer in males. In females, the rate is lower at 9.2% and 5.4%, respectively. The age-standardised mortality of colon and rectal cancer for females (4.0% and 2.3%) is also lower than for males (5.5% and 4.1%) (42). Compared to other nations, GLOBOCAN 2022 (42) reported that Western nations, including Europe, Australia/New Zealand, and North America, have a higher age-standardised incidence rate compared to other nations for both colon and rectal cancer. In contrast, both age-standardised colon and rectal cancer incidence rates are lower in Africa, and South and Central Asia (42).

In New Zealand, CRC is the second most common cancer (1, 2). According to Te Whatu Ora Health New Zealand (3) in 2021, there were 27,869 new cancer registrations with over 3,300 cases (11.8%) being CRC (male 1806, female 1562).

In New Zealand, the age-standardised incidence rate in 2021 (using the WHO standard World Population) of CRC was 43.8 per 100,000 for men and 34.6 per 100,000 for women (3). The age-standardised rate of CRC was 44.2 per 100,000 for Māori males and 32.4 per 100,000 for Māori females. Whereas the age-standardised rate (World) of CRC was 43.9 per 100,000 for non-Māori males and 32.4 per 100,000 for non-Māori females. Although Māori people were less frequently diagnosed with CRC than non-Māori people, their age-standardised incidence rate was similar to non-Māori for both genders.

Nationally, the number of deaths from CRC is the third highest among total cancers for men (644 cases) and the second highest for women (662 cases) (3) In New Zealand, a retrospective study found that the overall five-year survival rate for all ethnicities was 51% (95% CI: 50–53%), 42% (95% CI: 35–48%) for Māori group, 37% (95% CI: 26–50%) for Pasifika group and 51% (95% CI: 50–52%) for non-Māori-non-Pasifika (43). The overall five-year mortality rate was 37.8% (95% CI: 36.4–39.1%), 58.6% (95% CI: 44.9–70.0%) for Pasifika patients, 47.4% (95% CI: 40.4–53.9%) for Māori patients, and 37.8% (95% CI: 36.3–39.2%) for non-Māori-non-Pasifika people (43).

2.3.2 Global and National Trends in the Incidence Rates of colorectal cancer

High-income countries have recorded a stabilising and declining trend of CRC incidence for all ages combined in the past decades (42). The decreasing trend of CRC incidence in developed countries is due to the initiation of screening programmes which have allowed early detection and removal of pre-cancerous polyps during colonoscopy (42). Further, health education of populations has led to the transition to healthier diets, which included increased fibre intake (42).

However, the CRC incidence in young adults (≤ 50 years old) is increasing in high-income countries, including the USA, Canada, and Australia (42, 44). This is likely to be the result of early exposure to risk factors, such as reduced physical activity, obesity and early

exposure to antibiotics (45). In middle and low-income countries, the trend of CRC incidence is increasing because of the increase in the adoption of Westernised diets (44).

Despite its higher prevalence in New Zealand, the incidence rate of colorectal cancer has a decreasing trend over the past 20 years. An observational study studied the trend of CRC in the past two decades (2000-2020). They found there was no significant change in the crude incidence of CRC, but there was a significant reduction in age-standardised incidence, from 61.0 per 100,000 to 47.3 per 100,000, reflecting the ageing of the population (2). For Māori people, the incidence of CRC has been increasing, with a rise of 28% per decade (IRR 1.28, p=<0.0005) (2). This increase has largely been attributed to an increase in the incidence rate among Māori aged under 50 years (2).

2.4 RISK FACTORS OF COLORECTAL CANCER

Colorectal cancer is associated with multiple risk factors, including the non-modifiable risk factors of genetics, age and sex, and the modifiable risk factors of lifestyle and diet. In the following section, the modifiable risk factors are discussed.

2.4.1 Dietary Fibre

Mechanisms by which dietary fibre conveys protection against CRC are complex and not clearly understood. Fibre from grains, fruit, and vegetables may result in a healthier bacterial microflora in the colon, and promote faster colonic transit time (46), shortening the time of exposure to carcinogens (Rawla et al., 2019). Additionally, high-fibre-content foods usually contain high levels of antioxidants, vitamins and flavonoids, which are potentially beneficial for CRC prevention (46). Dietary fibre is accompanied by a low energy-dense diet, and lowers intake of high glycaemic foods, glycaemic load and fats, thereby reducing the risk of obesity (47).

Dietary fibre intake, often found in vegetables, fruit and whole grains, is known for its inverse relationship with colorectal cancer risk (46, 48, 49). However, there is a paucity of evidence as to which fibre sources provide the most benefit in lowering CRC risk. A

dose-response meta-analysis of ten prospective cohort studies on the relationship of different fibre sources in the risk of CRC demonstrated that all fibre sources (cereals, vegetables, fruits, legumes) may provide some benefits, with grains/cereals having the most significant effect (RR 0·89, 95 % CI 0·80, 0·99) in lowering CRC risk (48).

2.4.2 Red and Processed Meat

Carcinogenesis in the gut due to red meat and processed meat may be promoted by the heme iron, nitrites, nitrates and mutagenic compounds acting locally on the mucosa layer in the gut (50).

A recent systematic review and meta-analysis of 148 prospective studies found that red meat intake significantly correlated with a higher risk of colon cancer (RR = 1.17; 95% CI: 1.09-1.25) and rectal cancer (RR = 1.22; 95% CI: 1.01-1.46). For processed meats (including bacon, sausages, salami, hot dogs, or processed turkey), consumption was associated with an 18% greater colorectal cancer risk, a 21% greater colon cancer risk, and a 22% greater rectal cancer risk (51). In another systematic review of prospective studies, similar results were reported. Two servings per day of red meat and four servings per day of processed meat consumption were associated with a 1.8-fold risk elevation of CRC (52).

2.4.3 Obesity (High BMI)

How carcinogenesis is developed in overweight/obese people is not fully understood. Proposed mechanisms include the influence of increased adipose tissue mass on adipose hormones, levels of circulating leptin, resistin, TNF-α, IL-1, IL-6, IL-7 and IL-8 and their effect on the metabolism of epithelial cells such as increasing oxidative stress, mitogenic effects, inhibiting apoptosis of cells, among others (53).

High body mass index (BMI) positively correlates with increasing the risk of developing colorectal cancer (54, 55). BMI is an anthropometric measure usually used to define overweight and obesity, overweight is a BMI greater than or equal to 25kg/m^2, and obesity is a BMI greater than or equal to 30kg/m^2 (56). Epidemiological evidence indicates that

obesity is linked with a 30 - 70% higher risk of colon cancer in men, while the correlation is less consistent in women (57). This difference in risk ratio may be due to more visceral fat accumulation in men (57). Visceral adipocytes are known to be more metabolically active due to the release of inflammatory cytokines, which increase the risk of chronic diseases (58).

Systematic reviews of observational studies elucidated the positive association between body weight gain and increased CRC incidence risk (59, 60). Abar and colleagues (59) found risk ratios were 1.02 (95% CI: 1.01–1.02) per 5 kg increase in weight, 1.06 (95% CI: 1.04–1.07) per 5kg/m^2 elevation in body mass index (BMI), 1.02 (95% CI: 1.02–1.03) per 10cm increase in waist circumferences (WC) and 1.03 (95% CI: 1.01–1.05) per 0.1 unit increase in waist to hip ratio (WHR). They also found a stronger correlation between BMI and CRC aetiology in men than women (59).

2.4.4 Alcohol

Many mechanisms have been suggested as to the means by which alcohol may promote colorectal carcinogenesis (54), including metabolites of ethanol metabolism such as acetaldehyde having carcinogenic effects in the gut (61). Further, the formation of these metabolites may be augmented by changes in the colon microbiota or similar (61). Metabolites such as acetaldehyde accelerate DNA-adduct formation, oxidative stress, lipid peroxidation, epigenetic alterations, dysfunction in epithelial barriers and immune modulatory effects (61).

A positive association has been shown between increased CRC risk and alcohol consumption (62, 63, 64). A meta-analysis of cohort studies and case-control studies found the relative risks (RRs) of developing CRC were 1.21 (95% CI: 1.13–1.28) for moderate drinking (2-3 drinks per day) and 1.52 (95% CI:1.27–1.81) for heavy drinking (greater than or equal to 4 drinks per day) (62).

Several systematic reviews and meta-analyses of epidemiological studies reported a dose-dependent J-shaped relationship between CRC risk and alcohol drinking (62, 63, 64). The WCRF policy position statement is that for cancer prevention, it is best not to consume alcohol.

A New Zealand study estimated the population attributable fraction (PAF, the fraction of disease cases in a population attributable to a specific exposure) between hazardous alcohol consumption and CRC risk was 7%. The PAF varied by ethnicity and sex, with a PAF of 14% for Māori men and 9% for European men (65).

2.4.5 Smoking

Cigarette smoking is significantly associated with increasing the risks of growing polyps, the precursor to CRC (66). The metabolites of nicotine, such as hydroxycotinine and cotinine, are greatly associated with elevated CRC risk (67). An additional possible aetiology of CRC due to smoking is that tobacco products aid cancer growth by angiogenesis induction and inhibition of cell-mediated immunity (68).

A case-control study found that current smoking was significantly correlated with the risk of distal more than proximal polyps, and with serrated-polyps rather than adenomas (66).

Smoking duration, colorectal polyps and CRC risk has a dose-dependent relationship (66, 69). A systematic review and meta-analysis of 188 epidemiological studies reported that the RR for CRC incidence was 1.14 (95% CI: 1.10 – 1.18) for current smokers, and 1.17 (95% CI: 1.15-1.20) for former smokers (69). A linear relationship was observed between elevated CRC incidence risk, and intensity and duration of smoking (69)

2.4.6 Physical activity

Physical activity reduces body adipose tissue which establishes beneficial effects on decreasing CRC risk; this is potentially due to the decline of insulin resistance and inflammation, which correlate with CRC development (70). However, it remains uncertain whether physical activity without weight loss has a notable effect on these pathways (9). Another mechanism of physical activity's positive impact on reducing CRC risk is promoting digestion and shortening of gastrointestinal transit time reducing time for toxins to be exposed to epithelial tissue (71).

Physical activity decreases the risk of CRC incidence. A Netherland case-study embedded in a cohort study (n=7,601) reported that recreational physical activity

reduced CRC risk (72). A large multi-centre European cohort study (n=347,237) showed high physical activity levels combined with other lifestyle factors lowered CRC incidence (73).

2.5 GUIDELINE RECOMMENDATIONS

Health organisations have recommended evidence-based guidelines on diet and lifestyle for the prevention and management of colorectal cancer.

2.5.1 Guideline Recommendations on Diet for Cancer Survivors

To lower the risk of CRC, whole grains, vegetables, fruit, and legumes are recommended to be a major part of the daily diet. The WCRF/AICR states there is strong evidence that consuming dietary fibre-containing food, in particular wholegrain, decreases CRC risk, and consuming red meat, processed meat, and alcoholic beverages increases CRC risk (74, 75). See Figure 2.1.

- The guideline recommends that individuals consume a diet that provides at least 30g per day of fibre from food, including foods containing wholegrains, non-starchy vegetables, fruit and pulses (legumes) such as beans and lentils in most meals
- Eat a diet high in all types of plant foods, including at least five portions or servings (at least 400g or 15oz in total) of a variety of non-starchy vegetables and fruit every day, (If a person eats starchy roots and tubers as staple foods, they should eat non-starchy vegetables, fruit and pulses (legumes) regularly too if possible)
- Red meat consumption of no more than 3 portions per week (approximately 350-500g cooked red meat), very little processed meat, and no alcohol intake (76).
- Do not consume sugar-sweetened drinks
- For cancer prevention, it is best not to drink alcohol (If a person wishes to consume alcoholic drinks, they should not exceed national guidelines).

- Limit consumption of processed foods high in fat, starches or sugars – including ‘fast foods’; many pre-prepared dishes, snacks, bakery foods and desserts; and confectionery (candy)

The WCRF/AICR recommends for colorectal cancer survivors based on evidence from research with survivors that they follow existing recommendations for cancer prevention (74, 75).

Figure 2.1 Recommendations of the World Cancer Research Fund International guideline

Source: WCRF/AICR, 2018

2.5.2 Body Mass Index

WCRF/AICR recommend a person should (74, 75):

- Keep weight within the healthy range throughout life (BMI of 18.5–24.9)
- Ensure that body weight during childhood and adolescence projects towards the lower end of the healthy adult BMI range
- Avoid weight gain throughout adulthood

2.5.3 Physical Activity

WCRF/AICR recommended people (74, 75):

- To be at least moderately physically active (such as walking, cycling, household chores, gardening, swimming, and dancing) and follow or exceed national guidelines
- Limit sedentary habits

2.6 CANCER SURVIVORSHIP AND SUPPORTIVE CARE

2.6.1 Cancer Survivorship

According to the World Health Organization (WHO) mortality database (1989-2016) on colorectal cancer mortality rates and number of deaths in 42 countries, mortality rates have been decreasing in Asia, Europe, North America and Oceania (77).

A major factor in the decline is the bowel screening programmes allowing earlier detection of CRC tumours, and the advancement of treatments such as chemotherapy, radiotherapy and surgery (49, 78). As such, more people are surviving colorectal cancer, which has resulted in a refocus in care to survivorship.

An Institute of Medicine (IOM) USA report identified the need to define and focus on survivorship for cancer patients due to the special needs that arise from persistent toxicities and late-occurring health problems from the cancer and its treatment (79). The IOM named the essential components of survivorship to be (i) Prevention of recurrent and new cancers, and of other late effects; (ii) Surveillance for cancer spread recurrence, or second cancers; assessment of medical and psychosocial late effects; (iii) Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphoedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and (iv) Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (79).

2.7 ROLE OF HEALTH PROFESSIONALS AND NGOS IN CANCER SURVIVORSHIP

Healthcare professionals have a major role in managing CRC survivors' recovery journey, which is encompassed in the term 'Cancer Supportive Care'. This refers to the provision of the necessary services to meet patients' physical, social, emotional, nutritional, informational, psychological, sexual, spiritual and practical needs throughout the spectrum of the cancer experience (80). This model has similarities to the Māori Health model 'Te Whare Tapa Whā', a holistic approach to care that includes taha wairua (spiritual wellbeing), taha hinengaro (emotional and mental wellbeing), taha tinana (physical wellbeing), and taha whānau (family and social wellbeing) (81).

Healthcare Professionals have a critical role in supporting the care of colorectal cancer patients. They provide relevant treatment, care for patients' emotional health, and related information and encourage survivors' early mobilisation after their procedures (82).

General practitioners (GPs) and oncologists share responsibilities in follow-up care for cancer patients, including care coordination and management of the physical and psychosocial impacts of cancer, and its treatment (83).

Nurses at the primary, secondary, and tertiary levels act as educators in colorectal cancer prevention (84). A narrative review described that nurses provide information on risk factors for CRC, diet, exercise, weight control, and overall well-being to patients, their whānau, and their friends (84).

Patients are referred to a registered dietitian (RD) by an oncologist or GP (85). They can provide nutritional education and information on cancer recovery, and dietary interventions to address well-being, weight management, energy, and to improve side effects caused by cancer and its treatment (86, 87).

The Nutrition Care Process is a systematic method to provide quality nutrition care, and its domains are assessment, diagnosis, intervention, monitoring and evaluation (86). Nutrition education is usually a major part of the nutrition care process delivered by a dietitian. The good use of the "teachable moment" with a patient who has experienced

colorectal cancer may improve health outcomes in an efficient manner (86). Dietitians tailor their advice to match patient needs (86). A systematic review of 12 randomised controlled trials which included 544 colorectal cancer patients, found that dietetic consultations in community settings were effective in advising about intentional weight loss, improving quality of life, nutritional status, and increasing fruit and vegetable intake. As such, dietitians play a critical role in weight management and improving long-term health outcomes for cancer survivors (88).

2.8 BELIEFS AND BEHAVIOURS OF COLORECTAL CANCER SURVIVORS

To educate and guide behaviours of CRC survivors towards a healthier lifestyle, it is important to understand the beliefs of survivors on the role of diet and lifestyle in cancer risk.

2.8.1 Nutritional Beliefs of Colorectal Cancer Survivors

A national cross-sectional study (n=1,073, CRC n=121) in Ireland evaluated the cancer survivors' (all cancers) perceived importance of the role of nutrition in their cancer care and health (89). Almost 98% rated nutrition as 'important' by 97.8% of respondents, with 58.2% rating nutrition as 'extremely important', 30.3% rating it as 'very important' and 9.3% rating it as 'somewhat important'. Females rated the importance of nutrition more highly than males (89).

A recent prospective cohort study for CRC survivors (n=326) at one-month post-surgery assessed their beliefs on nutrition and cancer, and any association to health professional provision of nutritional information (6). The majority (62%) had received

nutritional information from one or more HCPs, and these participants strongly believed that nutrition influences feelings of well-being and improves cancer recovery. In contrast, respondents who did not receive nutritional information had weaker beliefs about the role of nutrition in well-being, cancer recurrence and recovery compared to those who did receive it. Interestingly, beliefs were stronger if three HCPs provided information to a respondent compared to a single HCP. The authors conclude that nutritional information provision by HCPs positively influences the beliefs of CRC survivors on the importance of nutrition in recovery (6).

2.8.2 Lifestyle Behaviours of Cancer Survivors

2.8.2.1 Dietary intake behaviours

Many cancer survivors (all cancers) change their lifestyle behaviours after diagnosis. Several cross-sectional studies showed that many colorectal cancer survivors improved their dietary habits post-cancer diagnosis (90, 91, 92). Hawkins et al. 2015 reported that CRC survivors' dietary habits increased their intake of lean, low-fat or fat-free meat, poultry and dairy (91). O'Callaghan and colleagues found that 35.5% and 40.8% of cancer survivors introduced and/or eliminated foods after treatment, respectively. Changes included increasing vegetable intake, reducing red and processed meat intake, or decreasing sugar consumption (92, 93). Additionally, cancer survivors preferred natural content when they purchased food (92).

