

Cancer-malnutrition care beyond the hospital walls: a survey of nutrition governance, practice, knowledge and education needs in the primary care and community sector

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Abstract

Purpose: Cancer-related malnutrition remains a prevalent issue in cancer survivorship. This study aimed to understand cancer-related malnutrition practice, knowledge and education needs in the primary care and community sectors, as well as the transition of nutrition care from hospital cancer services following cancer treatment.

Methods: A cross-sectional survey was conducted with general practitioners (GPs), general practice nurses (GPNs) and dietitians in hospital cancer services, community services and primary care in Victoria, Australia.

Results: The 184 respondents represented dietitians (n=152), GPs (n=22) and GPNs (n=10). GPs and GPNs, and dietitians working in primary care and community settings (78% and 63%, respectively) agree cancer malnutrition is going unrecognised in their service. Only 26% of community health services complete malnutrition risk screening and 35% of GPs and GPNs frequently weigh their patients with cancer. Most GPs and GPNs (88%) believe responsibility for malnutrition risk screening should be shared across disciplines and 94% would like access to a malnutrition screening tool. Only 32% of hospital oncology dietitians and 44% of GPs and GPNs frequently refer their patients to primary care or community dietitians.

Conclusion: Implementation of routine malnutrition risk screening in primary care and community services and improved transition of nutrition care between hospital, primary care and community practitioners is required. Targeted cancer malnutrition education and resources across all health sectors is warranted.

Implications for cancer survivors: Barriers to identification and management of cancer-related malnutrition in primary and community care should be addressed to improve transition of care.

Introduction

Malnutrition remains a prevalent issue for people with cancer and commonly leads to poor clinical outcomes [1]. Cancer-related malnutrition is associated with reduced treatment tolerance, increased morbidity and mortality, reduced survival and higher healthcare costs [2–5]. There is a growing body of literature and evidence-based guidelines describing best-practice nutrition care of patients with cancer [6–12]. Guidelines highlight the importance of malnutrition risk screening, early assessment and treatment with medical nutrition therapy, to help prevent and manage malnutrition and enhance the quality of life and outcomes of people with cancer [6–12]. Current guidelines primarily focus on nutrition care delivered in the acute hospital setting, with little guidance on strategies to manage malnutrition in the cancer survivorship phase. Evidence suggests the cost of managing malnourished patients in the community is more than twice that of managing well-nourished patients [13], supporting the need to better understand cancer-malnutrition care beyond the hospital walls.

Evidence-based guidelines for managing malnutrition in the general patient population recommend routine screening for malnutrition should occur in the rehabilitation, primary care and community settings to improve the identification of malnutrition risk and enable timely nutrition care planning [14–17]. Several of these guidelines focus on defining the roles of health professionals such as general practitioners (GPs), primary care nurses and dietitians in managing malnutrition in the community setting [15–17]. They emphasize the important role of the GP, primary care nurse and community-based allied health clinicians in screening for malnutrition risk and referring patients at risk of malnutrition to a dietitian [15–17]. A Canadian toolkit designed to detect, monitor, and treat malnutrition in the acute hospital setting also emphasizes the importance of discharge planning and referral of malnourished patients to community based clinicians on discharge from hospital [18].

The number of people surviving cancer is increasing and acute oncology services are finding it more and more difficult to provide high quality follow up care to all cancer survivors [19]. This has led to a growing need to manage the survivorship care needs of patients in the community. The transfer of nutrition care into primary care and community services is an essential step in improving and facilitating the continuity of care after completion of cancer treatment [20]. The use of survivorship or shared care plans has been suggested as a means of achieving this transfer of care. Survivorship care plans have been shown to facilitate access to knowledge about survivors' cancer history, recommended surveillance and potential late and long-term effects for primary care practitioners [21–22]. Practices relating to the transfer of nutrition care from hospital cancer services to primary care and community services should be determined to help inform targeted service improvements and/or further research.

In Australia, governance of nutrition care practices in the primary care and community setting is complicated with five national quality standards covering different segments of this sector [23–27]. Whilst the recently released National Safety and Quality in Primary and Community Healthcare standards support the need for regular risk screening [27], only the National Safety and Quality in Health Services (NSQHS) standards contain a specific nutrition standard [23]. The NSQHS nutrition and hydration standard outlines the importance of regular malnutrition risk screening, nutrition assessment and monitoring for those at risk [23] and applies to community rehabilitation centres and community health centres integrated within a health service. There are no national standards providing guidance on nutrition care that cover stand-alone community health centres, general practice or private practice services. Good nutrition governance is essential to ensure quality evidence-based nutrition care across the healthcare continuum; however, nutrition governance practices in the primary care and community sector are currently not well understood.

