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Review

The role of the nurse in meeting the educational needs for self-care in cachectic cancer patients and their family caregivers: A scoping review

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ABSTRACT

Objective: To give an overview of what is known about the nurse contribution to education in self-care by people with cancer cachexia and their family caregivers. Nurse-led patient education can help patients and their family caregivers to manage cancer symptoms, cancer treatments, and treatment side effects.

Methods: This scoping review explored the extent to which nurse-led education has become part of the multimodal management of cancer cachexia. It is based on a systematic search of Medline, Embase, CINAHL, APA PsycINFO, and the Cochrane Library. Search limits were English language, date ranges from January 2015 to March 2023, and adults 18 years and older.

Results: A total of 6370 titles were screened, 127 papers and conference abstracts were selected for full-text examination, and 9 publications were included in the review. The analysis found the nurses within the multidisciplinary cancer cachexia care team, like other healthcare professionals, do not have a shared understanding of cancer cachexia and its management. For nurses to be confident and competent in the provision of nurse-led cachexia education, they themselves need evidence-based education in cachexia care and how to tailor education according to cachexia stage, symptoms, emotional response, and social circumstance.

Conclusions: Nurses with the knowledge and confidence to provide cancer cachexia education for their patients can potentially play an important role in the management of cancer cachexia and mitigation of cachexia-related problems.

Introduction

Patients with cancer cachexia experience involuntary weight loss, poor appetite, fatigue, declining physical function and other troubling symptoms and problems.[1]

Clinical guidelines for the management of cancer cachexia recommend a multimodal approach that combines disease treatment, intervention to arrest the metabolic and inflammatory processes causing cachexia, and the management of associated physical problems (e.g., physical decline), emotional problems (e.g., distress), and social problems (e.g., conflict with family members over food).[1,2] Education provided by a multidisciplinary team is important if patients are to successfully self-manage cachexia-related problems.[3] Two of the nine domains of multimodal care for cancer cachexia focus on education: (1) the provision of evidence-based information and (2) education about cancer cachexia for patients and their family caregivers.[4] There is potential for education to enable self-care that (1) mitigates malnutrition and malnutrition risk and (2) mitigates cachexia-related distress with benefit to quality of life.[5]

Most effective interventions initiated by nurses, nurse-led, interventions for cancer symptoms include educational and psychological components.[6] However, in 2015, a scoping review with focus on nutritional care, nurses were found to lack sufficient knowledge and confidence to deliver nutritional care in cancer cachexia.[7] The review concludes that nurses have an unmet need for education if they are to fulfill an important nutritional care role in cancer cachexia.

Nurses need education in cancer cachexia

Nurses may be educating patients and their family members in cancer cachexia and its management, with their contribution unstudied and, therefore, not reported. Yet surveys of cancer and palliative care clinician knowledge and practice of guideline recommended cachexia care have found a lack of formal education and know-how[8–14] (Table 1).

For nurses, undergraduate and postgraduate education rarely includes preparation for the management of either cachexia or nutrition in cancer. More than 75% of nurses report no formal education in cachexia,

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Table 1
Nurse knowledge and confidence in cachexia care in cancer.

Authors and year	Survey sample	Finding	Country
Ellis et al.[12] 2023	$n = 192$, 90% doctors or nurses	56% neutral or not confident in managing cancer cachexia.	Australia and New Zealand
Baracos et al.[8] 2022	$n = 2375$, 33% doctors, 14% nurses, 28% dietitians, other health care professionals	32% confident in ability to provide care for patients with or at risk of cachexia.	Japan, Europe, and North America
Amano et al.[9] 2022	$n = 1320$ Healthcare Professionals (58.5% response rate) in 451 cancer designated hospitals	No profession reported adequate training and confidence in cancer cachexia management. $< 50\%$ used a clinical practice guideline for the management of cachexia.	Japan
Socratous et al.[13] 2021	$n = 197$, cancer nurses	75% report no formal education in cachexia.	Greece and Cyprus
Murphy et al.[10] 2021	$n = 610$, 31% nurses, 25% dietitians, 31% doctors	20% completely confident in giving nutritional advice in cancer.	UK
van Veen et al.[14] 2017	$n = 355$, oncology nurses	43% reported insufficient knowledge to provide advice on nutrition.	Netherlands

with authors concluding this contributes to inconsistent management of the complex needs of a patient with cancer cachexia,[13] as nurses do not have sufficient awareness of the risk, problems, appropriate assessment, and management.[13,15] Nearly half (43%) of 355 oncology nurses in the Netherlands reported insufficient knowledge to provide advice on nutrition.[14] Education of oncology nurses has been shown to increase their knowledge, self-confidence, and self-efficacy to deliver nutritional care to cancer patients.[16] If nurses are to raise awareness of cancer cachexia, its causes, and management in their work with patients, then they need cachexia education themselves.