However, other research specific to CRC survivors, has found that adherence to recommended lifestyle changes is not as prevalent. A Dutch cross-sectional study enrolled 155 CRC survivors (stage I-III, 2-10 years post-diagnosis) investigating concordance with WCRF/AICR lifestyle recommendations, where each of the ten WCRF/AICR recommendations was scored as 0 (no/low adherence), 0.5 (moderate adherence) or 1 point (complete adherence) and summed into an overall adherence score (range: 0-10). They found that the mean adherence score to the recommendations was 5.1 (Range: 1.5 – 8.5) (94).

In the same study, they assessed dietary intakes and compared them to WCRF/AICR recommendations on diet. The recommendation on high fibre intake had 57% adherence, 19% for high fruit and vegetable intake, 1% for limiting red meat consumption and avoiding processed meat, and 64% for limiting alcohol consumption (94). After adjusting for confounders, a higher adherence score was significantly associated with improved physical functioning and reduced fatigue (94). Further compliance checks against recommendations showed that 28% of the population followed the healthy BMI suggestion and about 50% for Physical Activity (PA) (94).

In New Zealand, a cross-sectional study indicated that one-third of CRC survivors changed their diet post-treatment (16). However, they also found that half of the respondents reported they were still eating a Western dietary pattern, which was linked to the promotion of a high recurrence of CRC (16).

In an Australian study, over half of cancer survivors reported taking dietary supplements (93). Other international studies also report supplement intake, including mineral or vitamin supplements, herbal remedies, juicing, or detoxes (16, 89, 93). CRC survivors usually begin taking supplements without consulting or seeking the advice of health professionals (16, 93, 95).

2.8.2.2 Alcohol consumption behaviours

Stopping or reducing alcohol intake is another healthy change that many colorectal cancer survivors choose. An Australian cross-sectional study (n=483 CRC survivors) reported that 37% of alcohol drinkers at the time of diagnosis had decreased their consumption of alcohol after cancer treatment (90). Another cross-sectional study (n=593) conducted in the US found that more than half (53.5%) of CRC survivors had no intake of alcohol in the past 30 days (91). Of the CRC survivors who still consumed alcohol, approximately 84% met the recommended weekly limit of the WCRF/ACIR, and 16% drank more than the recommendations (91). At 5 to 7 years post-diagnosis compared to habits at diagnosis, 23.2% of survivors reported drinking less, 31.6% the same amount, 0.9% more, and 44.2% abstained at both times (91).

2.8.2.3 Smoking behaviours

A large cohort study (n=1,407) in Australia investigating smoking habits after any cancer diagnosis showed that 51% of smokers had the intention to quit within 6 months post-diagnosis, and 71% of smokers had attempted to quit within 6-12 months post-diagnosis (96). In addition, the quitting attempts were the highest after receiving the diagnosis, and decreased over time (96).

2.8.2.4 Physical activity behaviours

Many CRC survivors complied with physical activity recommendations following diagnosis. A longitudinal population-based study in the Netherlands (n=5,726) found that 82% of CRC survivors met the Dutch PA guidelines, which recommend at least 150 minutes of moderate to vigorous PA per week (97). A multi-countries study (n=356) reported that 53.4% of CRC survivors achieved at least 150 minutes of moderate to vigorous PA per week (98). Similar findings were observed in a Canadian cross-sectional study (n=123, all cancer types) that found 60.2% of cancer survivors were achieving at least 150 minutes of moderate to vigorous intensity PA per week (99).

2.9 INFORMATION NEEDS AND INFORMATION SOURCES

Many CRC survivors experience post-treatment physical and psychosocial symptoms, they wish to prevent or reduce the risk of cancer recurrence, and they want to enhance their recovery. Information to address these issues is critical for survivorship. There are professional and non-professional sources of information including general and cancer-specialty health professionals, Governmental and cancer-specific NGO websites, social media, and informal cancer support groups, family and friends. This section will describe the information needs, sources, information seeking behaviours, and barriers to information provision.

2.9.1 Colorectal Cancer Survivors' Information Needs

A qualitative study (n=40) conducted in the UK examined CRC survivors' perceived information and support needs in the immediate post-treatment period (100). They found that patients required diet, physical activity, and lifestyle information to help manage a variety of physical and psychological challenges, including loss of control of bodily functions, fatigue, sleep problems, sexual dysfunction, fear of recurrence, and reduced mobility (100). Some CRC survivors who gained excessive weight after treatment were interested in advice on healthy diets to lose weight, while those who have lost weight wanted advice on gaining a healthy weight (100). They also assessed the long-term (at least 6 months after treatment) information needs. CRC survivors wanted advice on diet, physical activity and work-life balance (100). CRC survivors prefer information or interventions tailored to their unique needs. Brown et al. (2016) reported the major information needs were warnings about bowel habit changes post-treatment and more general information on how any treatment impacts their life (101).

Anderson et al. (2013) suggested two key time points for providing information: (1) during the transition from hospital to home, and (2) when CRC survivors move beyond the challenge of treatment symptoms to focus on long-term health (100).

2.9.2 Health Communication and Promotion

Health communication is a process that involves interpersonal or mass communication activities, focusing on health care delivery for individuals and public health promotion (102, 103). The objectives of disseminating health information through public health campaigns, health education, and between doctor and patient, are to influence health decisions and to motivate individuals and populations to adopt healthy behaviours, leading to better health outcomes (102, 103).

Healthcare professionals who build trusting relationships and rapport with patients during cancer care enhance the quality of decision making. Further, informed and shared decision-making between patients and doctors has been shown to positively correlate with better patient satisfaction (104).

2.9.3 Sources of Information

Healthcare professionals such as medical doctors, GPs, cancer and community nurses, and registered dietitians have responsibilities to provide dietary, lifestyle and health information to support colorectal cancer survivors to manage survivorship. In addition, Governmental health agencies play a role in health promotion and offer information through online sources. Non-governmental organisations such as the Cancer Society New Zealand, Bowel Cancer New Zealand, and other NGOs, provide dietary and lifestyle guidance, and clinical and psychosocial support to cancer patients and survivors. However, in some cases dietary information provided by HCPs is insufficient. A UK qualitative study (n=19) explored the provision of nutritional information to cancer survivors (all cancers) and found that participants did not receive adequate professional advice on diet or only received general information, and wished to receive more guidance (105).

2.9.3.1 Dietitians as an information provider

Dietitians provide education to patients and their families on dietary needs, food choices, and nutritional sources, as well as addressing the psychosocial aspects of health,

economics, physiology, and chemistry to optimise health (86). They employ a systematic approach called the 'Nutrition Care Process' to assess, diagnose, intervene and monitor nutrition care. These include assessing dietary habits and intake, forming nutrition diagnoses, planning for customised interventions, and monitoring and evaluating ongoing processes to help patients achieve better health outcomes and goals (86).

Dietitians are a key source of nutritional information for cancer survivors (106). A cross-sectional study (n=1,073) from Ireland conducted a national survey of cancer survivors. Survivors who attended dietitian counselling were significantly more likely to have received advice on healthy eating, physical activity, foods to eat or avoid, protein/energy supplements, recipes, portion sizes, texture-modified diets, fortified foods, interventions to gain weight or lose weight, and how to use diet to manage symptoms (89). A systematic review (n=26) of randomised controlled trials in primary care found that dietetic consultations were effective in improving diet quality, diabetes outcomes, blood pressure control and weight management (107).

2.9.3.2 Medical doctors as an information provider

Among the GPs' roles of care coordination, screening, diagnosing, managing bodily and psychological effects of cancer and its treatment, pain management, treatment of comorbid conditions, symptom management, monitoring for recurrence, and providing referrals, are health care promotion and information provision (108, 109).

Medical doctors including GPs are a key primary source of health information for cancer survivors. They are considered more trustworthy than the internet, family and friends (110), or Government health agencies (111).

2.9.3.3 Nurses as an information provider

Cancer specialty, district and primary care nurses have an important role in providing information to cancer survivors. They interact with cancer survivors more frequently than oncologists throughout the diagnosis and follow-up treatment phases (112). This increased interaction gives nurses more opportunities and time to build rapport to offer

guidance and advice on diet and PA to cancer survivors before, during and after treatment (113, 114).

An Australian and New Zealand cross-sectional study (n=123) found cancer nurses were an important source of nutritional information to cancer survivors (114). Nurses provided nutrition-related information prior to, during and after treatment, and believed healthy eating could improve HRQoL, aid in weight management, improve mental health, support daily living activities, decrease risks of other chronic diseases, cancer recurrence and cancer-specific comorbidities (114). Cancer patients also reported they felt information provided by cancer nurses was of a higher quality compared to that given by chemotherapy and radiotherapy staff, and hospital consultants (115).

2.9.3.4 Governmental health agencies as an information provider

Government health agencies are another source of information for cancer survivors (111). In a Health Information National Trend Survey conducted in the USA, older people asked about sources of cancer information reported that information found on government health agency websites was less trustworthy than information provided by doctors, but higher than that sourced from family and friends, charitable organisations and religious organisations and leaders (111).

Government health agencies are considered more credible than other healthcare sources available online (GesserEdelsburg et al., 2020). In New Zealand, Te Whatu Ora Health New Zealand and Te Aho o Te Kahu (Cancer Control Agency) are Government agencies that aim to assemble and disseminate cancer data and information to inform decision-making and service delivery.

2.9.3.5 NGOs as an information provider

The non-governmental organisation (NGOs) websites provide information to survivors of CRC (111). In Ireland, 15.6% of charitable organisation websites offered nutrition information for cancer patients, and an additional 9.3% for cancer survivors (116). The contents on those websites were of poor quality, with much of the information being

difficult to read and understand (116). The two important sources of information from NGOs for CRC in New Zealand are the New Zealand Cancer Society and Bowel Cancer New Zealand. An unpublished thesis describing a New Zealand descriptive qualitative study reported the information on these sites could be improved, and that there was a deficiency of adequate standardisation and support structures for information provision (87).

2.10 INFORMATION SEEKING BEHAVIOURS

Many cancer patients and survivors seek online health information resources, with the internet being the second most preferred source of health information after HCPs (13, 14, 15). Cancer patients and survivors who searched for health information online felt more prepared for their treatment and more confident in advocating for their needs during consultations with HCPs (15). The type of information cancer survivors prefer to search for are their specific cancer type, personalised information about treatment, prognosis, and risk factors (117).

Three major online sources for cancer information that cancer survivors trust are non-profit, governmental, and cancer centre or health care or hospital websites (117). Often, cancer patients and survivors seek information online regarding diet, as they received inconsistent or confusing information from HCPs during their cancer journey. A UK qualitative study (n=19) found that participants did not receive any professional advice on diet or only received general information, and wished to receive more guidance, or were confused about the information received (105). Cancer patients sought information from the internet and the media. A quote from a survivor cited in the paper was “I went onto the Internet and found a few things. I just put in ‘anti-cancer foods’ and got what came up”, “I saw on the Internet, someone suggested a book”, “the Internet for hours and hours and hours, and printing off and printing off…they gave me a website to have a look at and I had a look at it, a thyroid cancer site. I've looked at all of them”. However, on the internet, the patients also experienced difficulties in knowing what to believe (105).

A US national cross-sectional study (n=619, all cancer types) revealed that information-seeking behaviours are significantly associated with being female, having a regular healthcare provider, and being younger than 66 years old (118). These predictors for information seeking agrees with other research that also found that patients who seek information online are likely to be younger, of white ethnicity, more educated, and residing in urban suburbs (119, 120, 121).

2.10.1 Barriers to information provision

There are organisational, HCP-derived and patient-derived barriers to information provision. HCPs have identified several challenges in delivering dietary and lifestyle information, including lack of time, inadequate support structures from their organisation, gaps in knowledge, and not perceiving themselves as the appropriate person to provide dietary advice (114, 122, 123). In a New Zealand study, Peniamina and McLean (2022) reported that there was a lack of provision of nutrition information, limited access to support, including dietitian appointments, insufficient funding, and a lack of staff time and capacity, lack of access to evidence-based information and dietary expertise (124).

HCPs sometimes struggle to ask cancer survivors to change their ingrained, lifelong dietary and lifestyle habits to make sustainable and achievable changes (122). HCPs were concerned about weakening their rapport and relationship with the patient and were cautious not to make cancer patients and survivors feel guilty about past lifestyles. As such, they sometimes opted for a subtle approach when giving lifestyle advice, which may reduce the impact of the messaging to change embedded behaviours (122). Patients who have low mood and distress also hindered the implementation of the given advice (122).

The main barriers to the provision of nutrition information and support (including access to dietitian appointments) were insufficient funding and lack of time/staff capacity

To overcome these barriers to information provision, optimal dietary and lifestyle advice delivery should include personalised advice delivered consistently throughout the cancer journey. Additionally, small and achievable diet and lifestyle interventions should

be integrated into the treatment regime to improve adherence (122). If time is the primary barrier, HCPs could guide patients to reliable, evidence-based sources to gain knowledge on foods that have a positive or negative impact on health to aid better lifestyle choices (105). Peniamina and McLean (2022) recommend that New Zealand oncology services overcome these barriers by making dietary information more widely available, standardised across services, involving all healthcare professionals trained in the WCRF/AICR recommendations, and increasing access to dietitians for detailed tailored advice and interventions (124).

2.11 IMPORTANCE OF THE STUDY AND THE GAPS IN RESEARCH IN NEW ZEALAND

In New Zealand, colorectal cancer is the second most common cancer (1, 2). The number of deaths from CRC is the second highest and third highest among total cancers for women and men, respectively (3). Over the past three decades, there has been an increasing trend in the five-year survival rate for CRC, reflecting improved survival outcomes after diagnosis and treatment (125), and increasing the number of survivors from CRC.

Survivors fear CRC recurrence and want to improve well-being and recovery. HCPs understand that diet and lifestyle behaviours are the main modifiable risk factors for CRC recurrence. These include red and processed meat intake which is significantly associated with a higher risk of colorectal cancer (51), with the consumption of two servings per day of red meat and four servings per day of processed meat consumption demonstrating a 1.8 fold risk increase of CRC (52). Conversely, dietary fibre intake from sources such as vegetables, fruit, and whole grains shows an inverse relationship with CRC risk (46, 48, 49).

A prospective cohort study (n=992, colon cancer) found that survivors who followed the American Cancer Society Nutrition and Physical Activity Guidelines for Cancer Survivors (ACS guidelines) improved their survival rates (126). ACS guidelines include maintaining a healthy body weight, engaging in regular physical activity, and consuming a diet rich in

vegetables, fruits, and whole grains (126). Similarly, cancer survivors who adhere to WCRF/AICR recommendations were shown to have lower all-cause mortality (127).

Among CRC survivors, adherence to WCRF/AICR recommendations is associated with better HRQoL (94, 128), better physical functioning, role functioning, social functioning, global health status, and less fatigue (94, 128). In all cancer patients, concordance with WCRF/AICR recommendations, including dietary modification and regular physical activity, promotes weight loss in cancer patients (129). Further, dietary changes have been shown to improve diet quality, nutrition-related biomarkers, and body weight (130).

Physical activity interventions ameliorate cardiorespiratory fitness, muscular strength, physical function, fatigue, depression, self-esteem, cancer-related psychosocial variables, and quality of life (130, 131). Despite the overwhelming evidence of the benefits of a healthy diet for cancer survivors, a New Zealand cross-sectional study found that only one-third of CRC survivors changed their diet after treatment (16), with half of the respondents continuing to follow a Western dietary pattern, which is associated with increased risk of CRC recurrence (16). Cha et al. (2012) also reported similar findings, with only 50% of the CRC patients adhering to the New Zealand Food and Nutrition Guidelines of the Ministry of Health (132).

CRC survivors reported unmet informational needs and desired to receive more information from their HCPs (16, 132). An exploratory qualitative study found that healthy dietary changes were less important to New Zealand cancer survivors (all cancers) due to patients' limited knowledge about the role of nutrition in cancer prevention and recovery (12).

Peniamina and colleagues report in the New Zealand Medical Journal that a barrier to implementing dietary habit change is limited information and access to nutritional advice and support (12). To address this, they recommend that nutrition information and support should be widely accessible and standardised across New Zealand's oncology services (124). In addition, quality diet and lifestyle information for colorectal cancer survivors should be evidence-based and guideline-driven.

It is important that colorectal cancer survivors are equipped with the knowledge, information and skills to make healthy behavioural changes and modify their established

dietary habits. Registered dietitians, medical doctors, and both community and specialist nurses have a key role in providing reliable sources of information to cancer survivors (106, 110, 112). Currently, there is a paucity of high-quality evidence from CRC survivors and HCPs on the sources and quality of dietary and lifestyle information in New Zealand. Further, it is unclear about the roles of different healthcare professionals in delivering information to CRC survivors in New Zealand.

Exploring the dietary and lifestyle information currently provided by healthcare professionals according to the cancer survivors themselves, will identify gaps in access, resourcing, and allow assessment of the quality of information provision to meet survivors' needs in New Zealand.

Overall, this study aims to inform a proposed representative study by pilot testing cross-sectional surveys of colorectal cancer survivors and cancer-related HCPs. Within the pilot, preliminary evidence will be gathered on the sources and quality of diet and lifestyle information delivered to CRC survivors in New Zealand community settings, questionnaires for survivors will be evaluated for comprehension, and recruitment and data collection systems will be tested.

CHAPTER 3. RESEARCH MANUSCRIPT

This manuscript is formatted for submission to the New Zealand Medical Journal (Appendix A.3). The referencing style for the research manuscript has been conformed to be consistent between thesis chapters.

A pilot cross-sectional study examining the nutritional beliefs, behaviours, and access to dietary care of colorectal cancer survivors in New Zealand

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3.1 ABSTRACT

Background: In New Zealand, colorectal cancer (CRC) ranks as the second most common cancer. Over the past three decades, the survival rate of CRC patients in New Zealand has steadily increased. Diet and lifestyle advice affects cancer recovery and the prevention of cancer recurrence. Understanding CRC survivors' current dietary and lifestyle beliefs, behaviours, and advice and support from health services and other sources will identify gaps in service provision.

Aim: To gather preliminary evidence on the sources and quality of dietary and lifestyle advice delivered in community settings according to CRC survivors.

Methods: This study design is a pilot cross-sectional study. Participants were sought through convenience sampling. Survivors aged 18 years and older who had been diagnosed with colorectal cancer, received clinical treatment in New Zealand, completed treatment 6 months to 30 months before registration, and resided in the New Zealand community were invited to complete an online questionnaire. Data was collected using the online Qualtrics software. Descriptive statistics were used to examine quantitative data.