Effective reduction of the burden of cancer-related malnutrition in the community requires a focus beyond hospital cancer services. The primary aim of this study was to understand cancer-related malnutrition governance and management, and health professional knowledge and education needs in the primary care and community sectors. The secondary aim was to understand the current process for transition of nutrition care from hospital cancer services to primary care and community services.

Methods

Study design and setting:

Two cross-sectional surveys were completed; the first involving hospital, community and private practice dietitians between March 2018 and April 2018 and the second involving GPs and general practice nurses (GPNs) between March 2018 and May 2018. Eligible participants included dietitians, GPs and GPNs who work with adults with cancer in a Victorian healthcare setting and were over 18 years of age.

A link to the 24-item online dietitian survey in Survey Monkey™ was circulated via email invitation to a sample of dietitians identified through the Dietitians Association of Australia and Victorian Department of Health and Human Services service directories and professional networks of the researchers. A snowball approach was utilised whereby dietitians were encouraged to forward on the survey link to colleagues meeting the selection criteria. A link to the 14-item online GP and GPN survey was circulated through relevant key stakeholder groups including: Victorian Primary Health Networks; the Australian Practice Nurse Association; the Victorian Faculty of the Royal Australian College of General Practitioners; the Primary Care Collaborative Cancer Clinical Trials Group; the Victorian Primary Care Practice-based Research Network; Peter MacCallum Cancer Centre GP placement program and Peter MacCallum Cancer Centre and Eastern Health GP liaison officers. Hard-copy questionnaires were also distributed to GPs and GPNs attending relevant GP and GPN forums. Participants received an incentive to complete the GP and GPN survey (to enter a prize draw for AUD\$100 gift voucher) with the aim to increase participation. Ethical approval was obtained from the Peter MacCallum Cancer Centre Human Research Ethics Committee (Ref: LNR/18/PMCC/24) prior to data collection. Informed consent was obtained through a participant information sheet in Survey Monkey™ for surveys completed online and in written form for surveys completed in person, prior to commencing the survey.

Survey design:

The purpose designed online surveys were developed by the project team and steering committee, who comprised of clinical and research dietitians with a minimum of 10 years' experience, clinicians working in cancer survivorship, GPs and GPNs. The 24-item dietitian survey included questions on participant demographics, as well as questions relating to nutrition care governance and practices, cancer malnutrition knowledge and education needs for primary care and community dietitians; and transition of nutrition care for hospital dietitians including barriers to referring to dietitians in the primary care and community sectors (Supplementary File 1). The 14-item GP and GPN survey included questions relating to participant demographics, nutrition care practices including malnutrition risk screening and barriers to referring patients to a dietitian and cancer malnutrition knowledge and education needs (Supplementary File 2). The surveys were piloted by members of the project team and steering committee to test face validity to ensure readability and clarity of content and structure.

Frequency of nutrition care practices such as weighing patients, calculating body mass index, asking about recent weight loss, referral to a dietitian, providing a discharge summary to patients' GP were

assessed on a 5-point Likert scale (1 = always, 2 = very often 3 = sometimes, 4 = rarely, 5 = never). Knowledge of cancer malnutrition was assessed on a 5-point Likert scale (1 = extremely good, 2 = very good, 3 = good, 4 = moderate, 5 = poor). Where participants were asked which tools for malnutrition screening or diagnosis they used or if they had used existing cancer malnutrition resources, potential responses were identified by the project team and listed as multiple choice options.

Data Analysis:

Data analysis was conducted using Microsoft Excel. Demographics and questions relating to cancer malnutrition governance, practice and use of existing cancer malnutrition education resources were summarized using descriptive statistics. Location of dietitian work place was categorized according to the Accessibility/Remoteness Index of Australia (ARIA+) into major city, inner regional, outer regional, remote, very remote [28]. Likert-scale questions pertaining to frequency were dichotomised and recoded into a binary variable (frequent or not frequent). Frequent included very often and always responses. Not frequent included sometimes, rarely and never responses. Similarly, Likert-scale questions relating to knowledge were dichotomised into a binary variable of good or poor. Good included good, very good and extremely good responses. Poor included poor and moderate responses. Thematic analysis was applied to open-ended questions and comments to identify key themes in responses.

Results

Participant Characteristics

A total of 162 dietitians, 22 GPs and 10 GPNs responded to the surveys. Ten dietitian surveys were incomplete and therefore excluded from analysis, leaving a final sample of 152 dietitians (Table 1). The majority of dietitians worked in the hospital setting ($n = 98$, 64%), in major city locations ($n = 86$, 52%) and had been practicing as a dietitian for less than 10 years ($n = 94$, 62%). GP and GPN respondents represented all six Victorian Primary Health Networks (PHN), with 60% working in a metropolitan setting.

