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Nutrition screening, assessment, and intervention practices for children with cancer in Aotearoa, New Zealand

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ABSTRACT

Objective: The purpose of this study was to investigate dietetic resources and current nutrition screening, assessment, and intervention practices in pediatric oncology centers in Aotearoa, New Zealand.

Methods: A national survey of the two specialist treatment centers and 14 shared care centers that provide care to childhood cancer patients in Aotearoa, New Zealand, was conducted.

Results: The two specialist treatment centers in Aotearoa, New Zealand, were the only centers with a dedicated dietetic oncology full-time equivalent resource; this full-time equivalent resource was devoted to inpatient care. Only 5 shared care centers (44%) had access to general pediatric dietetic support. Dietetic cover for outpatients or day-stay patients and use of standardized nutrition screening and assessment tools were limited. Weight and height were commonly measured, but there was inconsistency in the frequency and recording of measurements. Nutrition interventions, including nutrition education, oral nutrition support, enteral nutrition, and intravenous nutrition, were available within all centers but criteria for initiating support varied. Common barriers to providing nutrition interventions included staff resourcing and ad hoc referral pathways. Awareness of the relevance and clinical benefit of nutrition in pediatric oncology was low. Suggestions to improve nutrition screening, assessment, and intervention within Aotearoa, New Zealand, included the creation of standardized screening and referral criteria.

Conclusions: Resource limitations and lack of nutritional screening and assessment prevent adequate nutritional intervention for children with cancer in Aotearoa, New Zealand. Akin to other high-income countries, there is a need to harmonize the management of nutritional challenges in children with cancer. This study provides a first step in establishing an evidence base to help support efforts to address this need in Aotearoa, New Zealand.

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Introduction

In Aotearoa, New Zealand, 150 children are diagnosed with cancer each year [1]. Child cancer services are delivered via two specialist centers in partnership with pediatricians at 14 regional centers, referred to as Shared Care Centers (SCCs). Specialist treatment centers retain overall responsibility for the cancer treatment plan with certain cancer therapies delivered in the SCC situated in the pediatric department of regional hospitals. This model of child cancer care allows children to receive specialist cancer therapy as close to home as possible and minimizes geographic variability in patient access to clinical services, therapeutic clinical trials, and

supportive care. This model, and continued access to modern therapies via clinical trials networks, has led to successive improvements in childhood cancer survival [1].

However, a large proportion of children diagnosed with cancer in Aotearoa, New Zealand, will suffer malnutrition. In a quality improvement project, involving a retrospective chart review of patients ($n = 66$) entering long-term follow-up between 2018 and 2020 (data not published), the proportion of children undernourished (body mass index [BMI] for age z score ≤ -1.0) rose from 3% at diagnosis to 11% at follow-up post-treatment. The prevalence of overnutrition also increased; at diagnosis 11% of children were classed as overweight or obese (BMI age z score ≥ 2.0) and by the end of treatment the prevalence had risen to 23% (data not displayed). These findings are consistent with other large international studies, which suggest malnutrition (inclusive of

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both over- and undernutrition) is present in $\leq 65\%$ of children diagnosed with cancer [2]. The high prevalence of malnutrition among children with cancer is concerning as there is an accumulating evidence base suggesting that nutritional status has an effect on child cancer outcomes, including overall survival, treatment tolerance, and quality of life [2–4].

There is general consensus that the nutritional status of children with cancer should be continually monitored throughout treatment and that children should have access to dietitians with experience in managing the complex needs of these patients [3,5,6]. However, inconsistencies in the nutrition support available to children with cancer are well documented. A recent study of children, teenagers, and young adults principal treatment centers within the UK found $> 50\%$ of centers had limited access to dietetic resource and that there were variations in the use of nutritional screening tools, anthropometric measures, and general assessment of nutritional status [7]. These findings are similar to earlier work conducted in member institutions of the Children's Oncology Group consortium in 2003; where across institutions, different indices were used to quantify nutrition status, and, when a nutrition intervention was clinically indicated, there was variability in which approach was adopted [8].

