Health Professionals' and Non-Governmental Organisations' Role in Dietary and Lifestyle Support for Colorectal Cancer Survivors in New Zealand: A qualitative study

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Abstract

Background: Diet and lifestyle change impacts recovery and the risk of recurrence of colorectal cancer (CRC). Understanding the means of information provision, resources and barriers to diet and lifestyle information provision by health professionals (HPs) and cancer-related non-Governmental organisations (NGOs) is vital to providing optimal care.

Aim: To explore HPs and NGOs perspectives on their role in providing advice and information on diet and lifestyle for CRC survivors.

Methods: HPs and NGOs were sampled purposefully and by convenience. In-depth semi-structured interviews were conducted, recorded, and transcribed verbatim. Transcripts were analysed by thematic analysis.

Results: HPs acknowledge the important role of healthy diet and lifestyle for CRC survivors. Three major findings were identified: 1) dietary and physical activity (PA) advice ideally should be tailored to the individual needs and circumstances of CRC survivors, 2) CRC survivor access to services was inequitable and determined by the referral process and availability of dietary and lifestyle services, 3) an inadequate standardisation and a lack of support structure for health information provision was experienced across HPs and NGOs.

Conclusion: Equitable access and standardised pathways are needed to ensure health professionals can provide timely and appropriate dietary and lifestyle information to cancer survivors, needed to enhance survivorship, and reduce CRC recurrence.

Please note**:* Chapter 5 provides a ***separate stand-alone chapter on a substudy that assesses the quality, navigation, readability, and content of information on diet and lifestyle of the two major cancer NGOs websites in New Zealand for CRC survivors. The substudy is to supplement the main study, as NGO websites are major sources of cancer-related lifestyle information.

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List of Abbreviations

Abbreviation	Definition
AICR	American Institute for Cancer Research
ASCO	American Society of Clinical Oncology
BMI	Body mass index
CRC	Colorectal cancer
DALY	Disability-adjusted life years
ESMO	European Society for Medical Oncology
ESPEN	European Society for Clinical Nutrition and Metabolism
FIT	Faecal immunochemical test
GP	General Practitioner
HP	Health professional
HRQoL	Health related quality of life
IGF-1	Insulin-like growth factor-1
NZ	New Zealand
NBSP	New Zealand Bowel Screening Program
NCI	National Cancer Institute
NGO	Non-Governmental organisation
PA	Physical activity
USA	United States of America
WCRF	World Cancer Research Fund
WHR	Waist-to-hip ratio

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

New Zealand has one of the highest prevalence of colorectal cancer (CRC) in the world and is the second highest cause of cancer death with approximately 1,801 new cases of men and 1,603 new cases of women diagnosed with CRC in 2020 [1]. More patients are surviving cancer, including CRC, due to the improvements in cancer therapies such as drug treatments, surgery, radiation therapy, alongside improved screening technology permitting earlier diagnosis [2, 3].

Certain modifiable risk factors including poorer diets and low levels of physical activity are strongly associated with the risk of CRC [4-6]. Therefore, prevention is the best method to reduce CRC incidence and mortality. Furthermore, diet and lifestyle continue to have an impact on CRC survivorship. The World Cancer Research Fund and American Institute for Cancer Research (WCRF/AICR) for CRC prevention recommend a quality diet that is high in dietary fibre (vegetables, fruit, legumes, wholegrains, cereals), low in red and processed meat, with low alcohol consumption. This diet is associated with reduced CRC risk and improved recovery and lower recurrence [7-10], increased health-related quality of life (HRQoL) and improved health outcomes [11-13].

For CRC survivors to change lifestyle behaviours and adopt recommended healthy diets, they require access to quality information about dietary recommendations from health professionals (HPs), and how to implement them [14]. Cancer survivors actively seek health information on diet and lifestyle [15] as they navigate life beyond cancer and need help with appropriate food choices to manage symptoms, enhance CRC recovery and general well-being, and often require specific support for CRC-related complex conditions (e.g. presence of a colostomy, upset bowels, fatigue, malnutrition). Survivors turn to trusted sources of information like general practitioners (GPs), nurses, dietitians, allied HPs, oncologists and cancer-related non-governmental organisations (NGOs) for dietary and lifestyle advice.

Survivors who receive adequate dietary recommendations that are tailored to suit their individual needs are more likely to make the connection between diet and cancer being a predictor of better recovery, reduced recurrence risk and future well-being [14, 16].To ensure optimal and equitable care, CRC survivors who require evidence-based dietary and lifestyle information and support should have access to HPs, including dietitians and physical therapy experts, and services in hospital and community settings to help these patients get optimal health outcomes and to improve cancer survivorship [16, 17].

A recent study by Peniamina and colleagues identified that there are barriers in New Zealand to the provision of nutrition information and support for cancer patients including access to dietitians due to insufficient funding and limited resources [18]. Despite the importance of diet and lifestyle in the risk and recovery of CRC, there is a scarcity of well-conducted research into the services providing dietary and lifestyle advice to CRC survivors in New Zealand. In this study, the exploration of the role of HPs and cancer-related NGOs in information provision in this patient population will provide an understanding of patient access, identification of gaps and barriers to information provision and support, and an understanding of required resources to provide an optimal service to enhance CRC survivorship.

Please note**:* Chapter 5 provides a ***separate stand-alone chapter with its own aims and objectives on a substudy that assesses the quality, navigation, readability, and content of information on diet and lifestyle of the two major cancer NGOs websites in New Zealand for CRC survivors. The substudy is to supplement the main study, as NGO websites are major sources of cancer-related lifestyle information.

1.2 CONTRIBUTORS TO THE STUDY

Researchers	Contributions
Joey Lew	Student researcher: recruited and interviewed participants, data analysis, health website analysis substudy, interpreted results, author of thesis manuscript.
Dr Hugh Senior	Academic supervisor: designed study, assisted with the structure of thesis manuscript, interpretation of results, revised and approved thesis manuscript.
Dr Judy Thomas	Academic co-supervisor: assisted with interpretation of results, assisted with website analysis substudy, revision and approved thesis manuscript

1.3 AIM AND OBJECTIVES

1.3.1 Aim

The aim of this study is to understand the dietary, physical activity, and lifestyle advice provided by hospital and community-based allied health professionals and NGOs specifically for CRC survivors in New Zealand.

1.3.2 Objectives

1. To explore the role of HPs and Cancer-related NGOs on providing dietary and lifestyle advice, information and support to survivors of colorectal cancer

2. To explore HPs and NGOs perspectives on service access, and the timing, formats, resources and quality of information provision

3. To explore HPs and NGOs views on follow-up care and referrals to other health professionals and programmes for dietary and lifestyle services

4. To identify any barriers and gaps in service in providing optimal and equitable care

1.4 THESIS STRUCTURE

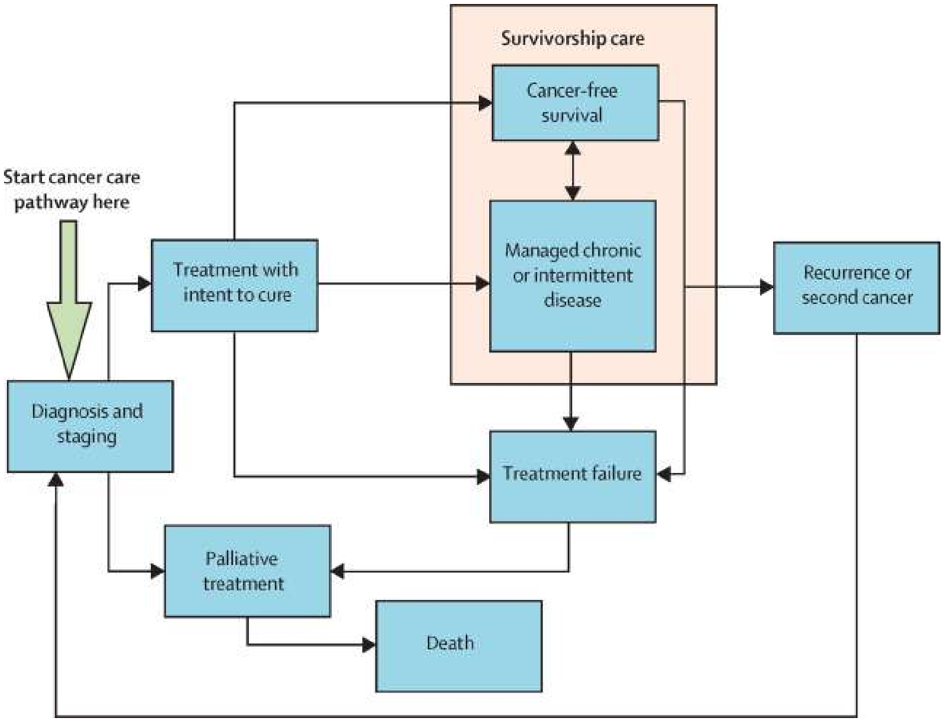
This research is divided into 5 chapters. Chapter 1 provides an overview and explains the significance of this study. Chapter 2 provides a literature review on the context of cancer survivorship, diet and lifestyle guideline recommendations, and the HPs role in information provision. Chapter 3 consists of a research manuscript including an abstract, introduction, methods, results, discussion, and conclusion. The research manuscript is targeted for the New Zealand Medical Journal, see **Appendix A** for author guidelines. Chapter 4 provides a summary of the main study, including the strengths, limitations and suggested recommendations for clinical practice and research. Chapter 5 provides a ***separate stand-alone chapter*** on a substudy that assesses the quality, navigation, readability, and content of information on diet and lifestyle of the two major cancer NGOs websites in New Zealand for CRC survivors. The substudy is to supplement the main study, as NGO websites are major sources of cancer-related lifestyle information.

CHAPTER 2: LITERATURE REVIEW

2.1 CANCER SURVIVORSHIP

Due to the increasing effectiveness of cancer therapies, including drug treatments, surgery, radiation therapy, and improved screening technology allowing earlier diagnosis, more patients are surviving cancer, including CRC [2, 3]. Associated with the increase in surviving cancer, HPs developed the concept of cancer survivorship. The most frequently accepted definition of cancer survivorship is a process that begins at the time of diagnosis and continues throughout one's life [3, 19-22]. Due to the nature of cancer and patients withtheir own subjective personal life experiences with different outcomes, the journey of the patient is a continuous process, covering different experiences and trajectories [19]. These trajectories are schematically shown in Figure 2.1. Further, the schematic shows the period of the trajectory that requires survivorship care.

FIGURE 2.1 POSSIBLE TRAJECTORIES IN THE CANCER JOURNEY



Source: Mayer et al, 2017[19]

2.2 SUPPORTIVE CARE IN CANCER SURVIVORSHIP

To improve and manage the patient's survivorship experience, the concept of “Cancer Supportive Care” is vital [23]. The aim of supportive care is to provide holistic and patient centered care, to show empathy, compassion, and sensitivity to patients [24]. This entails a continuum of care from diagnosis, anti-cancer treatment through to post treatment care including recurrent cancer prevention [2].

An individualised supportive care plan (or survivorship care plan) is recommended that includes strategies and interventions to support patients’ activities after completing cancer treatment [25, 26]. Supportive care plans have a holistic multidimensional approach that encompass physical functional, psychological, social and spiritual well-being to improve the quality of life of patients [24]. This model of care aligns with the Māori health model Te Whare Tapa Whā.

The ‘Te Whare Tapa Whā’ health model, which compares health to the four walls of a house, each of which is required to ensure strength and balance, with each wall representing a different dimension: taha wairua (the spiritual side), taha hinengaro (thoughts and emotions), taha tinana (the physical side), and taha whānau (the family side) [26].

2.3 PREVALENCE OF CANCER AND COLORECTAL CANCER

2.3.1 Definition of colorectal cancer

Colorectal cancer often develops from a polyp, a benign tumour formed in the mucosa that has become malignant [27, 28]. The cancerous tumour can grow into the different layers of the digestive tract, comprising the mucosa (epithelium, connective tissue, thin muscle layer), submucosa, thick muscle layers and subserosa. It can remain in situ in the mucosa or metastasise to other tissues causing metastatic cancer [29].

2.3.2 Prevalence of colorectal cancer

Globally, more than 1.8 million people are diagnosed with CRC each year, with the incidence higher in men than women according to the World Health Organization GLOBOCAN data base [30]. Risk of CRC increases with age, with the median age of 70 upon diagnosis [30, 31]. However, in the last decade there has been a significant increase in the incidence of earlier onset of CRC development, this is associated with more people adopting the western diet and lifestyle, leading to increasing obesity [32]. The 5-year survival rate has increased in North America, Europe, Oceania and urban areas of South Asia and China [33], most likely due to having access to screening / early diagnosis, optimum medical treatment, and a reduction in postoperative mortality [34].

New Zealand has a population of 4.8 million and in the year 2020, there were 35,934 new cases of cancer for both sexes, spanning across all age groups. Of these, 3,404 people were registered as having new CRC cases (9.5%) in the year 2020, of which 1,801 were men and 1603 were women [1]. Each year, about 1200 individuals die of CRC, and this is high according to international standards. The age-standardised incidence rate (World) for both sexes is 422.9, with males having a higher rate than females (461.7 vs 388.2) [30]. The five-year survival rate of CRC in New Zealand has increased over the last decades, with improved survival rate for rectal cancer, compared to colon cancer patients [35]. CRC occurs less frequently in Māori than non-Māori people. From 2011 to 2013, there was an annual registration of CRC per 100 000 people of 39.97 for Māori males and 28.04 for Māori females, 49.45 for non-Māori males and 37.12 for non-Māori females [36]. Although more New Zealanders are surviving colorectal cancer, inequities persist with Māori patients experiencing poorer survival rates compared to non-Māori regardless of stage of disease [37, 38]. Māori patients were 46% more likely to die than non-Māori patients and this has been largely attributed to disparities in access to, and the quality of care and treatments received [37, 39].

2.3.3 Screening for colorectal cancer

Screening by colonoscopy allows clinicians to identify colorectal polyps and remove them to prevent the development of cancerous cells [40, 41]. Early screening is the ‘Gold Standard’ and reduces mortality among patients compared with those who are not screened [42]. The use of faecal immunochemical test (FIT) [43] in the New Zealand National Bowel Screening Program (NBSP) is another method for the detection of possible precancerous cells by detecting occult blood in the faeces [43]. It is less invasive than colonoscopy [44, 45]. If the FIT test is positive, patients undergo a colonoscopy to aid diagnosis. The removal of neoplastic polyps also occurs during the procedure [46].

2.3.4 Staging of colorectal cancer

The American Joint Committee on Cancer (AJCC) established the TNM staging system for how cancer is communicated, to help clinicians better understand the cancer and prognosis [47]. The "T" is the local extent (size) of the untreated tumour in the initial stage of diagnosis. "N" is the status of the lymph nodes and "M" is distant metastatic disease [47, 48]. When the tumour has not spread beyond the primary site of formation, it is termed "localised", when the tumour has invaded nearby tissues or organs, it is termed "regional", and when the tumour has metastasised to distant organs or lymph nodes, it is called "distant" [47].

2.3.5 Risk factors for colorectal cancer

Certain risk factors, including age, genetics, lifestyle (e.g. diet, physical activity), obesity, and gut microbiome status [4, 5] have been reported to contribute to the increased risk of getting CRC. Prevention is the best method to reduce incidence and mortality, by controlling modifiable risk factors. Good knowledge of dietary and environmental risk factors are important for implementing strategies to promote a healthy diet and lifestyle. Below, modifiable risk factors are discussed in more detail.

Smoking Tobacco

People who smoke tobacco are more likely to develop CRC than never-smokers [49-51]. Smoking tobacco exposes the person to chemicals that may cause irreversible damage to the colorectal mucosa through the formation of precursor lesions of CRC [52]. Tobacco smoke contains procarcinogens which induce mutations that cause polyps to become malignant [52].

Alcohol Consumption

There is a paucity of studies investigating the association of the consumption of alcohol and risk of developing colorectal polyps [53]. However, a systematic literature review has shown moderate to heavy consumption of alcohol increases the risk of CRC [54]. Several studies have shown a dose-risk relationship between regular alcohol drinking and the risk of CRC compared with non-drinkers or occasional drinkers [55, 56]. A recent systematic review and meta-analysis found that very light or light alcohol drinking was associated with a mild increase in the incidence of CRC in men [8].

High Body Mass Index

A positive association has been shown between increasing Body Mass Index (BMI) and the risk of developing CRC [53, 57, 58]. Epidemiological data suggest that obesity is associated with 30-70% increased risk of CRC in men, but this association is less in women [59]. The higher risk in men is related to body fat distribution, especially visceral fat accumulation. Visceral fat causes a greater concern than subcutaneous fat in the context of chronic diseases, and it is associated with worse cancer outcomes, increased cancer recurrence and mortality. Extra adipose tissue can induce a state of chronic inflammation, resulting in circulating cytokines contributing to chronic diseases and increased risk of CRC [60].