To address the educational need of nurses in cancer cachexia, it is first necessary to identify what they need to know to fulfill their role. An important part of what cancer nurses do is to educate patients in self-care.[6] This scoping review examines the extent that patient education by nurses has become part of the multimodal management of cancer cachexia by asking the following question.

Review question

What is known about the role of the nurse in meeting the educational needs of self-care in cachectic cancer patients and family caregivers?

Methods

The scoping review was to identify gaps in the knowledge base with development of the question guided by population, concept, and context.[17] The search was of Medline, Embase, CINAHL, APA PsycINFO, and the Cochrane Library for publications about nurses and education for people with cancer cachexia or its defining characteristic, involuntary weight loss. Limits were the English language, January 2015 (the year of an earlier scoping review by the author about the nurse contribution to nutritional care in cancer cachexia) to March 2023, and human subjects. The search strategy was developed for Medline by the author, discussed with a librarian, and then translated into other databases.

The search combined selected MeSH terms and free-text terms seeking hits for (nurse) AND (nutrition) AND (education), (nurse) AND (cachexia) AND (education). These searches were cross-checked by re-runs from January 2015 to March 2023 of the search strategies for already published reviews about nurse nutritional care offered by nurses for cachexia[7] and multimodal interventions for cachexia with a psychosocial component[18] (Fig. 1). All hits were screened by the author for relevance to this scoping review.

The review comprised multiple searches because it was a scoping review to map breadth and depth of literature[19] [Appendix 1 for an example search in MEDLINE]. The eligibility criteria were broad, allowing inclusion irrespective of study design, methodology, or method. Inclusion criteria were peer reviewed publication (conference abstract or full paper), cancer cachexia, adults (18 years of older), nurse-led education, primary or secondary care setting, English language, date range January 2015 to March 2023. Data that related to nurse-led education for people with cancer cachexia and their family caregivers were extracted from selected publications. The reference lists of included publications were screened (backward chaining) and articles citing the selected publications sought (forward chaining) with one additional publication identified and included.

The data extraction was of any report of nurse-led cachexia education for a patient with cancer or their family caregiver. The extracted data were entered into a thematic conceptual matrix.[20] The initial thematic structure was derived a priori using the research question and literature leading to the question. The conceptual matrix was further developed during data extraction to accommodate newly emergent themes, such as, caregiver educational need.

For the review, nurses were considered to be providing cachexia education if reported to give information/advice, offer guidance, or to educate in the causes, symptoms and other associated problems, and/or management of cancer cachexia or involuntary weight loss in cancer. The scoping review is reported according to the PRISMA-ScR Checklist.[21]

Results

A total of 6370 titles were screened and 126 papers and conference abstracts selected for full-text examination (Fig. 1). Eight documents were selected and a ninth was added after searching and screening citations of these eight publications. Table 2 gives details of the nine publications. They included three empirical studies (four publications),[13,22–24] three literature reviews,[25–27] one service improvement project,[28] and one publication based on expert opinion.[15] The studies were conducted in Europe, UK, Japan, China, Mexico, and USA.

The findings of this review are reported under the subheadings, patient educational need addressed by nurses, family caregiver educational need addressed by nurses, nurse educational role in multimodal management, nurse-led education, and the impact of nurse-led education. Collectively, these themes comprise the component parts that can be deduced from the literature of the nurse role in the education of patients with cancer cachexia and their family caregiver.

Patient educational need addressed by nurses

Patients were thought to need nurse-led education in cachexia to help them cope with poor appetite and involuntary weight loss[22,23,26,27] and