In order to inform the development of guidance to harmonize assessment and management of nutritional challenges in children with cancer in Aotearoa, New Zealand, a survey of current practice was conducted. Specifically, this survey sought to determine 1) the availability of dietetic resource (full-time equivalents [FTEs]); 2) the frequency of nutritional screening and anthropometric, biochemistry, and dietary intake assessments; and 3) the types of nutrition interventions offered to patients and their families in specialist treatment centers and SCCs.

Materials and methods

Child cancer in Aotearoa, New Zealand

Care for childhood cancer is coordinated across New Zealand by the National Child Cancer Network. In 2021, the Starship Blood & Cancer Centre (Auckland) treated $\sim 75\%$ of new diagnoses and the Child Haematology and Oncology Centre (Christchurch) treated the remaining 25% [9]. Each child and their family are assigned a clinical nurse specialist who ensures continuity of treatment and communication between the SCC and primary center. There currently are no published national guidelines outlining the recommended FTE resource and dietitian-patient ratios for newly diagnosed childhood cancer patients in New Zealand. This has a significant effect on dietetic FTE across health care localities.

Study design

The content of the previously published cross-sectional survey of practice in the UK [7] was adapted to the New Zealand context, and questions regarding nutrition intervention and complementary and alternative medicine (CAM) were added. The survey was converted to electronic format using Research Electronic Data Capture (REDCap) electronic data capture tools hosted by the University of Auckland [10].

Participants and recruitment

The survey was distributed to the specialist treatment centers and SCCs in Aotearoa, New Zealand. The lead pediatrician, charge nurse, or dietitian involved with these pediatric cancer centers were invited to complete the survey. To capture a consensus of local practice rather than individual opinion, only one representative response was sought from each participating center. All participants provided electronic consent before commencing the online survey on REDCap [10].

Data collection

Respondents were asked to declare the average number of new patients registered each year, the typical age range of patients, and whether their center had the capacity to undertake stem cell transplantation.

To estimate the availability of dietetic resources, respondents were asked to report the FTEs of dietetic positions designated for pediatric oncology and the extent to which routine dietetic input was offered to inpatients, outpatients and day-care patients, and long-term follow-up patients.

Respondents were asked to report whether their center had a local policy relating to nutritional screening, assessment, and intervention. The frequency of nutrition screening and assessment at different points in the cancer continuum (diagnosis, inpatient stays, day clinic appointments, outpatient appointments, and when attending long-term follow-up) were recorded. Respondents were also asked to report the frequency of measuring weight and length/height, the use of validated screening tools, and how often additional anthropometric and nutrition assessment measures, such as micronutrient status (nutritional blood tests), mid-upper arm circumference (MUAC), skinfold thickness, dynamometry, bioelectrical impedance, and other measures of body composition, were collected. Data on the frequency of nutritional intake and estimation of energy expenditure were also collected. Respondents were asked to outline the type of nutrition support available at their center (nutritional counseling or education, oral nutrition support [ONS], enteral nutrition [EN], and intravenous nutrition [IVN]), the clinical indicators used to initiate such interventions in their center, and how the success of such nutrition interventions were monitored. Data on barriers to nutritional screening, assessment, and intervention were also collected alongside data about the extent to which respondents valued nutrition support during treatment, survivorship, and palliative care.

In a 2017 systematic review, $\leq 90\%$ of patients (range 6–91%) used some form of CAM, including dietary supplements, herbal extracts, homeopathy, and water therapy [11]. Globally, data on the widespread use of CAM in pediatric cancer are not well recorded. Attitudes toward and provision of advice about CAM and other practices to improve well-being for Maori patients based on Mataranga Maori (Maori knowledge) or Rongoa Maori (Maori healing) practices were collected.

Statistical analysis

All survey responses were downloaded from REDCap and transferred into statistical package SPSS version 26 (IBM Corp., Armonk, NY, USA). Descriptive statistics were produced to describe the frequency at which each nutritional screening, assessment, and intervention was conducted. Open-response questions were analyzed using the process of content analysis outlined by Elo and Kyngas [12]; a deductive approach to analysis was taken wherein open responses to each question were grouped and content analyzed for emerging patterns and themes.

Results

Characteristics of shared care centers

Responses from all 16 centers were collected (100% response rate); these included the two specialist treatment centers and 14 SCCs across Aotearoa, New Zealand. Responses were received from 10 dietitians, 6 nurses, and 5 pediatricians. Joint responses (where 2 colleagues completed the survey together) were received from 5 centers. Five SCCs did not have a dietitian involved in the care of children with cancer, and the survey was completed by the charge nurse ($n = 1$) or pediatrician ($n = 4$).