Table 1
Demographic characteristics of survey participants (n = 184)

Characteristics	No. (%)
General Practitioner & General Practice Nurse survey participants	(n = 32)
Profession	
General Practitioner	22 (69)
General Practice Nurse	10 (31)
Primary Health Network	
Eastern Melbourne (metropolitan)	4 (13)
North West Melbourne (metropolitan)	9 (28)
South West Melbourne (metropolitan)	6 (19)
Gippsland (regional)	2 (6)
Murray (regional)	3 (9)
Western Victoria (regional)	8 (25)
Dietitian survey participants	(n = 152)
Practice setting ^a	
Hospital oncology dietitian	98 (64)
Community health centre	59 (36)
Community rehabilitation	25 (16)
Private practice	30 (20)
Work across both acute and primary care/community	39 (26)
Location ^b	
Major city	86 (52)
Inner regional/Outer regional/Remote	79 (48)
Years of Practice (years)	
0–10	94 (62)
11–20	30 (20)
21–30	21 (14)
≥31	7 (5)

<i>Characteristics</i>	<i>No. (%)</i>
^a multiple responses allowed	
^b location of work place categorized according to the Accessibility/ Remoteness Index of Australia (ARIA+) into major city, inner regional, outer regional, remote, very remote	

Transition of nutrition care to primary care and community sectors

Only 32% of hospital oncology dietitians reported they frequently refer to dietitians in the primary care or community sector. When referrals are made, respondents reported they most commonly refer to dietitians working in community health (81%) and community rehabilitation (45%). Twenty six percent reported referring to dietitians in other hospital settings such as oncology day clinics, outpatient clinics, and inpatient rehabilitation. The most common barrier cited for not referring patients to dietitians working in primary care and community sectors was follow-up care is provided in hospital outpatient clinics or via phone consultation (Table 2).

Table 2

Barriers identified by dietitians to the transition of nutrition care from acute hospital to the primary care and community sector ranked by frequency of reporting

<i>Barriers^a</i>	<i>Rank (%)</i>
Patients in my health service are followed up in hospital outpatients	1 (54)
Patients continue to receive phone reviews until stable	2 (49)
Complex care needs of patients	3 (38)
Time/resources required to make referral	4 (28)
Long wait list for community dietitian	5 (22)
Don't know where to refer	6 (18)
Cost	7 (15)
Patients do not require ongoing dietetic care	8 (14)

^a multiple responses allowed

The majority of hospital oncology dietitians (54%) were aware of existing cancer rehabilitation programs in Victoria; however, referral to these programs was low. Nearly all (96%) respondents reported they would like more information about cancer rehabilitation programs.

Only ten percent of hospital oncology dietitians reported they frequently provide a discharge summary to a patient's GP on discharge. Analysis of open-ended responses regarding reasons for not providing a discharge summary highlighted lack of time or resources (45%), not part of standard practice (22%), and discharge summary provided by medical team (16%) as common themes.

Nutrition governance in primary care and community sectors

GPs and GPNs

The vast majority of respondents (88%) indicated GPs should have primary responsibility for malnutrition risk screening in people with cancer. Although, a high proportion of respondents also indicated oncologists (75%) and hospital oncology dietitians (63%) should bear responsibility for malnutrition risk screening. Open-ended responses regarding responsibility for malnutrition risk screening revealed that respondents felt responsibility should be shared across disciplines and that GPs do not feel included as part of the cancer care team.

Primary care and community dietitians

The majority (70%) of dietitians working in primary and community care agreed their health service complies with national performance standards for accreditation. Seven performance standards applying to the primary care and community sectors were identified, with the NSQHS standards the most commonly cited. Twenty percent of dietitians from community health, community rehabilitation and private practice settings were unsure if their health service complied with national performance standards. Of the 10 per cent of respondents who felt their service does not comply, the majority worked in private practice where there is no formal accreditation process.

Nutrition care practices in primary care and community sectors

GPs and GPNs

To screen for malnutrition risk, respondents frequently ask patients about appetite (74%) and recent weight loss (66%), but less frequently weigh the patient (34%) or calculate their body mass index (31%). The majority of GPs and GPNs (78%) agreed there are patients with cancer malnutrition going unrecognised in their practice. Reasons cited included time constraints and patients are missed as they move between health care providers. Whilst almost all (94%) respondents agreed having access to a malnutrition screening tool for all patients (not just cancer patients) would be beneficial, they indicated any tool should be quick and easy to administer.