Results: In total, six valid responses were received (83.3% female, mean age 50 years). CRC survivors believed in the important role diet and lifestyle changes played in aiding cancer recovery and preventing cancer recurrence. Five major findings were identified: 1) CRC survivors received insufficient dietary and lifestyle advice and ongoing support from HCPs, 2) CRC survivors prefer to receive individualised dietary information specific to their health status and symptoms, 3) current practice did not meet the NICE guidelines recommended for CRC by HCPs, 4) despite awareness of WCRF/AICR dietary guidelines among CRC survivors, for some, this did not lead to change in dietary habits 5) CRC survivors achieved the physical activity levels recommended in guidelines proposed by the U.S Physical Activity Guidelines Advisory Committee.

Conclusion: A structured and systematic approach should be developed to provide dietary and lifestyle information for CRC survivors throughout their cancer trajectory so that they will have a better quality of life and a reduced CRC recurrence.

3.2 INTRODUCTION

Globally, colorectal cancer is the third most frequent cancer and the second leading cause of cancer deaths for both sexes (42). GLOBOCAN 2022 reported higher age-standardised incidence rates of CRC in Western nations, including Europe, Australia/New Zealand, and North America, compared to lower rates in Africa and South and Central Asia (42).

In New Zealand, CRC is the second most common cancer (1, 2). In 2021, The New Zealand Governmental Health New Zealand Te Whatu Ora, reported that there were over 3300 new CRC cases (11.8%) out of 27,869 new cancer registrations (3).

In New Zealand, the overall five-year survival rate for all ethnicities was 51% (43). People of Māori ethnicity experience poorer survival rates (43), with poor access and quality of care recognised as being key contributors to these statistics (133).

According to the World Health Organization (WHO) mortality database (1989-2016) on colorectal cancer mortality rates and number of deaths in 42 countries, mortality rates have been decreasing in Asia, Europe, North America and Oceania (77).

A major factor in the decline is the bowel screening programmes allowing earlier detection of CRC tumours, and the advancement of treatments such as chemotherapy, radiotherapy and surgery (49, 78). As such, more people are surviving colorectal cancer, which has resulted in a refocus in care to survivorship.

CRC survivors face numerous challenges related to the disease, treatment, and recovery, including physical, psychosocial, economic, and health-related quality of life (HRQoL) impacts. Physical impacts after treatment may include anorexia, fatigue, lethargy, nausea, pain and peripheral neuropathy (29). Psychosocial consequences include depression, anxiety, and fear of cancer recurrence/progression (134). Economic stress is common in survivors due to out-of-pocket expenditure, loss of income and lost productivity (135). Health-Related Quality of Life (HRQoL) is the influence of disease and treatment on overall function and the physical, psychological, and social aspects of well-being (38, 39). CRC survivors were more likely to have a lower HRQoL if their quality of life was lower before treatment, were female, had co-morbidities, had experienced complications, had a family history of CRC, and had received chemotherapy (41).

Healthcare professionals (HCPs) manage CRC survivors' recovery journey. This involves providing 'Cancer Supportive Care', which addresses cancer patients' physical, social, emotional, nutritional, informational, psychological, sexual, spiritual and practical needs throughout the spectrum of the cancer experience (80).

Registered dietitians have a key role in providing dietary and lifestyle information to CRC survivors (106). Cancer survivors are more likely to have received advice on healthy eating, physical activity, interventions to gain weight or lose weight, and how to use diet to manage symptoms if they attended dietitian consultations (89). Similarly, doctors, including GPs, are a key primary source of health information for cancer survivors (110). Other HCPs, such as primary, community and cancer nurses, also have a role in nutritional and health information provision (114).

One of the key roles of registered dietitians and other HCPs in the treatment of CRC survivors is to reduce modifiable dietary and non-dietary risk factors for CRC recurrence, and to improve general health and well-being (136, 137).

Dietary risk factors for CRC include dietary fibre intake, red and processed meat consumption, and alcohol consumption. Higher dietary fibre intake is positively associated with a reduced CRC risk (46, 48, 49, 138), and a meta-analysis has demonstrated a dose-response relationship that for every 10g of fibre, they found a 90% reduction in risk (138). Conversely, red meat intake is significantly correlated with a higher risk of CRC (51). For processed meats (including bacon, sausages, salami, hot dogs, or processed turkey), consumption was associated with an 18% greater colorectal cancer risk, a 21% greater colon cancer risk, and a 22% greater rectal cancer risk (51). A positive association has also been shown between increased CRC risk and alcohol consumption (62, 63, 64). A meta-analysis of cohort studies and case-control studies found the relative risks (RRs) of developing CRC were 1.21 (95% CI: 1.13–1.28) for moderate drinking (2-3 drinks per day) and 1.52 (95% CI:1.27–1.81) for heavy drinking (greater than and equal to 4 drinks per day) (62).

Non-dietary or lifestyle risk factors for CRC include tobacco smoking, high body mass index (BMI), and low level of physical activity, all of which increase the risk of CRC (136, 137). Cigarette smoking is significantly associated with increasing the risks of growing polyps, the precursor to CRC (66). High body mass index (BMI) positively correlates with increasing the risk of developing colorectal cancer (54, 55). Systematic reviews of observational studies elucidated the positive association between body weight gain and increased CRC incidence risk (59, 60). Abar and colleagues found risk ratios were 1.06 (95% CI: 1.04–1.07) per 5 kg/m^2 elevation in body mass index (BMI), and 1.03 (95% CI: 1.01–1.05) per 0.1 unit increase in waist to hip ratio (WHR) (59). Physical activity decreases CRC risk by reducing body adipose tissue, which has an effect on insulin resistance and inflammation, which correlate with CRC development (70).

Despite the importance of modifiable risk factors, CRC survivors in New Zealand have experienced unmet informational needs and desire to receive more information from their HCPs. (16, 132). In addition to HCPs as an information source, cancer survivors rely on information from Governmental and Non-governmental websites which provide dietary and lifestyle guidance, and clinical and psychosocial support to cancer survivors.

Peniamina and colleagues conducted a survey of healthcare practitioners and support workers in New Zealand, and reported that HCPs provide limited nutritional information,

with barriers such as limited access to support services such as dietitian appointments, inadequate funding, insufficient staff time and capacity, and a lack of access to evidence-based information and dietary expertise (124).

In New Zealand, a survey has not been conducted seeking information from CRC survivors on the availability, sources, and quality of dietary and lifestyle information. Further, there is a lack of clarity about the roles of different healthcare professionals in delivering information to CRC survivors in New Zealand.

This pilot cross-sectional study aims to gather preliminary evidence on the sources and quality of dietary and lifestyle advice delivered in community settings according to CRC survivors. In addition, this pilot will test recruitment and data collection methods for a proposed adequately powered cross-sectional study.

3.3 METHODS

Study design

A pilot descriptive cross-sectional survey was conducted in the community from May to October 2024.

Participants

We recruited a convenience sample of participants to efficiently explore key study objectives (139) within the available timeframe and resources.

This study included colorectal cancer survivors aged 18 years and older, diagnosed with primary colon or rectal cancer (stage I - IV), received clinical treatment (surgery, chemotherapy, radiotherapy) in New Zealand, completed cancer treatment six months to thirty months prior to registration, resided in the community in New Zealand, and had sufficient literacy to comprehend the self-administrated questionnaire. Participants were ineligible if they had a terminal condition, had cancer of the appendix, or resided in residential care facilities.

Recruitment

A recruitment advertisement (see Appendix A.1) was emailed or placed in a newsletter by New Zealand Cancer-related NGOs to potential participants providing a link to an online registration form. The recruitment advertisement was sent to potential participants on three occasions during the recruitment period.

Participants who were interested in the present study completed a registration form with screening questions on eligibility (see Appendix C.1), and if potentially eligible, they provided contact details. Study researchers contacted potential participants to confirm their eligibility, and to seek informed consent. Eligible participants received a personal link to complete the online self-administered questionnaire. Participants were offered support to complete the survey if needed. The university-hosted Qualtrics Software (2024 Qualtrics) was used to distribute the self-administered questionnaire to participants.

CRC Questionnaire Development and Evaluation

A study-specific questionnaire (Appendix C.2) was developed to assess the medical history, information sources, dietary habits, and dietary changes of CRC survivors. The data collection tool validity was ensured as it was developed by experienced researchers who reviewed the literature of similar studies internationally. Due to challenges in recruiting CRC survivors, the evaluation of the CRC questionnaire prior to administration was conducted with healthy older people to provide an insight into the burden and quality of the questionnaire. The questionnaire was evaluated for comprehension, readability, and timing before being distributed to CRC participants. After evaluation, no amendments to the CRC questionnaire were deemed necessary.

Measures

The questionnaire was administered once only. The questionnaire (Appendix C.2) was divided into 11 sections with closed-ended and open-ended style questions. The first section collected demographic variables, such as gender, age, highest education level, ethnicity, location of living, living situation, weight and height. The second and third sections examined health status (e.g., rating of current health, smoking status and alcohol consumption level) and medical history (e.g., staging of cancer from the TNM

staging system, and location of cancer, year of diagnosis, treatment, symptoms, and weight history) of colorectal cancer. Section four was an assessment of information sources for CRC survivors, which asked if they received any nutritional advice and the source. Section five was a dietary assessment including the consumption of fibre-rich foods, foods rich in fat, processed meat, red meat, and sugary drinks. In section six, the questionnaire asked participants about their changes in diet after treatment. Section seven explored participants' familiarity with each item of the WCRF/AICR recommendations on cancer prevention using a Likert scale, with 1 meaning "Never heard of it" to 4 meaning "Very familiar".

In section eight, participants' beliefs on the role of nutrition in recovery from colorectal cancer, and in preventing a recurrence was measured on a 1-5 Likert scale, with 1 meaning "Extremely important" to 5 meaning "Not at all important". In section nine, participants reported whether they received sufficient support and advice on diet and dietary issues, and what information they would have liked to have received. Section ten enquired about advice received on physical activity and change in levels.

The final section assessed participants' current physical activity intensity using the International Physical Activity Questionnaire (IPAQ) short form, a widely accepted and rigorously validated questionnaire (140). Physical activity levels were reported as median MET-minutes per week (141). Data analysis of IPAQ involves calculating activity volume by weighting each activity type according to its energy requirements, as defined in METs, to produce a score in MET-minutes. One MET is a multiple of the resting metabolic rate, with a MET-minute computed by multiplying the MET value of activity by the minutes performed (141). The MET-min/week calculations are as follows: for walking, 3.3 MET-min/week is 3.3 x minutes of activity x days per week; for moderate-intensity activity, 4.0 MET-min/week x minutes of activity x days per week; for vigorous-intensity activity, 8.0 MET-min/week x minutes of activity x days per week. Total MET-min/week is the sum of walking, moderate and vigorous intensity MET scores performed (141)

Ethics

Ethical approval was sought from the Massey University Human Ethics Committee. This study was assessed as being low risk (Ethical application number: 4000028629). Written

informed consent was sought from all participants prior to study commencement. Participants were informed that they could withdraw from this study at any time. All data was securely stored on password-protected computer servers at Massey University.

Statistical analysis

Since this was a pilot study, a power calculation was not performed. Collected data was entered into IBM SPSS Statistics (v. 29) and was utilised for data analysis. Descriptive statistics were employed for participants' demographics, behaviours, knowledge and attitudes. Ordinal data were presented as frequencies or percentages. Normally distributed continuous data were reported as mean ± SD, and the median and interquartile range were used for non-normally distributed data. BMI was derived from the World Health Organisation calculation (weight in kg divided by height in m^2). T-tests were employed to investigate the association between variables, while Chi-square (X^2) tests were used to assess associations between categorical variables such as participants' characteristics and knowledge levels. A P-value of less than 0.05 was considered statistically significant.

3.4 RESULTS

Six potential participants expressed interest in this study by completing a registration form. After screening for eligibility, all six colorectal cancer survivors were invited to participate in this study, with a 100% response rate, all of which were included in the analysis. Our study collected data at a single time point. The incomplete item responses were 4.26%.

3.4.1 Participant Demographic Characteristics

Table 3.1 presents the demographic characteristics of participants. Six colorectal survivors completed the online questionnaire, with the majority being female (83.3%). The mean age of the respondents was 49.8 ± 12.1 years. Most participants in this study were New Zealand Europeans who resided in urban areas, lived with their partner or spouse, and held a university degree. The average time the participants took to complete the questionnaire was 16 ± 11 minutes.

Table 3.1 Summary of the demographic characteristics of the respondents to the survey

Respondents' characteristics	n (%) mean +/- SD
Gender	
Male	1 (16.7)
Female	5 (83.3)
Age (Years)	49.8 ± 12.1
Highest level of education	
High school	2 (33.3)
University degree	4 (66.7)
Ethnicity	
NZ European/Pakeha	5 (83.3)
Other	1 (16.7)
Area of residence	
City	5 (83.3)
Town	1 (16.7)
Living arrangement	
Living with partner/spouse	5 (83.3)
Living with others[1]	1 (16.7)

3.4.2 Health Status and Medical History

The health status and medical history of the participants are shown in Table 3.2.

Fifty percent self-reported that their health status was good, 16.7% were excellent, 16.7% were very good, and 16.7% rated fair. According to BMI measurements, half of the participants were overweight, and 16.7% were classified as obese or underweight. Over

[1] Living with others includes any person who is not a partner or a spouse

the last 6 months, 50% did not have body weight change, 16.7% lost five percent or more, 16.7% lost less than five percent, and 16.7% gained weight.

Half of the participants had colon cancer, and half had rectum/rectosigmoid/anus cancer. Half were diagnosed with colorectal cancer at stage III, one-third were diagnosed at stage II, and (142) one out of six were diagnosed at stage IV. All participants underwent surgery and chemotherapy. Five participants reported no other comorbidities, and one reported having one additional health condition, specifically liver disease secondary to chemotherapy.

Almost all participants consumed alcohol before the CRC diagnosis, and only one respondent did not drink alcohol. Half of the respondents stopped drinking after the treatment. Of those who still consume alcohol, two out of three reported they drink less compared to before diagnosis.

Table 3.2 Health status and medical history of the respondents

Respondents' characteristics	n (%)
Health Status	
Excellent	1 (16.7)
Very good	1 (16.7)
Good	3 (50)
Fair	1 (16.7)
Smoking status	
Current smoker	0
Past smoker	3 (50)
Never smoked	3 (50)
Alcohol status	
Before diagnosis	
Yes	5 (83.3)
No	1 (16.7)
After treatment	
Yes	3 (50)
No	3 (50)
Cancer stage (TNM System)	
II	2 (33.3)
III	3 (50)
IV	1 (16.7)
Cancer location	
Colon	3 (50)
Rectum/rectosigmoid/anus	3 (50)

Table 3.2 Continued:

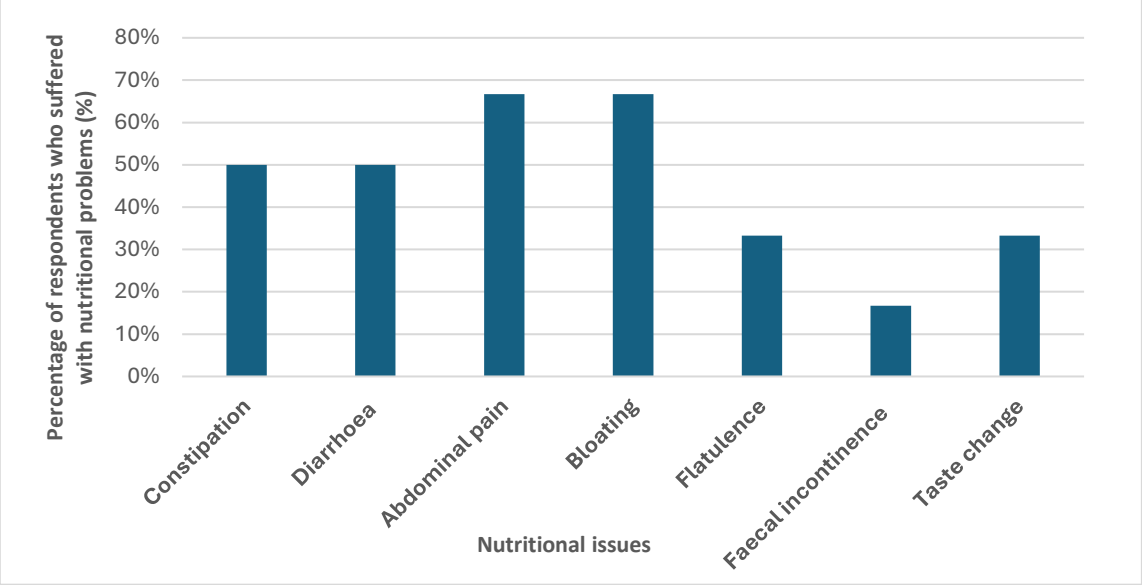
Respondents' characteristics	n (%)
Year of diagnosis	
2021	1 (16.7)
2022	2 (33.3)
2023	3 (50)
Current Stoma Fitted	
None	6 (100)
Treatment Types	
Surgery and Chemotherapy	6 (100)
BMI (kg/m^2)	
Underweight (<18.5 kg/m^2)	1 (16.7)
Normal weight (18.5-24.9 kg/m^2)	1 (16.7)
Overweight (25-29.9 kg/m^2)	3 (50)
Obese (≥30 kg/m^2)	1 (16.7)
Weight changes[a]	
Lost more than 5% of body weight	1 (16.7)
Lost less than 5% of body weight	1 (16.7)
Remained the same	3 (50)
Gained weight	1 (16.7)
Comorbidities	
None	5 (83.3)
One other medical condition	1 (16.7)
Nutrition problems[a]	
Yes	5 (83.3)
No	1 (16.7)

[1]Within the previous 6 months

3.4.3 Nutrition problems in the last 6 months

The majority of respondents reported experiencing nutrition problems in the last 6 months (Figure 3.1). These included abdominal pain (66.7%), bloating (66.7%), constipation (50%), and diarrhoea (50%). Other nutritional problems included flatulence (33.3%), faecal incontinence (16.7%) and taste change (33.3%).

