

Navigating Nutrition as a Childhood Cancer Survivor: Understanding Patient and Family Needs for Nutrition Support

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Abstract

Purpose: Nutrition challenges are common during childhood cancer treatment and can persist into survivorship, increasing the risk of non-communicable chronic diseases. Evidence based practice and implementation of nutrition support for childhood cancer survivors (CCS) has been poorly investigated and may influence the future health of survivors. This study aimed to explore the nutrition support needs of CCS and the barriers and facilitators to delivering follow-up services in New Zealand (NZ).

Methods: Qualitative thematic analysis of semi-structured interviews were performed at a specialist paediatric oncology centre in NZ with CCS and their family (N = 20 individuals) and health professionals (N = 9).

Results: Three key themes emerged from the analysis: 1) the current survivorship care pathway does not provide adequate nutrition support, 2) weight and dietary changes are common challenges, and 3) requirements for nutrition support in survivorship are varied. Common nutrition-related concerns included fussy eating, poor diet quality, difficulties tube weaning, and challenges with weight gain. Participants expressed a desire for education on healthy eating alongside information about cancer-related nutrition issues, such as learned food aversions. A preference for clear referral pathways and multifaceted interventions tailored to individual patient needs were identified by CCS and health professionals.

Conclusion: The trifecta of treatment side effects, negative feeding practices, and poor messaging from health professionals creates a challenging environment to optimise nutrition. A stepped care model matching the intervention intensity with the CCS is required. Education for healthcare professionals will improve the delivery of timely nutrition support and monitoring practices.

Introduction

Approximately one hundred and fifty children are diagnosed with cancer yearly in Aotearoa New Zealand (NZ) [1]. More than 80% of these children will survive five or more years following their diagnosis; however, many will develop health complications as a consequence of childhood cancer and its treatment [2]. Non-communicable diseases such as metabolic syndrome (MetS), diabetes mellitus (DM), osteoporosis, and cardiovascular disease (CVD) are common late effects in childhood cancer survivors (CCS) [3]. Research in the general population has shown poor nutrition contributes to the risk of developing these chronic conditions [4, 5]. The implications for poor nutrition in CCSs and the effects on future health warrants investigation.

In addition to adequate nutrition to ensure optimal growth and development, children with cancer experience increased requirements due to their diagnosis and treatment. Therefore, patients are vulnerable to malnutrition during treatment, resulting in reduced chemotherapy tolerance and an increased risk of morbidity and mortality [6, 7]. Common side effects, such as nausea, vomiting, mucositis, and changes in smell or taste, impact dietary intake, further increasing malnutrition risk [8, 9] and contributing to altered food habits during treatment which has been shown to persist into survivorship [3, 10-12]. Whilst the influence of nutrition on CCS long-term health is largely unknown, Children's Oncology Group (COG) Long-Term Follow-Up Guidelines [13] recommend CCS maintain healthy body weight, engage in regular physical activity, and follow healthy eating patterns [14]. Despite these recommendations, there is limited understanding of how nutrition support can be effectively integrated into CCS survivorship and follow-up services.

Understanding patient and health professional perspectives are central to facilitating appropriate diet and nutrition support within this setting [15, 16]. However, there is limited qualitative research exploring CCS experiences with nutrition or preferences for support following treatment completion. Interviews conducted in Australia and the United Kingdom suggest CCS have poor dietary intake, although they are open to receiving guidance from health professionals [17-19].

Multifaceted interventions which target food intake would be the preferred method of support. [17]. However, health professionals often cite limited resources and lack of formal training on health behaviour promotion as barriers to embedding such interventions into routine practice [20]. Not only do we poorly understand the evidence for best practice, there is very little research conducted on implementing optimal nutrition support for CCS and their families. Given the higher incidence of chronic disease in CCS versus their healthy counterparts, a need to investigate best practise and barriers and enablers is warranted. This study aimed to explore the requirements for nutrition support and the barriers and facilitators to its delivery for CCS who received treatment at a specialist paediatric oncology centre in NZ.

Methods

Setting

This study was conducted at a specialist paediatric oncology centre in Auckland, NZ. Treatment for childhood cancer occurs at two specialist centres in NZ that coordinate treatment with fourteen shared care centres to facilitate treatment closer to home for patients. Once treatment is completed, patients are initially followed up in survivorship clinics to monitor remission status. Depending on patient diagnosis, study surveillance, and individual needs, CCS will then be referred to the Late Effects Assessment Programme (LEAP) two to five years after treatment completion. This study draws on nutrition experiences in survivorship and LEAP programmes; however, it will also reference experiences during active treatment.

Study population:

Consistent with the National Cancer Institute definition [21], CCS was defined by the age of cancer diagnosis of 0-15 years and completion of all forms of active anticancer treatment. Health professionals were defined as members of the multidisciplinary team (MDT) involved in patient care.

Study design

CCS and their family were recruited through survivorship and LEAP clinics facilitated by the specialist paediatric oncology centre. Relevant health professionals received an email invitation to participate in the study. Due to the heterogeneity of childhood cancer diagnoses, inclusion criteria for patients and their families were broad to obtain a wide variety of perspectives. Semi-structured interviews were completed by one interviewer (E.C.) between June and August 2021. Participants provided written, informed consent before their interview. The study received ethical approval from the Auckland Health Research Ethics Committee on 19/03/2021 (reference: AH21521). Institutional approval was granted by the Auckland District Health Board Research Office (Project number: A+9123).

Data collection

Participating CCS or their family members completed a short demographic questionnaire before the semi-structured interview, including information on ethnicity, age, gender, household size, and employment. The interview followed a semi-structured interview guide (Supplementary Table 1). All interviews were audio-recorded.

Analysis

Upon completion of the interview, the quantitative demographic data were recorded into a spreadsheet, and the qualitative interview recordings were transcribed verbatim into NVivo (QSR International Pty Ltd. 2021, Version 12). A unique identifier was attributed to each participant. Transcripts from all interviews were analysed in NVivo using an inductive approach, employing Braun and Clarke's [22] thematic analysis framework. A multi-level consensus coding methodology was used where each theme and associated subthemes were discussed with the study team (E.C., G.P., and A.L.L.) for confirmation to ensure accurate coding and analysis. To provide consistency in interpretation, 24% of all interviews ($n = 6$) were coded independently by two investigators, who then reviewed their analysis and discussed any discrepancies. The final coding framework was used to analyse the remaining transcripts.