Approximately half (44%) of the GP and GPN survey respondents frequently refer patients to a dietitian, with limited availability and cost to the patient being the most common barriers (Table 3). Whilst 44% of respondents reported they frequently complete a chronic disease management (CDM) plan for patients

with cancer, only one-third (34%) of respondents reported these CDM plans frequently include a team care arrangement with a dietitian.

Table 3
Barriers to Victorian GPs and GPNs referring their patients to a Dietitian ranked by frequency of reporting

Barriers^a	Rank (%)
Limited availability / wait times	1 (44)
Cost	2 (32)
Patient receptiveness to see a dietitian	3 (24)
GP does not think to refer	4 (4)
Time required to make referral	4 (4)
Unclear of dietitian role in cancer care	4 (4)
Expectation patients are managed by acute team	4 (4)

^a multiple responses allowed

Primary care and community dietitians

Routine malnutrition screening in the primary care and community sectors was low, with only 44% of respondents agreeing their service routinely screens every new patient for malnutrition risk. When responses were analysed by sector, routine malnutrition screening was lowest in community health (26%) and higher in community rehabilitation (60%) and private practice (71%). Respondents commented that despite the inclusion of malnutrition risk screening in intake forms or common risk assessments, completion rates and accuracy of completion are poor. Two-thirds (63%) of primary care and community dietitians agreed there are patients with cancer malnutrition going unrecognised in their health service.

Of those respondents whose health service had routine malnutrition screening in place, 71% reported their service uses a validated screening tool, with 82% citing the Malnutrition Screening Tool (MST). Almost all services that did not use a malnutrition screening tool reported their service uses the following prompts within an integrated risk assessment: unintentional weight loss; reduced food and fluid intake; reduced appetite; obvious underweight/frailty. Respondents reported predominantly using clinical judgement (66%) to diagnose malnutrition. Validated diagnostic tools such as the Subjective Global Assessment (SGA) and Mini Nutrition Assessment (MNA) ranked second and third (52% and 22% respectively), whereas diagnostic criteria such as the International Classification of Disease-10 (ICD-10) and European Society of Parenteral and Enteral Nutrition were less common (11% and 1% respectively).

Cancer malnutrition knowledge

Knowledge of cancer malnutrition was low amongst GPs and GPNs with 75% of respondents rating their knowledge as poor.

Cancer malnutrition education needs

Awareness of existing cancer malnutrition resources was high for primary care and community dietitians (76%), but low for GPs and GPNs (16%). Evidence based guidelines and published literature were the resources most commonly used by both professional groups. The majority of GPs and GPNs (91%) and dietitians (73%) reported they would like additional cancer malnutrition education resources. The preferred format of education resources were webinars (69%) for dietitians, hard-copy resource for GPs and GPNs (53%) and e-learning modules (60%) were popular for all professional groups.

Discussion

To our knowledge, this is the first study to explore cancer-related malnutrition governance and management, health professional knowledge and education needs relating to cancer malnutrition in the Australian primary care and community sector. This study revealed that screening for malnutrition risk using a validated screening tool is not routinely conducted in general practice and community health centres. The majority of GPs, GPNs and dietitians working in primary care and community settings agreed that patients with cancer-related malnutrition were going unrecognised in their service. We found that for sectors such as community rehabilitation, in which nutrition governance standards are in place, reported compliance with these standards was good. The addition of nutrition standards outlining the importance of malnutrition screening at regular intervals and early referral to a dietitian to existing quality standards is an avenue to support improved adherence to malnutrition screening in the primary care and community sector.

The majority of GPs and GPNs in this study reported they would like access to a validated malnutrition screening tool and overwhelmingly agreed that responsibility for malnutrition risk screening should be shared across disciplines. These results are supported by a previous Australian study indicating that the majority of GPs perceive their role to include the assessment of malnutrition risk [29] and a recent survey of cancer clinicians which reported a strong perception of responsibility across multidisciplinary clinicians for recognising malnutrition and initiating appropriate management [30]. This perception of shared responsibility aligns strongly with a position statement on cancer malnutrition and sarcopenia, which emphasises that a broad range of health professionals across the multidisciplinary team should have the skills and confidence to recognise cancer-related malnutrition and facilitate timely referrals and treatment [11]. Further work is required to increase GP and GPN knowledge of and access to valid and reliable malnutrition screening tools and identification of enablers to translate this into effective nutrition care for patients.