Red meat consumption

According to the European Society for Medical Oncology (ESMO) Handbook of Nutrition and Cancer in 2011 [61], it was noted that red meat (beef, pig, lamb, and horse) and processed meat consumption significantly raises the risk of CRC. Processed meats include ham, bacon, pastrami, salami, sausages, hot dogs and others. The World Cancer Research Fund and American Institute for Cancer Research (WCRF/AICR) states that one intake of red meat per week increases the risk of CRC by about 40%, and each 50 g of processed meat increases the risk by about 20% [6]. The American Society of Clinical Oncology (ASCO) reported the same evidence about CRC risk and red meat and advised that people can consume up to 500g of red meat per week (average 70g a day) without raising risk for cancer [62, 63].Furthermore, the National Cancer Institute (NCI) of the United States (US) reported that the increased risk of CRC due to red and processed meat consumption are linked to mutagenic and/or carcinogenic compounds in meat raising cancer risk in the bowels [64].

Dietary Fibre

Many epidemiological studies have investigated the association between fibre intake and risk of CRC. Grains are either present in their whole form or ground into a flour while retaining all parts of the seed (bran, germ and endosperm). In terms of colon and rectal cancer, wholegrain products appear to have a preventable effect because they are high in dietary fibres and other bioactive substances such as vitamins (vitamins B group and vitamin E), minerals (e.g. magnesium, selenium), antioxidants, phytoestrogens, and other phytochemicals, all of which may protect against cancer risk [65, 66]. Furthermore, a diet rich in wholegrains may protect against type 2 diabetes and prevent weight gain, which are both risk factors for CRC [66].

Case control studies have shown a protective association [67, 68], whereas cohort studies have mixed results [33, 69-71]. Aune and colleagues (2011) conducted a systematic review and meta-analysis of prospective observational studies on fruit, vegetables, legumes and whole grain intake and the risk of CRC [72]. They found an inverse association between dietary fibre, cereal fibre, and whole grains intake and risk of CRC, but found no significant evidence for an association with intake of fibre from fruit, vegetables, or legumes [72]. The authors explained the possible mechanisms that whole grain diets are high in dietary fibre and may reduce the incidence of CRC by bulking up stool, diluting faecal carcinogens, and faster transit time, minimising carcinogen contact with the colorectum's lining [72]. In addition to dietary fibre, there are other constituents of whole grain that also provide protective factors such as thiamine, vitamin B-6, niacin, phytoestrogens, and phytates. These nutrients can work synergistically to protect human health [73]. For every 10g/day intake of total dietary fibre intake, there is a 10% reduction in CRC risk [72]. These findings are consistent with Egeberg et al (2010) who conducted a population-based prospective cohort of Danish men and women, and report increased consumption of total wholegrain products was linked to a 15% lower risk of colon cancer; with an adjusted incidence risk ratio (95% CI) of 0.85 (0.77-0.94) for colon cancer and 0.90 (0.80-1.01) for rectal cancer per daily 50g increment in intake [74].

In summary, it appears that wholegrain fibres have a protective effect against CRC risk, this association is stronger in males than females, and whole foods that contain dietary fibre, essential vitamins and minerals, have protective effects against CRC development and recurrence.

2.4 HEALTH AND SOCIAL IMPACTS OF COLORECTAL CANCER

CRC survivors who have received treatments can continue to suffer physical, psychological, functional impairments (physical, social, sexual), and fear of cancer recurrence, all of which impact health-related quality of life (HRQoL) [75]. HRQoL is an individual's or a group's perception of their physical and mental health over time [76]. In addition, other features such as satisfaction with care, unmet information and support needs, and psychological adjustment to cancer treatment, including adapting to an ostomy, may have a direct impact on their wellbeing [77]. Understanding the prevalence and severity of physical, social and psychological impacts that patients with CRC experience during their disease trajectory, is vital in determining patient needs. The major impacts are detailed below.

2.4.1 Physical Impacts

Common symptoms are pain, fatigue, depressive symptoms, nausea / vomiting, and diarrhoea in the six months after diagnosis across all stages of CRC, and in conjunction with most treatments. Additionally, moderate to severe symptoms were more frequently experienced in late-stage CRC and in patients who had more co-morbidities [78]. Patients with an ostomy reported lower HRQoL post-treatment. They often experience challenges in adjusting to living with their ostomy [77].

The effect of incident cancers on survival and disability is assessed in disability adjusted life years (DALYs) [48]. A DALY is the loss of one year of good health, whether due to premature death, living in a less-than-optimal health status, or a combination of the two [48]. Calculating the burden of cancer-related illness helps to show us the impact of additional morbidity adding to the total cancer burden, such as compromised HRQoL or long clinical duration. A systematic analysis for the Global Burden of disease study in 2017 reported CRC was responsible for 19.0 million (18.5-19.5) disability adjusted life years (DALYs) globally in 2017, with total burden age-standardised rate of 235.7 (229.7–242.0) DALYs per 100,000 person-years [79].

Costilla et al., (2013) calculated the DALY cancer burdens including those due to CRC [48]. They report that for females 12.9% of cancer DALY burden is due to CRC, and 13.5% for males. Both Māori females and males had lower CRC burden than non-Māori females and males respectively. They reported that among females, the total estimated DALY rate for

CRC diagnosed in 2006 for CRC was 333 and 444 for males (age-standardised rates per 100,000 people) [48].

2.4.2 Psychosocial Impacts:

Depression is common in CRC survivors, and commonly coexists with anxiety disorders, and pain [80]. These symptoms can be prevalent up to 5 years post-treatment [78]. CRC patients may experience changes in bowel habits, as well as sexual or urinary issues after surgery that have psychosocial consequences [77].

2.4.3 Economic impacts

In New Zealand, the financial cost of CRC diagnosis and treatment in 2011 was $70 million [81]. The Health Quality and Safety Commission NZ reported that on average people spent 10 days in a public hospital for surgical procedures. Māori and Pacific peoples tend to stay longer (average 11 days) than other ethnic groups (Asian and European) [82].

A meta-synthesis of qualitative studies found that the main financial concerns for survivors were the inability to afford caregiver support in their day-to-day life [77]. This includes activities of daily living including personal care, help with household tasks, driving, ostomy care and managing finances.

Qualitative data from patient-reported outcomes of their employment and work experience suggests they require special needs and face challenges to return to work after CRC treatment [77, 83]. These can be embarrassment caused by their symptoms such as having accidents [84], leakage and smell of their ostomy bag. It can be often difficult disclosing their stoma concerns and bowel symptoms to the employer and colleagues. Some changed careers due to inability to return to previous roles or found ways to manage their symptoms discretely to allow returning to work [77]. These issues may likely have an economic impact on patients from loss of income due to high costs of ongoing support and out of pocket expenses for stoma supplies. In summary, instability of income because of loss or limited employment poses a burden and exposure to financial toxicity.

2.5 IMPROVING THE HEALTH OF SURVIVORS

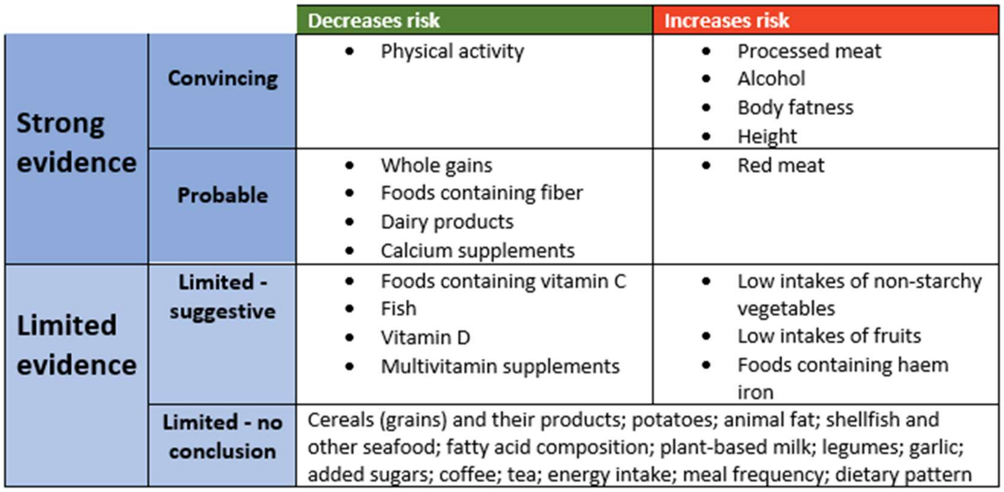
Comprehensive and evidence-based therapies for the treatment of CRC may comprise a mix of surgery, chemotherapy, targeted therapy, and/or radiation [85]. However, to provide patients with the highest quality of care, we need to meet the unique needs of the survivorship population, including implementing sustainable lifestyle (healthy diet and PA) strategies.

2.5.1 Expert advice on how to reduce the risk of colorectal cancer

Dietary intake and PA, appear to be more strongly connected with the risk of CRC than any other cancer [6]. The Western dietary pattern is generally characterised by high intake of sugar/fructose corn syrup and high fat foods, with low intakes of fruit and vegetables, and whole grains [86]. The Western diet increases the risk of obesity, whereas a healthy dietary pattern rich in whole grains, legumes, and vegetables help maintain a healthy BMI [86]. In 2007, the WCRF/AICR published its second Expert Report on Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective [6]. This can be applied to CRC prevention by reviewing the epidemiological evidence on the association between lifestyle behaviours (diet, physical activity), and body fatness with the risk of CRC (see Table 2.1).

They concluded there was strong evidence that risk is decreased by having a diet containing wholegrains, dietary fibre, and dairy products. Calcium supplements and being physically active also lower CRC risk. There is an increased risk from the consumption of red meat, processed meat, and consuming at least two or more standard alcoholic drinks daily. Being overweight or obese also increased CRC risk.

TABLE 2.1 RISK FACTORS ASSOCIATED WITH COLORECTAL CANCER



		Decreases risk	Increases risk
Strong evidence	**Convincing**	Physical activity	Processed meat Alcohol Body fatness Height
	Probable	Whole gains Foods containing fiber Dairy products Calcium supplements	Red meat
Limited evidence	**Limited - suggestive**	Foods containing vitamin C Fish Vitamin D Multivitamin supplements	Low intakes of non-starchy vegetables Low intakes of fruits Foods containing haem iron
	Limited - no conclusion	Cereals (grains) and their products; potatoes; animal fat; shellfish and other seafood; fatty acid composition; plant-based milk; legumes; garlic; added sugars; coffee; tea; energy intake; meal frequency; dietary pattern	

Source: 2017 WCRF/AICR second expert report

The risk of recurrent CRC increased with high intakes of refined grains, sugar, processed meats, and high saturated fat, whereas a dietary pattern high in fruits, vegetables, whole grains, poultry, and fish was found to be associated with reduced mortality [87-89]. To lower the risk of CRC, the WCRF/AICR issued joint diet, physical activity, and weight control guidelines. The WCRF/AICR recommendations for cancer prevention are [90]:

- “Be as lean as possible without being underweight”
- “Be physically active”
- “Limit consumption of energy-dense foods; avoid sugary drinks”
- “Eat mostly foods of plant origin”
- “Limit intake of red meat and avoid processed meat”
- “Limit alcoholic drinks”
- “Limit consumption of salt”
- “Aim to meet nutritional needs through diet alone”
- For cancer survivors, get nutritional advice from a qualified expert

Pooled case-control studies have shown that a higher adherence to the WCRF/AICR recommendations were significantly associated with a 30% CRC risk reduction [90]. These findings raise public awareness and encourage population compliance with recommendations.

Improving fruit and vegetable intake, and decreasing red meat intake and alcohol consumption have also been found to reduce CRC recurrence [7-9] and increase HRQoL [11-13]. Cancer survivors who had higher level of overall adherence to WCFR/AICR cancer prevention guidelines for health behaviours, such as maintaining an optimal body weight, remaining physically active, and eating a nutritious diet, had a decreased risk of mortality [91, 92]. Furthermore, in 2020, Molina-Montes and colleagues reported that a Mediterranean diet is associated with lower cancer mortality. This diet is predominantly a plant-based diet rich in fruits and vegetables; nuts and seeds; cereals and legumes; fish and seafood; moderate to low consumption of milk and dairy products and alcohol; and less frequent consumption of meat and meat products. These findings emphasise that having a healthy diet and lifestyle can impact survivorship through reduced cancer recurrence and improved overall health and wellbeing[93].

2.5.2 Physical activity and colorectal cancer

The WCRF/AICR report [6] on CRC prevention states there is strong evidence that being physically active decreases the risk of colon cancer. Physical activity has been demonstrated to be safe for CRC survivors (from localised to metastatic stage, during and after treatment) while also improving cardiorespiratory fitness and physical function in clinical trials [94]. A recent systematic review conducted by Balhareth et al. (2019) provided insights into the effectiveness of providing physical activity as part of a survivorship programme. It was found that incorporating PA can significantly help CRC survivors to maintain good health and wellbeing with improved quality of life and better physical functioning with less fatigue [95]. High intensity exercise in comparison to moderate intensity exercise appears to provide greater cardiorespiratory fitness and beneficial changes in body composition in oncology patients [96]. Furthermore, regular physical activity and reducing sedentary behaviour can provide an avenue for improving mental health such as depression and anxiety related to cancer [97]. According to the WCRF/AICR recommendations for cancer prevention individuals should be physically active and as lean as possible without being underweight [6].

2.5.3 Body Composition and colorectal cancer

Being overweight and obese puts individuals at risk for a range of malignancies and it has been estimated that about 20% of all cancers are caused by excess weight [98]. According to the WCRF/AICR report excess body fatness is linked to an increased risk of cancer in at least 13 anatomic locations, including the colon and the rectum [99-101].

Anthropometric measurements, such as the waist-to-hip ratio (WHR) or waist circumference (WC), provide better indications of obesity and cancer risk, in addition to BMI. Abdominal obesity or central obesity measured by WHR and WC is strongly associated with increased cancer risk [100].

The association between body fatness and CRC risk is higher for men than women [102]. The mechanisms underlying this difference, although not well understood, are thought to be related to sex steroid hormone exposures [99]. The main aetiological pathways between obesity and cancer for both sexes are 1) hyperinsulinemia, 2) sex hormones biosynthesis pathway, 3) chronic inflammation and oxidative stress, 4) abnormalities of the insulin-like growth factor-1 (IGF-1) system and signalling, 5) altered gut microbiome and microbiota contributing to inflammation and release of carcinogenic products [99]. The current evidence suggests excess body weight is a strong risk factor for CRC cancer. Following good eating patterns with more fibre and less red and processed meats, as well as lifestyle interventions such as quitting smoking, limiting alcohol intake, and staying fit, can all help survivors avoid recurrence and improve overall outcomes through the effects of healthy body weight.

2.5.4 Lifestyle related public and clinical guidelines

There are healthy eating and lifestyle recommendations for general cancer prevention for cancer survivors from the World Cancer Research Fund (WCRF) [101] which is depicted in Figure 2.2.. The Independent Expert Panel after considering the evidence from the literature concluded that the cancer guidelines' recommendations are relevant to cancer survivors to reduce the incidence of recurring malignancies.

FIGURE 2.2 RECOMMENDATIONS FOR THE PREVENTION OF CANCER

Source: World cancer research fund/American Institute for Cancer Research [101]

During cancer therapy, there are no standards for suggested food patterns. The European Society for Clinical Nutrition and Metabolism (ESPEN) nutrition guidelines for cancer patients [103], on the other hand, advocate for proper diet to combat malnutrition caused by the cancer and treatments. Malnutrition and muscle loss are common in cancer patients which can limit responsiveness to treatment options and survivorship. Inadequate dietary intake, low physical activity, and catabolic abnormalities may all play a role [103]. It is recommended that all cancer patients are screened regularly for the risk or the presence of malnutrition.

Both the public 'Eating and Activity' guidelines for New Zealand Adults issued by the Ministry of Health and cancer prevention guidelines like the ACS and/or WCRF/AICR have similar recommendations, including: achievement and maintenance of a healthy weight; regular physical activity of at least 30 minutes per day and at least five days per week; a plant-based diet high in fruits, vegetables and whole grains, low in saturated fats and red meats; and moderate alcohol consumption, if at all [6, 63, 104].

2.6 INFORMATION, ADVICE AND SUPPORT

Patients with cancer and their families have special communication needs throughout the cancer journey. Patients can feel anxiety and fear about their diagnosis, treatment options, costs, and family burden. There are many sources of information of varying quality in cancer care, making navigation and understanding difficult. Therefore, quality communication by HPs and Governmental and NGOs can optimise understanding and improve the patient's and their families' well-being and quality of life. Further, HPs are encouraged to use teachable moments to provide adequate nutrition, PA, and weight management advice to their patients, as well as to support policies and initiatives that help improve these factors in the community to reduce cancer risk and improve cancer survivorship [16].

