Food, nutrition and cancer: perspectives and experiences of New Zealand cancer survivors

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ABSTRACT

AIM: This research sought to understand and describe cancer survivors' perspectives and post-diagnosis experiences of food and nutrition, with a particular focus on barriers to healthy eating, health equity, and Māori and Pacific perspectives.

METHOD: Data were collected using semi-structured interviews with cancer survivors from three different ethnic groups (Māori, Pacific Peoples, and New Zealand European). Thematic analysis was undertaken to identify both similar and contrasting experiences and perspectives in relation to topics of interest. Data analysis also sought to identify any trends indicating differences between ethnic groups.

RESULTS: Limited awareness of the role nutrition has in cancer recovery or prevention, combined with little or no access to nutrition advice/support, meant that healthy dietary change was not a focus for some cancer survivors in this study, whereas others invested considerable time and money accessing nutrition information and support outside of cancer care services. Financial limitations (eg, cost of healthy food and low income) and lack of practical support were also important barriers to post-diagnosis healthy eating.

CONCLUSION: There is a need for more widely available cancer-specific nutrition advice and support in New Zealand. Interventions to address financial barriers and increase access to cancer-related nutrition advice and support have the potential to improve cancer outcomes and reduce inequities in cancer outcomes.

The New Zealand Cancer Action Plan 2019–2029 recognises the need to consider a more holistic approach to cancer care, encourage and support healthy living, improve cancer survival, respond to the preferences and needs of our communities, and focus on achieving equitable cancer outcomes.[1] A healthy diet has an important role in a holistic approach to cancer care, with potential benefits including better health outcomes during treatment and improved cancer survival.[2–4] A detailed report by the World Cancer Research Fund International (WCRF) and the American Institute for Cancer Research (AICR) outlines growing evidence that dietary changes can improve cancer-related and non-cancer-related health outcomes for those with cancer.[2] In response to this evidence, the WCRF and AICR recommend that all cancer survivors receive dietary support from a trained professional.[2] Evidence also shows that many cancer survivors (defined as "people in a wide variety of circumstances beginning at diagnosis, through cancer treatment to the end of life"[2]) want to improve their health and wellbeing through diet, seek advice from a variety of sources about healthful diets, and make changes at various stages of their cancer experience.[5–10] In New Zealand, research shows that Māori and Pacific Peoples consider holistic and culturally appropriate healthcare essential for optimal health outcomes.[11,12] However, how that fits with nutrition in cancer care has not been explored.

Cancer accounts for around one third of all deaths in New Zealand.[13] There are important inequities in health status, with adverse health outcomes and multimorbidity more prevalent among Māori and Pacific Peoples.[11,13,14] Māori are 20% more likely to get cancer than non-Māori and have substantially worse survival rates for cancer.[1] Pacific Peoples are more likely to get cancer and have higher mortality rates than New Zealand Europeans.[1] In addition, Māori and Pacific Peoples are disproportionately affected by material deprivation and poverty and have higher rates of food insecurity ("when the availability of nutritionally adequate and safe foods, or the ability to acquire such foods, is limited or uncertain"[15]) than non-Māori/non-Pacific New Zealanders.[15] Issues related to poverty, such as food insecurity, are a major barrier to healthy eating and increase the likelihood of chronic health conditions, with the resulting loss of income further exacerbating food insecurity.[16–18] This can lead to a cycle of increasing poverty and poorer health outcomes.[17] The extent to which lack of access to advice and support about healthy food, or lack of access to healthy and affordable food, contributes to gaps in health and wellbeing among cancer survivors in New Zealand is not known.

Although the ability to consume a healthy or normal diet can be directly impacted by cancer and cancer treatment,[19,20] many additional factors may impact on diet for cancer survivors. This research sought to understand and describe cancer survivors' perspectives and post-diagnosis experiences of food and nutrition, with a particular focus on barriers to healthy eating, health equity, and Māori and Pacific perspectives.

Method

Study design

This exploratory qualitative study took an interpretivist stance with a goal to understand participants' perspectives and experiences. The study design was informed by Māori and Pacific models of health and theories on the determinants of health.[21–23] Māori (eg, Te Whare Tapa Whā[22]) and Pacific (eg, Fonofale[21]) models of health are holistic models that encompass cultural, spiritual, and environmental elements in addition to physical and mental health, as well as emphasising whānau (extended family). Culture, poverty, and social/whānau/family support were important social determinants considered. Māori, Pacific, and New Zealand European members of the research team were actively involved throughout the planning, data collection, and data analysis/interpretation stages of the study. Ethical approval was obtained from the University of Otago Human Ethics Committee (Health), approval number H19/028.