GPs surveyed in this study reported low levels of referrals to primary care and community-based dietitians, with limited availability, wait times and cost to the patient identified as key barriers. These findings align with previous research exploring how GPs refer to dietitians in both general [31] and

diabetic patient populations [32], where limited availability, long wait lists and cost to the patient were also cited as barriers to dietitian referral. GPs should be supported with information on referral pathways to dietitians working in community health centres (where fees are means tested) [33] and encouraged to utilise chronic disease management plans, incorporating a GP management plan or team care arrangement with private dietitians [34] as a means of reducing the financial barriers and wait times associated with accessing a dietitian.

This study also found the transition of nutrition care from the hospital sector to primary and community care following cancer treatment was poor. The reasons underpinning this are multifactorial and include lack of provision of a nutrition care plan to GPs at the completion of treatment, ongoing care provided in the acute hospital and complex care needs of some patients that may be better suited to the acute hospital environment. Strategies that dietitians could be encouraged to use that have previously proven beneficial to assist this transition of care include enhanced multidisciplinary discharge summary templates, transfer of care letter templates and the use of survivorship care plans [21, 35, 36]. Rather than providing ongoing nutrition care in the outpatient setting, hospital dietitians should give early consideration during or immediately after cancer treatment to referral of appropriate patients into the primary care and community sectors for nutrition care and rehabilitation. Stratified cancer follow-up care pathways depending on the patient's specific needs have been suggested as a means of reducing the burden on acute cancer services [37]. Patients with lower nutrition risk could be supported to self-manage their nutrition needs; intermediate risk patients could be supported utilizing models of shared care between hospital and community practitioners [21, 35, 37]; whilst patients with complex care needs continue to be managed by specialist oncology dietitians [37].

GPs and GPNs participating in this study reported poor knowledge of cancer malnutrition and available cancer nutrition resources. Low confidence amongst Australian GPs and GPNs in providing general nutrition and cancer nutrition advice has been documented in previous studies [29, 38]. Similarly, a recent study of 610 healthcare professionals in the UK found that only 9% of GPs were aware of nutritional guidelines for cancer patients and 47% of GPs reported low confidence in providing nutrition advice [39]. The majority of GPs reported the need for further training on the nutritional care of cancer patients, with dietary advice specific to cancer type and stage and the assessment of nutritional status identified as key areas for nutrition education [39].

Targeted education and training are required to ensure patients with cancer receive appropriate and consistent nutrition advice in the primary care and community sector. Efforts should be made to increase awareness of existing cancer-related malnutrition resources and to develop new resources specifically for GPs and GPNs. Consideration should be given to the way in which education is delivered, being mindful of the limited protected time GPs have for professional development [39]. Decision support aids and patient-specific shared care plans (providing additional information about common issues or including integrated links to relevant guidelines) have been identified as promising tools to support primary care clinicians' knowledge of cancer care [40–42].

Strengths and limitations

The large sample of Victorian dietitians working with patients with cancer across the continuum of care, in both metropolitan and regional areas is a key strength of this study. However, there are some limitations. The methodology did not allow for the calculation of a response rate and despite an extension to the closing date and the addition of an incentive to complete the survey, GP and GPN recruitment was low. Furthermore, GPs and GPNs with an interest in nutrition and cancer may have been more likely to respond, thus skewing the survey results.

Conclusion

This study found that cancer malnutrition is likely going unrecognised and under-treated in Australian primary care and community health settings, and opportunities exist to improve malnutrition care practices across the continuum of care. Stratified pathways based on level of nutrition risk, as well as enhancements in hospital discharge processes to support transition of nutrition care between hospital, primary care and community services are required. Improvements in the identification of malnutrition risk in general practice and community health settings may be achieved through mandatory screening within relevant governance standards. Targeted education and resources are required for health practitioners working in primary care and community sectors to improve knowledge and confidence in the management of cancer malnutrition.

Declarations

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Conflicts of interest/Competing interests:

Financial interests: Author JS received a salary from the grant received by the Victorian Government. NK is supported by a fellowship from the Victorian Cancer Agency. JL, NS, AK have no financial conflicts of interest to declare.

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Availability of data and material:

Data can be available to the journal editors on request.

Code availability:

Not applicable

Authors contributions:

Study conception and design: Jane Stewart, Jenelle Loeliger and Nicole Kiss. Data collection and analysis: Jane Stewart. The first draft of the manuscript was written by Jane Stewart and all authors reviewed and edited previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval:

Ethics approval was obtained from the Peter MacCallum Cancer Centre Human Research Ethics Committee (Ref: LNR/18/PMCC/24).

Consent to participate:

Informed consent was obtained through a participant information sheet in Survey Monkey™ for surveys completed online and in written form for surveys completed in person.

Consent for publication:

Not applicable

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