2.6.1 Health communication during cancer care

Health communication is the interpersonal or mass communication activities to improve the health outcomes of an individual or populations [105]. The practice of disseminating promotional health information via public health campaigns, health education, and between doctors and patients is to impact personal health decisions by enhancing health literacy [105]. Accordingly, healthcare practitioners must create trust and rapport with patients and their families, as well as address their emotional concerns, to achieve the critical goals of these meetings [106, 107]. Patients are usually more satisfied with care and feel more in control when clinicians engage with their patients as active participants in shared decision making [108]. They are more likely to follow through with treatment, are more informed and comfortable. Patient-centred care is part of treating them as a person and not a disease. The quality of care is influenced by the patient's cultural views and language proficiency. HPs who are competent in providing culturally appropriate messages to patients by incorporating unique values and traditions of patients, their families, and communities show cultural safety. This can enable partnerships, power sharing, and decision-making in the delivery of care with better health outcomes if information is culturally appropriate and relevant to the individuals [109-111].

2.6.2 Cancer Survivors’ lifestyle information needs

Cancer survivors value guidance on diet, PA, and lifestyle in the immediate post-treatment period to help manage their symptoms, and fears of food choices as they experience physical and psychological challenges including loss of control of body functions, fatigue, sleep problems, sexual dysfunction, fear of recurrence and reduced mobility [15]. Many patients have experienced weight loss and are more interested in putting on weight than achieving a healthy diet, whereas others want dietary advice for a healthier diet [15]. In later post-treatment months, patients actively seek health information on diet and lifestyle [15]. Further, some patients want more information on culturally appropriate foods and diet that fits into their traditional lifestyle [112]. According to Anderson et al., (2013), there are two key time point for providing support. The first is during the transition from hospital to home, and the second is when people move beyond the difficulty of post-treatment symptoms to long-term health (which may take up to 6 months for some patients) [15].

According to some patients, the ideal timing for lifestyle advice is at the commencement of chemotherapy or early stages of treatment as the initial shock has subsided and they are in a better mental state to absorb information and have higher interest in pursuing a healthy lifestyle [113]. Other research has identified that follow up visits accounting for changing needs and barriers to interventions may be helpful for patients to make better lifestyle choices that fits their needs [15, 114].

2.6.3 Health professionals role as information sources

Cancer diagnosis often serves as a “teachable moment”, giving HPs the opportunity to introduce dietary and lifestyle change to benefit their patients (Demark-Wahnefried, Rock, Patrick, & Byers, 2008).

Medical doctors are a source of advice on diet and lifestyle information to cancer patients [115]. Patients are monitored by the medical team for cancer recurrence and new primary cancers, as well as evaluating and managing the late or long-term consequences from cancer treatments (surgery, chemotherapy, radiotherapy) [116, 117]. Oncologists usually co-manage post-treatment care with GPs about post-treatment status and care recommendations for almost all patients. However, this communication does not extend to co-managing survivors’ care [118].

Dietitians are also an important source for dietary and lifestyle advice to patients [113]. The aim of dietetic consultations is to help clients/patients to change dietary behaviours to improve health outcomes. Registered dietitians use a unique format called the Nutrition Care Process. This covers dietary assessment, nutrition diagnosis, followed by tailored interventions, and monitoring and evaluation for follow up appointments [119]. Dietitians not only educate patients and their families about diet, foods, and nutrition, but also about the psychosocial elements of health, economics, physiology, and chemistry [120]. They aim to improve patients' eating habits to improve health outcomes, and assess diet, anthropometric measures, and clinical indicators to direct and monitor treatment, while assisting patients in achieving their personal health goals. A recent systematic review of randomised controlled trials has shown that primary care based dietetic consultations are effective for improving diet quality, diabetes outcomes, blood pressure control and weight management [121]. In an Irish national survey of oncology survivors on dietetic care, researchers found that those who attended a dietetic consult in primary care setting were significantly more likely to have received advice on healthy eating, PA, what foods to eat or avoid, protein/energy supplements, recipes, portion sizes, texture modified diets, fortified foods, how to gain weight or lose weight, and how to use diet to manage symptoms [119].

Nurses play an important role in information provision regarding cancer related symptom management and diet, exercise, and weight control [122]. Many patients prefer nursing staff for delivery of information provision because they feel more comfortable and less rushed due to the perceived time constraint with their doctor consultations [113]. In an online survey in Australia and New Zealand, cancer nurses (n=123) self-report that they provide nutritional guidance to cancer patients, at a proportion slightly lower than dietitians, but substantially more than oncologists [123]. They provide nutrition related information before, during and after cancer treatment to their patients, as they felt that healthy eating had positive impacts on quality of life, weight management, mental wellbeing, physical functioning, and better health outcomes [123].

A study from the Netherlands showed that nutrition information provision by one or more health professionals (nurses, dietitian, doctor) is strongly associated with patients' believing that nutrition influences their recovery after treatment and recurrence risk compared with patients who received no nutritional guidance. Further, the more HPs involved in providing nutrition information, the stronger the beliefs held by patients [124].

2.6.4 Barriers to health information provision

Many survivors report that their needs are unmet and when they transition from active treatment to survivorship, they would like more guidance on diet, exercise, and weight management [113, 125, 126].

HPs are the most common and primary trusted source of information for patients followed by the internet, friends, and family [127]. Cancer survivors reported that they had unmet information regarding diet from their physician due to lack of follow up time and referral for extra support, this has prompted many to seek information elsewhere, but they are often unsure about credible sources [128].

Possible barriers to information provision described include lack of guidelines and resources on diet, weight management and exercise interventions, time to deliver information and to allow discussion, adequate support structure, and practitioners' uncertainty regarding appropriate messages to provide for cancer patients [113, 123, 129]. Oncology staff in an Australian study emphasised the importance of having sufficient time to tailor the diet, exercise, and weight management advice to avoid a “one size fits all approach” [113].

Methods to bridge potential barriers to health information provision include HPs engaging in interpersonal communication and providing personalised written cancer information to their patients based on cancer prevention guidelines [127], or if time is the main barrier, directing them to trusted evidence-based sources to gain knowledge on foods that have a positive or negative impact on health, to aid better lifestyle choices [130].

2.6.5 Information seeking behaviours of cancer survivors

There is a wealth of information on the internet regarding diet and cancer and an increasing reliance on internet use for health seeking behaviour, which puts patients at risk of misinformation.

Patients seek information about a range of cancer-related topics from multiple sources including HPs. These can be medical, interpersonal, media, internet, books and pamplets to learn about disease, treatment and chances of survival or cure [131]. On average, cancer survivors seek cancer-related information from more than five sources [125]. However, patients who seek more information do not necessarily share this knowledge or discuss conflicting information with their health care providers. On the other hand, information seekers may have all their questions addressed through their own research and may not feel the need to discuss with their physician [125].

A UK study by Beeken and colleagues (2016) reported that cancer survivors received insufficient information on diet and healthy lifestyle advice from health professionals, and were interested to know more, but were unsure about trusting sources online. As HP advice was insufficient, the participants investigated dietary information on their own from the internet. Whereas, some participants felt they received the information they were seeking, others felt the information was deliberately misleading to sell products [130].

Many patients use multiple sources for information on the internet, allowing them to cross-check the reliability of the information. Being a highly educated female was the strongest predictors of using multiple cancer-related information sources on the internet (disease/treatment, self-care management, health services) [131]. This finding is consistent with other research that found that patients who seek information on the internet are likely to be younger, white, more educated and reside urban suburbs. Meeting patients' needs for health information may increase satisfaction and care quality, so continual attention to patients' information needs along the care continuum is necessary. [132-134]

A study looking at cancer information seeking among cancer survivors from the US Health Information National Trends Survey discovered that annual household income was negatively associated with health information seeking behaviours and the ability to understand information. The authors recommended that information is tailored for survivors with low socioeconomic status to account for lack of skills, resources, and motivations to seek information independently [135].

2.6.6 Colorectal cancer survivors’ beliefs and awareness on the relationship between diet and cancer

Anderson et al., (2013) did a qualitative study in the UK on the beliefs, opportunities, and perceived needs of CRC survivors on lifestyle factors. They found participants suffered from gastrointestinal issues like diarrhoea and flatulence daily, for which they felt the need to seek their own practical dietary advice on foods to avoid. Pain and anxiety were other factors that made participants fearful of eating and they had doubts on trying to work out what they can and cannot eat. They were often told presumably by clinicians to have a “trial and error” approach by adapting their diet to manage their symptoms Participants expressed this advice was unhelpful and they would prefer knowing what their system is able to cope or unable to cope with.

Many of the participants had no idea why they developed CRC because they were unsure about the importance of nutrition, activity, and lifestyle in reducing the disease’s risk in the future. However, some participants speculated that stress, heredity, food, overexertion, life events, and bad luck may have had a role in the disease’s development [15]. This is a similar finding to a cross-sectional survey by Wold et al., (2005) in the USA that reports cancer survivors underestimate obesity and physical inactivity as risk factors for cancer [136].

2.6.7 Colorectal cancer survivors’ adherence to nutritional recommendations

Nutrition and physical activity guidelines are available and are intended for HPs to use and translate the information to patients [58, 137]. Findings consistently suggest survivors would welcome guidance from HPs for follow-up cancer care with expert advice covering healthy eating that is tailored [114, 130]. This section will discuss the literature in terms of CRC survivors’ adherence to nutritional recommendations.

In a New Zealand study investigating the dietary patterns and information needs of post-surgery CRC patients, Cha et al. (2012) demonstrated that a significant proportion of the study population did not meet the Ministry of Health Food and Nutrition Guidelines for Adult New Zealanders (FNG-MoH) [63] for recommended daily fruit and vegetable servings, and that there is an unmet information need in this patient group with more than half of all patients not receiving any dietary information [138].

A cross-sectional study investigating adherence to the WCRF/AICR recommendations for CRC cancer survivors in the Netherlands [76], found survivors who had higher adherence experienced better HRQoL, physical functioning and less fatigue. This finding was especially notable in women and obese/overweight survivors.

A similar study in the Netherlands by van Veen and colleagues [139] (N= 1096) revealed less than 50% of CRC survivors adhered to the WCFR/AICR recommendations for a healthy BMI, 5+ servings for fruit and vegetables, and lower red meat consumption. Whereas more than 50% adhered to PA and sugary drinks recommendations. The survivors with the highest adherence scores had better global health status, physical and social functioning, and less fatigue.

This finding was also observed by Grimmett et al., (2011) in which 57% of CRC survivors with 5 years of diagnosis do not consume more than five fruit and vegetables a day and 82% are not moderately physically active. Those that were physically active and consumed the recommended fruit and vegetable intake presented with better HRQoL, cognitive and physical functioning and less fatigue, pain and insomnia [7].

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

It is important that cancer survivors are equipped with knowledge and skills on healthy behaviour change to enhance short- and long-term self-management, reduce cancer recurrence, alleviate symptoms and fears about food choices, and improve quality of life and wellbeing [15]. Survivors are willing to adjust their diet after being diagnosed and treated but have reported that they do not receive sufficient information to suit their needs [112].

Other studies noted that time constraint and HPs feeling unsure about what advice to give to their patients contributes to the gaps in information provision. Survivors who had received dietary advice were more likely to have changed their diet and lifestyle habits [140].

In a New Zealand study, some cancer survivors (all cancers) did not place much importance on healthy dietary change due to a lack of knowledge about the role that nutrition plays in cancer recovery and prevention, as well as little or no access to nutrition counselling and support.[14] This was also reiterated by Cha et al, (2012) who found approximately half of CRC survivor’s post-surgery adhered to the recommendations in the MoH food and nutrition guidelines [138]. Moreover, a recent study has identified there is a need for standardisation of nutrition information and support across New Zealand oncology services [18].

Exploring dietary and lifestyle support information provided by dietitians, physical therapists, and cancer-associated NGOs will identify the gaps in access, resourcing, and information provision to meet survivors needs in New Zealand. Therefore, this present study aims to investigate dietary and lifestyle advice provided by HPs and cancer-related NGOs in New Zealand.

CHAPTER 3: RESEARCH MANUSCRIPT

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

Health professionals' and Non-governmental Organisations' Role in Dietary and Lifestyle Support for Colorectal Cancer Survivors in New Zealand: A qualitative study

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3.1 ABSTRACT

Background: Diet and lifestyle change impacts recovery and the risk of recurrence of colorectal cancer (CRC). Understanding the means of information provision, resources and barriers to diet and lifestyle information provision by health professionals (HPs) and cancer-related non-Governmental organisations (NGOs) is vital to providing optimal care.

Aim: To explore HPs and NGOs perspectives on their role in providing advice and information on diet and lifestyle for CRC survivors.

Methods: HPs and NGOs were sampled purposefully and by convenience. In-depth semi-structured interviews were conducted, recorded and transcribed verbatim. Transcripts were analysed by thematic analysis.

Results: HPs acknowledge the important role of healthy diet and lifestyle for CRC survivors. Three major findings identified: 1) dietary and physical activity (PA) advice ideally should be tailored to the individual needs and circumstances of CRC survivors, 2) CRC survivor access to services was inequitable and determined by the referral process and availability of dietary and lifestyle services, 3) an inadequate standardisation and a lack of support structure for health information provision was experienced across HPs and NGOs.

Conclusion: Equitable access and standardised pathways are needed to ensure HPs can provide timely and appropriate dietary and lifestyle information to cancer survivors, needed to enhance survivorship and reduce CRC recurrence.

3.2 INTRODUCTION

Globally, more than 1.8 million people are diagnosed with colorectal cancer (CRC) each year, with the incidence higher in men than women [30]. There has been an increase in the incidence of early-onset CRC detection, associated with the success of CRC screening on older age groups [32].

In New Zealand, in 2020 there were 3,404 new CRC cases and approximately 1,200 deaths [1]. CRC occurs less frequently in Māori than non-Māori people [36]. There is a disparity in survival rates with Māori patients experiencing poorer survival rates compared to non-Māori regardless of the stage of disease [38]. This is attributed to disparities in access to, and the quality of care and treatments received [37, 39].

More people are surviving CRC in North America, Europe, Oceania and urban areas of South Asia and China [33, 35], most likely due to having access to screening and early diagnosis, optimum medical treatment, and a reduction in postoperative mortality [34].

Health Professionals (HPs) have coined the concept of cancer survivorship defined as a process that begins at the time of diagnosis and continues throughout one's life [3, 19-22]. Cancer survivors may experience physical, psychosocial, and functional impairments in addition to a risk of cancer recurrence, financial stress, and a reduced health related quality of life (HRQoL)[77, 78, 80]. Specifically, CRC survivors can experience symptoms such as loss of control of body functions, weight change, fatigue, sleep problems, sexual dysfunction, fear of recurrence and reduced mobility [15]. The burden of cancer and risk of recurrence can be reduced for the cancer survivor by adopting healthier lifestyle choices.

Modifiable risk factors for CRC include diet, physical activity (PA), tobacco smoking, alcohol intake and obesity [4, 5]. Dietary risk factors include fibre intake, red meat consumption, and alcohol consumption. A systematic review and meta-analysis of prospective observational studies found an inverse association between dietary fibre, cereal fibre, and whole grains intake and the risk of CRC [72]. For every 10g/day intake of total dietary fibre intake, there was a 10% reduction in CRC risk [72]. These findings are consistent with a cohort study of Danish men and women demonstrating that an increased consumption of total wholegrain products was linked to a 15% lower risk of colon cancer and 10% lower risk for rectal cancer [74]. A systematic review and meta-analysis of studies of red and processed meat intake and the risk of colorectal adenomas found the relative risk per 100 g/day of red meat consumption was 1.27 (95 % CI 1.16-1.40), and for processed meat consumption, the relative risk per 50 g/day was 1.29 (95 % CI 1.10-1.53) [141]. An energy-dense, nutrient-poor diet can lead to an increase in body mass index (BMI). It is well established that BMI is associated with an increase in the risk of developing CRC [53, 57, 58].

For alcohol consumption, a systematic review has shown moderate to heavy consumption of alcohol increases the risk of CRC [54], and that there is a dose-risk relationship between regular alcohol drinking and the risk of CRC compared with non-drinkers or occasional drinkers [55, 56].

PA lowers the risk of colon cancer. A meta-analysis comparing people undertaking high levels of total PA report a 20 percent significant decrease in CRC risk (RR 0.80 (95% CI 0.72-0.88) [142].