Results

Semi-structured interviews were conducted with twenty individuals from sixteen families. One interview was excluded due to a documentation error, leaving fifteen interviews for analysis, with seven CCS and thirteen family members. Demographic information is presented in **Table 1**. Most participants were female (79%, $n = 11$). An interview was conducted with one CCS alone (7%), and the remaining fourteen were with a caregiver. Self-defined ethnicity was NZ European (36%; $n=5$), Māori (21%; $n=3$) and Pacific (21%; $n=3$)

Table 1 Demographic characteristics of CCS and family members who participated in a semi-structured interview on how to best support nutrition for CCS ($n = 14$)

Characteristic	Total
CCS and family	(n = 15)
Sex, <i>n (%)</i>	
Female	11 (79)
Male	3 (21)
Ethnicity, <i>n (%)</i>	
New Zealand European	5 (36)
Māori	3 (21)
Pacific	3 (21)
Asian	3 (21)
Age, <i>n (%)</i>	
18-24	1 (7)
25-29	0 (0)
30-39	3 (21)
40-49	6 (43)
50-59	2 (14)
Missing	2 (14)
Number of people in household, <i>mean (SD)</i>	5.4 (2.2)
Clinic attended, <i>n (%)</i> ^a	
Survivorship clinic	5 (36)
LEAP clinic	9 (64)
Employment status, <i>n (%)</i>	
Employed	8 (57)
Student	2 (14)
Self-employed	1 (7)
Homemaker	1 (7)
Looking for work	1 (7)
Unable to work	1 (7)
Main carer, <i>n (%)</i>	
Mother	9 (64)
Mother and Father	5 (36)
Health professionals	(n = 9)
Sex, <i>n (%)</i>	

Female	8 (89)
Male	1 (11)
Profession, <i>N</i> (%)	
Clinical Dietitian	4 (44)
Nurse Specialist	1 (11)
Oncologist	1 (11)
Psychologist	2 (22)
Research Dietitian	1 (11)
Years working with children with cancer, mean (<i>SD</i>)	10.1 (7.4)

^a Patients are transferred to survivorship clinics at the end of treatment; patients are transferred to LEAP clinics two to five years after treatment completion (dependent on diagnosis, study surveillance, and individual needs).

Abbreviations: CCS, childhood cancer survivor; LEAP, Late Effects Assessment Programme

Nine interviews were conducted with key health professionals, including four clinical dietitians, one research dietitian, two psychologists, one specialist nurse, and one oncologist. Other members of the MDT, including consultants, nurse specialists, social workers, and the Māori support service, were also contacted; however, they were unavailable. Most participants were female (89%; *n* = 8), and clinical dietitians (44%; *n* = 4). The mean (SD) time health professionals had worked with children with cancer was 10.1 (7.4) years.

The emerging themes were organised into three categories: 1) the current survivorship care pathway does not provide adequate nutrition support; 2) weight and dietary changes are common challenges for CCS; and 3) perspectives on nutrition support in survivorship. Sub-categories for these themes and representative quotes are outlined in **Table 2**.

The current survivorship care pathway does not provide adequate nutrition support

Interviewed stakeholders (CSS, family, health professionals) indicated a distinct absence of nutrition support in the follow-up services. Health professionals revealed a lack of funding and the prioritisation of patients on active treatment means no dietitian is available for survivorship. They also acknowledged health professionals often do not prioritise nutrition, with a lack of recognition for perceived 'milder' nutrition issues such as food aversions, poor diet quality, or weight fluctuations.

"I suppose once the tubes are out, we're probably guilty of – as long as the weight looks good, we're happy enough, really." – Oncologist

The current service delivery model of follow-up services means oncologists and nurse specialists provide nutrition support. CCS and their family raised concerns over the lack of nutrition support, resulting in some seeking answers from the internet or other parents.

"I don't know if you can call that the 'grey area' – we're kind of like, we don't know what really is best for him, particularly his nutrition." – Survivorship 1

Weight and dietary changes are common challenges for CCS

During treatment, patients experienced side effects that impacted food choices and intake. CCS and families often recalled being told to prioritise calories over nutritional quality and that there was a mindset of 'just try to get by' with food intake. Once treatment was complete, family members expressed it was difficult to reinstate healthy eating patterns. CCS often faced challenges, including persistent poor food choices and difficulties with tube weaning. However, some CCS were able to transition back to normal eating patterns upon treatment completion with few problems.

"So, you've got all these times where he vomited with different things, that he's got these memories, that he's like, "I'm never touching that again." But they're generally quite core everyday foods." – LEAP 9

Fussy eating was a commonly reported challenge. Food phobias and aversions rooted in the experiences of nausea and vomiting during treatment and poor diet quality were frequently discussed by participants. Weight changes in survivorship were also considered primarily by health professionals; however, family members often expressed distress associated with their child's dietary and weight changes.

"[Young patients] still have a lot of fussy eating or selective eating behaviours when they start treatment. They move through treatment with this mindset of 'any calories are good calories' for fair reason at the time, and often that can further skew the – how narrow their diet variety becomes and then, as they are able to tolerate adequate volumes of oral intake, their diet variety doesn't necessarily improve with that."– Dietitian 1

Perspectives on optimising nutrition support in survivorship

The transition from treatment back to 'normal life' is challenging for families, and participants expressed the need for support. Families discussed a variety of interventions that would be beneficial, including having age-appropriate general healthy eating advice available [23]. However, several families and health professionals also identified the need for behaviour change strategies to introduce healthy eating and manage fussiness.

While there was variation in opinions on the best time for nutrition intervention(s) to commence, it was apparent families required some autonomy in identifying the intervention timing, with a preference for support to begin before any nutritional challenges arise. Determining the preferred delivery method for nutrition interventions was challenging as there was variation in opinion. All groups of stakeholders discussed the need for access to a dietitian in survivorship; however, current funding models were identified as a significant barrier.

"I think seeing a dietitian would have been awesome. Just to see how [my child] went through treatment with their eating and stuff and what ideas – to get them to start eating more nutritious foods and things now that they're post-treatment." – LEAP 1

Finally, health professionals identified the need for a nutrition screening tool that provides clear referral criteria, relevant resources, and variables to monitor at annual clinic appointments. If such a tool was made available, health professionals expressed the need to upskill with appropriate education and support in its delivery.