The number of new cases seen at each cancer center ranged from 100 (a specialist treatment center) to 2 (an SCC). Bone marrow transplants were performed at the two specialist treatment centers only. There was substantial variation in the age range of patients cared for by each center. Most centers ($n = 10$; 63%) stated their upper age range as 16 y, five (31%) as 18 y, and one (6%) as 25 y.

Dietetic resources

Only one of the specialist treatment centers had 1.0 FTE dedicated to pediatric oncology. The two specialist centers reported the highest number of annual cancer diagnoses and are the only centers undertaking bone marrow transplant in Aotearoa, New Zealand. Eleven out of 14 SCCs (79%) reported not having any dedicated dietetic resource available for pediatric oncology. Nine SCCs (64%) had pediatric dietitian FTEs; however, this was spread across all pediatric specialties at their center, with no dedicated FTE to the oncology service.

Three centers (19%; one specialist treatment center and two SCCs) reported having full inpatient cover for the number of childhood cancer patients seen at their center; however, there was significant variation in the total number of patients at each of these centers for relatively similar FTE. Of those that indicated partial cover, nine SCCs (69%) commented that this cover was not specific to pediatric oncology and patients were seen if expressly referred to the pediatric dietetic service. One center (6%) reported only reviewing patients that were being enterally fed. Fourteen centers (88%), including the two specialist treatment centers, reported partial cover in outpatients or day-stay patients, with similar absorption of caseloads into general pediatric dietetic care in SCCs. One of the two specialist treatment centers was only able to review outpatients or day-stay patients acutely with no ability for regular follow-up, despite having the largest FTE. Thirteen (81%) centers (including the two specialist treatment centers) did not have any dietetic support in survivorship or late effects assessment programs, and the remaining three (19%) centers did not know whether any dietetic support was provided in these clinics. Six centers (38%) reported adequate staffing to manage their current caseload of oncology inpatients, and four (25%) reported adequate staffing in outpatients or day-stay patients.

Challenges associated with providing nutrition support to this patient group included high caseloads in other areas, reliance on ad hoc referrals, and inability to provide community care for patients when at home, and some lack of awareness of children in their SCC receiving or requiring nutrition support.

Screening tools

Only three centers, one specialist treatment center and two SCC (19%), confirmed that a nutrition screening tool was used for pediatric oncology inpatients with varying consistency. These tools were STRONGkids [13] and the pediatric nutrition screening tool [14]. Both centers agreed that screening should be completed at diagnosis or admission and weekly after that. Two SCCs (13%) reported having tried to implement a screening tool; however,

there was poor uptake, usually related to insufficient staff resourcing or support from nursing staff. One center reported that they had not been able to find a suitable tool, and another center reported the use of screening for all pediatric patients, however not with a specific or validated tool. No centers used screening tools in outpatient or day-stay units, with common reasons including lack of available staff and inadequate dietetic time to implement successfully.

Center-specific nutrition policies and training

Ten centers (63%) had local policies for taking anthropometric measures, such as height and weight. Three centers stated they had a hospital policy for screening, and no centers reported having a policy for formal nutrition assessment. The majority ($n = 10$; 63%) of centers reported staff receiving training for taking height and weight measurements and plotting these on the growth chart centiles. Training for nutrition screening and other methods of assessing nutritional status were variable, with six (38%) centers reporting no training for staff on nutrition screening.

Nutrition assessment

Weight and height

The frequency and settings of weight and height measurements are displayed in Table 1. Weight was the most frequently recorded (i.e., > 75% of patients) across all time points, with 88% ($n = 14$) of centers taking a weight measurement at diagnosis and inpatient admissions, 81% ($n = 13$) in day-stay, 94% in clinic ($n = 15$), and 75% ($n = 12$) at long-term follow-up appointments. Four centers (25%) reported not knowing whether weight or height were recorded at long-term follow-up clinic appointments. Nurses most frequently took weight ($n = 14$ [88%]) and height ($n = 15$ [94%]) measurements. Recording methods varied, with most centers ($n = 12$ [75%]) recording weight and height on patient paper notes and electronic records. Free text comments included reference to standard practice of measuring weight twice weekly and height monthly.