HPs and cancer-related Non-Governmental Organisations (NGOs) play a key role in providing quality dietary and lifestyle information to cancer survivors to reduce modifiable risk factors and improve well-being and HRQoL. CRC survivors value guidance on diet, activity and lifestyle in the immediate post-treatment period to help manage their symptoms [15]. HPs are patients’ primary trusted source of information followed by the internet, friends and family [127]. Dietitians are critical as sources of information provision to patients [113] on healthy eating, what foods to eat or avoid, protein/energy supplements, recipes, portion sizes, texture modified diets, fortified foods, how to gain weight or lose weight, and how to use diet to manage symptoms [119]. A recent systematic review has shown than primary care-based dietetic consultations are effective for improving diet quality, diabetes outcomes, blood pressure control and weight loss [121].

Other HPs are also essential sources of dietary and lifestyle advice. A recent study from the Netherlands showed that nutrition information provision provided by one or more HPs (nurses, dietitian, doctor) is strongly associated with patients’ believing that nutrition influences their recovery after treatment, and recurrence risk. Further, the more HPs involved in providing nutrition information, the stronger the beliefs held by patients [124].

For many cancer survivors their information needs are unmet, and when they transition from active treatment to survivorship, they would like more guidance on diet, exercise, and weight management [113, 125, 126]. Many receive insufficient information on diet and healthy lifestyle advice from HPs and are often unsure about credible sources of information. [130].

Barriers to information provision include lack of guidelines and resources on diet, weight management and exercise interventions, time available in a consultation, adequate support structure, and practitioners' uncertainty regarding appropriate messages to provide for cancer patients [113, 123, 129].

Ensuring patients receive adequate information as part of survivorship care is a significant challenge. Although studies have been conducted internationally on information provision, a recent study has identified there is a need for more standardised nutrition information and support across New Zealand oncology [18]. The aim of this study is to understand the dietary, PA and lifestyle advice provided by hospital and community-based allied HPs and NGOs specifically for CRC survivors in New Zealand. Further we sought their views on resources, access to patients, gaps in service provision, and barriers to providing optimal care.

3.3 METHODS

Study Design

This study employed semi-structured face-to-face interviews to explore HPs' and NGOs' experiences of health information provision on diet and lifestyle to patients with CRC.

Subjects and recruitment

Participants were selected through a mixture of purposive and snowball sampling. Purposive sampling selects the participants who have features, characteristics or criteria which allow an understanding and exploration of the research aims. Whereas snowball sampling contacts similar participants through referral of other study participants [143]. We sought a mixture of HPs involved in the care of patients living after CRC diagnosis and treatment.

Potential participants were identified through professional organisations' social media, and professional referral, and if expressed interest they were contacted by email and phone.

Dietitians, nurses, and allied HPs from hospital, community and NGO settings were provided with an information sheet and approached to participate. Recruitment was conducted between 28 Nov 2021 to 21 Dec 2021. The demographic characteristics of the HPs and

NGO representatives including role, gender, years of practice and location are shown in Table 3.1.

Data collection

An interview guide was developed to ensure consistency across interviews (Appendix A), which contained open ended questions to explore topics related to the study aim. Key topics explored included the role of HPs and NGOs in information provision, advice, and post-treatment support in dietary and lifestyle issues. HPs were interviewed by the researcher at their place of work by private videoconferencing (ZOOM™). Each interview was recorded and transcribed verbatim. All transcriptions were de-identified. Demographic information, regarding gender, job title and length of time in profession was also collected.

Data analysis

A thematic analysis of the anonymised interview transcripts was conducted to analyse the data utilising the Framework Approach [143]. Framework Analysis is an appropriate, rigorous and systematic method for undertaking qualitative analysis [144]. It consisted of five stages: familiarisation; identification of thematic coding framework; indexing; charting; mapping and interpretation [143]. Explanatory codes within the emergent themes were deductively assigned to segments of the transcripts using NVIVO 12 Software (QSR International). Two assessors regularly met to discuss and refine coding. Themes and codes were discussed until consensus was reached.

Ethics approval and informed consent

The project was deemed by Massey University Ethics Committee as being low risk. Each health professional involved in the study provided informed consent and were free to withdraw from the study at any time.

3.4 RESULTS

Seven participants were interviewed comprising two hospital-based registered dietitians, one community registered nutritionist and qualified personal trainer, one community registered nurse, and three representatives of NGOs who provide community-based cancer support services (Table 3.1). The participants were from across New Zealand.

TABLE 3.1 ROLES OF ALLIED HEALTH AND NGOS IN NEW ZEALAND IN SUPPORTING PEOPLE AFFECTED BY CANCER

Participant	Profession	Sex	Years of practice	Site
001	Registered Nurse	F	32	Bowel Cancer NZ
002	Community Registered Nutritionist	M	7	Private practice
003	Registered Dietitian	F	15	Hospital Inpatients /outpatients
004	Registered Nurse	F	-	Cancer Society NZ
005	Social Worker	F	-	Cancer Society NZ
006	Registered Dietitian	F	2	Hospital Inpatient
007	Community Registered Nurse	F	32	Auckland

NGOs provide community-based cancer support for patients, caregivers and families who are affected by cancer, supporting people due to all cancers or a single cancer such as CRC. NGOs reach patients via referrals from hospital, GPs, other allied health or self-referral, and patients choose when to opt-out. They provide online services for consumers needing information on diet, PA, financial, and psychosocial support.

Support groups are available for patients to engage with nursing staff through an online chat platform.

> *We have a supportive role in providing information, help assistance, advocacy. We have practical help in terms of information booklets, various other things, opportunity to get together with other people who have gone through the same experience (…) a telephone line for nursing support (…) CANCER chatline, where somebody can be put in touch with a trained volunteer who's had a similar experience. We provide support and help for anyone who is going through the cancer experience or has been through cancer experience (…) includes patient, the whanau, family as well.*
> *(004 NGO)*

A registered nutritionist offers evidence-based advice and information on the effects of food and nutrition on human health and well-being. Hospital-based registered dietitians utilise current public health and scientific data on food, health, and diseases, to diagnose needs and tailor interventions to help individuals make the best lifestyle and eating choices possible within a cultural context. Community nurses promote healthy behaviours, assess the wellness and needs of patients, educate and support patients on disease prevention, and provide access to rehabilitation and other services.

Service provider views on the role of diet in colorectal cancer recovery and the prevention of recurrence

All HPs highlighted the role of diet in improving an individual's health and nutritional status. They all agreed that diet plays an essential role in cancer recovery generally, and specifically in improving the function of the gut, while lowering of the risk of cancer recurrence.

> *Diet is paramount to any sort of cancer, diagnosis and journey, particularly with colorectal, purely and certainly because of anatomy, what you eat, and what you do, is going to have a huge impact on your whole GI system. And in particular, you know, that colorectal area, and how things are moving through or not moving through, and the health of that particular area.*
> *(007 Reg. Nurse)*

Service provider views on meeting diet and physical activity needs throughout the cancer journey

Health professionals and organisations have different referral procedures. For NGOs, referral for cancer care support occurs by self-referral, word of mouth from friends or family, hospital-based HPs, GPs and other sources. NGOs are well known in the community, and they have accessible Facebook pages and websites.

> *Facebook presence, we're starting to be known within the colorectal community, within DHBs, Cancer Society, HealthLink (GPs are able to find us and refer patients), word of mouth, community organisations, self-referral (email or via Facebook, our website).*
> *(001 NGO)*

For hospital-based dietitians, patients are referred based on specific criteria, namely, malnutrition or unintentional weight loss due to cancer cachexia and side-effects of treatment. These patients take priority for referral over other CRC patients. Often the patients seen are end-stage, dealing with complex dietary needs including weight loss, and the requirement for a low residue diet due to the risk of a bowel obstruction. They deliver a tailored approach and discuss the importance of whole grains, legumes, fruits, vegetables, with a focus on fibre intake (which may be increased to lower cancer risk or decreased to lower risk of bowel obstruction); the reduction of processed foods, red meat, and alcohol (linked to increased cancer risk); and managing caloric food intake for weight gain or weight loss, and considering food tolerance.

> *I see patients more kind of towards end stage. And in this stage, depending on whether they've just had a surgery, sometimes it's more important to make sure that they're actually eating a lower fibre and getting the protein and tolerating what they're eating, rather than I guess, maybe some of that more lifestyle related advice where you want them to be eating*
> *(006 Reg. Dietitian)*

All HPs stated the best time to intervene to address dietary and PA needs is at all points, namely, as soon as possible after diagnosis and continuing throughout the entire cancer journey. Targeting the needs of patients at various stages with specific advice at that point of their cancer trajectory allows patients to have optimal health to cope with cancer treatments (radiotherapy, chemotherapy), post-surgical outcomes and to improve recovery and reduce recurrence.

The HPs understand that patients have various levels of motivation, and that interventions may not be successful all of the time. For example, patients have higher levels of motivation for change in the post-treatment phase, compared to patients who may not be ready to absorb information around the time of diagnosis. Moreover, the HPs recognised the importance of being mindful of the patients' motivation levels for change in how they provided expert advice and the type of changes they may recommend.

> *I think it's probably appropriate all throughout that journey. But it's also thinking about if the patient is kind of ready to sort of make some changes or really to take that information in. So it's sort of balancing those two*
> *(003 Reg. Dietitian)*

The most utilised guideline by the HPs is the Ministry of Health Eating and Activity guidelines for Adults [63] for general healthy eating advice. This guideline forms the basis for NGOs' resources and information sheets. Other guidelines utilised by some participants include the World Cancer Research Fund [101] and ESPEN guidelines [103] which also contain strong evidence around nutrition, diet and PA for cancer care. Information can be tailored to a specific case to meet a patient's needs when their nutrition is being assessed and treated by a registered dietitian or registered nutritionist.

I would generally follow the recommended guidelines from the nutrition society that we have as well, which just follows Ministry of Health guidelines generally. I would tweak them case by case based on results that I've seen with clients. … in terms of fruit and vegetables, I am more extreme than the guidelines, mainly because they're just not as good as they used to be when the guidelines were created.
(002 Reg. Nutritionist)

However, the general guidelines from the New Zealand Ministry of Health [63] are not individualised to target specific CRC patients' needs and other guidelines are difficult to find online. HPs stated that dietary and lifestyle guidelines specific to CRC patients need to be accessible.

> *The guidelines could be improved… even as a nutritionist, I would have to go find those. There's no kind of like, here it is, no one kind of tells you about this stuff, or, I wouldn't have been told where to find them, I would have to go find them myself.*
> *(002 Reg. Nutritionist and qualified personal trainer)*

All of the HPs realised the importance of PA for health recovery, specifically to manage stress and fatigue from cancer treatments, to increase muscle mass and strength including pelvic floor and core strength, improve mobility, and to assist weight management for cardiovascular and overall health. Only the qualified personal trainer provided a detailed exercise plan, whereas all other HPs only provided general recommendations based on the Ministry of Health guidelines on PA (a minimum of 150 minutes a week) [63]. Moreover, all HPs emphasised that when making recommendations, factors that impact the patient's ability to tolerate and perform PA must be considered. These include the stage of their cancer journey, patients age, co-morbidity, fatigue, and upset bowels.

> *I do recommend patients do as much as they can actually manage. I don't prescribe exercise (…). I don't really have anything specific to recommend to be honest (…) I'm very careful because it's out of my scope. I'm not always sure exactly what their capabilities are, maybe some of the other medical conditions, but I do really stress that's something even if they just do small amounts of walking. I'll just say do as much as you can actually tolerate*
> *(003 Reg. Dietitian)*

> *You know, if you still got really upset bowels, I mean, bowels can take a year, 18 months to settle down after major surgery and…some people can't be away from a toilet for any length of time. So to advise them to be doing moderate sort of activity for 30 to 45 minutes a day might actually not work...go with the National recommendations with the proviso that you can only do what you can actually do*
> *(001 NGO)*

Referral or recommendation to other healthcare providers

Patients who would benefit from other specialities, were recommended or referred to other health providers. These included private physiotherapy programmes for mobility and strength training to facilitate a return to normal activities of daily living. As NGOs do not employ dietitians or registered nutritionists, patients needing specific dietary assessment and advice, including meal plans, were referred to a community or private dietitian through the patient's GP.

> *GP can do a referral to community dietitians or, although I do realise there's a wait for that…we have funded physiotherapy. … a nationwide physiotherapy group, which we can be provided for bowel cancer patients.*
> *(001 NGO)*

The representatives of the NGOs mentioned that they have access to and refer patients to outsourced physiotherapy sessions and gymnasium-based rehabilitation programmes depending on service location. The cost is covered by the NGO.

Hospital-based registered dietitians mentioned that they have physiotherapists and occupational therapists in the hospital, but they would not refer to a public-funded community dietitian or to a community lifestyle programme. They would rely on the patient's GP to recommend Green Prescriptions or Active Families, or to recommend local lifestyle programmes. One of the dietitians interviewed sometimes referred patients to a four-week programme talking about lifestyle change run by a dietitian at the hospital.

> *They wouldn't meet criteria to see a community dietitian for lifestyle. And if someone says they really want to continue seeing a dietitian, I might suggest to private dietitians that they can go and pay for themselves. But yeah, like I say the DHB doesn't unfortunately have capacity to see them for their lifestyle side of things.*
> *(006 Reg. Dietitian)*

Potential barriers to service provision:

i. ***Patients have individual needs requiring expert provision of dietary and physical activity advice***

HPs recognised that patients have specific dietary requirements, and accordingly advice ideally should be individualised to cater for their needs. They mentioned that the patient's individual needs are dependent on where they are in their cancer treatment and recovery, the type of treatment experienced (surgery, colostomy, radiotherapy, chemotherapy), current health status (co-morbidities, medications, weight loss), and nutritional factors that impact their oral intake (fatigue, taste changes).

NGO representatives mentioned that they mainly provide general dietary advice to patients, and do not always have qualified dietary expertise on their team. However, they do understand the importance of tailoring advice to address patients' specific needs. They recommend to their patients that they seek a referral from their GP to a registered dietitian for expert input into complex issues such as managing weight, specific diets (for example a low residue diet to avoid foods that may irritate the bowel or obstruct narrowed parts of the bowel), and tailored dietary plans.

> *I've normally dealing with a lot of weight loss…a lot of the patients I see had been put onto a low residue diet because of the risk of an obstruction*
> *(003 Reg. Dietitian)*

Both NGO representatives and dietitians stated that due to a lack of expertise, they provide general advice on PA to encourage activity at the level that patients can manage based on their age and health status. However, they recognised that patients should have a tailored individualised PA plan to improve their quality of life and ability to return to work. The plan should address improvement in mobility, and pelvic floor and abdominal core strengthening. Moreover, the plan should consider the patient's age, current health status (co-morbidities, chronic upset bowels), fitness and fatigue levels. They report that patients would benefit from prescriptive exercise plans developed and delivered by registered exercise professionals, who are knowledgeable about the needs and abilities of cancer survivors during their cancer trajectory.

> *This depends on the person's treatment, (…) treatment is quite intensive (…) they're very fatigued and stressed now, there's still movements and stuff that they can keep up that don't involve high intensity (…) more yoga based things or even just walking (…) for 30 minutes a day (…) whatever they manage long term is going to be beneficial.*
> *(002 Reg. Nutritionist and qualified personal trainer)*

Information, advice, and materials provided to patients are not individualised, necessarily CRC specific, or standardised, and are dependent on which service the patient accesses. NGOs have links on their websites to resources, recipes, and a booklet specifically addressing living after a bowel cancer diagnosis. Other NGOs have leaflets that are printable from the website on diet and PA and a general 'living well with cancer' booklet. Hospital based dietitians have diet sheets on low residue or high energy high protein diets or refer to the Heart Foundation website. Only the registered nutritionist utilised an app with a personalised meal plan.

ii. Gaps in provision of dietary services

The post-treatment phase provides a window of opportunity for patients to improve their health outcomes.

> *We do find post-treatment, people want to do whatever they can to maximize their chances of health and also minimise the risk of cancer returning. So most of the time people are really motivated.*
> *(005 NGO social worker)*

However, there are inconsistencies in the information provision across different organisations to support patients. NGOs do not have the expertise of dietitians to conduct dietary assessments or to provide expert individualised diet advice. Hence NGO representatives rely on their own expertise and relevant health backgrounds, and printed materials, to provide advice to patients as best as they can. NGO representatives understand the value of addressing patients dietary and PA needs, and expressed that they can only be supportive, and a point of contact for linking patients up with programmes, if available.

> *We don't do assessing, as I said, we're not really a treating when we don't have that expertise to be a treating or management team. We are there very much in a supportive role*
> *(004 NGO Reg. Nurse)*

NGOs are resourceful and do provide general dietary advice including how to manage and maintain a healthy weight, and they do consider individual patient circumstances. Ideally, dietary advice should be provided by a registered dietitian or nutritionist and be specific and tailored to patients. Dietitians are trained to educate and provide practical, personalised advice to patients, and their whānau; and are experts in cancer-specific issues such as unintentional weight loss and managing a post-colostomy or surgery restrictive diet. NGOs identified that by not employing or referring to these professionals, there is potentially a gap in service.