"I definitely don't feel like I have the best knowledge [...] So, I probably need to develop that a little bit better but, yeah, it's hard when you – I've only ever worked in oncology and [paediatrics], so you kind of have a distorted view of eating I suppose with these kids."

– Nurse

Table 2 Emergent themes from semi-structured interviews with CCS and family members ($n = 14$) as well as relevant health professionals ($n = 9$) on how to best support nutrition for CCS.

	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
THEME 1: NO NUTRITION SUPPORT FOR SURVIVORS				
Current survivorship system does not allow for adequate nutrition support				
No available nutrition support from dietitians	10	<i>"I don't know if you can call that the grey area – we're kind of like – we don't know what is best for him, particularly his nutrition." (Survivorship 1)</i>	8	<i>"She got quite overweight 'cause of steroids that she's been on, and she asked for... to see a dietitian as one of her Make-a-Wish." (Dietitian 3)</i>
Lack of funding	0		6	<i>"A lot of the support that the families would require [...] needs time and that's something we don't have just 'cause the acuity on the other side of the ward which is where the majority of our funding comes from." (Dietitian 4)</i>
Nutrition support provided by other health professionals	1	<i>"[The doctor] helped us when [CCS] was going through her treatment and she started putting on lots of weight. And she was like 'just try and stay away from the carbs.'" (LEAP 3)</i>	6	<i>"The nutrition support that they get is from us; [a specialist nurse], psychology and the doctor that sees them as well." (Nurse)</i>
Nutrition support provided by alternative sources	4	<i>"We just avoid [...] milk and [...] I just read some of the books says it has got lots of hormones" (Survivorship 4)</i>	2	<i>"When they've finished treatment, they might just want to start taking [vitamin supplements] but, you know, a lot of the stuff you can get from healthy eating; you don't necessarily have to take supplements" (Nurse)</i>
Nutrition is not viewed as a priority by health professionals				
Lack of referrals	0		7	<i>"[LEAP is] now in Greenlane so then I never get a referral from those patients." (Dietitian 3)</i>
Lack of awareness of importance of nutrition from other health professionals	0		4	<i>"It's up to us and the senior nursing looking after them to identify issues and seek help which I try to be proactive with [...] we're probably guilty of – as long as the weight looks good, we're happy enough, really." (Oncologist)</i>

	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
CCS with mild nutrition issues forgotten	1	<i>"it's not like he was starving and underfed and not being able to eat. So, it hasn't really been an issue, so I haven't really ventured further."</i> (LEAP 9)	5	<i>"If patients [...] weren't necessarily losing lots of weight and they weren't gaining weight but maybe they just have poor dietary intake [...] I think [there] wasn't necessarily awareness as much that they could also be seen by a dietitian, or that was a concern."</i> (Researcher)

THEME 2: WEIGHT AND DIETARY CHANGES ARE COMMON CHALLENGES FOR CCS

Experiences on treatment impact long-term diet

Prioritization of food intake over diet quality during treatment	4	<i>"When we think back to that session that we had, it was a case of "just anything that you can get into him" which [...] didn't seem very comprehensive."</i> (LEAP 2)	4	<i>"It isn't about 'just eat whatever you want during treatment' but trying to establish good eating patterns on treatment to the best of your ability when you can as a way of preventing poor dietary habits down the track."</i> (Researcher)
Focus on treatment of just getting by	4	<i>"At the time we were just very focused on the fact that he had just been diagnosed. So that was the focus as opposed to thinking too much about the advice that had been given around diet"</i>	3	<i>"I think the fact that you are at risk of cardiovascular disease, diabetes, metabolic disease, weight gain, all those endocrine kinds of shifts, bone health, that's not a thing that sits high next to 'let's get rid of this cancer.'" (Dietitian 4)</i>
Treatment side effects impacting long-term diet	9	<i>"So, you've got all these times where he vomited with different things, that he's got these memories, that he's like 'I'm never touching that again.' But they're generally quite core everyday foods" (LEAP 9)</i>	7	<i>"[Kids] who still long-term struggle with feeding issues and kids who struggle with swallowing issues – that could have been negative associations with the treatment that they have been on" (Dietitian 3)</i>
Overeating once treatment is complete	2	<i>"I just ate whatever, yeah. 'Cause I didn't get sick after that for like a year, at all. So, I just felt like I could eat anything."</i> (Survivorship 4)	2	<i>"They said, all of a sudden, they were overeating lots of food and people would comment "my god, your child eats a lot." So, they're almost</i>

				doing the opposite to what they did during treatment.” (Researcher)
Tube weaning	1	“He was still being fed through the tubes for a while. Yeah, he was quite picky with his foods. His appetite took a while to come back actually.” (LEAP 6)	4	“The majority of the phone calls that we get in that sort of outpatient setting are to do with tube weaning and support around that fussy eating” (Dietitian 4)
No issues experienced	6	“It’s obviously been a lot easier since he came off treatment. He’s just fallen back into how it was before he started treatment.” (LEAP 2)	3	“There’s the odd patient where you know they have come off treatment, they aren’t even using oral nutrition support and parents just want some support in getting children to return back to normal eating, whatever that looks like for the family” (Dietitian 4)
	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
Fussy eating				
Food phobias and aversions	8	“Cause there was a time where he was quite sick when he had [potato], he doesn’t go anywhere near it. So, you’ve got all these times where he vomited with different things, that he’s got these memories, that he’s like ‘I’m never touching that again.’ But they’re generally quite core everyday foods.” (LEAP 9)	7	“This is not behavioural fussy eating. This is beyond behavioural fussy eating. These are kids who’ve probably had – got significant food aversions because, you know, vomiting and nausea with food when they were younger.” (Researcher)
Poor diet quality	7	“For example, if I have a pantry full of junk food and then like a fruit cabinet or whatever, I’d probably go to the pantry full of junk food, even though I still like fruit a lot.” (Survivorship 3)	4	“They come through treatment and leave with a really limited dietary variety or perhaps a lot of unfavourable diet patterns that stay with them through treatment which later in life obviously go on to have negative metabolic consequences.” (Dietitian 1)
Frustration and concern associated with weight and dietary changes	7	“The thing I find frustrating is that sometimes your weight can be quite different and yet, to my mind, you’re not eating any worse or anymore. And that I find frustrating.” – LEAP 3	3	“There’s a lot of anxiety around coming off the feed and no longer relying on that feed to provide the majority of nutrition and actually [getting] the child eating normally.” – Dietitian 4
Challenge to	6	“Saying ‘no’ was a really big	4	“Parents are still saying that

correct diet

milestone." (LEAP 9)

they have had trouble to get them to eat better again after they've had their treatment because during treatment, they get whatever they want and there's no boundaries but now families struggle with [...] adapting that once they've finished their treatment" (Nurse)