Participant recruitment

Participants from three major ethnic groups (Māori, Pacific Peoples, and New Zealand European (NZE)) were recruited through Māori and Pacific healthcare providers, flyers and word of mouth. The purposeful sample included participants from different backgrounds (age, gender, ethnicity, type of cancer) to access a range of experiences and viewpoints. The inclusion criteria were: adults (18 years or older) who had completed the acute phase of cancer treatment within the past five years who were able to participate in a face-to-face English language interview.

Data collection

Participants took part in semi-structured interviews with a researcher from their ethnic grouping: Māori (CD, HT), Pacific (LM), NZE (RP). Interviews included questions with a focus on whānau (family), rongoā (traditional Māori therapies), cultural norms, and finances/cost. Participants were asked about their experiences of food and nutrition during and after their treatment for cancer, including the type of information they received about food and nutrition, any food or nutrition-related support they received during that time, and any dietary changes they made (refer to Table 1 for interview guide). The interviews were audio-recorded (with consent), transcribed verbatim by a transcription service, and checked for accuracy by the researchers.

Data analysis

RP, in collaboration with all other authors, led a thematic analysis[24] of the interview transcripts, which included both individual feedback from the other researchers and regular team meetings to discuss the themes. This included discussion of the themes/interpretation of the Māori and Pacific interview data with Māori and Pacific co-authors to ensure the themes accurately represented the data and that interpretations were appropriate. Manual coding was completed with the aid of the NVivo 12 software package (QSR International 2018).

Table 1: Interview guide (prompts shown in italics).

Can you share your story of cancer with me? *What cancer did you have? What treatment did you have? Length of treatment? Did you have other health problems that affected your cancer or that the cancer affected? Could you tell me about that?*
While you were having treatment, who supported you and your family with advice about kai/food and nutrition? *Dietitian? Nurse, practice nurse, general practitioner, hospital specialist? Whānau or health-worker? What about social media, personal trainer etc?*
What were you told about what to eat and drink? *Where else did you get information from (whānau, social media, internet…)?*
While you were having your treatment how did you manage your kai/food and nutrition? *Who did the cooking? Did you change what you ate? Complementary medicine/rongoā? Did you take dietary supplements? What about alcohol?*
Is there anything that made it hard to manage your kai/food and nutrition during this time? *Finances? Family circumstances? Treatment side effects? Lack of information?* • How did you get around these difficulties?
Is there anything that really helped you to manage your kai/food and nutrition during this time? *Whānau support? Support from health professionals? Financial support?*
Once your treatment had finished how did you manage your kai/food and nutrition? *Who did the cooking? Did you change what you ate? Complementary medicine/rongoā? Did you take dietary supplements? What about alcohol?*
Is there anything that made it hard to manage your kai/food and nutrition during this time? *Finances? Family circumstances? Treatment side effects? Lack of information?* • How did you get around these difficulties?
Is there anything that really helped you to manage your kai/food and nutrition during this time? *Whānau support? Support from health professionals? Financial support?*
What advice would you give someone else going through cancer treatment about managing their kai/food and nutrition?
What could be done in the health system to make it easier for people with cancer to manage their kai/food and nutrition? *Māori/Pacific providers; hospital; other agencies; Cancer Society.*
What other supports could be put in place to make it easier for people with cancer to manage their kai/food and nutrition?
Is there anything else you would like to tell us?

Passages were grouped based on the themes identified from the data that related to the research aims, with a focus on both similar and contrasting experiences or perspectives within the themes, as expressed by the participants. Representative quotes were identified and annotated according to ethnicity (Māori, M; Pacific Peoples, P; New Zealand European, NZE) and the participant number within the ethnicity grouping (eg, M3 refers to Māori participant 3).