> *We don't have a specific expertise, in my view to do targeted, individualised advice. Around the country, there might be some, like some of our nurses may feel that they've got some of those skills, some people with that relevant health background, but it's not routine as an organisation that we can sit down and do an individualised assessment and provide that dietary and I think it is a gap (...) And it's quite hard to get to see hospital dietitians. It seems quite a limiting resource.*
> *(005 NGO Social worker)*

> *I wouldn't provide advice or weight management, that's more of a dietitian, nutritionist expertise (…) we do have quite a lot of information resources, on diet but a lot of it covers a range of cancers and not just colorectal. With specifically to colorectal cancer, we don't have a lot of information that is specific.*
> *(004 NGO Reg. nurse)*

From the perspective of NGOs, there is a recognition that there is an inconsistency nationally on how the service meets the dietary and PA needs of their clients.

> *I suppose re-examination of the whole organisation in terms of being a bit more consistent right through nationally. But also, on a more local level, our general model of care how we provide what we provide. … what I'm saying is that there is a recognition, I think that diet and exercise do play quite a critical role in recovery. And work is underway to see how we can best meet that need.*
> *(004 NGO)*

In contrast, registered dietitians and nutritionists can conduct assessment, deliver clinical advice and provide follow-up care to monitor and evaluate patients' health outcomes. However, this service compared to private care is limited in the public hospital setting due to time and financial constraints, and as such, end-stage patients take priority. The difference in service provision between public and private settings leads to a disparity in patients' ability to address changing dietary needs, and to support behavioural changes. In the public setting, if the patient has been seen by a dietitian, they may get referred to programmes for education on lifestyle change or instead have to rely on referral to community services from their GP.

> *We do not have the capacity to see patients for lifestyle type of advice. We do have a group that is called "Eating for your health," which is a four-week programme, talking about lifestyle change, and it's done by a dietitian, the diet side of things (…). So, we can sometimes refer patients into that, but they would not necessarily get a one on one follow up.*
> *(006 Reg. Dietitian)*

> *But there's often not a lot of support around. Can I do this? Should I do this? Why? How do I do this?... But there's still a lot of mindset stuff that needs to go along with diet and lifestyle work. You know there's a lot of, you know, do 30 minutes a day, eat vegetables. But, you know, how do I do that, you know, long term and maintain it?*
> *(007 Reg. Nurse)*

iii. Gaps in services in providing physical activity advice

NGOs provide general advice regarding PA, dependent on the patients' capabilities. PA programmes that are available for cancer survivors are dependent on location (major urban centres) and funding (paid by the NGO or patient-funded); these include physiotherapy and gymnasium programmes. Follow up appointments for PA in the post-treatment phase are mostly in outpatient clinics or by NGO-funded or patient-funded private registered physiotherapists and exercise professionals. There is a lack of professionally delivered lifestyle programmes for cancer survivors.

> *As far as diet and exercise go. There's not that many lifestyle programmes*
> *(007 Reg. Nurse)*

Hospital-based dietitians recognise the importance of PA for CRC patients and enquire about PA levels, but they lack the scope and resources to provide personalised assessment and plans.

> *I don't prescribe exercise, but I will often say look, have a think about some resistance training, but maybe have a chat to your GP, just to check, you're safe to do it, first of all…think about what you can do, if it's an app you might be able to tap into, and I don't really have anything specific to recommend to be honest… maybe have a chat to a gym instructor or if there's anything you're doing just to get some support around some extra stuff you can be doing.*
> *(003 Reg. Dietitian)*

> *It's not really my scope. So I sometimes if someone asked me directly, I would say what the Ministry of Health recommends, so I think it is 150 minutes a week. But I wouldn't really go more into depth because I don't feel like it's my area to be able to advise them*
> *(006 Reg. Dietitian)*

Moreover, the hospital-based dietitians report that they do not have the resources or services to provide specific PA advice, and state that better resourcing is needed.

> *In terms of physical activity, maybe not. And I guess I don't myself know of any particular like dietitian related resource that I could use either. So there could be more.*
> *(006 Reg. Dietitian)*

> *It's a lot outside of my scope, but I will often bring it up with patients. I'd love to be able to, you know that there was a little bit more support …, for them to be referred somewhere. I think there's a bit of gap there definitely…like a physical specialist.*
> *(003 Reg. Dietitian)*

3.5 DISCUSSION

The health professionals in this study concur with the evidence that healthy diets and lifestyle enhance recovery, improve survival, and lower the risk of recurrence for CRC patients [145]. Additionally, they recognised the importance of PA for improving fatigue, stress management, muscle mass and strength, core and pelvic floor strength, mobility, and cardiovascular health.

HPs felt that the best time to address dietary and PA needs starts from diagnosis and throughout the whole cancer trajectory to optimise patients' health to cope with cancer treatments and enhance post-treatment recovery. However, a UK study of the views of surgeons, physicians, nurses and allied HPs were mixed between providing advice at diagnosis, at the end of treatment, at all visits, or that the timing was individual patient-dependent [129]. A study by Anderson and colleagues (2013) report that most CRC survivors appreciate dietary advice in the initial post-treatment period to alleviate anxieties about food choices. Whereas another study reports that CRC patients want information soon after diagnosis to be able to make informed decisions on how to change their lifestyles [146]. This range of viewpoints of HPs and CRC patients leads to a challenge as to when is the most appropriate time to offer lifestyle advice. Given the limited resources in healthcare, more research is required to address this issue, and to identify the most effective timing to impact lifestyle behaviours.

HPs emphasised the individual needs of patients which is reported in other studies. Previous research has shown that personalised care enables individuals to achieve small sustainable changes to their lifestyle [15, 129]. Moreover, patients who receive input from dietitians are more likely to receive advice on how to achieve an optimal diet with consideration of patients' food preferences, symptoms, lifestyle, beliefs and concerns [119]. In a large mixed methods study that investigated the dietary support needs for CRC patients in the Netherlands [146], eighteen percent of the survivors wanted tailored answers, information, and advice to make an informed decision dealing with their disease and treatment-related complaints. They felt they would be unable to start and maintain lifestyle changes without professional input and required tailored care in a supportive environment to allow autonomy [146]. In our study, the HPs were aware that patients benefit from individualised advice that considers factors such as the type of CRC, treatment experienced, current health status including co-morbidities, weight loss, fatigue, and taste changes. However, the HPs from the NGOs, who are a major source of information for CRC survivors, reported that they only provide general dietary advice which may be altered based on their own knowledge, but the service does not employ qualified dietitians for dietary assessment and individualised plans. For many patients without complex needs, individualised advice is not accessible as they are not seen by hospital-based dietitians. Instead, the emphasis is on these patients getting referred from their GPs to community or private dietitians.

As with dietary changes, the benefits of PA in reducing recurrence, comorbidities, mortality and CRC specific mortality, and improved health related quality is well-established [147] [148] [149] [95]. We found that HPs acknowledge the importance of regular PA, and that for many patients the advice should be specific to a person's current health status and tolerance level. Factors to be considered include age, co-morbidity, motivation, chronic upset bowels and bowel function, time since treatment, fitness and fatigue. However, most HPs interviewed only delivered general PA advice based on general guidelines due to a lack of professional scope and education in this area. However, an issue with relying on general PA guidelines is that they are not specific to CRC patients' needs, and adherence to the recommendations are low in cancer survivors, especially among CRC survivors [150]. If available based on location, NGOs have contracted physiotherapists and exercise gym programmes to refer patients. One of the HPs emphasised that there is a need for CRC specific guidelines, a modification of the general guidelines that account for varying patients' needs and circumstances, and as such, these may improve dietary and PA adherence in CRC survivors. All HPs and NGOs mentioned that there is a paucity of services that offer individualised PA programmes for CRC survivors.

A recent study in New Zealand found that nutrition support and information were not widely available in oncology practices and cancer support services [14]. Namely, there is a lack of a standardised approach in the provision and quality of written and online materials for survivors in both the public and private healthcare settings. The WCRF/AICR report states professional expert advice and support on diet should be provided to all cancer patients [101]. In our study, the HP and NGOs provided information via booklets and recommended health websites, and these are often general and often based on the general Ministry of Health Eating and Activity guidelines [63] or written by a contracted dietitian. Hospital-based dietitians provided cancer-specific information sheets (low residue diet, high energy, high protein diet) and tailored advice for patients, and only the private registered nutritionist provided a personalised meal plan. Our findings agree with Peniamina and colleagues; that the lack of standardisation, the type and quality of information and resources, the lack of specificity to the needs of a CRC survivor, is dependent on which health professional or service they access, potentially leading to a gap in information provision and inequities in cancer care [14].

The HPs in our study were concerned that there was not a standardised and clear pathway for CRC survivors to receive tailored dietary and lifestyle advice, due to limited resources. For many patients, often they do not see a dietitian in hospital settings due to lack of time, unless they have end-stage disease or require a complex dietary plan, and this care is not continued after discharge. In the community, NGOs lack the capacity to employ or contract dietitians for clinical dietary assessment and follow-up. An inequity we identified is that access to quality dietetic care for many patients is challenging due to the cost of private dietetic services. This inequity results in many patients not receiving the valuable information on the role of diet and PA in CRC and its recurrence [130] [136], and are not assessed to allow individualised dietary information provision, especially in the post-treatment phase, which is when patients are highly motivated for lifestyle change. This lack of service places the emphasis on GPs to identify and address the need for dietary and PA change, and possibly to refer to publicly funded community dietitians and physical therapists.

There is an opportunity for public and NGO health services planners and clinicians to recognise the potential gaps in service for CRC survivors to enable these patients to have tailored information and support for dietary and PA changes. Registered dietitians are best placed to provide individualised dietary support in the long term, and these changes will reduce CRC recurrence and enhance quality of life. Moreover, the standardisation of paper and online information provision based on CRC specific diet and PA evidence-based guidelines, greater access to services and programmes, and a clearer pathway will ensure a more equitable health service. This will require a greater communication between the public, NGO and private sectors, and case-finding to identify patients who would benefit from individualised dietary support and the most appropriate time in the cancer journey to intervene.

Strengths and limitations

To our knowledge, this is the first study in New Zealand to explore the views of HPs on information provision regarding diet, PA, and lifestyle support for CRC survivors. We sampled a variety of HPs involved in cancer care, including dietitians, nutritionists, nurses and NGO representatives from public and private hospital and community settings which gave us an overview of the current health service.

The in-depth nature of the interviews with open ended questions encouraged the participants to guide the conversation with minimal input from the interviewer. However, there are limitations to consider. Our qualitative approach has provided in-depth information about the health services, but the findings cannot be generalised and may not be representative of all HPs or NGOs. In addition, we did not explore the role of the GPs or community dietitians (although we did interview a community based registered nutritionist) in CRC care including referrals to community services, or the experiences of the cancer survivors themselves. Future research could explore the current role of community health care including GPs and community dietitians in New Zealand on supporting the dietary and PA needs of CRC survivors. Likewise, future research should focus on interviewing CRC survivors to get their viewpoints on the information provision they received to meet their dietary and lifestyle needs, its appropriateness and applicability, and if any information was lacking.

3.6 CONCLUSION

A potential fragmentation has been identified in cancer health services, with inequitable access, and gaps in information provision to meet the dietary and lifestyle needs of many CRC survivors. Information provided is generally based on general health guidelines, is non-standardised, and is dependent on which health professional the patients have access to. For many patients, they do not see a registered dietitian or physical therapist for needs assessment and information provision, and as such support structures for lifestyle change across settings are not implemented. These barriers to care may be leading to ongoing unmet needs in CRC survivors and an increased risk of CRC recurrence and reduced quality of life.

CHAPTER 4: CONCLUSION AND RECOMMENDATIONS

4.1 STUDY SUMMARY

This research provides insight into the perspectives of HPs and NGOs information provision to CRC survivors including the overview of the facilitators and barriers actively influencing CRC survivorship care in New Zealand. HPs and NGOs are common providers of cancer related information. However, little is known about the views of HPs and NGOs on the delivery and quality of information provision addressing diet and PA, both generally and specifically, to meet the needs of CRC survivors.

The aim of this study is to understand the dietary, physical activity and lifestyle advice provided by hospital and community-based allied HPs and NGOs specifically for CRC survivors in New Zealand. Further we sought their views on resources, access to patients, gaps in service provision, and barriers to providing optimal care.

Most HPs and NGO representatives agreed that diet and PA are paramount for patients' recovery, improved wellbeing and reducing risk of recurrence. A tailored approach when working with survivors for changing behaviour was emphasised to be helpful in addressing complex and individualised needs associated with CRC survivorship.

Our findings indicate that HPs and NGOs play a key role in enhancing CRC survivorship through providing information regarding a healthy diet and an active lifestyle, and often referring to lifestyle programmes. Registered dietitians are important providers of dietary assessment, nutrition diagnosis and tailored interventions, and PA advice. NGOs provide general information provision and have a key role in connecting patients and families to relevant support networks and programmes. HPs and NGOs reported that provision of dietary and PA advice should be available throughout the entire cancer trajectory, beginning at diagnosis.

CRC survivors have specific needs in regard to diet and PA beyond general recommendations due to the disease and past and ongoing treatments. Many have experienced weight loss, are malnourished, have ongoing bowel issues such as discomfort, constipation or diarrhoea, have fatigue, anxiety and depression, co-morbidities, variable tolerances, and are concerned about recurrence. Some may have a colostomy. As such they often require tailored professional advice and guidance including programmes.

Our study identified a number of barriers to tailored service provision and potential gaps in service delivery. HPs employed by NGOs can only provide general information regarding diet and lifestyle advice. There are funding constraints within the NGOs for dietetic services to provide tailored and expert dietary input to support patients' behaviour change, and to advise and follow-up dietary outcomes. In addition, the resources and guidelines utilised by NGOs are more suitable for targeting healthy eating for the public, whereas CRC-specific dietary guidelines were seldom used. There is a paucity of CRC-specific guidelines and training available for the HPs in NZ, and as such they rely on general guidelines for providing advice.

Hospital-based dietitians due to time-constraints can only prioritise patients with malnutrition, and complex needs such as those with end-stage cancer. This results in many CRC survivors not consulting registered dietitians within the hospital setting and thus relying on either a GP referral to a community dietitian which may not occur, or advice sought from the NGOs or relevant websites (See chapter 5). Further, an inequity may exist if services are not provided in the public sector, as access to private dietetic services for many survivors may not be affordable or available across New Zealand.

Dietitians did not address PA needs to any detail other than provide advice based on general PA guidelines. For many they believe this was outside their scope of practice. NGOs referred survivors to internal programmes or external private services, that were sometime funded by the NGOs. But access to tailored PA plans by a registered physical therapist and gym-based programmes was limited and was dependent on the patients’ location within New Zealand. The gap in service provision for dietary and PA input for CRC survivors was reflected in the viewpoints of the HPs and NGOs who were concerned that there was not a standardised and clear pathway for receiving tailored dietary and lifestyle advice.

In summary, there is a requirement for a standardised pathway for patients to receive diet and PA services to ensure that patients who will benefit from specific and tailored professional dietary and PA advice to improve wellbeing and reduce recurrence, will not fall through the gap. Currently, this lack of a standardisation of information provision, and unequal allocation of access to service and resources contributes to inequity in cancer care for CRC survivors. This finding was recently also identified in a study by Peniamina et al. who found a lack of a standardised approach in the provision and quality of written and online materials for survivors in both the public and private healthcare settings for cancer patients in New Zealand [18].

4.2 RECOMMENDATIONS FOR CLINICAL PRACTICE

This study has identified a number of opportunities to improve clinical practice. It is important that survivors are equipped with knowledge and skills on healthy behaviour change following diagnosis to enhance short- and long-term self-management needs (cancer recurrence, alleviate symptoms and fears about food choices) and live a long healthy lifestyle that improves their quality of life and wellbeing, and reduces recurrence. It is known that survivors who receive dietary advice are more likely to change their diet and lifestyle habits depending on their motivations [140].

There is an opportunity for public and NGO health service planners and clinicians to recognise the potential gaps in service for CRC survivors to enable these patients to have information and support structures for dietary and PA changes. HPs and NGOs need to be trained on what advice for CRC survivors will most likely have an impact on their dietary and lifestyle behaviours. Dietitians are best placed to provide individualised nutritional support. Over the long term, these changes may reduce CRC recurrence and enhance quality of life.

Moreover, the standardisation of paper and online information provision based on evidence-based guidelines for CRC, greater access to affordable services and programmes across New Zealand, and a clearer pathway will ensure a more equitable health service. Factors to consider that will ensure that information is evidence-based and is consistent across services include the following: a greater communication between the public, NGO and private sectors; contracting of registered dietitians by NGOs; a system to identify patients who would benefit from individualised dietary support; a system to identify the most appropriate time in the CRC journey to intervene; and a standardisation of the information provided across all settings.