Table 1

Frequency of anthropometric measures and dietary intake assessment reported by pediatric oncology centers across Aotearoa, New Zealand

Proportion of patients	Majority (>75%) of patients		Most (50–75%) patients		Some (25–50%) patients		Few (<25%) patients		Never		Do not know	
<i>n</i> (%) of centers recording weight and height												
	Height	weight	Height	Weight	Height	Weight	Height	Weight	Height	Weight	Height	Weight
Diagnosis	14 (88)	10 (63)	2 (13)	5 (31)	0	0	0	1 (6)	0	0	0	0
Inpatient admission	14 (88)	5 (31)	1 (6)	4 (25)	1 (6)	2 (13)	0	5 (31)	0	0	0	0
Day-stay	13 (81)	4 (25)	3 (19)	7 (44)	0	1 (6)	0	4 (25)	0	0	0	0
Clinic	15 (94)	4 (25)	1 (6)	7 (44)	0	1 (6)	0	4 (25)	0	0	0	0
Long-term follow up	12 (75)	12 (75)	0	0	0	0	0	0	0	0	4 (25)	4 (25)
<i>n</i> (%) of centers recording nutritional status												
Weight and height on centiles	12 (73)	3 (19)	0	1 (6)	0	0						
Weight and height, %	9 (56)	2 (13)	1 (6)	2 (13)	0	2 (13)						
Weight loss from diagnosis, %	3 (19)	2 (13)	3 (19)	5 (31)	2 (13)	1 (6)						
BMI	11 (69)	2 (13)	0	1 (6)	1 (6)	1 (6)						
Weight z scores	8 (50)	2 (13)	1 (6)	2 (13)	2 (13)	1 (6)						
<i>n</i> (%) of centers recording anthropometric measures												
Mid-upper arm circumference	0	0	1 (6)	5 (31)	9 (56)	1 (6)						
Triceps skin-fold thickness	0	0	0	2 (13)	12 (75)	2 (13)						
Hand grip strength	0	0	0	1 (6)	14 (88)	1 (6)						
Bioelectrical impedance	0	0	0	1 (6)	14 (88)	1 (6)						
<i>n</i> (%) of centers recording anthropometric measures												
Diet history	8 (50)	1 (6)	1 (6)	6 (38)	0	0						
Food record	1 (6)	5 (31)	4 (25)	6 (38)	0	0						
Food diary	0	1 (6)	1 (6)	10 (63)	0	1 (6)						
Food and symptom diary	0	0	4 (25)	8 (50)	6 (19)	1 (6)						
24-h recall	4 (25)	1 (6)	4 (25)	4 (25)	1 (6)	2 (13)						
Weight food record	0	0	0	0	15 (94)	1 (6)						

Most centers used weight and height measurements to plot growth on a growth chart or percentile in > 75% of patients (Table 1). Variation in electronic growth charts was recorded across all centers, with some centers reporting that these were difficult to integrate with the patient management system or did not display z scores. Monitoring change through calculating percent weight loss was performed in 50% of patients only. Weight SDs (z scores) were determined in > 75% patients, as was BMI. A mixture of equipment shortages, lack of training, and low confidence was cited when calculating percent weight/height or weight z scores.

Other anthropometric measurements

Centers were asked about other methods of measuring anthropometry or body composition (Table 1). Thirty-one percent of centers ($n = 5$) reported taking MUAC measures in < 25% of patients, with free text comments indicating the potential for implementation after a recent professional development session on use of MUAC in clinical settings. Other measures of muscle mass or body composition, such as triceps skinfold thickness, handgrip strength, and bioelectrical impedance, were not performed in any centers, usually due to a lack of equipment and staff training.

Biochemical parameters

Nutritional blood tests, outside of those included in a full blood cell count or urea and electrolytes, are not routinely measured. Albumin and transferrin were reported as “sometimes” useful in the nutrition assessment (75% and 63%, respectively). Eighty-eight percent of centers stated that they were able to assess micronutrients in situations, such as prolonged IVN, long-term EN support, significant losses (through vomiting or diarrhea), nutrients at risk after dietary assessment, or faltering growth. No centers reported having specific policies for measuring nutritional blood tests.