Changes in weight

Weight gain	2	"So, I wasn't too careful about my nutrition...until I started gaining weight" (LEAP 4)	8	"If I did get a referral, it would be mainly for patients who [...] had significant weight gain, so they were seeing the BMI percentiles go up exponentially" (Researcher)
Weight loss	1	"Just thinking about it now, he was tiny – he was tiny for a long time." (LEAP 6)	4	"Occasionally we do see some children who have come off treatment and we do experience weight loss 'cause they're not eating properly" (Dietitian 4)

	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
THEME 3: PERSPECTIVES ON OPTIMISING NUTRITION SUPPORT IN SURVIVORSHIP				
Need for a multifaceted intervention				
Variety in approach	6	“[...] ‘cause everybody’s different, and everybody has different types of health and different types of support.” (LEAP 9)	8	“There are definitely families that really would benefit from that knowledge that they could talk to a dietitian one-on-one in this setting. And then there are families that probably don’t need that like intensive support but would actually benefit from, just relearning about what healthy eating is for kids their age.” (Dietitian 4)
Pre-emptive support ahead of challenges	7	“I probably would’ve been ready after about six months, but some people might be before. Like if they just had one child, maybe then they’d want it straight away. But because I had the four kids and I was just dealing with everybody else,” (LEAP 9)	7	“The biggest problem with that is, is that parents have still got heaps going on in [early survivorship] so that’s why I don’t know where the sweet spot is. It might be 6 or 12 months after treatment. You can’t wait until five years, it’s too late.” (Researcher)
Multiple platforms to access support	11	“You know if we could see someone in person – that’s good thing because we can ask particular questions.” (Survivorship 4) “Maybe like an online chart that I	8	“[‘Cause] they don’t have WiFi at home and [...] that’s just usual [...] so it] is maybe having two or three different ways.” (Psychologist 2)

could go to if I need it, 'cause I always have my phone on me." (Survivorship 3)

<i>Face-to-face support with health professional to supplement resource</i>	3	"I found is quite good of having pamphlets or materials [...] but there was a contact number if I needed to ask questions or have further information, and you could make an appointment if you needed." (LEAP 9)	3	"I think for some families it would just be a matter of still talking it through with them because some families just don't go well with just reading off paper, so you just have to know how they learn as well and [adapt] it for them, particularly." (Nurse)
<i>Group sessions</i>	0		3	"It would be amazing if we had something like a dietitian that had, you know, like an afternoon a month where families could come in and [...], you could do a session on something, theme it." (Dietitian 4)
<i>Hard copies</i>	4	"It's a good thing that written something, you can always go back." (LEAP 8)	0	

	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
<i>In-person, personalised contact</i>	5	"I think having somebody giving you those messages face to face maybe it is better heard. You know what I mean, you've got the person's	6	<i>I'm a fan of wherever possible an in person. [...] to me that's the ideal because I think then you can personalise it and I also think you create a relationship and I think that having a relationship with people is fundamental to making that change.</i> (Psychologist 2)

attention.”
(LEAP 2)

Online content	3	“But I think an online resource because I get most of my information online, I do all my work on my laptop [...] I think that would probably be the best resource for me. I’d be using that one the most.” (LEAP 4)	6	“Something online/video would potentially be more beneficial because it’s not just a piece of paper that is gonna get filed away and lost or added to piles and piles of paper they already have. It’s not disappearing or going anywhere.” (Dietitian 2)
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Access to a dietitian

Dietitian allocated to survivorship space	4	“I think seeing a dietitian would have been awesome. Just to see how they went through treatment with their eating and stuff and what ideas... to get them to start eating more nutritious foods and things now that they’re post-treatment.” (LEAP 1)	6	“Yeah, I mean obviously in-person dietitian input or virtual dietitian input would be amazing...and it would probably help parents to get to the crux of some core issues or give them a specific place to start that then broader education tools could build on.” (Dietitian 1)
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Dietitian FTE not feasible	0		4	“I mean I think, in an ideal world we would have a designated LEAP dietitian, which is never going to happen.” (Nurse)
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Education for CCS and families

Healthy eating for CCS	6	“Yeah, maybe some of this research or something like that can give him an overview on	3	“Any of the interventions out there, they’re focussing on providing education about nutrition which is important because parents need to be aware, and I don’t think they’re told about why nutrition is important” (Researcher)
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like [how] unhealthy stuff won't [give him sustained energy] and improving habits might benefit his own health." (Survivorship 3)

Nutrition at different ages	2	<i>"Particularly [for] their age, yeah whatever is good that sort of thing." (LEAP 8)</i>	2	<i>"Refamiliarizing families with what actually is appropriate for a child of their child's age" (Dietitian 4)</i>
Recipes	5	<i>"A list of recipes that would probably be good for you for energy, for health in general. That would have been nice. I probably would still use it." (LEAP 4)</i>	0	