Figure 3.1 Nutrition issue in last 6 months



3.4.4 Nutritional Advice and Support

Most of the respondents (83.3%) received nutritional advice from HCPs before the end of their treatment (Table 3.3). After treatment, just over one-third of the respondents continued to receive nutritional advice. Of those who received nutrition advice, 16.7% received advice from one HCP, and another 16.7% from three HCPs.

Registered dietitians were the primary source of advice (Table 3.4). Over half of the respondents found the advice from registered dietitians to be somewhat helpful to extremely helpful. The type of advice and support received from HCPs included introducing supplements (33.3%), introducing foods (16.7%), losing weight (16.7%), and reducing or removing food (16.7%) (See Table 3.4). No respondents reported receiving advice or support in gaining weight.

Other sources of advice and information sought by CRC survivors included online resources, non-governmental organisations, and additional sources such as personal trainers (See Table 3.4).

Table 3.3 Nutritional information provision during and after treatment

Response	n (%)
Information provided by a health professional after diagnosis or during treatment	
Yes	5 (83.3)
No	1 (16.7)
Information provided by a health professional after treatment	
Yes	2 (33.3)
No	4 (66.7)
Information provided by other sources	
Yes	2 (33.3)
No	4 (66.7)
Types of other sources	
Internet	1
Bowel Cancer New Zealand	1
Other (Personal Trainer)	1
A friend or family member	0
Media	0
Cancer society of New Zealand	0
Facebook Cancer Support Group	0

Table 3.4 Nutritional information provision from healthcare professionals

Healthcare professionals involved in providing dietary advice	
Response	**n (%)**
Registered dietitian	4 (66.7)
Cancer specialist	1 (16.7)
Stomatotherapist	1 (16.7)
General Practitioner	0
Nurse at the GP practice	0
Cancer nurse	0
Nutritionist	0
Other HCPs	0
Number of healthcare professionals involved per participant	
One HCP	1
Two HCPs	0
Three HCPs	1
Advice and support from healthcare professionals	
Response	**n (%)**
Gain weight	
No	6 (100)
Lose weight	
Yes	1 (16.7)
No	5 (83.3)
Introduce foods	
Yes	1 (16.7)
No	5 (83.3)
Reduce or remove food	
Yes	1 (16.7)
No	3 (50)
Introduce supplement	
Yes	2 (33.3)
No	1 (16.7)

3.4.5 Dietary Information Needs and Beliefs

Approximately 67% of the participants reported that they received insufficient support and advice regarding their nutritional issues (See Table 3.5). When asked about the type of support and advice they would find beneficial, the participants suggested regular follow-up consultations with dietitians or nutritionists, tailored advice on managing their dietary needs with their new bowel conditions, proactive assistance from HCPs in assessing their dietary needs, and advice on maintaining a healthy balanced diet.

In terms of dietary beliefs among colorectal cancer survivors, four out of six participants felt that diet was very important for their recovery, one participant rated it as extremely important, and one as somewhat important. When considering the role of diet in preventing cancer recurrence, the majority of the participants deemed it very important, while one participant rated it as not so important.

Table 3.5 Dietary information needs and beliefs on the importance of diet in recovery and recurrent

Dietary Information needs	n (%)
Sufficient support received	
Yes	2 (33.3)
No	4 (66.7)
Type of additional support needed	
Regular follow ups from dietitians/nutritionist	1
Tailored advice on managing symptoms	1
Proactive assistance from HCPs to assess dietary needs	1
Advice on healthy balanced meals	1

Table 3.5 Continued

Dietary Beliefs	n (%)
Importance of diet in recovery	
Extremely important	1 (16.7)
Very important	4 (66.7)
Somewhat important	1 (16.7)
Not so important	0
Not at all important	0
Importance of diet in preventing recurrence	
Extremely important	0
Very important	5 (83.3)
Somewhat important	0
Not so important	1 (16.7)
Not at all important	0

3.4.6 Knowledge of WCRF/AICR Dietary Recommendations

Familiarity with the World Cancer Research Fund and the American Cancer Institute Research (WCRF/AICR) recommendations was high, with 83.3% being very familiar with all the recommendations. The recommendation with the highest proportion having never heard of it involved limiting red and processed meat consumption.

3.4.7 Dietary Habits and Changes Post-treatment

Participants were asked about their current dietary habits to assess their compliance with the WCRF/AICR recommendations (Table 3.6). CRC survivors report that they are relatively compliant with the recommendations. The majority have included in their daily diet whole grains, vegetables, fruits and pulses. In addition, they have low levels of foods high in fat, starches or sugars, and have limited the consumption of sugary drinks. Some CRC survivors are still consuming more than three portions of red meat per week, and consuming processed meats in their daily diet.

Table 3.6 Post-treatment dietary habits

Dietary habits	Never/Rarely n(%)	Sometimes n(%)	Mostly/Always n(%)
Ensure that whole grains, vegetables, fruits, and pulses are a major part of your usual daily diet.	1 (16.7)	1 (16.7)	4 (66.7)
Have a low level of processed foods high in fat, starches, or sugars in your daily diet.	0	2 (33.3)	4 (66.7)
Eat less than 3 portions per week of red meat.	3 (50.0)	1 (16.7)	2 (33.3)
Eat little, if any, processed meat in your daily diet.	2 (33.3)	0	4 (66.7)
Limit consumption of sugar-sweetened drinks or soft drinks.	0	0	6 (100)

Table 3.7 displays the participants' reported dietary changes post-treatment, with 16.7% introducing new foods and 66.7% reducing certain foods. The most frequently mentioned change was a reduction in sugar consumption (50%). In addition, processed meat, fried foods, and processed foods consumption were reduced by 16.7%, respectively.

Half of the respondents introduced new supplements, while the other half did not introduce any supplements after treatment. The most common choice of vitamin and mineral supplements were fibre supplements (33.3%), zinc (33.3%), followed by vitamin D (16.7%) and probiotics (16.7%). In the free-text data, one respondent introduced vitamin C, and one other magnesium and potassium.

Table 3.7 Post-treatment Dietary Changes

Dietary changes	n (%)
New foods introduced	
Yes	1 (16.7)
No	5 (83.3)
Type of food introduced	
Animal fat	1 (16.7)
New foods introduced due to HCP's advice	
Yes	0
No	1 (16.7)
Foods reduced or removed	
Yes	4 (66.7)
No	2 (33.3)
Type of foods reduced or removed	
Sugar	3 (50.0)
Processed meat (e.g., bacon, ham, sausages, salami, pepperoni)	1 (16.7)
Fried foods	1 (16.7)
Processed foods	1 (16.7)
Red meat	0
Dairy foods (cheese, milk, butter)	0
Foods reduced or removed due to HCP's advice	
Yes	1
No	3
Dietary supplementation introduced	
Yes	3 (50.0)
No	3 (50.0)

Table 3.7 Continued

Dietary changes	n (%)
Type of supplement	
Fibre supplement	2 (33.3)
Zinc	2 (33.3)
Probiotics	1 (16.7)
Vitamin D	1 (16.7)
Vitamin B9	0
Selenium	0
Calcium	0
Dietary supplementation introduced due to HCP's advice	
Yes	2
No	1

3.4.8 Provision of Advice on Physical Activity

Physical activity (PA) advice provision by HCPs and the perceived needs of colorectal cancer survivors are summarised in Table 3.8. Overall, 66.7% of the respondents received advice on PA after treatment, and three-quarters of the respondents increased their PA as a result of the advice received. While 50% of the colorectal survivors felt they had received adequate advice and support on PA, the other half reported that the advice and support were insufficient.

The respondents' physical activity was assessed using the International Physical Activity Questionnaire (IPAQ) Short Form (140) (See Table 3.9). Five participants reported physical activity of 297 MET-min/week due to walking, two participants reported 840 MET-min/week from moderate-intensity physical activity, and three participants reported 1920 MET-minutes from vigorous physical activity. Overall, respondents had a total physical activity of 3,057 MET-minutes/week. The median sitting time was 360 minutes, ranging from 180 to 540 minutes per week.

Table 3.8 Physical activity information provision and information needs

Response	n (%)
PA Advice provided from HCP	
Yes	4 (66.7)
No	2 (33.3)
Increased PA due to HCPs' advice	
Yes	3 (75)
No	1 (25)
Sufficient advice and support received on PA	
Yes	3 (50)
No	3 (50)

Table 3.9 Physical activity status and sedentary behaviours of colorectal cancer survivors

Participants (n=6)	Median Level of Physical Activity
Walking (MET - min/week) n=5	297
Moderate (MET - min/week) n=2	840
Vigorous (MET - min/week) n=3	1920
Total physical activity (MET - min/week) n=6	3057

3.5 DISCUSSION

This pilot cross-sectional study, a first of its kind, examined the experience of and access to nutritional care and information by CRC survivors in the New Zealand community, as well as their nutritional beliefs and behaviours. It shows several key findings that require further research on the gaps in nutritional care and support of CRC survivors. In addition, this study tested recruitment and data collection methods to inform a proposed larger cross-sectional study.

We also evaluated the pilot CRC questionnaire. Overall, the findings from the evaluation questionnaire testing demonstrated that the CRC questionnaire is easy to understand for respondents with adequate length. The ethical process were tested by distributing the questionnaire to healthy older people, and it is feasible for CRC survivors to answer the questionnaire as the wording was straightforward and the length meant it would be unlikely to cause mental fatigue. Distributing the questionnaire using an online platform is another advantage, as it is easy to navigate between different questions. No amendment was required for the pilot CRC survey.

In the CRC study, we found a clear need for CRC survivors to receive tailored and ongoing dietary and PA information and support, equipping them with the knowledge necessary to make positive changes to their nutritional and lifestyle behaviours, and to reduce the risk of cancer recurrence.

Due to the small sample in this pilot study, the participants were not representative of CRC survivors. They were highly educated European females, aged 49.8 ± 12.1 years on average, generally of good health, who resided with their spouses or partners in a New Zealand city.

Most participants reported experiencing gastrointestinal problems over the past six months, including abdominal pain (66.7%), bloating (66.7%), constipation (50%), diarrhoea (50%), flatulence (33.3%), faecal incontinence (16.7%), and changes in taste (33.3%), which significantly impact the quality of life. These findings align with a national cross-sectional survey conducted in the UK, which highlighted that CRC survivors were frequently affected by gastrointestinal problems (143). Similarly, Keaver et al. (2023) identified changes in taste and smell as the major nutrition-related problem across all

cancer types (142), a trend that affected a third of our cohort. A study by Matsell and colleagues reported that CRC patients often experienced diarrhoea, and underwent bowel resection, all of which significant impacted their quality of life and well-being (143). The role of dietetic care in the management of symptoms is discussed in the next section.

Furthermore, half of the CRC survivors in the present study reported weight changes over the last 6 months. Of those, one respondent gained weight, while two experienced weight loss, with one losing less than 5% and the other more than 5%. Sullivan et al. 2021(89) reported of 216 patients with GI cancer, 57% experienced unintentional weight loss. This level of weight loss as a nutritional issue for CRC patients was also identified in a UK study (n=75) by Matsell et al. 2020 (143).

Worryingly, half of the respondents from our study are currently overweight or obese and there is a positive association between body weight gain and increased CRC incidence risk (59, 60). CRC survivors with nutritional issues including weight management require dietary support and advice (16, 89).

Nutritional information provision by HCPs and other sources

Most respondents in this cohort received nutritional advice from HCPs during treatment. On the contrary, a New Zealand hospital-based study reported approximately one-third of CRC patients received nutritional advice during treatment (16). Two-thirds of respondents from the present study received no nutritional advice post-treatment, which aligns with findings from a UK-based study of CRC survivors (n=40) (100).

As dietary guidance provided after treatment has been found to relieve symptoms and fears about food choices in CRC patients (143), the lack of after-treatment dietetic care is a significant gap in service provision.

Almost all CRC survivors reported that RDs were their primary source of nutritional information, with other HCPs involved in information provision being cancer specialists and stomatotherapists.

The finding that the primary source of nutritional information was RDs in the present study needs to be interpreted with caution, as the small sample size (n=6) is not generalisable, and leads to the risk of a cognitive bias.

Other New Zealand studies report low levels of access to dietitians, Pullar et al. 2012 (16) report that only 6 of 40 CRC hospital patients received advice from a dietitian. International studies also report that approximately a fifth to a third of nutrition advice for all cancers was provided by registered dietitians, with patients with complex morbidities or surgeries having priority (6, 92, 142).

The difficulty in accessing a dietitian reflects a shortfall within oncology services internationally and in New Zealand resulting in limited or no service to cancer survivors, and unmet needs. In Ireland, there is a ratio of one registered dietitian per 4,500 patients in oncology services (92). Inadequate staffing status is similar in the USA, with a dietitian to patient ratio of 1:2,308 (144). The authors of the present study could not find the dietitian to patient ratio in oncology services in New Zealand. However, Peniamina and McLean (124) report that nutrition information and support were not widely available through oncology practices and cancer support services in New Zealand.

In New Zealand and the UK, the major barriers to information provision for patients included limited access to support including dietitian appointments. Barriers to service provision included insufficient funding, a lack of staff time and capacity, and lack of access to evidence-based information (124, 143).

The UK-based NICE guidelines on managing CRC recommend that HCPs: “Prepare people for discharge after treatment for colorectal cancer by giving them advice on diet, including advice on foods that can cause or contribute to bowel problems such as diarrhoea, flatulence, incontinence and difficulty in emptying the bowels; and adapting physical activity to maintain their quality of life” (145). Findings from this present study suggest that these guidelines are not being adequately implemented in New Zealand hospital and community settings for most CRC patients and survivors. Further research from a large cross-sectional study is required to gain a better understanding of patient needs and nutritional care for CRC survivors in New Zealand, and whether guideline dietary recommendations are being addressed.

In light of the difficulty in dietitian access, CRC survivors seek dietary advice from other sources, including nurses, doctors, family members and friends, or online sources (6, 16,

92, 142). In our study, other than information provision from HCPs, a third of participants sought information from other sources.

The common online information sources in our study and a study by O'Callaghan 2022, include the internet, social media, and online cancer support groups. (92) These platforms can be beneficial in certain aspects, as they facilitate patient engagement, and empowerment and enhance informational support (146). Although online resources are favourable in some regards, there is a risk of misinformation, and survivors being overwhelmed with excessive information (147). It is common for patients to explore alternative approaches, such as supplement use and fad diets, from information gained from the internet, many of which are not backed by scientific evidence (148). This highlights that HCPs should provide direct informational support to patients or clear referral to appropriate online resources.

Dietary Information needs

CRC survivors need individualised dietary information on symptom management after treatment and surgery, weight management, and general healthy eating (7, 142, 149).

The type of advice and support received from HCPs was minimal for our cohort. Two respondents received advice on introducing new supplements, one on introducing foods, one on reducing or eliminating foods, and one on losing weight. However, no respondent received advice on how to gain weight.

Two-thirds of CRC survivors reported receiving insufficient support and advice about their nutritional and gastrointestinal problems. Despite dietitians being the primary source of nutritional information, only half of the respondents found the information helpful. One rated it as 'not so helpful', while one participant stated it was 'not at all helpful'. Survivors reported that they needed regular follow-up, tailored advice to address specific symptoms, and advice on a balanced meal.This is consistent with an Irish national study (89) that reports that almost all cancer survivors who attended a dietitian's consultation found it at least somewhat helpful. Those survivors who had not accessed a dietitian, reported that they required additional dietary advice on gastrointestinal issues (89).

Beliefs, knowledge and dietary changes post-treatment

All respondents in the present study believed that diet was very important to cancer recovery, and only one respondent considered it unimportant for prevention of cancer recurrence. This aligns with a large national cross-sectional study from Ireland, where 86% of participants rated nutrition as being very or extremely important in all cancer recovery, and recurrence prevention (89).

In our present study, most participants were very aware of the items included in the WCRF/AICR recommendations on cancer prevention (54) and were relatively compliant with the guidelines. Concerningly, red meat intake is still more than three portions per week in some CRC participants, and daily processed meats consumption was still high for some participants. These findings suggest that despite knowledge of the recommendations, this has not led to dietary behavioural change for some participants, and this highlights the importance of ongoing dietary support in these survivors from HCPs.

Half of the respondents introduced dietary supplements, including fibre supplements and zinc. Zinc supplements are favourable in CRC survivors due to their protective effects against tumours. An Australian population-based case-control study (n=1,812) supported these findings and reported a decreased risk of CRC for zinc, phosphorus, and iron supplements (150). The potential mechanisms include inhibiting free radical production, which may subsequently lower the occurrence of harmful gene mutations (150). Fibre supplements, such as Metamucil and psyllium husks, increase fibre intake and are associated with reduced CRC recurrence risk, and improved bowel symptoms such as constipation.

Half of the respondents in the present study reduced alcohol consumption without receiving advice from an HCP. This is similar to a cross-sectional survey by Breedveld-Peters's in the Netherlands, who report 64% CRC survivors limited alcohol intake (94) and in an Australian population-based study where more than one-third of CRC survivors limited alcohol consumption (90).

Physical activity advice provision

Two-thirds of respondents received PA advice from an HCP, resulting in 75% of these respondents increasing PA. The U.S. Physical Activity Guidelines Advisory Committee suggests most health benefits are achieved with at least 150 minutes of moderate-intensity PA per week (or approximately 500 MET-minutes/week) (151). Each respondent from this study met this recommended PA guideline, with an average of 509 MET-minutes per week.

However, half of the participants felt they received insufficient PA advice and support. Survivors require clear and specific PA guidelines for them to follow after treatment and repeat follow-up visits and motivation from a HCP to maintain PA at recommended levels that are patient-specific relative to their exercise capacity and co-morbidities (152). CRC survivors desired support to make lifestyle changes, and accountability seems to play a role in the motivation and self-control of individuals (152).

Strengths and Limitations

Please refer to Chapter 4, this is a brief summary of strengths and limitations.

The focus of this present pilot study was to provide an overview of current practices across New Zealand, and to inform a larger study. The design of this study employed the application of a quantitative survey which included open-ended questions to explore the sources and quality of dietary and lifestyle advice.

This study is not representative due to the small sample size. Recruitment was also challenging despite recruiting from the major cancer and CRC non-Governmental agencies in New Zealand. Possible reasons for low recruitment may be that this reflects a lack of perceived relevance of the importance of diet and lifestyle in CRC recovery and preventing recurrence.