Results

Participant characteristics

Participant characteristics are summarised in Table 2. The study participants (n=25) included cancer survivors from three ethnic groups: Māori (n=10), Pacific (n=5), and NZE (n=10). Participant age at interview ranged from 41 to 77 years and 68% of participants were female. Different cancer types were represented. The largest number were diagnosed with breast cancer (n=10), followed by gastrointestinal cancers (n = 4), gynaecological cancers (n = 4), prostate cancer (n=3), and then other cancers (n=4). Participants had undergone different treatments (including surgery, radiation, and chemotherapy). Self-reported co-existing health conditions were more common among Māori and Pacific participants, the most common being diabetes/prediabetes (Māori n=4, Pacific n=3), followed by high blood pressure (Māori n=2, Pacific n=1).

Theme 1: need for more nutritional information and support in cancer care

Our results indicate that cancer-related nutritional information or support is not commonly included as part of cancer treatment and follow-up care. Table 3 outlines the sub-themes and representative quotes related to this theme. Apart from a few participants who recalled being told to eat a healthy diet without being given specific information on how to achieve that, most participants received no advice about healthy eating. However, when advice was offered, it appears to have been well received.

> *"He said, 'I'm going to give you some advice', you know, 'If you want to stay healthy and not potentially ever have anything like breast cancer then you need to have a healthy diet, you need to look really carefully at what you eat and arm yourself for the future', he said. Yeah it was good advice, it was really good advice." – M10*

Often, when dietary information was provided, the focus was on the management of treatment side-effects (eg, maintaining hydration, eating small portions regularly, avoiding certain foods) or co-existing conditions (such as diabetes, obesity). A few participants with co-existing conditions were referred to dietitians for specialist

Table 2: Participant characteristics.

	Māori (n=10)	**Pacific (n=5)**	**NZ European (n=10)**
Age range	48–67	46–70	41–77
Gender			
Female	7	4	6
Male	3	1	4
Types of coexisting conditions			
Diabetes/prediabetes	4	3	
High blood pressure	2	1	
Other[a]	6		3

[a] Other conditions: arthritis, gout, angina, asthma, kidney disease, no gallbladder and spleen, mental health conditions.

Table 3: Sub-themes and quotes for theme 1: need for more nutritional information and support in cancer care.

Little/no nutritional information or support offered
“They don’t provide you any information at all” NZE2 “No, not at all. I mean it was cut it out, kick ‘em out, you’re on your own.” NZE6 “I feel like I’m very much doing it by myself.” NZE8 “I had no guidance on nutrition.” M4 “No, no, they just said to make sure you look after yourself and drink water.” M6 “No one.” P6 (when asked who supported them with advice about food and nutrition)
Just told to eat a healthy diet without information or support
“They basically just said, ‘Maintain a healthy diet’.” NZE2 “They said ‘try and have a healthy diet’, that was about all.” M2
Dietary advice given was about managing cancer/treatment effects
“The radiation clinic gave us good sound advice about what to avoid, in terms of being ready for treatment.” NZE1 “Keep up your liquids because you don’t want to get dehydrated.” NZE8 “There were foods that they did warn me about that could affect my insides due to the medicines they were giving me.” M9
Wanting dietary support during and after treatment
“I kind of knew that there was a whole lot of information out there about food and what foods you should and shouldn’t eat. Um, and... I wanted to be spoon-fed that information from my consultants rather than go falling down a rabbit hole on the internet.” NZE2 “I would have liked to have spent time with a nutritionist. Because after the surgery, you know of course I had concerns you know in the back of my head that okay, maybe my diet was lacking, because I’m looking for the reason why I got the cancer. And I think well, if it is the diet, what should I be eating?” NZE5 “But I do know that kai [food] and cancer goes together and I would love to know more if I could.” M2 “I think actually you should get more advice about that kind of stuff, you know, about the food.” M10
Didn’t realise diet was important because the medical practitioners didn’t mention it
“There’s been nothing about diet, so it can’t be considered a, too much of a factor amongst the medical people”… “I would’ve thought if the food was going to make a difference, we would have been told about it, you know, by now. Like, as I’ve been discussing, I was never told anything”… “I’d definitely need to know about it [information about nutrition for cancer recovery/prevention] and I would follow it.” NZE4 “I just ate normally. I didn’t know about the nutrition”… “We didn’t even know about this so if we had of known there was different foods, well we could of asked those questions. It’s asking the right questions.” M4 “I’m just thinking about all the different places that you become involved with when you go through the treatment and all of that, there’s nothing there that talks about kai [food]. There’s nothing at all”… “So I may suggest that maybe kai [food] is not that important a thing during that time [cancer treatment], cause there’s nothing there.” M10
Issues due to having to access own information
Not knowing what information to trust (misinformation and scare tactics) “There’s a lot of information out there [on the internet] that you couldn’t really call reliable, you know?” NZE1 “If no one’s going to support me, I have to do the research myself. And then, of course you find things that scare you.” NZE2 “There is a lot of information out there but sometimes when you go on the internet you get more than you bargain for and it just scares you, so that’s why I don’t go near the internet, just stayed right away from it.” M10 “I didn’t know where to look. You look on the internet, you get a thousand different answers.” NZE5 *Concern about interference/interaction with cancer treatment* “But does that counteract or do something that it shouldn’t be? You know?” NZE8 *Finding own information is too tiring (for already fatigued cancer patients)* “It’s just me trying to work it out myself. That’s what’s really, really tiring.” NZE3 *Having to access costly privately funded support* “I had to spend $95 to see the dietitian, and then I’ve seen her again and that was another $60.” NZE3 “But that [dietary advice/support] was all privately funded.” NZE10