Furthermore, the often-utilised Ministry of Health Eating and Activity guidelines [63] do not necessarily target the specific and complex needs experienced by CRC survivors. Further, physical activity guidelines should make activity recommendations based on the CRC patients' abilities and tolerance. Therefore, CRC specific resources and guidelines within

New Zealand cultural contexts should be developed and utilised by HPs and NGOs as part of their information provision service.

4.3 RECOMMENDATIONS FOR FUTURE RESEARCH

HPs vary in their opinions as to the best time in the cancer journey to provide dietary and lifestyle advice. In our study, HPs stated advice should be provided at all times in the cancer journey. Other research reports a range of time points such as at diagnosis, or at the end of treatment, at all times, or timing is patient-specific [129]. Given the limited resources of health services and access to HPs, the most appropriate and effective time to provide dietary and lifestyle input for CRC survivors needs further research to inform clinical practice.

Future research is required to explore the role of GPs and practice nurses in providing dietary and lifestyle advice to CRC survivors in New Zealand, and their perspectives on how they identify patients who would benefit from referral to dietitians and other HPs, and what follow up care is provided for patients with complex dietary and PA needs. Moreover, research is required into the role of public and private community-based dietitians, the service eligibility criteria, the process of referral to the service, involvement of other HPs including physical therapists, and the type of communication with the patients' GPs.

Survivors are willing to adjust their diet after being diagnosed and treated, but they often do not get enough information to suit their needs [112]. A United Kingdom study found that many survivors actively seek lifestyle counsel, but were confused, received inconsistent messages, received culturally incorrect advice, and were unsure about the evidence of benefit [15]. Future research is required to evaluate dietary and lifestyle advice received for CRC survivors in New Zealand across ethnicities and cultures, and in urban and rural settings. This will allow an understanding of the needs of CRC survivors, the amount and quality of information they have received, the acceptability and usability of the information, and help to identify any unmet information requirements.

4.4 STUDY STRENGTHS AND LIMITATIONS

To our knowledge, this is the first study in New Zealand to explore the views of HPs and NGOs on information provision regarding diet, PA, and lifestyle support for CRC survivors. In this study we sampled a variety of HPs involved in cancer care, including dietitians, nutritionists, nurses and NGO representatives from public and private hospital and community settings, which gave us an overview of the current health service and CRC care pathways. The in-depth nature of the interviews with open ended questions encouraged the participants to guide the conversation with minimal input from the interviewer.

However, there are limitations to consider. Our qualitative approach has provided in-depth information about the health services, but the findings cannot be generalised and may not be representative of all HPs. In addition, we did not explore the role of the GPs in CRC care including referrals to lifestyle-based community services. We did not explore the role of public and private community-based dietitians (although we did interview a community based registered nutritionist) or the experiences of the cancer survivors themselves.

CHAPTER 5: AN EVALUATION OF THE QUALITY AND CONTENT OF NON-GOVERNMENTAL ORGANISATIONS WEBSITES IN NEW ZEALAND FOR COLORECTAL CANCER SURVIVORSHIP

Chapter 5 provides a ***separate stand-alone chapter*** *on a substudy that assesses the quality, navigation, readability, and content of information on diet and lifestyle of the two major cancer NGOs websites in New Zealand for CRC survivors. The substudy is to supplement the main study, as NGO websites are major sources of cancer-related lifestyle information.*

5.1 INTRODUCTION

General Practitioners have a role in informing patients how to achieve health and wellness through diet and physical activity and are considered a trusted source of cancer information. However, patients express that they often felt time constrained and received insufficient information in their appointments with their family physicians [113, 127].

Research findings indicate that cancer survivors experience unmet needs, and they require more support with information provision regarding diet, physical activity and weight management (weight loss or weight gain) in their cancer journey [113].

Many organisations around the world provide diet and lifestyle information for cancer patients. Trusted sources in New Zealand for CRC-related information include registered non-governmental organisation (NGO) websites such as those of Bowel Cancer NZ or the Cancer Society NZ. It is reasonable to assume that the information provided on these major websites are up-to-date and evidence-based, with a high readability level and delivered in a way that is easy to navigate.

5.2 AIM

The aim of the substudy is to assess the quality, navigation, readability, and content of information on diet and lifestyle advice for CRC survivors published on the major New Zealand non-Governmental organisation websites.

5.3 METHODS

Two websites were selected by the investigators as they were major well-known charitable non-Governmental organisations with a directive of cancer information provision and advocacy to the public. Namely, the two major NGOs in New Zealand, Bowel Cancer NZ (https://bowelcancernz.org.nz/) and Cancer Society NZ (https://www.cancer.org.nz/)

5.3.1 Webpage data selection

Websites were accessed from October 2021 to December 2021. Web-pages were selected if they contained content on diet and lifestyle recommendations for cancer survivors and their caregivers, including advice on diet, weight management, physical activity, alcohol consumption, and smoking.

5.3.2 Data extraction and evaluation

The websites were evaluated independently by 2 reviewers (JL, JT) for both sites, and any disagreements, conflicts and discrepancies were noted and reviewed by third reviewer (HS) to reach consensus.

Layout, content and navigation of diet and lifestyle information on the webpages were evaluated to determine ease of use, type of information provided to the reader, and utilisation of evidence-based recommendations.

To evaluate the quality of the webpages, the DISCERN tool and the JAMA benchmark criteria were applied that have been developed to evaluate the quality of web-based health information, and the presence of the certification by the Health on the Net Code (HONcode) was determined (see below).

The DISCERN tool was developed and validated to specifically analyse and evaluate the quality of web-based health information [151]. It was developed out of a worldwide attempt to set quality standards for written information on treatment options offered by United Kingdom National Health Service organisations, charities and self-help groups, the pharmaceutical sector, and other consumer health information sources [151]. The DISCERN tool was developed in two stages, expert panels were recruited to test and analyse consumer health information. The tool was evaluated and tested for reliability on a variety of consumer health information on treatment options by a national sample of health information providers and self-help group members[152]. This tool has been widely used in studies assessing website delivered health information [153-155]. The tool comprises 16 questions, of which the first 8 questions address reliability, the next 7 questions focus on treatment information, and the last question asks the user to grade the overall quality based on all the questions. Each question is rated on a 5-point LIKERT scale, with 1 being lower and 5 indicating higher quality and reliability, with a maximum score of 80. The DISCERN categorises the quality of websites as excellent (score 63–80); good (51–62); fair (39–50); poor (27–38); or very poor (16–26) [152].

A second validated tool that assesses of web-based information is the Journal of the American Medical Association (JAMA) benchmark criteria. It determines the quality of websites based on authorship, attribution, disclosure, and currency [156]. Authorship requires the authors and contributors to provide their affiliations and credentials. The referencing of information presented is referred to as attribution. Disclosure involves identifying conflicts of interest and/or sponsorship. The provision of the dates on which the data were posted or updated is referred to as currency. For each of the four criteria, if met, 1 point is scored, for a total of 4 points. Using previously published definitions, sites that meet 3 or more JAMA criteria are classified as high quality, and sites with less than 3 are classified as low quality [157].

Thirdly, the Health on the Net Code (HONcode) seal is a trustworthy, recognisable accreditation symbol that confirms a website has undergone a series of quality checks and meet the overarching principles for justifiability, transparency, and financial disclosure. A Geneva based foundation (https://www.hon.ch) that advocates for the publishing of accurate health information on the internet [158] provides certification that sites meet the HONcode criteria [156, 159].

Lastly, readability can be assessed using the Flesch Reading Ease (FRE) scale and Flesch-Kincaid Reading Grade Level (FKRGL) tests. Both are valid for measuring the readability of written text from US grade 5 to college level [160]. FRE and FKRGL scores can be obtained by importing at least 400 words from a webpage into Microsoft Word which generates a score under the readability statistics function [154, 156].

The FRE score ranges from 0 (unreadable) to 100 (very easy to read). A FRE score of 61-70 being standard, 71-80 is fairly easy to read, 81-90 is easy, 91-100 is very easy. Scores of less than 60 range from fairly to very difficult to read [160]. Written health care information should be aimed at students in grades 8 and up in the United States, which is the equivalent of year 9 student literacy level (12-14 years old) in New Zealand equating to a FRE score of 60.0 to 70.0 [160].

The FKRGL rating is based on America school grades ranging from 1 to 18. FKRGL is calculated using a method used to determine how difficult a text is to understand based on two key factors. The first is syntactic difficulty, which is determined by the number of words per phrase. The second factor is word difficulty, which is measured in syllables per word [161]. It is scored out of 18, with scores of 0-1 indicating understanding by a 1st grade USA student (age 3-7 years), score of 1-5 indicating understanding by a 1st-5th grader (age 7-11) and designated as 'very easy to read', scores of 5-11 indicating understanding by a 5th-11th grader (age 11-17) and designated as average level, and scores of 11-18 indicating understanding by a 11th-18th grade (age 17 and above) and designated as skilled reader [160].

To evaluate the quality, navigation, readability and content of the webpages, an evaluation form was created (see appendix C) comprising the tools as detailed above.

5.4 RESULTS

5.4.1 Quality assessment of websites

The mean DISCERN score was 51, and JAMA score was 1.5. Cancer Society New Zealand scored the highest ratings for DISCERN and JAMA (60, 3). Bowel Cancer NZ had the lowest ratings for DISCERN and JAMA (42, 0). No websites had the HONcode seal presented. Table 5.1depicts the rating for each website.

5.4.2 Readability

For Bowel Cancer NZ and Cancer Society NZ, FRE were 48.2 and 60.9 (mean of 54.6/100), and for FKRGL were 10.8 and 9.1 (mean of 10.0/18) respectively.

Table 5.2 provides a summary of quality and readability assessment scores for each website.

TABLE 5.1 MEAN SCORES FOR ALL REVIEWED SITES (N=2)

Measurements	Mean scores
Quality	
DISCERN	51/80
JAMA	1.5/4
HONcode seal	No sites displayed HONcode seal
Readability	
FRE	54.6/100
FKRGL	10.0/18

TABLE 5.2 SUMMARY OF QUALITY AND READABILITY ASSESSMENT SCORES FOR REVIEWED SITES

Measurement	Bowel Cancer NZ	Cancer Society NZ
QUALITY ASSESSMENT		
DISCERN		
Are the aims clear?	2	2
Does it achieve its aims?	3	4
Is it relevant?	5	5
Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	1
Is it clear when the information used or reported in the publication was produced?	1	2
Is it balanced and unbiased?	4	4
Does it provide details of additional sources of support and information?	2	5
Does it refer to areas of uncertainty?	5	5
Does it describe how each treatment works?	4	5
Does it describe the benefits of each treatment?	2	4
Does it describe the risks of each treatment?	1	4
Does it describe what would happen if no treatment is used?	1	1
Does it describe how the treatment choices affect overall quality of life?	2	4
Is it clear that there may be more than one possible treatment choice?	4	5
Does it provide support for shared decision-making?	2	5
Overall rating of the publication	3	4
Total /80	42	60

Measurement	Bowel Cancer NZ	Cancer Society NZ
QUALITY ASSESSMENT CONTINUED		
JAMA BENCHMARK CRITERIA		
Display of authorship	0	1
Display of attributions or references	0	0
Date of original posting and update	0	1
Disclosures	0	1
Total/4	0	3
HEALTH ON THE NET CODE (HONCODE) SEAL		
Present	No	No
READABILITY TEST		
FRE/100	48.2	60.9
FKRGL/18	10.8	9.1

5.4.3 Assessment of lifestyle advice provision for colorectal cancer patients

Both Bowel Cancer NZ and the Cancer Society NZ provide information regarding PA, weight management, alcohol, smoking and diet on the websites. Certain information referred to published peer-reviewed guidelines from the World Cancer Research Fund (WCRF) [137], and the Ministry of Health NZ [63].

Dietary and physical activity information provision from both organisations were detailed and comprehensive compared to the other lifestyle information (smoking, alcohol, weight management). Table 5.3 is a summary of the lifestyle advice provided on the websites. The following paragraphs provide more detail.

Diet

Dietary advice on the Bowel Cancer NZ website focuses on including the four food groups, namely, at least 3 servings of vegetables and at least 2 servings of fruit every day, 6 servings of grains every day, 2 servings of milk and milk products a day, 2 servings of plant protein or 1 serving of meat and seafood a day. They advise limiting certain foods that may heighten the risk of developing CRC (e.g., limit intake of fat, red and processed meat, alcohol, and sugar). These recommendations follow the general advice from the NZ Ministry of Health eating and drinking guidelines for the public [63]; and share similar aspects of the recommendations from the gold standard guideline for diet and cancer risk, namely, the AICR/WCRF nutrition report [162].

The advice provided on the website is for the prevention of cancer in general, and is not specific to CRC, as outlined in the "Diet, nutrition, physical activity and CRC" report[163]. For example, the website does not mention the use of calcium supplementation to decrease CRC risk (minimum 200mg), and the recommended minimum alcohol intake to reduce CRC risk (up to 2 drinks a day).

However, the downloadable booklet ("Living Beyond Bowel Cancer") on the website, provides comprehensive advice on how to manage a healthy diet while on treatment and recovery. The guidelines utilised in the booklet offer specific information on the impacts of treatment and recovery on nutrition, and how to manage this. Bowel Cancer NZ also provides recipes under the "support" tab, that are of high fibre, low sugar, and low fat.

The Cancer Society NZ webpages provide healthy eating messages that reiterate the AICR/WCRF nutrition guidelines for general cancers. It includes the WCRF cancer prevention diagram and actions to reduce cancer risk. The page also explains healthy eating (enjoy a variety of foods from the four food groups, and limiting processed foods, saturated fat, salt, sugar, and alcohol). We found that the recommended amount of red meat of less than 350 - 500g cooked or 700-750 grams raw and no more than three portions per week align with the findings from the WCRF report summary of evidence for red meat.

When CRC is selected under "types of cancer", there are no nutrition and lifestyle recommendations specific to CRC on the website. The page describes what is CRC, the types of CRC, symptoms, and tips for talking to doctor, and risks of getting CRC The generic description of risk factors for cancer are present, but it does not address specifically the type of dietary risks (e.g., amounts consumed for red and processed meats, lack of wholegrains and fibre) associated with CRC.

The webpage includes coping mechanisms for eating problems as a result of cancer treatments. For example, small and regular meals to support fatigue, experimenting with herbs and spices for loss of appetite, ways to manage colorectal problems, and promoting food safety tips for patients who have low immunity.

Both Bowel Cancer and the Cancer Society have their own version of healthy eating booklets for use during and after cancer treatment available on their websites for download, and a hard copy can be requested.

The Bowel Cancer NZ "Eating Well booklet" was written by NZ registered Dietitian [164] and contains CRC specific information that addresses dietary needs during cancer treatment and recovery. The booklet utilises evidenced based research and recommendations from the NZ Ministry of Health Eating and Activity guideline [63]. It recommends the type of diet to consider before and after surgery, as certain foods are restricted. It details the importance of adequate nutrition for preparing the body for surgery, and diets that aid the colon and rectum to recover post-surgery (e.g., low fibre diet). Healthy eating advice during treatment focuses on nutritional impact symptoms that affect an individual's oral intake such as low appetite, nausea, vomiting, diarrhoea and constipation. Recommendations surround tips on how to boost food intake, and what to eat to help with side effects as a result of treatment. Advice and support for eating well with a stoma for colostomy includes an initial low fibre diet and gradually transitioning to well-tolerated foods and a well-balanced diet. After treatment, the advice follows the same general healthy eating recommendations by the Ministry of Health.

The "Living Well with Cancer" booklet by Cancer Society NZ has four sections: 1) Eating well during cancer treatment, 2) Healthy eating after cancer treatment, 3) Cancer and food discussion, 4) Recipes and support services. General recommendations on eating are reiterated in the booklet similar to its webpage such as limiting red and processed meat, being at a healthy weight by keeping fit and reducing sugar and fats, having plenty of fibre from fruit, vegetables and wholegrains and avoiding alcohol. The booklet states recommendations for food choices based on the 'World Cancer Research Fund Cancer

Prevention Recommendations'[163] and the 'Ministry of Health Eating and Activity Guidelines' [63]. The booklet also gives details on how cancer and treatments affect oral intake and provides advice on how to increase oral intake to maintain weight and support recovery. However, it does not have specific advice on eating after CRC surgery such as low fibre diets, or on caring for a stoma.

Weight management

Both organisations recommend following a healthy eating plan and increasing physical activity to maintain healthy weight. Emphasis on eating from the four food groups with plenty of fibre from wholegrains and reducing sugary drinks were made. Both organisations had their own online guides with a section on how to maintain healthy weight, including downloadable resources to use.