In addition, we used convenience sampling, which could lead to sampling bias and attract CRC survivors who are already interested in this topic, resulting in biased data and results. In this study, CRC survivors were recalling their experiences sometime after the service provision. As such, there is a risk of recall bias as memory is imperfect and

recalled events can be inaccurate. Further, the cross-sectional design has limitations in investigating causal relationships. With the small and heterogeneous sample, it is challenging to reach definitive conclusions about the presence or absence of patterns based on respondents' characteristics. Furthermore, the suitability of nutrition advice for cancer stage, symptoms or morbidity was not assessed. The frequency of the advice provision to CRC survivors was also not examined. A structured and systematic approach should be developed to provide dietary information for CRC survivors throughout their cancer trajectory. However, this needs to be supported through a larger study. To increase the sample size, researchers may need to approach the hospital to contact past CRC survivors from the register, and/or to invite participants from GPs.

3.6 CONCLUSION

Most participants received dietary advice during treatment, but did not receive any information to address their gastrointestinal symptoms after treatment, a key and vulnerable timing for the survivors mentally, financially, and physically. The current practice did not meet the NICE guidelines recommended for managing colorectal (bowel) for HCPs: to prepare patients for discharge after treatment for CRC by advising on diet, including general advice on foods that can trigger or alleviate gastrointestinal problems, and adapting physical activities (145). Although all participants met the U.S Physical Activity Guidelines Advisory Committee guidelines by achieving at least 150 minutes of moderate-intensity PA per week, the CRC survivors reported insufficient support. The result of the present study suggests that dietary and PA support, and the needs of CRC survivors are unmet. A larger study is required to examine the current service provision for dietary and lifestyle information and support, to identify resources and barriers, to identify the CRC survivors who would most benefit, and to inform a standardised care package for CRC survivors. The present study has provided preliminary information on information and service provision, and allowed the evaluation and testing of the questionnaires, and recruitment processes to inform the larger study.

CHAPTER 4. CONCLUSION AND RECOMMENDATIONS

4.1 STUDY SUMMARY

This research investigated the experience of and access to nutritional care and information, dietary beliefs, and behaviours of CRC survivors in the community of New Zealand. It also showed several significant findings that need future research to provide insights into the gaps in nutritional care and support of CRC survivors. The conclusions of the present study informed a proposed representative cross-sectional study to answer these aims.

Further, to aid ease of use of the questionnaire for CRC survivors and to inform the proposed cross-sectional study, an evaluation test was conducted on the pilot CRC questionnaire. The evaluation test indicated that the pilot questionnaire is most likely easy to understand for respondents, and is of adequate length.

Key findings from the pilot cross-sectional study indicated that most respondents received nutritional advice from HCPs during treatment, but not post-treatment. The lack of post-treatment advice and support is concerning as most participants experienced gastrointestinal problems and weight changes over the past six months. The NICE guidelines on managing colorectal (bowel) cancer recommended that HCPs: “Prepare people for discharge after treatment for colorectal cancer by giving them advice on diet, including advice on foods that can cause or contribute to bowel problems such as diarrhoea, flatulence, incontinence and difficulty in emptying the bowels; and adapting physical activity to maintain their quality of life” (145). Our study has shown that there is a lack of individualised dietary information from HCPs that addresses the specific nutritional needs and gastrointestinal problems of CRC survivors, and systems need to be developed to ensure the NICE guidelines are met in New Zealand.

In the present study, dietitians were CRC survivors’ primary sources of nutritional information. In contrast, other New Zealand studies (12, 16) and international studies (6, 92, 142) reported difficulty in accessing a dietitian, which reflects a lack of dietetic

support to cancer survivors and unmet needs. Our findings that CRC survivors did access dietitians may be due to the small sample size, and the participants were not representatives of CRC survivors in New Zealand. Hence, the findings should be interpreted with caution.

CRC survivors in this study believed that diet is very important for cancer recovery and the prevention of cancer recurrence. Although they were aware of the items in the WCRF/AICR recommendations on cancer prevention (76), low adherence to some of these WCRF/AICR recommendations was observed. Concerningly, red meat intake is still more than three portions per week in some CRC participants, and daily processed meat consumption was still high for some participants. These findings suggest that despite knowledge of the recommendations, this has not led to dietary behavioural change for some participants, and this highlights the importance of ongoing dietary support in these survivors from HCPs.

Regarding physical advice provision, the present study discovered that most respondents increased PA as a result of the advice received from HCPs and achieved the U.S Physical Activity Guidelines Advisory Committee guidelines of at least 150 minutes of moderate-intensity PA per week (151). However, respondents reported receiving insufficient PA advice and support, and that they require clear and specific PA guidelines to follow after treatment and regular follow-up visits from an HCP to maintain PA (152).

There is a potential gap in cancer care and accessibility to dietitian support for CRC survivors. Not all CRC patients have access to a dietitian to address side effects after treatment, and HCPs do not consistently provide dietary and lifestyle advice to every patient (See Chapter 5). Further, due to the small sample in our present study, we cannot assess the level of access to dietetic care for CRC survivors after diagnosis and during treatment. These gaps in service provision will result in unmet needs in CRC survivors, impact recovery, increase risks of CRC recurrence, and reduce health-related quality of life.

In summary, there is an urgent need to create a structured pathway for CRC survivors to access evidence-based dietary and lifestyle advice and care from HCPs, especially dietitians with expertise in CRC symptom management and recovery, to make sure they

are equipped with the essential knowledge to aid cancer recovery and reduce cancer recurrence.

4.2 STUDY STRENGTHS AND LIMITATIONS

To the best of our knowledge, this is the first study to explore the beliefs, behaviours, and access to information of CRC survivors in New Zealand.

The focus of this present pilot study was to provide an overview of current practices across New Zealand, and to inform a larger study.

The design of the present study utilised the application of a quantitative survey, which included open-ended questions to explore the sources and quality of dietary and lifestyle advice, and changes in behaviour. We also conducted an evaluation test on the CRC online questionnaire, and confirmed the readability, comprehensiveness, and suitability of the questionnaire for CRC survivors.

There are some limitations. This study is not representative due to the small sample size. Recruitment was also challenging despite recruiting from the major cancer and CRC non-governmental agencies in New Zealand. Possible reasons for low recruitment may be that this reflects a lack of perceived relevance of the importance of diet and lifestyle in CRC recovery and preventing recurrence.

In addition, we used convenience sampling, which could lead to sampling bias and attract CRC survivors who are already interested in this topic, resulting in biased data and results. In this study, CRC survivors were recalling their experiences sometime after the service provision. As such, there is a risk of recall bias as memory is imperfect and recalled events can be inaccurate.

Further, the cross-sectional design has limitations in investigating causal relationships. With the small and heterogeneous sample, it is challenging to reach definitive conclusions about the presence or absence of patterns based on respondents' characteristics.

Additionally, the suitability of nutrition advice for cancer stage, symptoms or morbidity was not assessed. The frequency of the advice provision to CRC survivors was also not examined. A structured and systematic approach should be developed to provide dietary information for CRC survivors throughout their cancer trajectory. However, this needs to be supported through a larger study.

4.3 RECOMMENDATIONS FOR CLINICAL PRACTICE

The findings from the present study suggest that there is a lack of dietary and lifestyle advice and support for CRC survivors, especially tailored advice for side effects after treatment. CRC survivors believe it is important to provide nutritional advice that is individualised and accessible in different stages of the cancer journey (from diagnosis to post-treatment) to deal with the side effects and symptoms.

A standardised care package and referral pathway utilising clinical screening where 'Right patient to the right place at the right time' principles are applied, and the NICE guidelines on managing colorectal (bowel) cancer are implemented. This care package should identify the optimal patient and timing for dietitians to consult and ensure patients receive holistic support to recover and improve their well-being. Dietitians and other HCPs can enhance the standardised care package for individual CRC survivors by developing an individualised care plan to address individual needs and symptoms. The care plan should include follow-up consultations if indicated. Currently, there is a gap in access to dietitians, and after treatment follow-up. Our study indicated that despite dietetic consultation during treatment, for some survivors the WCRF/AICR recommendations on cancer prevention were not adhered to. This emphasises the importance of ongoing consultation for this patient cohort.

Following the treatment, non-governmental organisations and cancer focus groups will continue to support CRC survivors, however, this support does not replace the important role and expertise of dietitians in the care and ongoing support of CRC survivors in their recovery. As follows, further research is required into the health system of New Zealand in the provision of dietetic services and community services to CRC survivors.

4.4 RECOMMENDATIONS FOR FUTURE RESEARCH

In the present study, the small sample size limits the generalisability of findings. For future studies, researchers can collaborate with hospitals and GPs across rural and urban settings in New Zealand to recruit previous CRC patients who have received treatment and are in survival stage of the disease. This approach will allow the sample to be representative to ensure generalisablity.

Convenience sampling could lead to sampling bias and attract CRC survivors interested in this topic, resulting in sampling bias. Future studies could employ a random sampling method to guarantee that every individual in the population has the same likelihood of being included in this study to reduce sampling bias.

The present study did not assess the suitability of nutrition advice for cancer stage, symptoms, or morbidity. In addition, the frequency and quality of the advice provision to CRC survivors were also not examined. Anderson and colleagues (2013) found that many CRC survivors in the UK sought lifestyle guidance. However, they faced confusion, inconsistent messaging, culturally inappropriate advice, and uncertainty about the evidence supporting its evidence (100). Future research in New Zealand could assess the frequency, timing, and quality of advice provision. Given New Zealand has an indigenous population and is multicultural, future research should assess the sources and quality of advice and information to cultural groups, assess its suitability, and to identify any unmet information needs.

Finally, research is required to assess if the current health system in the provision of dietary and lifestyle advice and information to CRC survivors leads to changes in beliefs about the role of diet in recovery, recurrence, and well-being, and if the advice leads to healthier behaviours. The pilot study presented in this thesis will inform the design and conduct of a representative cross-sectional study to answer these questions.

CHAPTER 5. A PILOT CROSS-SECTIONAL STUDY EXAMINING THE DIETARY AND LIFESTYLE GUIDANCE PROVIDED BY NURSE PRACTITIONERS AND CANCER SUPPORT WORKERS IN NEW ZEALAND

Chapter 5 provides a **separate stand-alone chapter** on a substudy which is a pilot cross-sectional collection of data to describe the role and resources of HCPs in the provision of dietary advice and support to CRC survivors in New Zealand. The pilot substudy is to gain preliminary data and to inform a larger cross-sectional survey on the role of HCPs in CRC cancer survivorship.

5.1 INTRODUCTION

Colorectal cancer survivors often experience physical, psychosocial, economic, and HRQoL impacts from the cancer and subsequent treatment (29, 36, 41, 134). They require supportive care and information from HCPs to address these impacts.

Healthcare professionals have a major role in managing CRC survivors' recovery journey through cancer supportive care. One of the key roles of HCPs in cancer supportive care is the provision of trustworthy and evidence-based dietary and PA information and programmes to aid recovery, improve well-being, and to prevent recurrence (110).

A recent New Zealand study on all oncology types reported that insufficient dietary information provision is due to a limitation in access to health professionals (e.g., dietitian appointments), insufficient funding, limited staff time and capacity, and gaps in access to evidence-based information (124). Older international studies investigating the needs of CRC survivors reported they experienced unmet information needs and wanted more information regarding diet, physical activity, and weight management from their HCPs (123, 132). A 2012 New Zealand study on diet and CRC outpatients in a hospital setting, 32.5% received dietary advice, mainly from a dietitian (6/40, 15%) or friend/family

member, with no dietary information received from their doctor or nurse. Sixty-one percent of the patients felt they received little or too little information, and 98% of participants would be interested in receiving additional dietary advice (16).

Specifically, CRC cancer survivors need to be provided with the knowledge and skills for a healthy behaviour change to improve self-management, reduce cancer recurrence, address fears about food choices, alleviate ongoing symptoms, and improve quality of life and well-being.

In New Zealand, the role of HCPs in dietary assessment, knowledge and role in providing advice and support on diet and lifestyle, and referral pathways for CRC survivors residing in the community is unknown.

The aim of this study is the pilot collection of data to gain preliminary insights into the role and resources of HCPs in the provision of dietary and lifestyle advice and support to CRC survivors in New Zealand. Further, we aimed to test the feasibility of recruitment and data collection strategies (Please note: These findings are not reported in this chapter).

5.2 METHODS

Study Design

This pilot descriptive cross-sectional survey was conducted in the community in New Zealand from May to October 2024.

Participants and Recruitment

A convenience sample of HCPs was recruited through major cancer non-governmental organisations in New Zealand. Inclusion criteria required participants to be HCPs (e.g., nurses, dietitians, or general practitioners) aged 18 and older who had experience providing care to CRC survivors in the community or government-funded health services. Convenience sampling was employed due to time constraints and limited access to the National Cancer Registry, ensuring the recruitment of as many participants as possible within the available resources.

The recruitment advertisement (see Appendix A.2) was emailed three times by major cancer non-governmental organisations, and the New Zealand Nursing Organisation (NZNO) to their support staff and members. HCPs who were interested in participation were asked to complete informed consent, and a link was provided to the online questionnaire. Participants accessed the questionnaire via Massey University hosted Qualtrics Software (2024). All data was securely stored in a password-protected server at Massey University.

Questionnaire Development

A questionnaire (Appendix C.3) was developed based on the investigators utilising a literature review on the quality of dietary and physical activity advice, and CRC survivors' information needs. The questionnaire encompassed 11 sections. These included basic demographic and employment information, service access, nutrition assessment for CRC survivors, HCPs' perceptions of the role of nutrition in CRC care, provision of information, nutrition issues, referral trajectory and barriers encountered when providing nutrition information, and HCPs' practice related to CRC care.

Statistical analysis

A power calculation of sample size for a cross-sectional survey was not conducted as this pilot study gathered preliminary data only to gain insights into the role of HCPs, and to inform a proposed larger study.

Collected data was entered into IBM SPSS Statistics (v. 29) and analysed. Descriptive statistics were employed for participants' demographics, behaviours, knowledge and attitudes. Ordinal data were presented as frequencies or percentages. Continuous data was reported as mean + SD, and the median and interquartile range were used for non-normally distributed data. Body mass index (BMI) was derived from the World Health Organisation calculation (weight in kg divided by height in m^2).

Ethics

This study received ethical approval from the Massey University Human Ethics Committee, which granted it low risk (Ethical application number: 4000029285).

5.3 RESULTS

A total of six participants were recruited into this study, with data collected at a single time point. This was a 100% recruitment rate during the recruitment period. There was 1% of missing data on questionnaires. Table 5.1 presents the characteristics of participants. Five of the respondents were female nurse practitioners from District Health Boards (DHBs) and one HCP was a cancer support worker. All worked within urban areas of New Zealand. Half of the respondents were between the age of 56 and 65, with the rest younger than 55 years.

Table 5.1 Summary of the demographic characteristics of the healthcare professionals

Respondents' characteristics	**n (%)**
Gender	
Female	6 (100)
Age	
26 to 35 years	1 (16.7)
36 to 45 years	1 (16.7)
46 to 55 years	1 (16.7)
56 to 65 years	3 (50)
Current professions	
Oncology nurse specialist	2 (33.3)
Clinical nurse specialist	2 (33.3)
Cancer nurse co-ordinator	1 (16.7)
Cancer support worker	1 (16.7)
Health Sectors	
DHB	6 (100)
Location of practice	
City based	6 (100)

Referral to healthcare professionals

Colorectal cancer patients/survivors were referred to the HCPs by hospitals and general practitioners. Healthcare professionals' assessment and management strategies for triaging patients are outlined in Table 5.2. All HCPs reported measuring weight and height to estimate body mass index (BMI), with 83.3% conducting a nutritional assessment. Only a single HCP reported they used a validated screening tool, the Malnutrition Universal Screening Tool (MUST). Sixty-seven percent of the respondents assessed alcohol consumption, and 100% assessed physical activity levels.

Table 5.2 Nutrition assessment by healthcare professionals

Assessment	n (%)
Measure weight and height to estimate BMI	
Yes	6 (100)
Nutritional assessment	
Yes	5 (83.3)
No	1 (16.7)
Nutrition status screening tool	
Yes	1 (16.7)
No	4 (66.7)
Screening tool	
MUST	1
Physical activity level assessment	
Yes	6 (100)
Alcohol consumption assessment	
Yes	4 (66.7)
No	2 (33.3)

Beliefs of the healthcare professionals

Healthcare professionals' beliefs regarding the role of diet and physical activity in colorectal cancer recovery and recurrence are shown in Table 5.3. All respondents deemed diet to be very important (66.7%) or important (33.3%) for colorectal cancer recovery. In terms of diet's role in colorectal cancer recurrence, responses were varied: 16.7% felt diet was not important, 33.3% viewed it as slightly important, 16.7% as fairly important, 16.7% as important, and 16.7% as very important. Regarding alcohol consumption, 33.3% of respondents considered it very important, 33.3% deemed it important, 16.7% slightly important, and 16.7% not important.

HCPs perceived physical activity to be very important (33.3%), important (33.3%), fairly important (16.7%), and slightly important (16.7%) for cancer recovery. Regarding physical activity's role in cancer recurrence, 16.7% of HCPs considered it very important, 33.3% important, 33.3% fairly important, and 16.7% not important.