Dietary intake, estimated expenditure, and requirements

The most common method of assessing dietary intake was a diet history, with > 75% of patients receiving this assessment method by 50% of centers (Table 1). Other methods of dietary assessment, such as nurse-completed food charts, food diaries, food-symptom diaries, and 24-h recalls, were used to varying degrees across centers. Weighed food records were never used.

No centers measured energy expenditure due to a lack of equipment. Estimated energy requirements were calculated in > 80% of centers, using predictive calculations, such as the Schofield equation for age and sex [15], with appropriate application of a disease factor.

Nutrition interventions

Only 56% ($n = 9$) of centers viewed nutrition interventions as a fundamental element of the treatment plan, with 38% ($n = 6$) centers acknowledging their relevance but reporting that they are performed only occasionally. Criteria for initiating a nutrition intervention ranged from 5% to 10% weight loss, crossing two centiles on the growth chart, and less than tenth centile weight for height or age. One center used the Children’s Oncology Group nutrition intervention algorithm to make clinical decisions on nutrition support [16].

All centers offered the spectrum of nutrition interventions, ranging from nutrition education to ONS to EN and to IVN. Indications for ONS included 5% weight loss, refusal of EN, < 70% estimated energy intake, and predicted quick recovery of appetite after treatment. Common criteria for EN included < 50% estimated energy intake, malnutrition diagnosis, and > 10% weight loss. Three SCCs (19%) reported that they did not make decisions on EN

and that these decisions were led by specialist treatment centers. Free text comments highlighted that patients often return to SCCs with a nasogastric tube in situ after an admission at a specialist treatment center. Criteria for IVN included contraindication of EN, intestinal dysfunction, mucositis, postoperative or post-bone marrow transplant management, or malnutrition. Centers outside of the two specialist treatment centers reported liaising with the lead dietitian for support. Tracking success of nutrition interventions was commonly achieved by improvements in oral intake, anthropometry, or biochemical measures. Open responses indicated that provision of nutrition interventions was commonly limited by staff resourcing and inconsistent referrals.

There was significant variation in the attitudes toward the importance of nutrition support during treatment, survivorship, and palliative care. More than 40% of centers valued nutrition support “a lot” during treatment, survivorship, and palliative care. Suggestions for improving the awareness of the clinical effect of malnutrition included increasing knowledge on the topic, New Zealand-specific research, and the creation of protocols and referral pathways. Free text comments highlighted variation in hand-over to smaller centers and significant limitations in practice due to a lack of specialized oncology FTE available for outpatient services.

Complementary and alternative medicine

Over half of the centers (56%) reported that their center provided support for CAM where appropriate and not in conflict with medical advice. Seven centers “somewhat” valued the role of CAM in pediatric oncology. Only one SCC (6%) reported that Matauranga Maori (Maori knowledge) and Rongoa Maori (Maori healing) expertise were available to provide whanau (family) with dietary support or nutrition information at one of the two specialist treatment centers. This support was available to whanau (family) by request only and no specifics were provided by respondents.

Discussion

It is well recognized that children with cancer should have access to nutrition care across the cancer continuum through, diagnosis, treatment, and follow-up and palliative care [5,17]. This study presents data suggesting in Aotearoa, New Zealand, the availability of dietetic support in pediatric oncology is limited and highly variable between centers.

Nutrition assessment and screening are required to identify patients at risk of nutritional deficit. Several international consensus statements recommend nutrition screening and assessment using standardized methods be performed on all children with cancer at diagnosis, periodically throughout treatment, and at follow-up [18,19]. Within this study, it was apparent that the use of nutritional screening tools is limited mainly to specialist treatment centers. Weight and height measurements were the most common nutrition assessments conducted; however, there was inconsistency in the frequency of measurement and recording methods between centers. There was also variation in the use of centile charts. Limited use of other forms of nutrition assessment such as MUAC, dynamometry, bioelectrical impedance, and dietary intake assessment, was also common. These findings reflect previous cross-sectional surveys of nutrition screening and assessment practices within both pediatric and adult oncology settings [4,18,20]. Barriers to nutritional screening and assessment included lack of trained staff and both inadequate knowledge and resourcing to initiate an intervention if screening or assessment indicated action would be appropriate.