dietary support for those conditions but not for cancer. Participants who did receive nutrition-related encouragement and support from healthcare workers or support services found that support helpful. Most of the participants reported not receiving any/enough support related to diet and nutrition as part of their care, but only a few asked their healthcare team for information or support if it was not offered. Compared to Māori participants, the NZE participants were more likely to have asked their oncology team for dietary information and support during their treatment, although it was not always provided, and they were more likely to actively seek out information from other sources (eg, internet searches, privately funded dietitian or nutritionist). Pacific participants did not report actively seeking out nutrition information. Several participants were not aware that nutrition can have a role in cancer recovery and prevention. Some had assumed diet/nutrition was not important because their oncology doctor did not mention it, expressed disappointment that they had not been informed, and suggested that they would have followed advice had it been given. Compared to both NZE and Māori participants, fewer Pacific participants were aware of a role for nutrition in cancer recovery and prevention.

Attempts to access nutrition information outside of the healthcare setting exposed participants to misinformation, scare tactics, and marketing of unproven expensive remedies, and placed an extra burden on their already low energy levels. Not knowing where to find correct up-to-date information and whether suggested foods/supplements might interfere or interact with their medical treatment were common concerns. These issues were often discussed in the context of wanting to have the important up-to-date dietary information provided to them by a trusted source (such as their oncologist or a dietitian accessible through oncology services) to reduce their burden at an already difficult time. Some participants paid to see a dietitian, nutritionist, or naturopath because this support was not available as part of their cancer care. However, privately funded dietary support was expensive and participants reported being constrained by their budget, especially while they were unable to work.

Theme 2: dietary changes during and after treatment

Table 4 outlines the sub-themes and representative quotes related to dietary changes. Many participants, largely Māori and Pacific Peoples, did not change their diets except in response to treatment side effects. In the absence of advice on nutrition, they did not explore diet as an option in their recovery. Keeping things normal during treatment and just getting through the cancer was the main focus for some of this group. Others believed their diet was already healthy and did not feel the need to make changes.

Participants who made changes to their diet that were not aimed at managing the effects of treatment did so to manage their weight or general health and/or to aid cancer recovery and reduce the risk of recurrence. Dietary changes commonly reported by participants included increasing their intake of fruit and vegetables, reducing red meat, and reducing processed foods and convenience foods such as takeaways and pre-prepared meals. Although less common, there were also some reports of more stringent diets as well as use of unproven supplements and remedies.

Theme 3: barriers to and enablers of healthy eating with cancer (during and after treatment)

Table 5 outlines the sub-themes and representative quotes related to barriers to and enablers of healthy eating with cancer. A major barrier to healthy eating with cancer was a general lack of awareness of the role that a healthy diet can have in cancer prevention and recovery. Awareness was associated with information seeking and attempts to make healthy dietary changes. However, implementing dietary changes was hampered by limited access to information about dietary recommendations and how to implement them, and the expense of food they believed was healthy (eg, fresh fruit and vegetables and fresh fish). Although some participants reported that they were lucky to not have their food choices limited by their budget, others had difficulty being able to afford the food they wanted. Some Māori and Pacific participants reported that low income was a barrier to accessing enough food, healthy or otherwise. Participants from all three ethnic groups

Table 4: Sub-themes and quotes for theme 2: dietary changes during and after treatment.