Table 5.3 Healthcare professionals' beliefs about the role of nutrition on colorectal cancer recovery and recurrence

Beliefs	Very Important n (%)	Important n (%)	Fairly important n (%)	Slightly important n (%)	Not important n (%)
Diet role in recovery	4 (66.7)	2 (33.3)	0	0	0
Diet role in recurrence	1 (16.7)	1 (16.7)	1 (16.7)	2 (33.3)	1 (16.7)
PA role in recovery	2 (33.3)	2 (33.3)	1 (16.7)	1 (16.7)	0
PA role in recurrence	1 (16.7)	2 (33.3)	2 (33.3)	0	1 (16.7)
Alcohol role in recurrence	2 (33.3)	2 (33.3)	0	1 (16.7)	1 (16.7)

Practices of healthcare professionals

Common management strategies (Table 5.4) for CRC survivors included referrals to internal or external registered dietitians, referrals to internal or external nutritionists, referrals to cancer survivors' programmes offered by non-governmental organisations, and referrals to internal and external exercise programmes. Funding for the dietitian consultations was provided by respondents' organisations (16.7%), publicly funded sources (50%) or privately funded (33.3%)

Table 5.4 Management strategies by healthcare professionals

Patient Management strategies	n (%)
Referral to internal registered dietitian	
Yes	5 (83.3)
No	1 (16.7)
Referral to external registered dietitian	
Yes	3 (50)
No	3 (50)
Methods of external referral	
Directly referred	3
Referred through their GP	1
Self-referred	1
Funding of the services	
Paid by my organisation	1 (16.7)
Publicly funded	3 (50)
Privately funded	2 (33.3)
Referral to internal nutritionist	
Yes	2 (33.3)
No	4 (66.7)
Referral to external nutritionist	
Yes	1 (16.7)
No	5 (83.3)

Table 5.4 continued

Patient Management strategies	n (%)
Referral to cancer survivors programme	
Yes	1 (16.7)
No	5 (83.3)
Referral to internal exercise rehabilitation programme	
Yes	1 (16.7)
No	5 (83.3)
Referral to external exercise rehabilitation programme	
Yes	2 (33.3)
No	4 (66.7)

Ideal timing for dietary and PA information provision

HCPs were asked of the most appropriate time(s) to address diet and lifestyle for CRC patients/survivors (Table 5.5). Two-thirds (66.7%) of the HCPs felt the best time to provide dietary advice was 'during recovery' (66.7%), followed by 'at diagnosis' (50%), 'immediately after treatment' (50%), and 'during treatment' (33.3%). For physical activity advice, 83.3% of HCPs considered it to be 'at diagnosis', followed by 'during recovery' (66.7%), 'during treatment' (50%), and 'immediately after treatment' (50%).

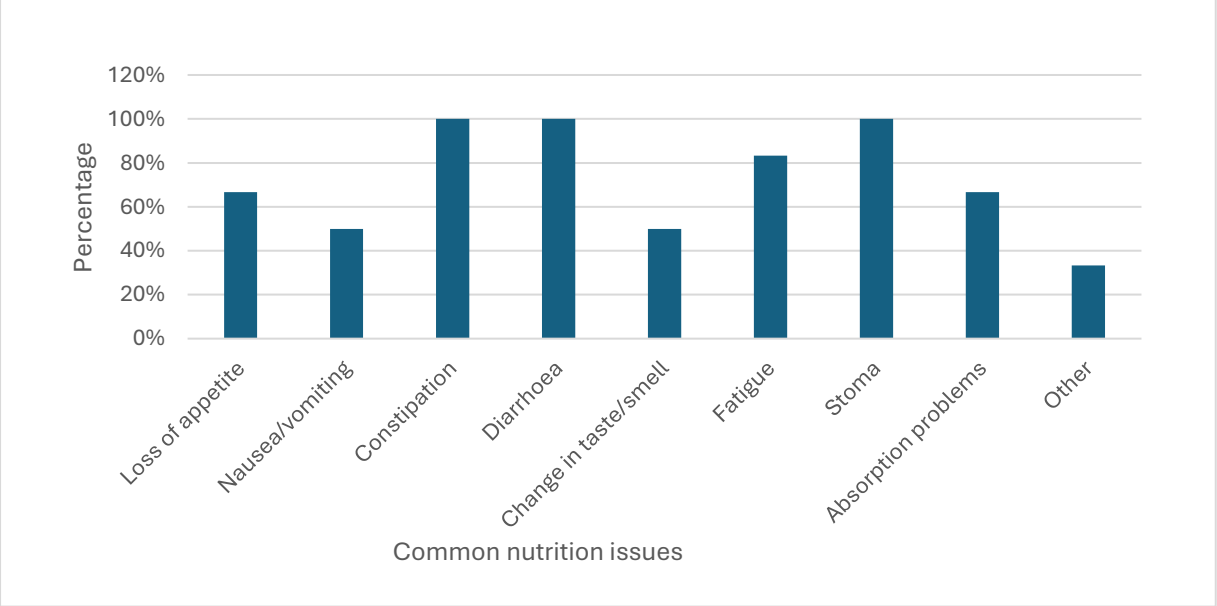
Table 5.5 Healthcare professionals' recommended timing to dietary and physical activity information provision during cancer trajectory

Time	At diagnosis n (%)	During treatment n (%)	Immediately after treatment n (%)	During recovery n (%)
Dietary Advice				
Yes	3 (50)	2 (33.3)	3 (50)	4 (66.7)
No	3 (50)	4 (66.7)	3 (50)	2 (33.3)
Physical Activity Advice				
Yes	5 (83.3)	3 (50)	3 (50)	4 (66.7)
No	1 (16.7)	3 (50)	3 (50)	2 (33.3)

Nutritional issues experienced by CRC patients/survivors

Healthcare professionals commonly observed nutritional issues resulting from surgery and treatment, including constipation, diarrhoea, stoma, fatigue, loss of appetite, absorption problems, nausea or vomiting, and changes in taste or smell (Figure 5.1).

Figure 5.1 Nutrition issues that colorectal cancer survivors experience



Additional clinical needs of patients/survivors identified by the HCPs included providing dietary recommendations for Low Anterior Resection Syndrome, managing bowel function, tailoring diets for altered bowel function and bloating after surgery.

HCPs' provision of dietary and physical activity advice

HCPs' provision of dietary and physical activity advice is as follows (Table 5.6). Only one of the HCPs provided dietary advice to all patients. For other HCPs, dietary advice was based on the patient's needs, namely, those who requested nutritional advice, had poor nutrition status, were underweight or overweight, had other medical conditions, or had special needs due to treatment. HCPs responded to an open-question that information was limited, and not routinely provided and dietary advice is symptom-specific (nausea, constipation, diarrhoea, reflux, etc.).

Table 5.6 Information provision and patient needs

Item	n (%)
Information provision on Diet to some patients	6 (100)
Information provision on Diet to all patients	1 (16.7)
Type of patients	
Patients asked nutritional advice	5 (83.3)
Patients with poor nutrition status	5 (83.3)
Patients who are underweight	5 (83.3)
Patients with special needs caused by treatment	4 (66.7)
Patients who are overweight	2 (33.3)
Patients with other conditions	1 (16.7)

HCPs' confidence in providing dietary advice and educational needs

Two-thirds of HCPs who offered dietary advice reported being moderately confident in giving advice (Table 5.7), while 16.7% felt very confident, and another 16.7% were somewhat confident. Only a third of the HCPs had received formal training in providing dietary advice, and the majority expressed interest in additional professional

development. The majority of HCPs reported that their organisation requires better policy with evidence-based guidelines on the dietary information provided to CRC patients.

Table 5.7 Confidence in providing dietary advice and training

Confidence level in giving advice	**n (%)**
Very confident	1 (16.7)
Moderately confident	4 (66.7)
Somewhat confident	1 (16.7)
Education needs	**n (%)**
Education on diet received	
Yes	2 (33.3)
No	4 (66.7)
Further education on diet required	
Yes	5 (83.3)
No	1 (16.7)
Organisation requires improvements in their evidence-based policy to guide diet information provision to CRC patients	
Yes	5 (83.3)

Resources provided to CRC patients/survivors by the Organisations

Resources provided to CRC patients/survivors by the organisations are reported in Table 5.8. Eighty-three percent indicated that their organisations supplied educational resources. The most common resources were verbal advice (83.3%), pamphlets or leaflets (66.7%), booklets (33.3%), and links to online information (16.7%).

Specifically, in addition to verbal advice on diet, some HCPs provided physical activity advice (66.7%), cooking advice (33.3%), and written healthy recipes (16.7%). Pamphlets are provided for patients with stomas (particularly an ileostomy) and a pamphlet for patients with Low Anterior Resection Syndrome.

Table 5.8 Dietary resources provided to CRC patients by organisations

Resources	**n (%)**
Yes	5 (83.3)
No	1 (16.7)
Type of resources	
Verbal advice	5 (83.3)
Pamphlets/leaflets	4 (66.7)
Booklets	2 (33.3)
Links to websites	1 (16.7)
Specific advice provided to patients/survivors	**n (%)**
Written healthy recipes	
Yes	1 (16.7)
No	5 (83.3)
Cooking advice	
Yes	2 (33.3)
No	4 (66.7)
Physical activity advice	
Yes	4 (66.7)
No	2 (33.3)

World Cancer Fund and American Institute for Cancer Research (WCRF/AICR) recommendations

HCPs were asked if they discuss the WCRF/AICR recommendations (76) with patients (Table 5.9).

With reference to the WCRF/AICR recommendations:

Healthy weight: approximately one-third of the respondents provided this advice most of the time, one-third provided it some of the time, a third offered it rarely.

Healthy balanced diet: most of the respondents provided this advice most of the time, with 16.7% providing it some of the time.

Increased fibre intake: 83.3% of HCPs recommended some of the time.

Increase vegetable and fruit intake: 16.7% of the respondents provided this advice always, one-third offered it most of the time, and 50% provided it some of the time.
Reduce/stop alcohol intake: 33.3% provided this advice most of the time, another 33.3% offered it some of the time, 16.7% gave it rarely, and 16.7% never provided this advice to CRC survivors.
Limiting red meat intake: half of the respondents advised intake some of the time
Limiting 'processed' meat intake: approximately two-thirds some of the time.
Fibre supplement use: 50% of HCPs recommended supplementation some of the time.

In an open question, HCPs report that they provide advice on diet and bowel function, foods that may increase the risk of cancer occurrence, protein supplementation, alcohol consumption, undertaking daily activity, smoking cessation

Perceived barriers to providing dietary and lifestyle information

All respondents reported experiencing barriers to providing dietary and lifestyle information to CRC patients and survivors (Table 5.10). Five out of six participants reported there was not adequate screening to identify nutritional risks. Four out of six respondents believed that there needs to be an improvement in the referral process to registered dietitians.

Table 5.9 Provision of WCRF/AICR recommendations to colorectal cancer survivors

Recommendations	Always n (%)	Most of the time n (%)	Some of the time n (%)	Rarely n (%)	Never n (%)
Healthy weight	0	2 (33.3)	2 (33.3)	2 (33.3)	0
Healthy balanced diet	0	5 (83.3)	1 (16.7)	0	0
Increase fibre intake	0	1 (16.7)	5 (83.3)	0	0
Increase vegetable and fruit intake	1 (16.7)	2 (33.3)	3 (50)	0	0
Reduce/stop alcohol intake	0	2 (33.3)	2 (33.3)	1 (16.7)	1 (16.7)
Limit red meat intake	0	1 (16.7)	3 (50)	2 (33.3)	0
Limit processed meat intake	0	1 (16.7)	4 (66.7)	1 (16.7)	0
Fibre supplement use	0	1 (16.7)	3 (50)	0	2 (33.3)

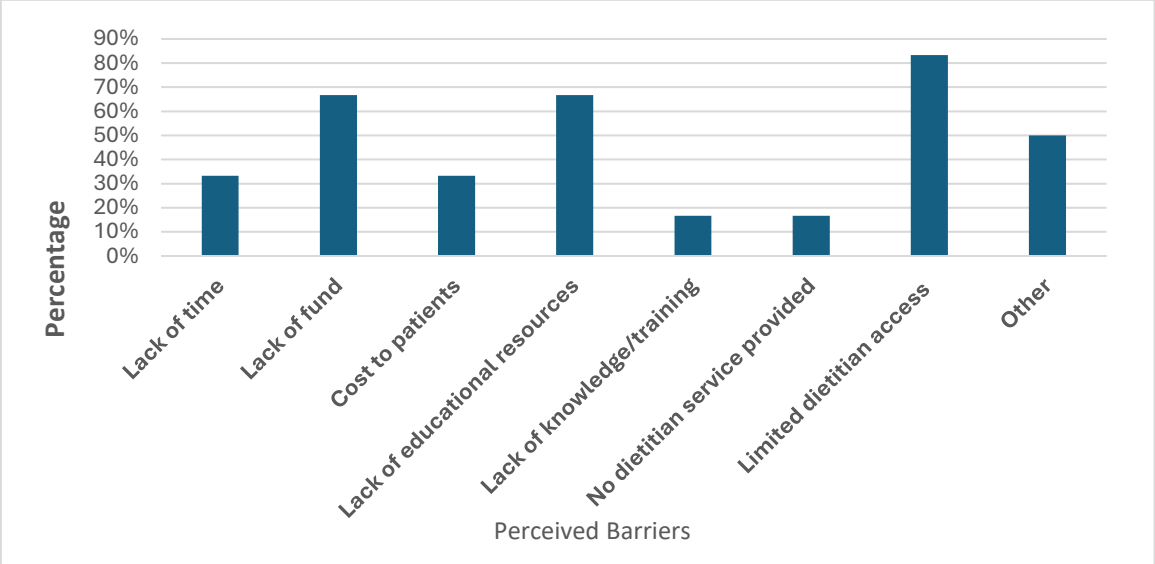
Table 5.10 Healthcare professionals perceived barriers to information provision, screening needs, and improvement in the referral process to a dietitian

Issues facing in practice	n (%)
Perceived Barriers	
Yes	6 (100)
Adequate screening to identify nutrition risk	
Yes	1 (16.7)
No	5 (83.3)
Improvement required for the referral process to a dietitian	
Yes	4 (66.7)
No	2 (33.3)

The most reported barriers to information provision included limited access to dietitians (83.3%), lack of funds (66.7%), insufficient educational resources (66.7%), time constraints (33.3%), cost to patients (33.3%), limited knowledge or training (16.7%), absence of dietitian services within their organisations (16.7%) (See Figure 5.2).

Other responses were that there was a lack of a free community dietitian service, and that within organisations there were insufficient dietitians employed to consult with all oncology patients, with other cancer patients often having priority over CRC patients. Further, “referrals to community dietitians get declined or have a long waitlist creating a significant inequity for cancer patients”. Clinical nurse specialists report that they try to give advice to CRC patients, but ideally it should be a dietitian. HCPs also stated that it would be “great to have a dietician available pre-surgery or chemotherapy to talk to our patients about good nutrition through treatment and after treatment”.

Figure 5.2 Perceived barriers to information provision



Ideal and actual information provision by healthcare professionals

Healthcare professionals responded that ideally the following health professions had the primary role of providing nutritional advice to a CRC survivor (Table 5.11). The majority of the respondents (83.3%) believed that registered dietitians, specialised cancer dietitians, GPs, specialists, primary care nurses, nurses and other HCPs should provide dietary and physical activity information to CRC patients and survivors. However, in actual practice (Table 5.11), the health professionals providing nutritional advice to CRC survivors included general practitioners (50%), specialists (33.3%), primary care nurses (33.3%), nurses or other HCPs (16.7%), and others (50%).

Table 5.11 Primary role in providing nutritional advice to a colorectal survivor

Profession	Ideal Practice n (%)	Actual Practice n (%)
General practitioner	5 (83.3)	3 (50)
Registered dietitian	5 (83.3)	0
Specialised cancer dietitian	5 (83.3)	0
Specialist (oncologist/surgeon)	5 (83.3)	2 (33.3)
Primary care nurse	5 (83.3)	2 (33.3)
Nurse or other healthcare professionals	5 (83.3)	1 (16.7)
Nutritionist	3 (50.0)	0
District community nurse	2 (33.3)	0
Surgical team	1 (16.7)	1 (16.7)
Nurse specialists	1 (16.7)	2 (33.3)

5.4 DISCUSSION

This pilot cross-sectional sub-study aimed to gain preliminary evidence into the role and resources of healthcare professionals in providing dietary and lifestyle recommendations and support to CRC survivors in New Zealand. The HCPs who responded to the recruitment advertisement were nurse practitioners (oncology nurse specialist, clinical nurse specialist, cancer nurse coordinator) and cancer support workers. All were city-based working for the District Health Board.

The present study provides preliminary evidence that there is a potential gap in cancer care and accessibility to dietetic support for CRC survivors. Not all CRC patients have access to a dietitian to address side effects after treatment, and HCPs did not consistently provide dietary and lifestyle advice to every patient and required further professional development.

Practices of HCPs

HCPs reported that many CRC patients and survivors have complex nutritional issues, with the most prevalent being loss of appetite, nausea, constipation, diarrhoea, change in taste and smell, fatigue, absorption problems, and the nutritional issues associated with ostomy. Additionally, patients presented with issues related to Low Anterior Resection Syndrome, managing bowel function, tailoring diets for altered bowel function and bloating after surgery.

In practice, all HCPs conducted BMI assessments, the majority conducted nutritional assessments and lifestyle assessments (alcohol and PA), but only one respondent utilised a validated screening tool for malnutrition.

Ideal and actual information provision

In the present study, most of the HCPs held strong beliefs in the role of diet in cancer recovery, while their views on its role in cancer recurrence were less consistent. Almost all respondents in our study believed that registered dietitians, specialised cancer dietitians, GPs, specialists, primary care nurses, nurses and other HCPs should provide dietary and physical activity information to CRC patients and survivors. However, in practice, GPs, specialists, primary care nurses, nurse specialists, and surgical teams were more likely to provide the advice, while dietitians were not the primary sources of information. These findings are in agreement with an Irish study, where only one-third of cancer patients attended a dietitian appointment in either a hospital or community setting (89). Cancer survivors experiencing unintended weight loss were more likely to see a dietitian (89).

In our study, common management strategies included referrals to internal or external dietitians, nutritionists, cancer survivor programmes offered by NGOs, and exercise programmes. In the present study, it is not known if some referrals to dietitians are declined due to strict referral criteria or resource constraints.

Our study revealed that only one HCP provided dietary advice to all patients. Others provided dietary advice when patients requested it, had poor nutrition status, were

underweight or overweight, had comorbidities, or had special needs after treatment. Similarly, a New Zealand study reported CRC survivors received insufficient information to meet their needs (16). In a semi-structured interview, CRC survivors without a stoma received limited dietary support compared with those who had a stoma (152). Despite the stoma status, the CRC survivors articulated a need for dietary information and support after treatment (152).