	CCS and family members		Health professionals	
	Number of respondents (n = 14)	Quote	Number of respondents (n = 9)	Quote
Strategies to manage change for CCS and families				
Managing transition to normal life	4	<i>"I think it was kind of that transition from doing whatever you can to get by, to getting some normality back. And that bridge to cross over, I think, having some guidelines that weren't making you feel like you had failed" (LEAP 9)</i>	3	<i>"[...] to kind of get kids or families to work through certain things as they navigate normal life again" (Dietitian 4)</i>
Support to introduce healthy eating	3	<i>"So, I think it's important that that message [of healthy eating] gets through and any kind of practical advice to support that as well is helpful for families coming through the other side" (LEAP 2)</i>	6	<i>"So, I think education is needed but I think it's...we need to go beyond going 'oh, your child needs to eat fruit and vegetables.' I think there's a lot of behavioural stuff that we need to work on as well." (Researcher)</i>
Support for managing fussy eating	3	<i>"Just trying to get him back into having little bits of food, not a big portion like everybody else just little bits and then keeping that going consistently" (Survivorship 2)</i>	3	<i>"[...] how do they go about reintroducing foods in a way that they will be able to continue to develop how much they eat, and the variety of foods that they eat." (Nurse)</i>
Family involvement in change	7	<i>"I can cook it for him and for us as well. I don't want him to have this just for himself and we eat different things. So, whatever you give us I will try to cook for all of us as a family so [CCS] will eat with us." (LEAP 5)</i>	2	<i>"Some of it's about trying to normalise [healthy eating] within the family so that it's not just the child that has to go and undertake this change in their eating habits, but doing as a whole family perspective" (Nurse)</i>
Support for health professionals				
Support for delivering nutrition support	0		5	<i>"We have really picky eaters, and I don't know anything about how to address that, so having some support [...] would be good." (Nurse)</i>
Need for nutrition screening tool	0		4	<i>"So, their first encounter with survivorship would be... perhaps be an opportunity to kind of get a baseline of any nutrition concerns and pick up specifically what parents would like to be addressed in terms of nutrition issues." (Dietitian 1)</i>

Abbreviations: CCS, childhood cancer survivor; FTE, full time equivalent; LEAP, late effects assessment programme

The relationship between emergent themes

A concept map was developed to demonstrate the relationship between the emergent themes (**Figure 1**). CCS are predisposed to nutrition challenges in survivorship due to their experiences during treatment. The absence of nutrition support and health professionals not prioritising nutrition concerns contributes to the prevalence of nutrition challenges, including weight changes and fussy eating behaviours in CCS. The complexity of these issues justifies the need for a multifaceted intervention that can address multiple nutrition support topics.

A variety in approach, accessibility, and timing is necessary, with nutrition education, strategies to assist behaviour change, and access to a dietitian. Adjunct to this support, a screening tool for health professionals and education on its use and value would allow for the delivery of appropriate and timely support.

Discussion

This study aimed to explore the requirements of nutrition support for CCS and the barriers and facilitators to providing this supportive care in NZ. CCS experience a variety of nutrition-related challenges in survivorship, including fussiness, weight changes, and poor diet quality due to experiences during treatment. However, there is no consistency in the delivery of nutrition support after active treatment, with the most significant barrier is a lack of funding to support a dietitian in survivorship.

The two most prevalent nutrition-related challenges CCS faced were weight changes and fussiness. Health professionals primarily discussed both weight loss and gain. A systematic review evaluating studies on the prevalence of malnutrition in paediatric cancer patients found both undernutrition (median: 20%) and overnutrition (median: 38%) were prevalent issues upon completion of treatment [24]. An almost two-fold increase in the prevalence of overweight and obesity has also been reported in ALL survivors, increasing from 20.5% at diagnosis to 40.5% at 5-years post-treatment [25]. Interventions to encourage healthy lifestyle behaviours and address overnutrition have been successful, with one targeting parents of CCS with obesity showing decreases in CCS BMI percentile, waist-to-hip ratio, and sugary beverage consumption, and increases in daily step count [26].

Over half of the interviewed families reported food fussiness and/or low diet quality. High rates of fussy eating have been reported in Australian CCS where parent-reported “picky eating” rates were significantly higher in CCS than in age-matched controls [27]. In the present study, families reported that negative nutrition experiences during treatment could be a potential cause of limited dietary intake in survivorship. Negative treatment side effects were experienced by many CCS and associations between certain foods, and aversive side effects were reported to have evolved into learned food aversions. This relationship was originally identified by Bernstein [28] as early as 1978 when paediatric cancer patients acquired food aversions during their treatment if consumption of a certain food occurred before symptoms of nausea or abdominal discomfort.

Challenges correcting poor eating habits once treatment was complete were common. Potential reasons for this have been outlined in the literature, where families felt nutrition was the only part of their child’s health they could assist with during treatment [29]. However, with treatment side effects leading to food refusal, parents often resort to negative feeding practices such as placing pressure on their child to eat, threatening nasogastric tube insertion, or allowing their child to dictate their dietary intake [29]. These practices could lead to learned food aversions or altered food habits, which have been shown to persist into adulthood in CCS [3, 10-12]. A previous intervention to reduce negative feeding practices in parents of CCS with obesity resulted in decreased pressure to eat, decreased food restriction, and increased frequency of family meals [26].

Health professionals acknowledged a general lack of understanding of the importance of nutrition and nutrition-related behaviours in survivorship. These sentiments are echoed in a review of medical training programmes, where the authors concluded that “nutrition is insufficiently incorporated into medical education” [30], highlighting a significant gap in

health professional knowledge. The impact of the “any calorie is a good calorie” message and prioritisation of total energy intake over diet quality to maintain weight may lead to families overlooking food aversions and encouraging the consumption of high energy and low nutrient density foods. This trifecta of treatment side effects, negative feeding practices, and poor messaging from health professionals creates a challenging environment to optimise nutrition. While interventions exist to address unhealthy behaviours amongst CCS and can include strategies to address negative feeding practices [26, 31, 32], no studies have examined the nutrition messages provided by health professionals within the MDT.

Due to the heterogeneity in CCS needs and the complexity of the contributors to poor nutrition, a multifaceted, patient-centred approach to optimising nutrition should be taken. Stepped care models are commonly used in psychology and mental health disorders where every ‘step’ involves an evidence-based intervention that increases in intensity the further a patient works through the model [33]. Patients progress through the levels of intervention until they see a benefit, with the majority of patients seeing benefit at the first, low-level intervention, making this a cost-effective model of care [33]. Health care professionals frequently mentioned the need for a progression of interventions, however, stepped care models are yet to be trialled in CCS.

The first ‘step’ nutrition intervention could encompass general healthy eating support for the survivor’s age, stage, and activity level, including practical behaviour change strategies to be implemented in the home setting. Existing education-based interventions promoting healthy lifestyles among CCS have been effective [26, 31], and similar to previous research [34, 35], the interviews in the present study highlighted the importance of family involvement. An existing programme that focuses on behaviour change strategies to restore healthy eating practices using an online, parent-led intervention is Reboot-Kids® [36], which has demonstrated an increase in parent confidence in providing more nutritious foods to CCS [32]. Using an online platform aligns with the desire for participant autonomy in intervention timing.