Carried on eating as normal
“Basically carried on eating the same foods as before because I was already, felt like I was already on a good diet.” NZE5 “Just kept to what we usually eat or what was there.” M4 “No didn’t change my diet, didn’t allow it to affect me. I think it was more of a mentality thing. Yeah, just carried on eating even if I didn’t feel hungry.” M9 “Nothing, no diet, just eat normal, whatever.” P4
Managing the effects of cancer/treatment
“As a result of the treatment, I sort of avoid certain foods now.” NZE1 “It was just about trying to get anything in.” NZE3 “I couldn’t eat so I tried really hard to drink and then after that people would bring me the things that I were craving for so that I would eat.” M10 “I come home [after chemotherapy], I’m too tired and sleep all the time. Yeh, I can’t eat, I can’t drink.” P1
Managing weight
“I needed to cut off something and try and lose a bit of weight.” M4 “I’m trying to cut the way I eat, the eating. Just a little bit at night-time, and from now I lose weight.” P4
Nutrition for cancer recovery and prevention
“It was about I can’t have this happen again. What can I do naturally to build up my body and to make it stronger.” NZE3 “It was sort of like feeling like you’re doing something.” NZE10 “I look at it [healthy food] as medicine.” M8

reported difficulties changing established food preferences and habits as a barrier to healthy eating. These included wanting familiar foods (eg, traditional Pacific foods) and not knowing how to prepare/cook unfamiliar foods.

Short-term effects of cancer and cancer treatment presented barriers to healthy eating, with fatigue, feeling sick, and not being able to tolerate some foods being commonly reported factors influencing the types of food eaten. Food support from whānau (family) and friends enabled participants who were not feeling well to have better access to food, which saved them from having to prepare food while feeling unwell. However, this sometimes resulted in a loss of control over what food was eaten. Being alone or having no family support was a barrier to eating well. Some participants who were hospitalised as part of their treatment (eg, for surgery) felt that the food provided in hospital was poorly suited to their dietary needs and did not fit with healthy eating recommendations.

Theme 4: improvements to nutritional information and support

When asked for suggestions to improve services for cancer patients, most participants said that ongoing advice and support from a dietitian trained in cancer-related nutrition would be beneficial. One participant stated: “If there was a place where people could actually go and talk to some of these wonderful specialists… I think people may be more equipped to actually understand the value of eating properly” (M1). Some wanted personalised one-on-one support, whereas others suggested access to dietitian-led support groups or provision of reliable up-to-date written and/or online information. Such information should be easy to understand and concise, and practical advice on how to implement suggested dietary changes should be included. Other suggestions included offering courses on diet and how to prepare healthy meals, education of the general population to increase knowledge of healthy eating for cancer prevention, and hospital food that is better suited to cancer patients’ needs. Many also suggested involving whānau/support people when information is provided, so they can better support the person with cancer, and providing written information for whānau/friends with hints on practical ways to help.

Many participants also acknowledged the increased financial burden that comes with a cancer diagnosis and suggested that some financial or practical support would be useful. Examples included enabling subsidised access to healthy pre-prepared meals and financial and practical help with food shopping and preparation. Further, participants suggested that all patients should be made aware of and actively encouraged to access these services, as many would otherwise not ask for help because, in the words of one participant, “there’s a lot of proud people out there who will not put up their hand and say, ‘I need help’ [if that help were not offered]” (NZE8).

Discussion

This qualitative research identified a shortage of nutrition-related support for cancer survivors. Survivors’ desire for more dietary information and support, either as part of a focus on health and wellbeing into the future, or as an important component of holistic healthcare during and after treatment, indicates an unmet need in the provision of cancer care and support in New Zealand. This research also indicates that a lack of dialogue about diet as part of cancer care is sometimes interpreted by patients as an indication that diet is not an important component of cancer care, recovery, and future health and wellbeing. This is of particular concern because belief in a connection between diet and cancer is predictive of successful healthful dietary change.[26,27] Our research indicates that more nutrition-related information and practical support is required to improve cancer outcomes and reduce inequities. This is consistent with international research,[25] but it is the first time this has been explored in a New Zealand context.