Furthermore, there was a variation in the discussion of WCRF/AICR recommendations with CRC patients between respondents. The most discussed recommendation was maintaining a healthy balanced diet. Other recommendations, such as increasing fibre intake, limiting processed meat intake, limiting red meat intake, and increasing vegetable and fruit intake, were only discussed with CRC patients occasionally. There is a potential for a gap in information provision to CRC patients, as many do not get referred or are consulted by a dietitian, which provides an essential need for other HCPs to provide this service in discussing the WCRF/AICR recommendations. Compliance to these guidelines have been associated with increased health related quality of life, physical functioning, and reductions in fatigue (153, 154).

Ideal timing for dietary and PA information provision

HCPs in the present study stated that the ideal time to provide dietary advice is any stage from diagnosis to recovery, but less advisable during treatment.

In terms of PA advice provision, most HCPs considered the ideal time to be at any time point in the stages of diagnosis, treatment and recovery. Interestingly, an Australian scoping review found that treatment providers often failed to provide dietary advice after treatment or explain their role in recovery (149). Similarly, a previous UK study reported HCPs had mixed beliefs about the timing of dietary and lifestyle advice (122). While some HCPs believed that advice should be patient-driven and advice provided when the patient requires it, others suggested that it should begin at diagnosis and be repeated during each follow-up consultations (122). Another UK study demonstrated that CRC survivors preferred to receive advice at the end of the treatment to mitigate stress, anxiety, and nutritional problems (100). In contrast, a Dutch mixed-method study highlighted that

CRC survivors preferred receiving support both during and after treatment, especially immediately after treatment (7). These variations highlighted the need for patient-centred approaches to determine the timing of dietary and PA advice, with a preference for support after treatment.

Perceived barriers to providing dietary and lifestyle information

HCPs in the present study reported experiencing barriers to providing dietary and lifestyle information to CRC survivors. These included limited access to dietitians, lack of funds, insufficient educational resources, time constraints, the cost to patients, limited knowledge or training, and the absence of dietitian services within their organisations.

In addition, almost all participants highlighted inadequate screening for nutritional risks, and the need for improving the referral process to dietitians. A recent New Zealand study reported in cancer services there was a lack of nutrition information provision, limited access to support including dietitian appointments, insufficient funding, staff time and capacity, and access to evidence-based information and dietary expertise (124).

Interestingly, in our present study, despite two-thirds of HCPs indicating moderate confidence in giving dietary advice, most HCPs expressed a desire for additional training and believed their organisations required better evidence-based guidelines to improve care for CRC survivors.

Strength and limitations

The present substudy provides novel insights into the roles and practices of HCPs to CRC survivors in New Zealand and to inform a larger study.

This sub-study is not representative due to its small sample size. Recruitment was also difficult despite recruiting from major cancer non-governmental organisations and the New Zealand Nursing Organisation (NZNO). In addition, convenience sampling was utilised and this could lead to sampling bias and attract HCPs who are already interested in this topic, resulting in biased data and results. The cross-sectional design has limitations in investigating causal relationships. With the small and heterogeneous sample, it is challenging to reach definitive conclusions about the presence or absence of patterns based on respondents' characteristics.

5.5 CONCLUSION

The present substudy recognises a potential gap in cancer care and accessibility to dietetic support for CRC survivors. Not all CRC patients have access to a dietitian to address side effects after treatment, and HCPs do not consistently provide dietary and lifestyle advice to every patient or consistently provide evidence-based information at critical time points throughout the cancer journey. These gaps may result in unmet needs in CRC survivors, increased risk of CRC recurrence, and reduced quality of life. Providing dietary and lifestyle information provision should become a shared responsibility between healthcare professionals with adequate training. Although the small sample size restricts the generalisability of the findings, this study offers valuable preliminary evidence that requires further investigation in larger populations in New Zealand. Addressing these gaps can enhance supportive cancer care, benefiting all patients.

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CHAPTER 6. APPENDICES

6.1 APPENDIX A.1: ADVERTISEMENT TO RECRUIT COLORECTAL CANCER SURVIVORS

Are you a colorectal cancer (bowel cancer) survivor?

We invite you to participate in a survey

Recovery from colorectal cancer/bowel cancer (CRC) treatment is a different experience for everyone. Massey University researchers want to learn about the dietary advice and lifestyle information that you received during your cancer journey and recovery.

What will participants be asked to do?

You will be asked to complete an online questionnaire about the dietary information and lifestyle advice that you received. It will take about 30 minutes to complete.

Who can join?

If you are 18 years and older and have received a diagnosis of CRC, and you have completed clinical treatment 6 to 30 months ago in New Zealand.

Why are we conducting this study?

We wish to know about your experiences to better support recovery. If interested, please get in touch with us.

Link to a Contact Form for more information:
https://massey.au1.qualtrics.com/jfe/form/SV_8CX2kzssaMc2iwK

Email: h.senior@massey.ac.nz

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

6.2 APPENDIX A.2: ADVERTISEMENT TO RECRUIT HEALTHCARE PROFESSIONALS

Are you a Healthcare Professional Advising Colorectal Cancer Survivors?

We invite you to participate in a survey

Recovery from colorectal cancer (CRC) treatment is a different experience for everyone. Massey University researchers want to learn about the dietary advice and lifestyle information you provide to your patients or clients during their cancer journey and recovery.

What will participants be asked to do?

You will be asked to complete an online questionnaire about dietary and lifestyle advice given to CRC survivors.

Who can join?

If you are a healthcare professional who has experience with CRC survivors.

Why are we conducting this study?

Your insights could significantly improve the care and recovery of CRC survivors. If interested, please get in touch with us.

Link to a Contact Form for more information: LINK HERE

Email: h.senior@massey.ac.nz

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

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

6.3 APPENDIX A.3: AUTHOR INSTRUCTIONS NZMJ

NEW ZEALAND
TE ARA TIKA O TE HAUORA HAPORI
MEDICAL JOURNAL

PMA PASIFIKA MEDICAL ASSOCIATION Group

Author instructions and submission guidelines

How to prepare your manuscript for submission

Document formatting

Please use Word for all submitted manuscripts. Use 1.5 line spacing and UK English. Number the pages and insert the date of the draft into the header or footer.

The order the elements of a submitted manuscript should follow is:

Title

Type of manuscript

- Original article / Viewpoint article / Review article / Case report / Medical image / Letter

Full author list (to be removed before submission for anonymous review)

- First and family names of all authors (plus middle initials if desired)

Abstract (Aim, Method, Results, Conclusion)

- We require abstracts for Viewpoint articles and Original Articles

Body of the article (Introduction, Method, Results, Discussion)

- Avoid symbols if possible (e.g., use mcg rather than µg; betablockers not ß- blockers).
- Write out numbers under 10 in full except if they are associated with units including time, e.g., 2 days, 6mg, five hospitals, 7 hours, seven patients, 12 patients. If a number begins a sentence, then write it in full. If there are a mix of large and small numbers in the same sentence or short paragraph, then all can be written as numerals.
- Insert reference citation numbers AFTER closing punctuation, and for three or more consecutive references use an en-dash to indicate range (so, in the example below, references 14, 22, 23 and 24 are cited).
    - *For example:*
      International research has demonstrated lower referral to cardiac rehabilitation programmes for women,[14,22–24] with women being 20% less likely to be referred.[22]

Competing interests

- This section should be anonymised for review.
- If none, state "Nil".

Acknowledgements (if any)

Author information (to be removed before submission for anonymous review)

Must include:

- Full names (middle initial[s] may be included) of each author
- Job positions (e.g., cardiologist, director, senior lecturer, etc.)
- Department (if any)
- Institution/Company
- Location (e.g., city, town; plus country if not New Zealand).

Corresponding author

- Name, department, institution/company, postal address, telephone number and email address of the corresponding author.

References/Bibliography

- All references must follow the Vancouver style. For more information, check the Vancouver guidelines here: https://www.nlm.nih.gov/bsd/uniform_requirements.html.

Reference limit per article type

Editorial: 12

Original article: 30

Viewpoint: 30

Clinical correspondence: 10

Letter to the editor: 10

Research letter: 12

Proceedings: Maximum of 5 references per abstract

- Put References in a numbered list. *Do not use* Word's footnote or endnote feature.

6.4 APPENDIX C.1 REGISTRATION FORM AND INFORMED CONSENT FORM OF COLORECTAL CANCER SURVIVOR SURVEY

Study Registration Form

Colorectal cancer survivors' nutritional beliefs, behaviour and access to dietary and lifestyle care

Researchers Introduction

My name is Danielle Cao, and I am a postgraduate student undertaking a thesis project to complete a Master of Science degree in Nutrition and Dietetics at Massey University. I am under the supervision of Associate Professor Hugh Senior (PhD in medicine, Postgraduate diploma in Public Health) from the School of Health Sciences at Massey University, and Dr Judy Thomas (PhD in exercise science) from the Department of Exercise Sciences at the University of Auckland.

Invitation to participate in research study

There is a growing number of colorectal cancer survivors in New Zealand. There is a need to understand the diet and lifestyle of cancer survivors, and to understand the advice and information that they received during their cancer diagnosis, treatment and recovery. These include identifying sources of information, and understanding if the information provided is resulting in improved lifestyle behaviours.

This online study aims to examine the dietary and lifestyle information and advice provided to colorectal cancer survivors by health professionals, and to gain an understanding of lifestyle of people after cancer treatment. This will enable the project to

make broad findings and inform policy for the development of initiatives to optimise information provision for colorectal cancer survivors living in the community.

You are invited to participate in this research.

Participant Identification and Recruitment

We are seeking approximately 200 participants in this study. We advertised the study through online patient groups and health professionals.

You have been invited to participate as you have experienced colorectal cancer and completed treatment.

There are no foreseeable discomforts or risks to participating in this study.

Project procedures

We will ask you to complete a questionnaire online at one time only. The questionnaire will ask about yourself, about dietary and lifestyle advice and information that you received or sought from a health professional or elsewhere. We will also seek information on your current health, diet and lifestyle. We anticipate that the questionnaire will take between 30 and 60 minutes.

What about confidentiality?

All your information will be kept confidential and no-one will ever know your information was used for this study. You will not be identified in the data. All data will be stored in a secure office and a password protected computer server at the School of Health

Sciences at Massey University. No personal information collected in this study will be used by persons outside of the research team. You will not be named or identified in any reports or publications that come out of this study. At the end of the study, all data will be deleted.

What if I change my mind about being in this study?

If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study (you can leave by closing the questionnaire);
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher

Will I get to know the results of this study?

We will send a summary report of the results to you.

Contact details

Associate Professor Hugh Senior

School of Health Sciences | College of Health

Massey University | Auckland | New Zealand

Ph: +64 9 213 6030

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Ms Danielle Cao

School of Sport, Exercise and Nutrition| College of Health

Massey University | Auckland | New Zealand

Email: d.cao@massey.ac.nz

"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact the Director, Research Ethics, email humanethics@massey.ac.nz".

If you are interested in participating in this study, please provide the following information		
For a researcher to contact you to discuss the study, we need your contact details.		
What is your name		
	First name	Surname
What is your email address		
What is your mobile phone number		
Please answer the following questions to determine whether you are potentially eligible for this study		
	YES	NO
Are you aged 18 years and older		
Have you had a diagnosis of primary colon or rectal cancer (stages I-IV).		
Have you completed clinical treatment (surgery, chemotherapy, radiotherapy)		
Did you complete clinical treatment six to 30 months ago		

THANK YOU, A RESEARCHER WILL BE IN CONTACT WITH YOU		

We could do this over the phone, once receive the email address, email PLEASE, and arrange a time for discussion to check eligibility and consent

Eligibility criteria included:

1. Diagnosis of primary colon or rectal cancer (stages I-IV). Participants with cancer of the appendix are excluded)

2. Treatment for cancer was in New Zealand

3. Has not been informed by a medical doctor that they have a terminal condition

4. Has completed clinical treatment (surgery, chemotherapy, radiotherapy)

5. Completed treatment 6 months to 30 months prior

6. Residing (free-living) in the community in New Zealand (namely, not residing in residential care)

7. Aged 18 years and older

8. Ability to understand English

9. Level of computer skills to answer an online questionnaire

10. All participants provide informed consent

Participant consent

I have read and I understand the Information Sheet. I meet the above eligible criteria of the study.

I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

Please tick below, if you consent to participate in this study.

I consent to participate in this study.

Yes No

6.5 APPENDIX C.2 COLORECTAL CANCER SURVIVOR QUESTIONNAIRE

MAIN QUESTIONNAIRE

We would like to thank you for participating in the study and ask you to complete the 11 sections of the questionnaire below. These will assess your health and the health services that you have received related to diet and lifestyle, and to understand your information needs and the changes that you have made in your lifestyle. First, we will ask you some general questions

Section 1	GENERAL QUESTIONS	
1.0	What are your initials?	
1.1	What is your gender?	1. Male 2. Female
1.2	What is your date of birth?	D D M M Y Y Y Y
1.3	What is the highest level of education that you attained?	1. Primary School 2. High School 3. Polytechnic

		4. University degree
1.4	What ethnicity do you most identify with?	1. NZ European/Pakeha 2. NZ Māori 3. Pacific people 4. Asian 5. Other, please specify _____
1.5	Where setting is your usual place of residence?	1. City 2. Town 3. Rural
1.6	What is your current living situation?	1. Living with spouse or partner 2. Living with others 3. Living alone
1.7	What weight are you in kilograms?	_____ Kg
1.8	What height are you in centimetres?	_____ cm
Section 2	HEALTH STATUS	
2.1	How would you rate your current health?	1. Excellent 2. Very good 3. Good

		4. Fair 5. Poor
2.2	What is you smoking status?	1. I currently smoke 2. I was a smoker, but I have quit 3. I have never smoked
2.3	Did you drink alcohol before your cancer diagnosis?	1. Yes 2. No
2.4	Do you currently drink alcohol?	1. Yes 2. No If yes continue to **Question 2.4.1**. If no go to QUESTION 3.1.
2.4.1	What is your current level of alcohol consumption now compared to the time of your cancer diagnosis?	1. More than before 2. The same amount 3. Less
Section 3	MEDICAL HISTORY	
3.1	What stage was your colorectal cancer at diagnosis?	1. Stage I 2. Stage II

		3. Stage III 4. Stage IV 5. Do not know
3.2	Where was the cancer located?	1. Colon 2. Rectum/rectosigmoid/ anal 3. Do not know
3.3	What year were you diagnosed with cancer?	YYYY
3.4	Do you currently have a stoma fitted?	1. Yes 2. No
3.5	Have you previously received any of the following for colorectal cancer?	1. Surgery 2. Chemotherapy 3. Surgery and Chemotherapy
3.6	Since completion of your cancer treatment, have you experienced any gastrointestinal problems in the last 6 months?	1. Yes 2. No If yes is selected continue to **Question 3.6.1**. If no is selected go to **Question 3.7**.
3.6.1	If you answered yes to the question above, please select all that apply.	1. constipation 2. diarrhoea 3. abdominal pain 4. buttock pain

		5. bloating 6. blood and mucus in stool 7. flatulence 8. faecal incontinence
3.7	Which statement best describes your weight over the last 6 months?	1. I have lost MORE than 5% of my body weight 2. I have lost LESS than 5% of my body weight 3. I have remained the SAME weight 4. I have GAINED weight
3.8	Do you have other medical conditions that may affect your diet (e.g., diabetes, or cardiovascular disease or others)?	1. 0 2. 1 3. 2 or more
3.8.1	If you answered yes to the question above, please write the major conditions that MAY AFFECT YOUR DIET.	
Section 4	INFORMATION SOURCES	
4.1	**Since diagnosis and before the end of treatment,** did you receive any nutritional advice from a health professional?	1. Yes 2. No

		If yes continue, if no go to **QUESTION 4.3**
4.2	Select the health professional form who you received dietary advice (**tick all that apply**).	1. Registered Dietitian 2. General Practitioner 3. Nurse at the GP practice 4. Cancer Specialist 5. Cancer nurse 6. Stomatotherapist 7. Nutritionist 8. Other
4.2.1	If other, please write the type of professional.	
4.3	**After the end of treatment,** have you received any nutritional advice from a health professional?	1. Yes 2. No If yes continue, if no go to **QUESTION 4.4.**
4.3.1	How many health professionals have provided nutritional advice?	1. None 2. One 3. Two 4. Three 5. Four and more
4.4	Have you received individual dietary advice from a registered dietitian?	1. Yes 2. No

		If yes continue, if no go to **QUESTION 4.5.**
4.4.1	How would you rate the information that you received from the registered dietitian?	1. Extremely helpful 2. Very helpful 3. Somewhat helpful 4. Not so helpful 5. Not at all helpful
4.5	Have you received dietary advice from any other source than a health professional?	1. Yes 2. No If yes continue, if no go to **QUESTION 5.0.**
4.5.1	What was the source of this information (tick all that apply)?	1. A friend or family member 2. The internet/website 3. The media 4. Cancer Society of New Zealand 5. Bowel Cancer New Zealand 6. Facebook Cancer Support Group 7. Other, please specify _____
4.5.1.1	If other, please write the source of information	
Section 5	DIETARY HABITS	

5.0	How often do you currently do any of the following?	
5.1	Make whole grains, vegetables, fruits, and pulses (legumes) such as beans and lentils a major part of your usual daily diet.	1. Never/Rarely 2. Sometimes 3. Mostly/ Always
5.2	Limit consumption of processed foods high in fat, starches, or sugars (including fast foods; many prepared dishes, snacks, bakery foods and desserts; and confectionery).	1. Never/Rarely 2. Sometimes 3. Mostly/ Always
5.3	Eat no more than moderate amounts (less than 3 portions per week) of red meat (beef, pork, and lamb).	1. Never/Rarely 2. Sometimes 3. Mostly/ Always
5.4	Eat little, if any, processed meat (including ham, bacon, corned beef, and some sausages like salami, chorizo and hot dogs).	1. Never/Rarely 2. Sometimes 3. Mostly/ Always
5.5	Limit consumption of sugar-sweetened drinks or soft drinks.	1. Never/Rarely 2. Sometimes 3. Mostly/ Always
Section 6	DIETARY CHANGE	