Contact with a dietitian is preferable for more concerns such as food aversions, sudden weight changes, or nasogastric tube weaning. As these were common challenges for families in this study, group education sessions facilitated by a dietitian may be appropriate in the proposed model. Group interventions to improve bone health behaviours in adolescent CCS have been trialled, with improved dietary calcium intake at one month following the intervention compared to controls [37]. Group interventions facilitate a support network for families experiencing similar issues, foster a more interactive learning environment [38], and are a resource-effective method of providing support for multiple families in a single session. For significant or persistent nutrition concerns such as obesity, undernutrition, pre-diabetes or DM, and eating disorders [39], individual dietetic support is crucial to reducing the risk of chronic conditions later in life for at-risk CCS [4, 5].

To allocate CCS to the appropriate intervention level an effective screening tool and education on its application is required. The nutrition screening tool for childhood cancer (SCAN) is the only validated paediatric, cancer-specific nutrition screening tool available and considers malnutrition risk factors such as weight loss and oral intake as well as cancer-specific factors such as diagnosis, treatment intensity and gastrointestinal symptoms [40]. Implementing SCAN in survivorship clinic appointments will identify CCS at risk of malnutrition; however, it may be limited in identifying other nutrition concerns such as fussy eating or food aversions. Applying additional standardised screening questions to identify these patients will assist in delivering effective and timely nutrition interventions.

This study is the first of its kind in NZ and validates previous findings from international cohorts [17-19]. It considers the experiences of CCS and their families and identifies issues for prioritisation in NZ through using an Implementation Framework [16]. The qualitative study design provided a rich data set that identified gaps in current nutrition care processes and possible solutions for changes in practice. The number of interviews completed is within the range of those reported in the literature [17-19]. Hearing perspectives from Māori, Pacific, and Asian families provides insight into

developing responsive interventions that reflect Manaakitanga (to extend love and compassion to others) and Tikanga (Māori customs) related to healthy kai (food) [41]. Māori representation (21%) in this cohort was comparable to the latest data from The National Child Cancer Network, where 23% of annual cases in 2020 identified as prioritised Māori ethnicity [42].

The study is limited by the sample size and heterogeneity of the CCS sample, as differences in ages, diagnoses, treatment exposures, and family environments led to a variety of perspectives. Additionally, males were under-represented as seen in other cohorts [18, 29], and there was a risk of sampling bias when interviewing CCS and their families. As participation was voluntary, those with strong opinions or distressing experiences with nutrition may have been more likely to agree to participate. Thematic analysis was used to process the interview data. This flexible method of analysis could have led to inconsistencies when pulling data from transcripts and developing themes. However, cross-checking and secondary coding of the manuscripts were conducted to ensure validity in the themes. Finally, due to the local focus of this qualitative research, these conclusions and recommendations may not be generalisable to CCS living outside the catchment area of this oncology service, and other countries.

Conclusion

Despite having an elevated risk of chronic diseases such as MetS and CVD, CCS and their families have minimal opportunity for dietetic support in NZ once active cancer treatment is complete. A stepped-care approach to address the wide variety of needs warrants further investigation and should be coupled with screening questions in survivorship clinics to identify CSS that need support. Evaluation of intervention feasibility within survivorship in NZ is warranted.

Declarations

Data availability

The data generated and analysed in the current study are not publicly available due to regulations provided by the Auckland Health Research Ethics Committee of the University of Auckland to protect data and maintain participants' privacy. The nature of this study was qualitative, meaning that sharing full interview transcripts and initial codes before analysing and emerging main themes is not easy to understand. However, data are available from the corresponding author on reasonable request.

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Competing Interests

The authors have no relevant financial or non-financial interests to disclose.

Author Contributions

ALL, EvdH, and EK contributed to the study's conception and design. Material preparation, data collection and analysis were performed by EC, GP, and ALL. The first draft of the manuscript was written by EC, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Auckland Health Research Ethics Committee (19/03/2021/AH21521). Written informed consent was obtained from all participants. They were reassured about the principle of anonymity, confidentiality, voluntary entry into the study and freedom to withdraw from the study at any time. All methods were carried out per relevant guidelines and regulations.

Consent to Participate

Written informed consent was obtained from all individual participants included in the study.

Consent to Publish

Not applicable

References

1. Ballantine K, the NZCCR Working Group. The incidence of childhood cancer in New Zealand 2010–2014: A report from the New Zealand Children’s Cancer Registry. Auckland: National Child Cancer Network; 2017.
2. Ballantine K, the NZCCR Working Group. Child Cancer Survival in New Zealand 2005–2014: A report from the New Zealand Children’s Cancer Registry. Auckland: National Child Cancer Network; 2017.
3. Cohen J, Collins L, Gregerson L, Chandra J, Cohn RJ (2020) Nutritional concerns of survivors of childhood cancer: A “First World” perspective. *Pediatric Blood & Cancer* 67. <https://doi.org/10.1002/pbc.28193>
4. Ley SH, Hamdy O, Mohan V, Hu FB (2014) Prevention and management of type 2 diabetes: dietary components and nutritional strategies. *The Lancet* 383:1999–2007. [https://doi.org/10.1016/S0140-6736\(14\)60613-9](https://doi.org/10.1016/S0140-6736(14)60613-9)
5. Schwingshackl L, Hoffmann G (2015) Diet quality as assessed by the Healthy Eating Index, the Alternate Healthy Eating Index, the Dietary Approaches to Stop Hypertension score, and health outcomes: a systematic review and meta-analysis of cohort studies. *Journal of the Academy of Nutrition and Dietetics* 115:780–800. <https://doi.org/10.1016/j.jand.2020.08.076>
6. Diakatou V, Vassilakou T (2020) Nutritional Status of Pediatric Cancer Patients at Diagnosis and Correlations with Treatment, Clinical Outcome and the Long-Term Growth and Health of Survivors. *Children* 7. <https://doi.org/10.3390/children7110218>
7. Bauer J, Jürgens H, Frühwald MC (2011) Important aspects of nutrition in children with cancer. *Advances in Nutrition* 2:67–77. <https://doi.org/10.3945/an.110.000141>
8. Aiuppa L, Cartaxo T, Spicer CM, Volberding PA, National Academies of Sciences E, Medicine (2020) Treatment Modalities for Childhood Cancers. *Childhood Cancer and Functional Impacts Across the Care Continuum*, National Academies Press (US), Washington (DC).
9. The Children’s Oncology Group (2011) Treatment Options. The Children’s Oncology Group. <https://www.childrensoncologygroup.org/treatmentoptions>. Accessed: Aug 19 2020.
10. Robien K, Ness KK, Klesges LM, Baker KS, Gurney JG (2008) Poor adherence to dietary guidelines among adult survivors of childhood acute lymphoblastic leukemia. *Journal of Pediatric Hematology/Oncology* 30:815 – 22. <https://doi.org/10.1097/MPH.0b013e31817e4ad9>
11. Smith WA, Li C, Nottage KA, Mulrooney DA, Armstrong GT, Lanctot JQ, et al. (2014) Lifestyle and metabolic syndrome in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort Study. *Cancer* 120:2742–50. <https://doi.org/10.1002/cncr.28670>