Weight loss as a result of cancer and cancer treatment is acknowledged. Weight gain recommendations is displayed in a table with a list of high energy and high protein food to help maintain weight and strength during treatment in the "Living Well with cancer" by the Cancer society NZ. However, this was not addressed in 'The Eating Well booklet' by Bowel Cancer NZ. They have tips on how to increase weight prior to surgery, as opposed to recovering after weight loss due to disease and therapy. Instead, dietary changes post treatment related to altered digestive process appears to be the focus.

Alcohol and Smoking

Both organisations advise against drinking alcohol as it increases the risk of several cancers including CRC. Alcohol drinking guidelines are available on the Cancer Society NZ website, advising no more than two drinks a day for men and one drink a day for women, and at least two alcohol free days a week. Bowel Cancer NZ recommends avoiding alcohol completely to reduce the risk of several types of cancer including CRC. If someone chooses to drink, they advise limiting alcohol (no more than 2 or more standard drinks per day). No links are provided on both organisations websites to direct patients for alcohol and drinking support groups. Both organisations recommended smoking cessation to lower risk of any cancers. Cancer Society provides hyperlinks to smoking cessation support groups for individuals who want to quit smoking. For example, on the Cancer Society "Smokefree" page, they have links to “Quitline Me Mutu” and “Quit Strong”. In contrast, Bowel Cancer NZ does not have links to smoking cessation support pages, but it does advise quitting.

Physical Activity

All organisations highlighted the importance of physical activity to help reduce risk of weight-related cancer and overall health, these are the physical activity recommendations sourced from the NZ Ministry of Health Activity guidelines [63]. Both recommended some form of vigorous activities throughout the week with emphasis on the higher amounts of physical activity, the better. Cancer Society recommends up to 2.5 hours per week of moderate intensity and 1.25 hours per week of vigorous intensity. Bowel Cancer NZ recommends building up to 30 minutes (or more) of moderate-intensity physical activity every day and breaking this up into smaller sessions of activity throughout the day.

Both organisations provided examples of activities with varying intensities in their information resources (Eating Well booklet from Bowel Cancer NZ and the Healthy Eating and Active Living position statement from Cancer Society NZ).

Cancer Society website encourage searching for local activity classes (walking groups, yoga classes, gym programmes and healthy steps classes) and additional links provided on the website introduced readers to some activity programmes (e.g., Green Prescription, PINC and STEEL). Bowel Cancer NZ have 30-Minute Exercise Guide available on the website to encourage readers to engage in free and easy ways to increase physical activity. As these recommendations are guidelines only, the websites recommend individuals to work out at an intensity that they can cope with and slowly build their activity level. However, none of the websites mentioned specific advice on physical activity for stoma patients.

5.4.4 Navigation and layout of website content

A layout of web pages that is difficult to navigate can be a barrier to obtaining objective information for patients. A study conducted by Lee et al., (2017) found that consumers with low health literacy are likely to have increased navigation needs [165]. The Cancer Society NZ webpage has a search bar to make it easier for consumers. Consumers can search what they would like to look for, however we found that a search using keywords such as nutrition, diet and/or physical activity do not direct the website user to relevant dietary and physical information provision.

It was noted that even though physical activity, diet and lifestyle information have their own pages, there was not a drop-down menu that takes viewers to these pages straight away. Instead they have to select “Cancer” > “Living with Cancer” > “Eating Well with Cancer” or “Keeping Active with Cancer”. This could potentially mean that consumers may miss one or the other topics as they are not all on the same page. Moreover, there are links available at the bottom of the page which directs to other relevant websites that promote healthy, safe, and affordable eating and drinking.

Bowel Cancer New Zealand webpage layout is similar to the Cancer Society website for nutrition, physical activity, and other lifestyle information provision, which requires consumers to further navigate to look for this information, using a search bar. Consumers must select “About bowel cancer” > “prevention”, to be directed to both diet and physical activity content, which are located on the same page. There are no additional links displayed on the page that directs users to other lifestyle resources such as alcohol or smoking cessation support.

TABLE 5.3 SUMMARY OF ONLINE DIET AND LIFESTYLE INFORMATION

Bowel Cancer NZ

Physical activity	Weight management	Alcohol	Smoking
• Regular daily exercise of any type for at least 30 minutes of moderate-intensity physical activity. Explains rationale and benefits of physical activity • Provides examples of exercises (e.g. washing car, walking, cycling, swimming) • Short bouts of moderate-intensity (10 or 15 minutes) activity are just as effective at improving health factors. • Has some information on physical activity in the Eating Well booklet	• Diet and lifestyle recommendations for weight management: • Eating Well booklet recommends achieving a healthy weight through eating a healthy balanced diet (focusing on the four food groups). • Encourage regular daily exercise of any type for at least 30 minutes a day may help reduce the risk of cancer, includes the 30 minutes free exercise guide • Booklet includes information on how to increase weight pre-surgery. • States link between obesity and chances of developing colorectal cancer and other risk of chronic diseases.	• Eating Well Booklet suggests: There is no safe limit for alcohol when it comes to certain cancers. Drinking alcohol raises your risk of several cancers, including colorectal cancer. Advise limiting alcohol intake.	• Quit smoking to lower risk of colorectal cancer

Bowel Cancer NZ

Diet	Guideline Referred to Online	URL
- Can download Eating Well booklet for during and after treatment and recovery - Has detailed information on eating before surgery, eating after surgery, tips to help reduce discomfort, low fibre diet, dietary advice to help with colorectal problems during treatment, low appetite, nutritional impact symptoms, eating well with a stoma, probiotic, considerations for vegetarian and vegan diets, healthy eating after treatment - Recipes available - Statements on the four food groups, with emphasis on fruit, vegetables and fibre	- Ministry of Health guidelines	https://bowelcancernz.org.nz/about-bowel-cancer/early-detection-and-prevention/prevention

Cancer Society NZ

Physical activity	Weight management	Alcohol	Smoking
- Recommendation for adults to reduce cancer risk: - At least 2.5 hours of moderate-intensity activity spread over the week. Or do one hour and 15 minutes a week of vigorous activity, or a mix of both over the week. Gain even more benefit by increasing moderate activity amounts to at least five hours per week with some high intensity activities at least 2 days per week	- Managing weight and tips for losing weight: - Follow healthy eating tips - have smaller meals - Increase wholegrain intake - Have plenty of fruit and vegetables - Limit fat and sugary treat foods - Increase activity - Choose water as main source of hydration	- Lower risk drinking guidelines and standard drinks - Two standard drinks a day for women and no more than 10 standard drinks a week - Three standard drinks a day for men and no	- Provides information on exposure of toxic chemicals from smoking and cancer risk (especially lung cancer) - Provides links to smoking cessation websites

Physical activity	Weight management	Alcohol	Smoking
• Provides examples of different intensities of activities (e.g. walking, gardening, brisk walking) • Has link to Ministry of Health Physical Activity Guidelines [63] • Position Statement- "Diet and Cancer" includes activity information: -Break up extended periods of sitting -Do at least 2 ½ hours of moderate or 1 ¼ hours of vigorous physical activity spread throughout the week. -Do muscle strengthening activities on at least 2 days each week • For extra health benefits, aim for 5 hours of moderate or 2 ½ hours of vigorous physical activity spread throughout the week.	• Position Statement- "Diet and Cancer" includes information on how to achieve a healthy body weight. • Advice to avoid gaining weight: -eat mostly nutritious foods that are low in energy (for example, include vegetables or fruit where possible in meals and as snacks) -drink plain water instead of sugary drinks and/or alcoholic drinks • eat smaller portions of food -sit less and move more • Be as active as possible.	more than 15 standard drinks a week • AND at least two alcohol-free days every week.	

Cancer Society NZ

Diet	Guideline Referred to in document	Source	URL
• Recommendation to reduce cancer risk: • Can download Living Well with Cancer -Eating Well booklet -be a healthy weight -be physically active -eat a diet rich in wholegrains, fruit, vegetables, nuts and beans (lentils and legumes) -limit 'fast foods' and other processed foods high in fat, starches or sugars -limit red and processed meat -limit sugary drinks -avoid or limit alcohol -do not use supplements for cancer prevention -breastfeed your baby, if you're able • Provides healthy kai recipes, hints on how to eat healthier • Provides specific advice on some foods regarding cancer risk including, supplements and storage e.g. processed meats, burning toasts, plastic containers • Have discussions around nutritional related impacts	• NZ Ministry of Health Physical Activity Guidelines. • Low-Risk Drinking Guidelines (for adults). Source: www.alcohol.org.nz/	• Ministry of Health - Green Prescriptions • Cancer Council Australia - Living with Cancer • Macmillan UK - Eating Well and Keeping Active • Ola Ora - Health App for Māori and Pasifika • Live Stronger for Longer - Information for People 65+ • PINC & STEEL - exercise programmes for cancer recovery • QuitStrong • Quitline • New Zealand eating and activity guidelines HealthED - Healthy eating, active living PDF World Cancer Research Fund - Cancer prevention recommendations	https://www.cancer.org.nz/cancer/reducing-your-cancer-risk/

5.5 DISCUSSION

Searching the internet is a convenient, affordable and anonymous means of gathering information about health and wellbeing [166]. Online information provision regarding diet, lifestyle strategies and treatment options are readily available for patients and their carers affected by CRC. The substudy reported in this chapter reported the type and quality of information on the websites of the two major non-Governmental organisations advocating for general cancer care and specific CRC support, according to quality, readability, useability, and health-content.

Quality assessment: The quality of the websites were assessed by the DISCERN tool and were of fair to good quality according to the mean DISCERN score of 51, with Cancer Society NZ scoring higher than Bowel Cancer NZ, 60 versus 42 respectively. Our mean score is similar with findings from studies in the UK, Netherlands and USA that analysed Governmental and unofficial websites on CRC returning a mean DISCERN score of 52 [153], 45 [167], 42 [168], and 41 [169] respectively.

The JAMA score for Bowel Cancer NZ and NZ Cancer Society, indicated low and high quality, respectively. We found that no criteria within the JAMA benchmark was met for the Bowel Cancer NZ website. Principles of authorship, attribution, disclosure, and currency were not displayed on the website. Cancer Society NZ scored 3 out of 4 criteria, but did display attributions or references for their online content.

The HON code is an important element to consider when assisting patients because it is one of the oldest and most trusted indicators for quality online health-related information [170]. As yet, the evaluated NGO websites in this study do not display the HON seal.

Readability of the websites:

About 570,000 adult New Zealanders have low literacy or numeracy skills [171]. Reading and being able to convey information is important to make informed health decisions. Information must be clear and suitable to avoid misinterpretation [172, 173]. Further, plain language enhances patient understanding and increases the chances of improved health outcomes and reduced health care costs [174].

The mean readability FRE scores for both organisations indicated the content as being standard to difficult. Out of the websites, Cancer Society had the higher FRE readability score at a level that is understood at a reading age of 13 - 15 years [160]. Whereas Bowel Cancer NZ scored at a ‘difficult level’ of reading difficulty, and is understandable by an 18 year old. Bowel Cancer NZ scored higher in the FKRGL than Cancer Society NZ (10.8, 9.1), indicating understanding by a person aged 11-17 years and designated as average level. This does not comply with the NZ Government recommendations for digital content, that information should be presented at a reading age of 12 years [175].

Website Navigation: As diet and physical activity are important aspects to a patient’s health at all stages of the cancer journey, it is important that websites allow user friendly navigation to source this information[165]. Both Bowel Cancer NZ and Cancer Society NZ do not have a drop-down menu linking to nutrition and physical activity information. A well-organised and transparent navigation system will aide as a road map to the relevant sections and content that the patient is seeking. This will entice the patient to remain, read the material, and have a great user experience leading to increased engagement. Often patients are unsure what they are looking for, therefore better menu-driven navigation on these websites will assist patients to be better informed about their health [165].

Website content: The reviewers assessed the content on diet and physical activity provided on the two organisations’ websites and their resources as being of high standard.

The Cancer Society website displayed more detailed information about cancer including treatments and what to expect compared to Bowel Cancer NZ. Both NGOs websites did not state the author of the material or provide a date of when the information was published, or the source. Displaying authorship, attributions, and references throughout statements on webpages help consumers and health professionals trust the information is legitimate and evidence based.

Bowel Cancer NZ utilised the Ministry of Health eating and physical activity guidelines [63] that advocate and promote healthy eating and physical activity to make substantial contributions to protect health for the entire population, and are not cancer-specific.

The Bowel Cancer NZ website provides general recommendations for healthy eating and outlines the benefits of physical activity. The nutrition and diet information on the website is general, and any information specifically related to CRC issues is limited.

However, the downloadable booklet [164] on the website, written by a dietitian, does inform about diet and nutrition during CRC treatment and recovery. The booklet [164] is more informative with addressing CRC issues, especially eating after surgery. This information is appropriate and sufficient for patients/survivors needing relevant and specific needs throughout the cancer journey. It accounts for low residue diet post-surgery to reduce bloating, diarrhoea, and discomfort. Gentle exercise and avoiding sitting for long periods of time was also advised in the booklet, which is different to the advice stated on the website. This may help survivors to understand the need to start at a low intensity post-surgery and building this up to a level they can manage as time goes on. Stoma information was available in the booklet and ways to manage this with eating and drinking. Healthy eating messages after treatment is reiterated in the booklet, similar to the general webpage.

Cancer Society NZ utilised the AICR/WCRF cancer guidelines[176] for their website. The AICR/WCRF report [176] is the gold standard for evidence-based recommendations on cancer prevention and survivorship through diet and physical activity. The WCRF website (www.wcrf.org) includes a range of reports specific to types of cancers including CRC and provides cancer-related recommendations for health practitioners who provide advice and interventions to improve diet and physical activity.

The Cancer Society produces informative booklets which are downloadable from their website, these include ‘living well with cancer-eating well’ and ‘living well with cancer-keeping active’. The website and booklet are general and do not cater to specific nutrition and activity needs related to CRC. The only CRC specific information on the website details what is CRC, and how to cope with symptoms.

Our findings inform the following recommendations under the subheadings:

Quality and Reliability

- Both NGO websites will benefit from providing clear aims of the websites purpose and having dates and sources of publications referenced, attributions, to provide patients and HPs with trust and dependability.

- The items of the DISCERN for Bowel Cancer NZ suggests more detail is required on the available treatments.
- Bowel Cancer NZ would benefit from informing patients about available support offered by them and the importance of having family members present for shared-decision making in discussions with clinicians.
- Applying for the HONcode seal of approval on both websites will validate and ensure that contents are regulated and trustworthy.

Readability

- Increasing readability of both websites to aim for a reading age of 12 years to help viewers understand the website's content. The NGOs should apply the readability tools to their webpages.

Website navigation

- A drop-down link to Diet, PA, and lifestyle information on the home page will allow viewers ease of use and navigation.

Website content

- Bowel Cancer NZ webpages would be enhanced by including CRC-specific information regarding diet, nutrition, PA from the recommendations of the World Cancer Research Fund/American Institute for Cancer Research report on Diet, Nutrition, physical activity and colorectal cancer [163].

5.6 CONCLUSION

Both organisations have provided information sourced from guidelines with general information on diet and lifestyle to help patients and family members to make their own health choices. The information provision on diet and lifestyle does provide a good basis of understanding of how to eat well and stay well to help with cancer treatments and prevention of cancer. However, for CRC specific needs and how to manage eating after surgery, health professionals should consider utilising booklets that cover the basis for CRC needs such as eating strategies, physical activity, types of post-surgery diet including living with a stoma.

Additionally, CRC specific nutrition and activity guidelines like the WCRF/AICR report should be used alongside the Ministry of Health Eating and activity guidelines in the provision of evidence-based information. Furthermore, websites should be easier to navigate with drop down menus for dietary and physical activity information. Websites should be updated by increasing readability and ensuring DISCERN, JAMA and HONcode criterias are met.

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CHAPTER 6: APPENDICES

6.1 APPENDIX A: AUTHOR INSTRUCTIONS NZMJ

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THE NEW ZEALAND

MEDICAL JOURNAL

Instructions to Authors

Document formatting

Please use Word for all submitted material. Use 1.5 line spacing and UK English.

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

Title

Type of manuscript

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

Full author list

- 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; beta-blockers not ßblockers).
- Write out numbers under 10 in full except if they are associated with units including time— eg, 2 days, 6 mg, five hospitals, 7 hours, seven patients, 12 patients. If a number begins a sentence, then write it in full unless it is >100. 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 a 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] ☐

Author information. Must include:

- full names (middle initial[s] may be included) of each author
- job positions (eg, cardiologist, director, senior lecturer, etc)
- department (if any)
- institution/company
- location (ie, city, town; plus country if not New Zealand).