The WCRF/AICR report recommends that all cancer patients receive professional expert advice and support on diet and nutrition that is consistent with WCRF cancer prevention recommendations in order to improve survival, reduce risk of a new primary cancer, and minimise the impact of other non-communicable diseases.[2] However, our results indicate

Table 5: Sub-themes and quotes for theme 3: barriers to and enablers of healthy eating with cancer (during and after treatment).

Lack of awareness of nutrition and little/no nutritional information or support (see Table 3)
Financial limitations
“A lot of my food choices are actually dictated by price so it’s a balance between what I want to do and what I can do.” NZE1 “I was on sick leave last year, so I was getting paid. So I spread out, all the costs over my pays and haven’t done anything this year.” (talking about cost of accessing information/support) “The money is probably the biggest thing.” “I’ve got to earn money first to be able to afford that stuff.” NZE3 “Food’s expensive”… “I live in a cold house but I eat veggies so, you know? It’s sort of a balance, I guess. Balancing game.” NZE7 “Finances have always been a bit of a barrier for me.” M2 “You have to budget and those carbs do stretch your meals.” M7 “Finances have been an issue because basically I haven’t been able to do anything [work] for the last five or six months.” M8 “It was hard to me to divided the money to go where it goes to but I want the bread and butter on the table for the kids.” P2 “My finance is not very good.” P3
Established food habits/preferences
“A lot of those processed meats and stuff that’s bad for you actually does appeal to your taste buds.” NZE1 “I love food, I love rich food.” M3 “Especially I love eating takeaways [laughs] yeah I try to cut down”… “My family, husband love eating… so whatever I’m trying to cut the way I eat, I see my husband and kids [laughs].” P4
Effects of cancer/treatment
“I notice that when I get really tired, I eat, I eat more rubbish. I think it’s just to compensate.” NZE9 “The problem has been up until this week is that I haven’t been able to eat. And so the food that I have been eating has been the food that I’ve been craving for so that at least I will eat.” M10 “Yeah, can’t eat like before.” P3 “I was really scared that I would fall asleep [due to overwhelming fatigue] and I’d leave something on the stove”… “So that’s why I didn’t really cook a lot on the stove because I didn’t want to set fire to the house.” NZE9
Lack of support
“To try and get something out of WINZ [financial support] is hard and I just didn’t have the energy to do it.” M8 “I did not find ‘the person’ I was looking to find here who could support me.” (talking about access to knowledgeable nutritional support for cancer recovery) NZE10 “And then, when you’re out [after surgery] you just kind of fend for yourself.” NZE7

that this is not currently available to cancer patients in New Zealand. There is increasing recognition that health literacy, which can be aided with dietary support, is an important component of holistic healthcare for cancer patients,[4] and there is evidence of a desire among cancer patients to pursue dietary changes as a way to improve their health (both in the current study and published research).[5–7,9,28] Consistent with other studies,[5,29] this study found that a major barrier to following WCRF recommendations is a lack of awareness that diet is important in cancer recovery.

Although dietitians were seen as the most reliable source of dietary support, participants identified that medical and other healthcare workers had an important role in highlighting the importance of diet in recovery and survival, something that is increasingly recognised internationally.[4] The current research suggests that the systematic incorporation of nutrition advice, information, and support into oncology care and support services would be beneficial for improving cancer-related outcomes and reducing cancer inequities in New Zealand. A comprehensive medical assessment at the time of cancer diagnosis, including attention to co-morbidity, has been suggested,[30] which could be an ideal time to introduce dietary support to help cancer patients during treatment and the post-treatment period.

In common with other evidence,[5] increasing the intake of fruit and vegetables and limiting convenience foods were highlighted by many in this study as dietary changes that were made or attempted. This is consistent with WCRF advice; however, specialist nutritional support would confer additional benefits, including support with how to achieve dietary goals (improved health literacy and self-efficacy),[31,32] information on other less well-known recommendations (such as increasing wholegrains), and recommendations specific to particular cancers and individual patient needs. Healthcare workers also have an essential role in accessing additional support for patients in the form of monetary assistance, food delivery, and referrals to specific support agencies. These forms of support will have an important role in addressing some of the barriers to dietary change and healthy eating identified from this research.