12. Lesko L (1989) Psychosocial issues in the diagnosis and management of cancer cachexia and anorexia. *Nutrition* 5:114–6.
13. The Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers USA: The Children's Oncology Group; 2018.
14. Rock CL, Thomson CA, Sullivan KR, Howe CL, Kushi LH, Caan BJ, et al. (2022) American Cancer Society nutrition and physical activity guideline for cancer survivors. *CA: A Cancer Journal for Clinicians* 72:230–62. <https://doi.org/10.3322/caac.21719>
15. Bate P, Robert G (2006) Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *BMJ Quality & Safety* 15:307–10. <https://doi.org/10.1136/qshc.2005.016527>
16. Mitchell SA, Chambers DA (2017) Leveraging implementation science to improve cancer care delivery and patient outcomes. *Journal of Oncology Practice* 13:523–9. <https://doi.org/10.1200/JOP.2017.024729>
17. Pugh G, Hough R, Gravestock H, Haddrell JB, Beeken RJ, Fisher A (2018) The lifestyle information and intervention preferences of teenage and young adult cancer survivors: a qualitative study. *Cancer Nursing* 41:389–98. <https://doi.org/10.1097/NCC.0000000000000508>
18. Cohen J, Wakefield CE, Tapsell LC, Walton K, Fleming CA, Cohn RJ (2015) Exploring the views of parents regarding dietary habits of their young cancer-surviving children. *Supportive Care in Cancer* 23:463–71. <https://doi.org/10.1007/s00520-014-2394-x>
19. Beeken R, Williams K, Wardle J, Croker H (2016) “What about diet?” A qualitative study of cancer survivors' views on diet and cancer and their sources of information. *European Journal of Cancer Care* 25:774–83. <https://doi.org/10.1111/ecc.12529>
20. Pugh G, Petrella A, Pabary A, Cross A, Hough R, Soanes L, et al. (2022) Health Professionals' Views on Lifestyle Advice Delivery to Teenage and Young Adult Cancer Patients: A Qualitative Study. *Cancer Nursing* 45:E238-E45. <https://doi.org/10.1097/NCC.0000000000000906>
21. National Cancer Institute (2015) Survivor. National Cancer Institute Web site. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor>. Accessed: 5 May 2022.
22. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3:77–101. <https://doi.org/10.1191/1478088706qp063oa>
23. Ministry of Health. Food and Nutrition Guidelines for Healthy Children and Young People (Aged 2 – 18 years). Wellington: Ministry of Health; 2012.
24. Iniesta RR, Paciarotti I, Brougham MF, McKenzie JM, Wilson DC (2015) Effects of pediatric cancer and its treatment on nutritional status: a systematic review. *Nutrition reviews* 73:276–95. <https://doi.org/10.1093/nutrit/nuu062>
25. Zhang FF, Rodday AM, Kelly MJ, Must A, MacPherson C, Roberts SB, et al. (2014) Predictors of being overweight or obese in survivors of pediatric acute lymphoblastic leukemia (ALL). *Pediatric Blood & Cancer* 61:1263–9. <https://doi.org/10.1002/pbc.24960>
26. Stern M, Bleck J, Ewing LJ, Davila E, Lynn C, Hale G, et al. (2018) NOURISH-T: targeting caregivers to improve health behaviors in pediatric cancer survivors with obesity. *Pediatric Blood & Cancer* 65. <https://doi.org/10.1002/pbc.26941>
27. Fleming C, Murphy-Alford A, Cohen J, Fleming M, Wakefield C, Naumann F (2021) Poor diet quality and adverse eating behaviours in young survivors of childhood cancer. *Pediatric Blood & Cancer* 69. <https://doi.org/10.1002/pbc.29408>
28. Bernstein IL (1978) Learned taste aversions in children receiving chemotherapy. *Science* 200:1302–3.
29. Fleming CA, Cohen J, Murphy A, Wakefield CE, Cohn RJ, Naumann FL (2015) Parent feeding interactions and practices during childhood cancer treatment. A qualitative investigation. *Appetite* 89:219–25. <https://doi.org/10.1016/j.appet.2014.12.225>