☐ **Acknowledgements** (if any) ☐

Correspondence

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

6.2 APPENDIX C: PARTICIPANT INFORMATION SHEETS

Participant Information Sheet- Health Professionals

Evaluation of Dietary and Lifestyle Advice for Colorectal Cancer Survivors:

Health Professionals Viewpoint

INFORMATION SHEET

Invitation to participate in a research study

My name is Joey Lew, 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 Dr Hugh Senior and Dr Judy Thomas from the School of Health Sciences at Massey University.

Project Description

More patients are surviving colorectal cancer (CRC). Studies have shown that greater adherence to healthy eating and other lifestyle advice for cancer prevention as detailed in clinical guidelines, can reduce risk of recurrence, and improve wellbeing and quality of life.

There are many challenges for health professionals in providing lifestyle and advice information to cancer survivors. These include the most appropriate format for information provision, ensuring evidence-based information, identifying preferred sources of information, and understanding if the information provided is being utilised and resulting in improved lifestyle behaviours.

This study aims to examine the dietary and lifestyle information and advice provided to colorectal cancer survivors by health professionals, NGOs who advocate for and support cancer survivors, and other sources. This will enable the project to make broad findings and inform policy and it will inform the development of initiatives to optimise information provision for colorectal cancer survivors in the community.

You are invited to take part in this research study due to your role in cancer care.

Participant Identification and Recruitment

You have been invited to participate as you care for patients with colorectal cancer. We will interview 10 health professionals, and representatives of NGOs. 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.

As General Practitioners are non-salaried health professionals, the usual consultation fee will be reimbursed by the study upon invoice.

Project Procedures

We will interview you about information provision to these patients. We will do this at a date, time and location which is convenient to you. We anticipate the interview will take 30-45 minutes. The interview will be conducted by a post-graduate student. The interview will be tape recorded to assist analysis. You can request a copy of the audio recording.

All data generated from this study will be treated with utmost confidentiality without reference to your name. In the study documents you will only be identified by your initials, and a study number. The data will always be treated confidentially, and in the event of publication your identity or that of your organisation will not be disclosed under any circumstances.

All hard copies of data forms will be stored in a locked filing cabinet only accessible to the researchers at Albany Campus, Massey University in a restricted access building. Electronic data obtained from this study will be kept securely on the database at Massey University, so no-one other than the researchers on this project will be able to access them. Data will be destroyed 5 years after the completion of the project.

We will be happy to send a summary report of the results to you on your request.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- During the recording of interviews, you can ask for the recorder to be turned off at any time during the interview.

Committee Approval Statements

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 researchers 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 Prof Craig Johnson, Director, Research Ethics, telephone 06 356 9099 x 85271, email humanethics@massey.ac.nz.

Compensation for Injury

If physical injury results from your participation in this study, you should visit a treatment provider to make a claim to ACC as soon as possible. ACC cover and entitlements are not automatic and your claim will be assessed by ACC in accordance with the Accident Compensation Act 2001. If your claim is accepted, ACC must inform you of your entitlements, and must help you access those entitlements. Entitlements may include, but not be limited to, treatment costs, travel costs for rehabilitation, loss of earnings, and/or lump sum for permanent impairment. Compensation for mental trauma may also be included, but only if this is incurred as a result of physical injury.

If your ACC claim is not accepted you should immediately contact the researcher. The researcher will initiate processes to ensure you receive compensation equivalent to that to which you would have been entitled had ACC accepted your claim.

6.3 APPENDIX C:HEALTH PROFESSIONAL AND NGO REPRESENTATIVE INTERVIEW SCHEDULES

Health Professionals Interview Schedule

Preamble

- Thank you for giving your time for an interview. It should take 30-45 minutes
- I will be recording our conversation, but what you say will be treated as confidential and anonymous, and used for research, do you agree to be recorded
- ***Start recorder, state registration number of the participant***
- If you do not understand a question, let me know and I will rephrase it
- We can stop for a break if you need one
- Do you have any questions before we start?

Introduction

- Today I would like to talk to you about your experience in providing information and advice on diet and lifestyle to people who have been treated for colorectal cancer.

General Information

I will begin by getting some information about you

1. Can you please state your profession

2. How many years have you been practicing

3. Do you work with primarily patients residing in the community, hospital inpatients, and/or hospital outpatients

Prompt: At what stage during a colorectal cancer patients treatment, would you typically first see a patient, Are patients referred to you from other health care providers, do patients self-refer to you?

Advice on Diet

4. What are your views on the role of diet in colorectal cancer recovery, and preventing recurrence

5. What typical advice would you provide to a colorectal cancer survivor regarding diet and/or weight management

Do you prescribe fibre supplements/bulk-forming laxatives

Do you advise on consumption of fibre-containing foods.

Do you provide advice on drinking alcohol

7. Do you recommend any specific lifestyle programmes to patients, or refer patients to lifestyle programmes

Prompt: (details on programmes)

8. Do you refer patients to other health professionals (e.g. dietician, nutritionist, exercise physiologist).

Prompt: What are the reasons for the referral. Are there other health professionals who should be involved in support lifestyle behavioural change advice or support

9. Do you utilise guidelines on diet and physical activity (lifestyle) for cancer patients or general guidelines

Prompt: (which guidelines)

10. Do you provide a written care plan that includes diet and/or physical activity

Prompt (is a care plan provided to the patient)

11. What do you think are the barriers in providing dietary or physical activity advice to survivors of colorectal cancer

Prompt: time available in consultation to allow counselling, do not think patient will change behaviour (e.g. due to specific patient characteristics), patient too frail, limited reimbursement, lack of training and experience/ information in discussing diet, weight change issues, physical activity, alcohol, behavioural changes), lack of educational resources

12. Do you feel you have adequate resources and knowledge to address lifestyle change for a colorectal cancer survivor, including diet, weight management, physical activity, alcohol use

13. Is there any gap in information provision or support about lifestyle management that patients should be getting

Advice on Physical Activity

14. What are your views on the role of physical activity in colorectal cancer recovery, and preventing recurrence

15. Do you recommend undertaking physical activity to cancer survivors at the end of their treatment

Prompt: What would you advise the patient regarding physical activity, Frequency (amount per week), intensity (light, moderate, vigorous), amount of time per week, Type of activity

General Lifestyle Advice

16. Do you provide any written materials, apps or links to websites regarding lifestyle advice to patients

Prompt: what are the websites or other material

17. Is there any follow-up with patients regarding changing lifestyle behaviours and maintaining change

18. During which part of the patients journey after diagnosis of or treatment for colorectal cancer, do you think is the most appropriate time for advice or intervention on healthier diets and physical activity

Prompt: what health professional is responsible to give this advice, what is the role of the GP or primary care. Do you assess if dietary intake and physical activity levels need improvement or do you provide general advice

19. Is there anything else that you would like to add

If you think of something you want to add later, please phone or email me

Non-Governmental Representative Interview Schedule

Preamble

- Thank you for giving your time for an interview. It should take 30-45 minutes
- I will be recording our conversation, but what you say will be treated as and used for research, do you agree to be recorded
- The name of your organisation will not be identified in any publication
- ***Start recorder, state registration number of the participant***
- If you do not understand a question, let me know and I will rephrase it
- We can stop for a break if you need one
- Do you have any questions before we start?

Introduction

- Today I would like to talk to you about your experience in providing information and advice on diet and lifestyle to people who have been treated for colorectal cancer.

Demographics

1. Can you please state your profession

2. What organisation do you work for?

3. What are the key roles of your organisation in supporting recovery from cancer

4. Does your organisation work with primarily patients residing in the community, hospital inpatients, and/or hospital outpatients

5. How do clients/patients find your organisation

Prompt (are they referred by hospital, oncology staff, NGO volunteers, self-referral, what proportion of cancer patients with CRC are referred?)

Advice on Diet and Physical Activity

1. What are your views of your organisation on the role of diet in colorectal cancer recovery, and preventing recurrence
2. Does your organisation give colorectal cancer survivors advice on diet and/or weight management

   Prompt (when do you provide the advice)

3. What typical advice does your organisation provide to a colorectal cancer survivor regarding diet and/or weight management
4. Does your organisation recommend any specific lifestyle programmes to patients or refer patients to lifestyle programmes

   Prompt: (details on programmes)

5. Does your patients/clients see a dietician, nutritionist or exercise physiologist employed by your organisation, or are they referred by your organisation to an external health professional.

   Prompt: Internal or external, what professionals, public or private funded, what are the reasons for the referral. Are there other health professionals who should be involved in support lifestyle behavioural change advice or support

6. During which part of the patient's journey after diagnosis of or treatment for colorectal cancer, do you think is the most appropriate time for advice or intervention on healthier diets and physical activity

   Prompt: what health professional is responsible to give this advice, what is the role of the GP or primary care, when do you first see patients, HOW LONG AT THEY IN YOUR SERVICE. Does your organisation assess if dietary intake and physical activity levels need improvement or do you provide general advice

7. Does your organisation utilise guidelines on diet and physical activity (lifestyle) for cancer patients or general guidelines
8. Does your organisation provide advice on drinking alcohol
9. What are the barriers for your organisation in not providing dietary or physical activity advice to survivors of colorectal cancer

   Prompt: time available in consultation to allow counselling, do not think patient will change behaviour, patient too frail, limited reimbursement, lack of training and experience/ information in discussing diet, weight change issues, physical activity, alcohol, behavioural changes)

10. Does your organisation recommend undertaking physical activity to cancer survivors at the end of their treatment

11. What does your organisation advise regarding physical activity, Frequency (amount per week), intensity (light, moderate, vigorous), amount of time per week, Type of activity

General Lifestyle Advice

1. Does your organisation provide any written materials, apps or links to websites regarding lifestyle advice, especially diet and physical activity, to patients

Prompt: what websites or other material

2. Does your organisation check with the patients if they are changing lifestyle behaviours and maintaining change

3. Does your organisation have adequate resources and expertise to address lifestyle change for a colorectal cancer survivor, including diet, weight management, physical activity, alcohol use

4. Is there any gap in information provision or support about lifestyle management that you feel patients should be getting

5. Is there anything else that you would like to add about the role of your organisation in providing advice and influencing change in lifestyle for the colorectal cancer survivor

If you think of something you want to add later, please phone or email me

6.4 APPENDIX C: WEBSITE EVALUATION FORM

Colorectal Cancer Survivorship Diet Study

FORM CI: Consumer Information Substudy: Websites Evaluation Form

1.1	**URL of website**								
1.2	**Date Accessed**			/			/		
		d	**d**		**m**	**m**		**y**	**y**
1.3	**Name of the Publisher**								
1.4	**Name of Accessor**								

2. DISCERN INSTRUMENT

Instructions: See DISCERN Handbook

Section 1: IS THE PUBLICATION RELIABLE?

2.1 **Are the aims clear?**

No		Partially		Yes
1	2	3	4	5

HINT Look for a clear indication at the beginning of the publication of:
- what it is about
- what it is meant to cover (and what topics are meant to be excluded)
- who might find it useful.

If the answer to Question 1 is ‘No’, go directly to Question 2.3

2.2 **Does it achieve its aims?**

No		Partially		Yes
1	2	3	4	5

HINT Consider whether the publication provides the information it aimed to as outlined in Question 1.

2.3 **Is it relevant?**

No		Partially		Yes
1	2	3	4	5

HINT Consider whether:
- the publication addresses the questions that readers might ask
- recommendations and suggestions concerning treatment choices are realistic or appropriate.

2.4	**Is it clear what sources of information were used to compile the publication (other than the author or producer)?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT • Check whether the main claims or statements made about treatment choices are accompanied by a reference to the sources used as evidence, e.g. a research study or expert opinion. • Look for a means of checking the sources used such as a bibliography/reference list or the addresses of the experts or organisations quoted. **Rating note:** In order to score a full '5' the publication should fulfil both hints. Lists of additional sources of support and information (Q2.7) are not necessarily sources of evidence for the current publication.					
2.5	Is it clear when the information used or reported in the publication was produced?					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Look for: • dates of the main sources of information used to compile the publication • date of any revisions of the publication (but not dates of reprinting) • date of publication (copyright date). **Rating note:** The hints are placed in order of importance – in order to score a full '5' the dates relating to the first hint should be found.					
2.6	**Is it balanced and unbiased?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Look for: • a clear indication of whether the publication is written from a personal or objective point of view • evidence that a range of sources of information was used to compile the publication, e.g. more than one research study or expert • evidence of an external assessment of the publication. **Be wary if:** • the publication focuses on the advantages or disadvantages of one particular treatment choice without reference to other possible choices • the publication relies primarily on evidence from single cases (which may not be typical of people with this condition or of responses to a particular treatment) • the information is presented in a sensational, emotive or alarmist way.					

2.7	**Does it provide details of additional sources of support and information?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Look for • suggestions for further reading or for details of other organisations providing advice and information about the condition and treatment choices.					
2.8	**Does it refer to areas of uncertainty?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT • Look for discussion of the gaps in knowledge or differences in expert opinion concerning treatment choices. • Be wary if the publication implies that a treatment choice affects everyone in the same way, e.g. 100% success rate with a particular treatment.					
Section 2: HOW GOOD IS THE QUALITY OF INFORMATION ON TREATMENT CHOICES? N.B. The questions apply to the treatment (or treatments) described in the publication. Self-care is considered a form of treatment throughout this section.						
2.9	**Does it describe how each treatment works?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Look for a description of how a treatment acts on the body to achieve its effect.					
2.10	**Does it describe the benefits of each treatment?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Benefits can include controlling or getting rid of symptoms, preventing recurrence of the condition and eliminating the condition, both short-term and long-term.					
2.11	**Does it describe the risks of each treatment?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Risks can include side-effects, complications and adverse reactions to treatment, both short-term and long-term.					
2.12	**Does it describe what would happen if no treatment is used?**					
	No		Partially		Yes	
	1	2	3	4	5	
	HINT Look for a description of the risks and benefits of postponing treatment, of watchful waiting (i.e. monitoring how the condition progresses without treatment) or of permanently forgoing treatment.					

2.13	**Does it describe how the treatment choices affect overall quality of life?**				
	No		Partially		Yes
	1	2	3	4	5
	HINT Look for: • description of the effects of the treatment choices on day-to-day activity • description of the effects of the treatment choices on relationships with family, friends and carers.				
2.14	**Is it clear that there may be more than one possible treatment choice?**				
	No		Partially		Yes
	1	2	3	4	5
	HINT Look for: • a description of who is most likely to benefit from each treatment choice mentioned, and under what circumstances • suggestions of alternatives to consider or investigate further (including choices not fully described in the publication) before deciding whether to select or reject a particular treatment choice.				
2.15	**Does it provide support for shared decision-making?**				
	No		Partially		Yes
	1	2	3	4	5
	HINT Look for suggestions of things to discuss with family, friends, doctors or other health professionals concerning treatment choices.				
Section 3: OVERALL RATING OF THE PUBLICATION					
2.16	Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices				
	Low		Moderate		High
	Serious or extensive shortcomings		*Potentially important but not serious shortcomings*		*Minimal shortcomings*
	1	2	3	4	5
End of DISCERN					

3. Journal of the American Medical Association (JAMA) benchmark criteria

	Score	Criteria (1 point each)	Requirement to pass (each must be fulfilled to receive 1 point)	
3.1		Display of authorship	• Authors or contributors should be listed • Author affiliations should be listed • Author qualifications should be listed	
3.2		Display of attributions or references	• References and sources should be listed clearly • Relevant copyright information should be listed	
3.3		Date of original posting and updates	• Date of original posting and dates of updates should be listed (1 point assigned if < 3 years old or update within past 3 years)	
3.4		Disclosures	• Website ownership – this was given a yes if a copyright was listed on the webpage or the term “all rights reserved” listed • Website sponsorship, funding, or support listed – *this was given a yes if an owner for the website was listed* • Website advertising policy specified or linked anywhere on page • Any potential conflicts of interest listed	

4. Health on the Net Code (HONcode) seal

4.1	**Is the HONcode seal present on the website?**	Yes		No	

5. Readability: the Flesch Reading Ease (FRE) scale and Flesch-Kincaid Reading Grade Level (FKRGL).

	Instructions	Import 400 words from each site into Microsoft Word on page relevant to diet recommendations, and assess the text using the readability statistics function, record both the FRE and FKRGL scales. FKRGL is reported as a numerical grade level and FRE is scored on a scale of 0 to 100, with lower scores suggesting poor readability. In general, a grade 6 reading level is recommended for patient education materials. • Go to File > Options. • Select Proofing. • Under When correcting spelling and grammar in Word, make sure the Check grammar with spelling check box is selected. • Select Show readability statistics. • After you enable this feature, open a file that you want to check, and check the spelling by pressing F7 or going to Review > Spelling & Grammar. When Word finishes checking the spelling and grammar, it displays information about the reading level of the document.		
5.1	**FRE score**			
5.2	**FKRGL score**			