Nutrition interventions, including nutrition education, ONS, EN, and IVN, were available within all centers, but criteria for initiating support varied. Common barriers to providing nutrition interventions included staff resourcing and ad hoc referral pathways. Clinical practice guidelines on the nutrition management of a child with cancer have been produced; however, there is inconsistent use of criteria in institutions [20,21]. For children with cancer who are adequately nourished, can maintain a stable weight, and are consuming 50% of recommended nutritional intake orally, nutritional counseling is considered sufficient. There is a general consensus that EN should be initiated for children who are unable to meet 50% of their daily energy requirements orally, have > 5% weight loss since diagnosis, or are severely malnourished as indicated by a BMI for age or MUAC score below the fifth percentile or a BMI z score < -1. When EN is not feasible or inadequate, for example, in the presence of severe malabsorption or intractable vomiting, IVN is recommended [22]. This present study has highlighted a need for Aotearoa, New Zealand-specific standards of care regarding the initiation and use of nutrition interventions in pediatric cancer patients. Standards of care should include screening criteria and clear referral pathways. However, such guidelines must be developed collaboratively between centers and ensure screening, and intervention recommendations are feasible within practice given staffing constraints [23].

Approximately half of the centers surveyed indicated that nutritional approaches to CAM were supported when not in conflict with medical advice. Although use of natural health products, such as plant-derived bioactive compounds, and alternative diets, such as ketogenic or calorie restriction, is common in cancer patients, there is no high-quality evidence to indicate benefit for pediatric cancer outcomes [24,25]. Notably, there is little evidence of the benefit of restrictive neutropenic diets and caution of the risk of restrictive neutropenic diets leading to inadequate food intake is counseled [19,26]. However, the holistic and supportive care benefit of CAM nutrition approaches is well recognized. Although no formal guidance about CAM nutrition is available in pediatric oncology, careful collaborative discussion between health professionals and families is encouraged [24,27]. Specific to Aotearoa, New Zealand, is Rongoa Maori, the traditional Maori healing system consisting of herbal remedies, physical therapies, and spiritual healing [28]. This study indicated that, representative of most settings across the country, access to Rongoa Maori was limited. Substantial health reforms are underway within Aotearoa, New Zealand [29], and pathways to provide more accessible and culturally acceptable services (including dietetic support) designed for Maori and by Maori, are being established.

The limited availability of screening, assessment, and intervention in Aotearoa, New Zealand, can largely be explained by the limited dietetic resource available to support patients. The two specialist treatment centers were the only centers with dedicated FTEs to inpatient pediatric oncology. Nine SCCs reported available coverage if requested from dietitians within general pediatrics and 11 SCCs reported having no dietetic resource available for pediatric oncology patients. No centers had dietetic resource to support long-term follow-up or survivorship. The lack of available dietetic resource within Aotearoa, New Zealand, is concerning given the high prevalence of malnutrition in children during and after treatment (quality improvement project, data not shown). Practical recommendations for expanding dietetic support available within pediatric oncology have previously been published [23,30]. Recommendations include raising awareness of the value of nutrition within pediatric oncology and advocating for additional staffing (particularly in outpatient, long-term follow-up, and survivorship settings) through research studies and quality

improvement initiatives. Research improvement and quality initiatives could include implementation of nutrition screening and referral pathways or nutrition interventions. Often health professionals are required to undertake such projects as part of formal training or career development; incorporating nutrition into such projects is likely to increase buy-in from clinicians, improve early identification of malnutrition, and generate subsequent referrals for support.

Strengths and limitations

This survey study provides a cross-sectional insight on the current nutrition support available to children with cancer in Aotearoa, New Zealand. Similar to other surveys of practice, the primary limitations of this study are the sample size and generalizability of the results to other countries. However, a 100% response rate was achieved and a thorough insight on nutrition screening, assessment, and intervention gained. Future studies should aim to investigate patient load (inclusive of patients receiving outpatient and follow-up care) relative to dietetic FTEs available to establish care acuity.

Conclusions

It is widely recognized that there is a need for harmonized assessment and management of nutritional challenges in children with cancer. This study provides a first step in establishing an evidence base to help support efforts to standardize nutrition screening, assessment, and intervention practices for children with cancer in Aotearoa, New Zealand.

Declaration of Competing Interest

None.

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