Inequalities in cancer outcomes by socioeconomic status and ethnicity persist in New Zealand and are due to a range of factors, including material deprivation, comorbidity, and health service factors (including institutional racism).[33–35] Differences in active information seeking between ethnic groups in this study are of concern and indicate that relying on patients to question healthcare workers and actively seek out their own information about nutrition may contribute to the gap in equitable cancer outcomes. Sociocultural barriers such as language proficiency, social/cultural norms, level of trust in the health system, stigma, and cultural taboos can limit information-seeking behaviour in disadvantaged and minority populations.[36–40] For example, listening quietly (as opposed to questioning) is common among both Māori and Pacific Peoples and demonstrates respect for someone of higher status such as a doctor.[41,42] In addition, a system that expects patients to ask for information and assumes patients know what questions to ask favours those who are already well informed.[43]

This research identified cost or finances as an important barrier to both accessing dietary support and implementing healthy dietary changes. Access to publicly funded dietitian support was unavailable to many, and support from a privately funded dietitian is financially untenable on a tight budget. The cost of healthy food and the difficulty balancing this with other financial pressures such as housing and family commitments were barriers to healthy eating, and some even struggled to access enough food because of financial or practical constraints. Food security is essential to maintaining a healthy diet at this time. Food insecurity impacts substantially on Māori, Pacific, and low-income families in New Zealand and is associated with increased psychological distress and decreased diet quality.[15,44] A diagnosis of cancer can result in reduced income or loss of employment, which impacts disproportionately on those already food insecure. The added costs of healthcare and time off work are often associated with financial stress and increased reliance on family and other support.[11,45] Financial as well as practical support will be essential for many cancer patients at this time. Providing all cancer patients with access to dietary advice and support, as well as the means to achieve optimal nutrition, is an important component of equitable cancer care that is likely to contribute to more equitable cancer outcomes.[2]

The credibility of information found outside of standard cancer care services was questioned. This is consistent with other studies that show the availability of dietary information that is seen to be credible is important, especially for achieving persistent dietary change.[6,29] Dietary and other behaviour changes are often made by people looking to achieve greater agency over their prognosis and can be an important part of psychological support and improved quality of life during cancer treatment.[6,28] A recent New Zealand study with Māori and Pacific participants with multi-morbidities confirmed the importance of holistic and culturally competent healthcare for optimal health outcomes.[11] Nutritional recommendations must take into account both food preferences and cultural norms. Māori and Pacific healthcare providers have the potential to deliver such support in culturally appropriate ways. However, they would need to be well resourced and have support for appropriate capacity building.

Strengths and limitations

This study provides valuable insights into the nutrition-related experiences of New Zealand cancer survivors during and after acute cancer treatment. It includes participants from three ethnic groups in three regions of New Zealand in order to explore diversity of experiences, particularly as they relate to health and health service equity. Although this study provides valuable insight of similarities and differences in perspectives and experiences of Māori, Pacific, and New Zealand European cancer survivors, the lower number of Pacific participants and the use of English-language interviewing may have limited the depth of the Pacific participant data. The requirement for interviews to be in English may have contributed to difficulties recruiting Pacific participants. In addition, language barriers can impact on both understanding of the questions and the confidence to provide detailed (as opposed to succinct) answers.[46] This may have resulted in missing potentially important perspectives and limiting the depth of understanding.

Conclusions and recommendations

This research has exposed a need for more nutrition information and support for cancer patients during and after treatment. Cancer patients should be informed about the importance of nutrition and specific cancer-related nutrition recommendations, but provision of support (dietary, practical, financial) in a culturally appropriate context will also be necessary to ensure that those who wish to make dietary changes are able to do so. In addition to supporting cancer recovery with good nutrition, providing information and support has the potential to reduce stress introduced by having to search for information, and limit exposure to misinformation and expensive unproven remedies. A consistent and systematic approach to nutrition support that ensures all cancer patients have equal opportunity to benefit from good nutrition during and after treatment is important to support equity in cancer outcomes. Interventions to address financial barriers and increase access to cancer-related nutrition advice and support are needed to reduce inequities and improve cancer outcomes. A nationwide study to understand the provision of nutrition advice and support from the perspective of healthcare professionals (including barriers and enablers) will contribute to determining the best way forward to address this need. Further Pacific-led research with Pacific cancer survivors with the option to converse in their preferred language is recommended to gain an in-depth understanding of their specific nutrition information/support needs and how best to address those needs.

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