6.1	Were you given advice by a health professional on how to gain weight?	1. Yes 2. No
6.2	Were you given advice by a health professional on how to lose weight?	1. Yes 2. No
6.3	Have you introduced any new foods since completing your cancer treatment?	1. Yes 2. No If yes continue, if no go to **QUESTION 6.4**
6.3.1	Which foods have you introduced (tick all that apply)?	1. More Fruits 2. More Vegetables 3. More Pulses (Beans and Peas) 4. More Nuts and Seeds 5. More Fish 6. More Wholegrains (wheat, corn, rice, oats, barley, quinoa, sorghum, spelt, rye)
6.3.2	Name any other foods that you introduced.	
6.3.3	Did you introduce new foods due to advice from a health professional?	1. Yes 2. No

6.4	Have you introduced any supplements since your diagnosis or completing your treatment (for example vitamins or minerals, or fibre or probiotics)?	1. Yes 2. No If yes continue, if no go to **QUESTION 6.5**
6.4.1	What type of supplement (tick all that apply)?	1. Vitamin B9 (Folic acid/folate) 2. Vitamin D 3. Calcium 4. Zinc 5. Selenium 6. Probiotic 7. Fibre supplement (e.g., Metamucil, psyllium husks)
6.4.2	Name any other supplements that you introduced.	
6.4.3	Did you introduce supplements due to advice from a health professional?	1. Yes 2. No
6.5	Have you reduced or removed any foods from your diet **since completing your cancer treatment?**	1. Yes 2. No If yes continue, if no go to **QUESTION 7.0**
6.5.1	Have you reduced or removed from your diet any of these foods (**tick all that apply**)?	1. Red meat

		2. Processed meats (e.g., bacon, ham, sausages, salami, pepperoni) 3. Fried foods 4. Processed foods (foods that are altered from its natural state) 5. Dairy foods (cheese, milk, butter) 6. Sugar
6.5.2	Name any other foods that you have reduced or removed from your diet.	
6.5.3	Did you reduce or remove these foods due to advice from a health professional?	1. Yes 2. No
Section 7	GUIDELINES	
7.0	How familiar are you with the following recommendations?	
7.1	Be a healthy weight	1. Never heard of it 2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.2	Be physically active	1. Never heard of it

		2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.3	Eat a diet rich in whole grains, vegetables, fruits, and beans	1. Never heard of it 2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.4	Limit consumption of “fast foods” and other processed foods high in fat, starches, or sugars	1. Never heard of it 2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.5	Limit consumption of red and processed meat	1. Never heard of it 2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.6	Limit consumption of sugar-sweetened drinks	1. Never heard of it 2. Slightly familiar 3. Mostly familiar 4. Very familiar
7.7	Limit alcohol consumption	1. Never heard of it

		2. Slightly familiar 3. Mostly familiar 4. Very familiar
Section 8	ROLE OF DIET	
8.1	How important is nutrition in recovery from colorectal cancer?	1. Extremely important 2. Very important 3. Somewhat important 4. Not so important 5. Not at all important
8.2	How important is nutrition in preventing a recurrence of colorectal cancer?	1. Extremely important 2. Very important 3. Somewhat important 4. Not so important 5. Not at all important
SECTION 9	INFORMATION NEEDS	

9.1	Have you received sufficient support and advice regarding diet and dietary issues?	1. Yes 2. No If no continue, if **yes**, go to **QUESTION 10.0**
9.2	Explain what other support would you have liked to have received.	
SECTION 10	PHYSICAL ACTIVITY ADVICE	
10.1	Have you received advice from a health professional on physical activity/exercise?	1. Yes 2. No If yes, continue, if no go to **QUESTION 10.2**
10.1.1	Have you increased your level of physical activity/exercise due to this advice?	1. Yes 2. No
10.2	Have you received sufficient support and advice regarding physical activity/exercise?	1. Yes 2. No If no continue, if **yes**, go to **QUESTION 11**
10.2.1	Explain what other support would you have liked to have received.	
SECTION 11	CURRENT PHYSICAL ACTIVITY (IPAQ)	

11	We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.	
11.1	Think about all the **vigorous** activities that you did in the **last 7 days. Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.	
11.1.1	During the **last 7 days**, on how many days did you do **vigorous** physical activities such as heavy lifting, digging, aerobics, or fast bicycling?	_____ days per week If No vigorous activities, go to **QUESTION 11.2**
11.1.2	How much time did you usually spend doing **vigorous** physical activities on one of those days?	_____hours per day _____minutes per day ☐ Don't know/Not sure

11.2	Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.	
11.2.1	During the **last 7 days**, on how many days did you do **moderate** physical activities such as carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.	_____ days per week If No moderate activities, go to **QUESTION 11.3**
11.2.2	How much time did you usually spend doing **moderate** physical activities on one of those days?	_____hours per day _____minutes per day ☐ Don't know/Not sure
11.3	Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.	
11.3.1	During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?	_____ days per week

		If No moderate activities, go to **QUESTION 11.4**
11.3.2	How much time did you usually spend **walking** on one of those days?	_____hours per day _____minutes per day ☐ Don't know/Not sure
11.4	The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.	_____hours per day _____minutes per day ☐ Don't know/Not sure
SECTION 12	END OF THE QUESTIONNAIRE	Thank you for your participation

6.6 APPENDIX C.3 HEALTHCARE PROFESSIONAL QUESTIONNAIRE

The Healthcare Professionals Dietary and Lifestyle Advice for Colorectal Cancer Survivors Survey

Researchers Introduction

My name is Danielle Cao, and I am a postgraduate student undertaking a thesis project to complete a Master of Science degree in Nutrition and Dietetics at Massey University. I am under the supervision of Associate Professor Hugh Senior (PhD in Medicine, Postgraduate diploma in Public Health) from the School of Health Sciences at Massey University, and Dr Judy Thomas (PhD in Applied Science) from the Department of Exercise Sciences at the University of Auckland.

Invitation to participate in research study

There is a growing number of colorectal cancer survivors in New Zealand. There is a need to understand the diet and lifestyle of cancer survivors, and to understand the advice and information that they have received during their cancer diagnosis, treatment and recovery. These include identifying sources of information, and understanding if the information provided is meeting needs and resulting in improved lifestyle behaviours.

This online study aims to examine the dietary and lifestyle information and advice provided to colorectal cancer survivors by health professionals. This will enable the project to make broad findings and inform policy for the development of initiatives to optimise information provision for colorectal cancer survivors living in the community.

You are invited to participate in this research.

Participant Identification and Recruitment

You have been invited to participate as you are a health professional that has supported recovery of colorectal cancer patients. There are no foreseeable discomforts or risks to participating in this study. You have been invited to participate as you care for patients with colorectal cancer. We are seeking approximately 200 participants in this study. We believe this number will provide a framework of the information provision among health professionals.

There are no foreseeable discomforts or risks to participating in this study. Your personal details or those of your organisation will not be included in any reports or the publication of the results in scientific journals.

Project procedures

We will ask you to complete a questionnaire online at one time only. The questionnaire will ask about yourself, about dietary and lifestyle advice and information provided to colorectal cancer survivors. We anticipate that the questionnaire will take less than 30 minutes

.

What about confidentiality?

All your information will be kept confidential and no-one will ever know your information was used for this study. You will not be identified in the data. All data will be stored in a secure office and a password protected computer server at the School of Health Sciences at Massey University. No personal information collected in this study will be used by persons outside of the research team. You will not be named or identified in any reports or publications that come out of this study. At the end of the study, all data will be deleted.

What if I change my mind about being in this study?

If you decide to participate, you have the right to: decline to answer any particular question; withdraw from the study (you can leave by closing the questionnaire); ask any questions about the study at any time during participation; provide information on the understanding that your name will not be used unless you give permission to the researcher

Will I get to know the results of this study?

We will send a summary report of the results to you.

“This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University’s Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact the Director, Research Ethics, email humanethics@massey.ac.nz”.

Participant consent

I have read and I understand the Information Sheet.

I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

Please tick below, if you consent to participate in this study.

I consent to participate in this study.

Yes No

Healthcare Professional Questionnaire

We would like to thank you for participating in the study and ask you to complete the XX sections of the questionnaire below. These will assess your experience in providing information and advice on diet and lifestyle to people who have been treated for colorectal cancer and have completed treatment

Section 1	GENERAL QUESTIONS	
1.1	What is your gender?	3. Male 4. Female 5. Rather not say
1.2	What is your age range?	6. ≤25 years 7. 26-35 years 8. 36-45 years 9. 46-55 years 10. 56-65 years 11. ≥66 years
1.3	What is your current profession?	5. Community/ District Nurse

		6. General Practice Nurse 7. Cancer Support Worker 8. Medical Specialist 9. General Practitioner 10. Dietitian 11. Other _____ (please specify)
1.4	What sector do you work in?	1. DHB 2. NGO 3. Private Practice
1.5	Where is your clinical setting?	4. City based 5. Rural/Town based 6. City and Rural, Town based
Section 2	SERVICE ENROLMENT	
2.1	How are patients referred to your service (tick all that apply)?	1. Self-referral 2. GP referral 3. Hospital referral 4. NGO service
Section 3	NUTRITIONAL ASSESSMENT	

3.1	During the visit(s) with a patient, do you	
3.1.1	Routinely measure weight and height (BMI)?	1. Yes 2. No
3.1.2	Assess the diet (nutritional status)?	1. Yes 2. No
3.1.3	Do you use a formal screening tool in your assessment of nutritional status?	1. Yes 2. No
3.1.4	Do you use any of the following screening tools (tick all that apply)?	1. Assessment tool developed by your organisation. 2. Malnutrition Universal Screening Tool (MUST) 3. Mini-nutritional Assessment (MNA) 4. Nutrition Risk Screening (NRS) 5. Malnutrition Screening Tool (MST) 6. Other (please specify)_____
3.1.5	If you DO NOT assess or manage the nutritional status, please provide a reason (tick all that apply).	1. Lack of resources/ infrastructure 2. Lack of time 3. Do not feel adequately trained 4. Not primary importance 5. Do not feel it is important

		6. Other (please specify)_____
Section 4	PHYSICAL ACTIVITY ASSESSMENT	
4.1	During the visit(s) with a patient, do you assess physical activity levels?	1. Yes 2. No
Section 5	ALCOHOL CONSUMPTION ASSESSMENT	
5.1	During the visit(s) with a patient, do you ask about alcohol consumption?	1. Yes 2. No
Section 6	ROLE OF DIET AND LIFESTYLE IN CANCER CARE	
6.1	How important do you rate diet in the recovery from colorectal cancer and treatment?	1. Very important 2. Important 3. Fairly important 4. Slightly important 5. Not important
6.2	How important do you rate diet in lowering the risk of recurrence of colorectal cancer?	1. Very important 2. Important 3. Fairly important

		4. Slightly important 5. Not important
6.3	How important do you rate achieving recommended physical activity levels in the recovery from colorectal cancer and treatment?	1. Very important 2. Important 3. Fairly important 4. Slightly important 5. Not important
6.4	How important do you rate achieving recommended physical activity levels in lowering the risk of recurrence of colorectal cancer?	1. Very important 2. Important 3. Fairly important 4. Slightly important 5. Not important
6.5	How important do you rate reducing alcohol consumption in lowering the risk of recurrence of colorectal cancer?	1. Very important 2. Important 3. Fairly important 4. Slightly important 5. Not important
6.6	Based on your clinical experience, when do you think is the most appropriate time for providing advice to a patient on healthier diets (tick all that apply)?	1. At diagnosis 2. During treatment 3. Immediately after final treatment

		4. During the cancer recovery
6.7	Who do you think SHOULD have the primary role to provide nutritional advice to a colorectal cancer survivor (tick all that apply)?	1. GP 2. Dietitian 3. Specialised cancer dietitian 4. Nutritionist 5. Specialist (surgeon/oncologist) 6. Nurse (primary care) 7. Nurse (district/ community) 8. Nurse or other health professional (NGO/ cancer support services) 9. None of the above 10. Other (please specify)_____
6.8	From your clinical experience, who is MOST LIKELY to provide nutritional advice to a colorectal cancer survivor (tick all that apply)?	1. GP 2. Dietitian 3. Specialised cancer dietitian 4. Nutritionist 5. Specialist (surgeon/oncologist) 6. Nurse (primary care) 7. Nurse (district/ community)

		8. Nurse or other health professional (NGO/ cancer support services) 9. None of the above 10. Other (please specify)_____
Section 7	REFERRAL TO OTHER HEALTH PROFESSIONALS	
7.1	Are your patients referred to a registered dietitian within your organisation?	1. Yes 2. No
7.1.1	Do you feel that your organisation requires an inhouse registered dietitian?	1. Yes 2. No
7.2	Are your patients referred to a registered dietitian external to your organisation?	1. Yes 2. No
7.2.1	How are patients referred to an external dietitian from your organisation (tick all that apply)?	1. Directly referred 2. Referred through their GP 3. Self-referral
7.2.2	How is the service provided by the dietitian financed (tick all that apply)?	1. Paid by my organisation 2. Publicly funded 3. Privately funded 4. Not sure

7.3	Are your patients referred to a nutritionist within your organisation?	5. Yes 6. No
7.4	Are your patients referred to a nutritionist external to your organisation?	1. Yes 2. No
7.5	Are your patients referred to a cancer survivors programme that discusses healthy eating options?	1. Yes 2. No
7.6	Are your patients referred to an exercise physiologist or exercise/physical rehabilitation programme within your organisation?	3. Yes 4. No
7.7	Are your patients referred to an exercise physiologist or exercise/physical rehabilitation programme external to your organisation?	1. Yes 2. No
Section 8	PROVISION OF DIETARY ADVICE AND INFORMATION	
8.1	Who are the colorectal cancer survivors that you are most likely to provide ongoing nutritional advice or information for (tick all that apply)?	1. All patients 2. Patients who ask for nutritional advice 3. Patients with poor nutritional status 4. Patients who are overweight 5. Patients who are underweight 6. Patients with other health conditions

		7. Patients with specific nutritional needs due to the treatment for their colorectal cancer 8. We do not provide nutritional advice 9. Patients who lack support from a caregiver
8.2	How confident do you feel in providing nutritional advice to colorectal cancer survivors?	1. Not at all confident 2. Somewhat confident 3. Moderately confident 4. Very confident 5. Completely confident
8.3	Have you received training in providing nutritional/dietary advice either formally or part of professional development?	6. Yes 7. No
8.4	Do you wish to have further training to be able to provide nutritional advice to colorectal cancer survivors?	1. Yes 2. No
8.5	Does your organisation provide advice and/or sources of nutritional information or resources to your patients?	1. Yes 2. No
8.6	Do you believe that there needs to be improved evidence-based policy in your organisation to guide the advice you deliver to colorectal cancer survivors?	1. Yes 2. No

8.7	What is the format of the information that you provide to cancer survivors on diet (tick all that apply)?	1. Verbal advice 2. Pamphlets/ leaflets 3. Booklet 4. Recipe book 5. Links to Website(s) 6. Apps for mobile phones or computers 7. Nutrition support groups (e.g., Facebook) 8. Other (please specify)_____
8.8	Can you please provide more detail on the information that you provide to colorectal cancer or all cancer survivors related to diet and lifestyle?	
8.9	Do you as a health professional or your organisation provide patients with written healthy recipes?	1. Yes 2. No
8.10	Do you as a health professional or your organisation provide advice on cooking to either the patient or the caregiver?	1. Yes 2. No
8.11	Do you advise your patients to maintain a healthy weight or to lose weight (if they are overweight)?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely

		5. Never
8.12	Do you advise your patients to eat a healthy, balanced diet?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
8.13	Do you advise colorectal cancer survivors to increase fibre in their diet?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
8.14	Do you advise colorectal cancer survivors to increase vegetable and fruit consumption?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
8.13	Do you advise colorectal cancer survivors to decrease or stop drinking alcohol?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely

		5. Never
8.15	Do you advise colorectal cancer survivors to decrease red meat consumption?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
8.16	Do you advise colorectal cancer survivors to decrease consumption of processed meats (e.g., ham, bacon, sausages, salami)?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
8.17	Do you prescribe or recommend fibre supplements to colorectal cancer survivors?	1. Always 2. Most of the Time 3. Some of the Time 4. Rarely 5. Never
Section 9	NUTRITIONAL ISSUES	
9.1	What are the major nutritional issues that you notice colorectal cancer survivors are experiencing (tick all that apply)?	1. Loss of appetite 2. Nausea/ Vomiting

		3. Constipation 4. Diarrhoea 5. Change in taste or smell 6. Fatigue 7. Stoma 8. Problem with absorption of nutrients due to part of gastrointestinal tract removed 9. Other (please specify)
9.2	In your professional opinion, what are the most important nutritional issues or diet needs for colorectal cancer survivors?	
Section 10	BARRIERS TO PROVIDING NUTRITIONAL ADVICE/INTERVENTIONS	
10.1	Are the any barriers to providing dietary advice or interventions to colorectal cancer patients?	1. Yes 2. No
10.1.1	Are any of the following barriers to providing dietary advice or interventions to colorectal cancer patients (tick all that apply)?	1. Lack of time 2. Lack of funding 3. Cost to the patient 4. Lack of educational resources

		5. I do not have the knowledge or training 6. Our organisation does not employ or contract a dietitian 7. The dietitian employed/ contracted by our organisation only consults specific cases 8. Lack of patient interest 9. Patients are too unwell 10. Any dietary advice or interventions will not change behaviour 11. Due to location, services are not available 12. Do not wish to overload patients with information 13. Other (please specify)_____
10.2	Is there any gap in information provision or support regarding diet, weight management, alcohol consumption that you believe colorectal cancer survivors should be receiving?	

10.3	Is there anything else that you would like to add regarding the role of the health professional providing information and advice to colorectal cancer survivors?	
10.4	Do you believe that there is adequate screening of colorectal cancer survivors to identify nutritional risk?	1. Yes 2. No
10.5	Do you believe that there needs to be an improvement in the referral process to a dietitian for colorectal cancer survivors?	1. Yes 2. No
Section 11	INFORMATION ON PHYSICAL ACTIVITY	
11.1	Based on your clinical experience, when do you think is the most appropriate time to provide advice to a patient on physical activity (tick all that apply)?	1. At diagnosis 2. During treatment 3. Immediately after final treatment 4. During the cancer recovery
11.2	Do you recommend undertaking moderate physical activity to colorectal cancer survivors at the end of their treatment?	1. Yes 2. No
SECTION 12	END OF THE QUESTIONNAIRE	3. Thank you for your participation

END OF THESIS