30. Crowley J, Ball L, Hiddink GJ (2019) Nutrition in medical education: a systematic review. *The Lancet Planetary Health* 3:e379-e89. [https://doi.org/10.1016/S2542-5196\(19\)30171-8](https://doi.org/10.1016/S2542-5196(19)30171-8)
31. Cox CL, McLaughlin RA, Rai SN, Steen BD, Hudson MM (2005) Adolescent survivors: a secondary analysis of a clinical trial targeting behavior change. *Pediatric Blood & Cancer* 45:144–54. <https://doi.org/10.1002/pbc.20389>
32. Touyz LM, Cohen J, Garnett SP, Grech AM, Gohil P, Cohn RJ, et al. (2020) Acceptability and feasibility of a parent-targeted dietary intervention in young survivors of childhood cancer: “Reboot”. *Pediatric Blood & Cancer* 67:e28533. <https://doi.org/10.1002/pbc.28533>
33. Richards DA, Bower P, Pagel C, Weaver A, Utley M, Cape J, et al. (2012) Delivering stepped care: an analysis of implementation in routine practice. *Implementation Science* 7:1–11. <https://doi.org/10.1186/1748-5908-7-3>
34. Molassiotis A, Roberts S, Cheng HL, To HK, Ko PS, Lam W, et al. (2018) Partnering with families to promote nutrition in cancer care: feasibility and acceptability of the PlcNIC intervention. *BMC Palliative Care* 17:1–12. <https://doi.org/10.1186/s12904-018-0306-4>.
35. Raber M, Swartz MC, Santa Maria D, O’Connor T, Baranowski T, Li R, et al. (2016) Parental involvement in exercise and diet interventions for childhood cancer survivors: a systematic review. *Pediatric Research* 80:338–46. <https://doi.org/10.1038/pr.2016.84>
36. Touyz L, Cohen J, Wakefield C, Grech A, Garnett S, Gohil P, et al. (2018) Design and rationale for a parent-led intervention to increase fruit and vegetable intake in young childhood cancer survivors (Reboot): protocol for a pilot study. *JMIR Research Protocols* 7. <https://doi.org/10.2196/resprot.9252>
37. Mays D, Black JD, Mosher RB, Heinly A, Shad AT, Tercyak KP (2011) Efficacy of the Survivor Health and Resilience Education (SHARE) program to improve bone health behaviors among adolescent survivors of childhood cancer. *Annals of Behavioral Medicine* 42:91–8. <https://doi.org/10.1007/s12160-011-9261-5>
38. Donze JR, Tercyak KP (2006) The survivor health and resilience education (SHARE) program: Development and evaluation of a health behavior intervention for adolescent survivors of childhood cancer. *Journal of Clinical Psychology in Medical Settings* 13:161–8. <https://doi.org/10.1007/s10880-006-9013-z>
39. Hudson MM, Ness KK, Gurney JG, Mulrooney DA, Chemaitilly W, Krull KR, et al. (2013) Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA* 309:2371–81. <https://doi.org/10.1001/jama.2013.6296>
40. Murphy AJ, White M, Viani K, Mosby TT (2016) Evaluation of the nutrition screening tool for childhood cancer (SCAN). *Clinical Nutrition* 35:219–24. <https://doi.org/10.1016/j.clnu.2015.02.009>
41. Healthy Families New Zealand. National Kai Impact Report: Food System Transformation in Aotearoa. New Zealand: Healthy Families NZ; 2022.
42. National Child Cancer Network. New Zealand Children’s Cancer Registry Snapshot 2020 New Zealand: National Child Cancer Network; 2020.

Figures

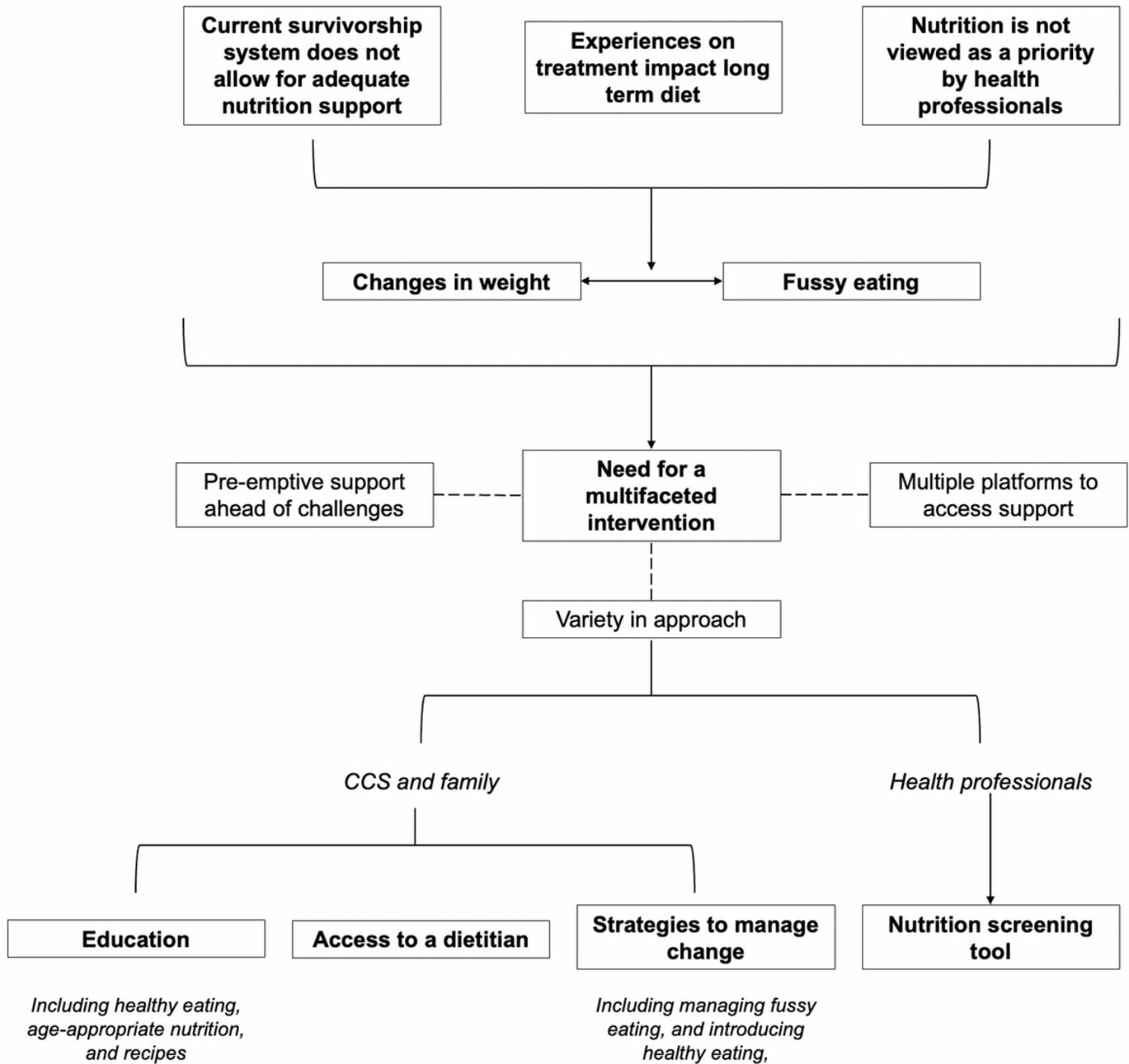


Figure 1

Concept map of emergent themes from interviews with CCS, family members, and health professionals on their experience of nutrition as a supportive care

Supplementary Files

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- [SuppTable1.docx](#)