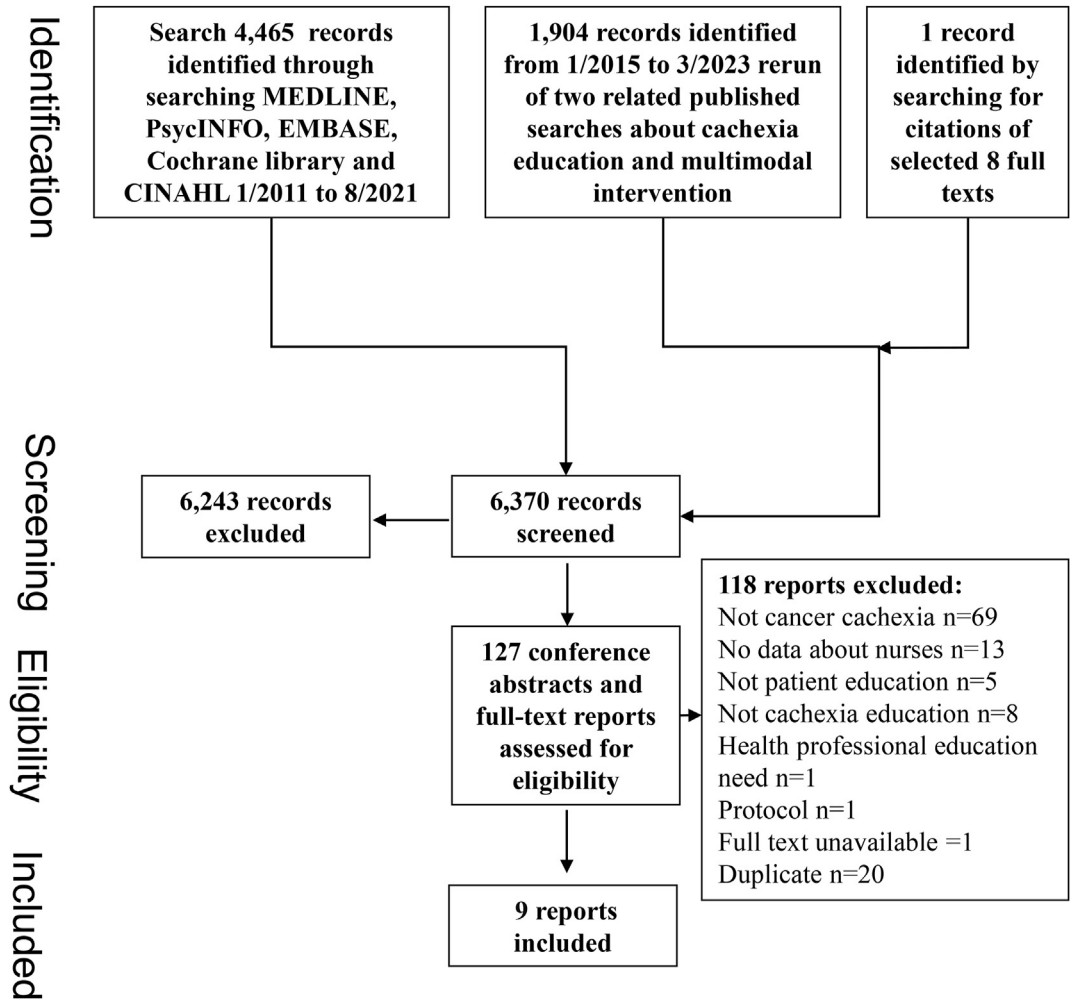

Fig. 1. Flow of information through the phases of the search.

to manage interpersonal relationships disrupted by the symptoms of the syndrome[22–24] and other cachexia-related psychosocial problems causing distress.[24,26] Education was also reported as necessary for patients to learn skills in symptom management, such as energy conservation techniques to manage life with fatigue.[25,27] One publication recommended that the education provision should extend beyond the specialist clinic to help patients manage cancer cachexia cared for in any setting, hospital, or community.[15]

Family caregiver educational need addressed by nurses

Family caregivers were thought to need nurse-led education in cachexia to help them cope with the patient's poor appetite and involuntary weight loss[22–24,28] and to manage interpersonal relationships disrupted by the symptoms of the syndrome[22–24] and other cachexia-related psychosocial problems causing distress.[22–24,26] Carers had been found to take on a nourishing role of patients with advancing cancer and involuntary weight loss and thus needed guidance on how to best help the patient.[24] A particular need was identified for education in nutrition and hydration as the patient approached end of life, for example talking about reasons for loss of appetite as end-of-life approaches to reduce the likelihood of inappropriate feeding.[27]

Nurse educational role in multimodal management

Multimodal management of cachexia was offered by a multidisciplinary team with nursing a core role. Other core roles were dietitian, physiotherapist, and doctor.[15] Nurses provided psychoeducation (practical examples of how to manage cachexia-related problems and emotional response tailored to the experience of patient and family caregiver), along with an information booklet about coping with cachexia to encourage self-care of cancer cachexia-related problems thus influencing coping and self-confidence.[22,23] Nurses were described as encouraging and motivating patients to take part in interventions[26] and educating them in symptom management.[27]

Nurse-led education

Nurses provided patients and family caregivers with nutritional information and guidance.[13,22–25,27,28] For example, they offered advice on safe feeding, diet management, and unproven diets.[25] They also provided education to help the patient and family caregiver to understand the physical and psychosocial problems that can accompany cachexia[22–24,26] and to make them aware of successful coping strategies.[22,23,26,27] In addition to talking about nutrition and providing psychosocial support, they taught skills in symptom management, such as the modification of food texture to mitigate the pain of mucositis.[27] One study described a nurse navigator educating to facilitate the acceptance of screening for risk of cachexia-related problems, intervention, and follow-up care.[15] Other authors also noted the potential for psychosocial support to improve adherence to interventions.[15,27] Booklets, posters, health education prescriptions, and online videos uploaded to public websites were used to support the cachexia education provided.[22,28] A method of education described was the use of open questions and a non-judgmental

Table 2
The role of the nurse in meeting the educational needs of self-care in cachectic cancer patients and caregivers.

Empirical research							
Author, country, year	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Buonaccorso et al.[22] Italy, 2023	Mixed-methods single arm feasibility and acceptability study conducted 2019 to 2021. 24 cancer patients with refractory cachexia/ cachexia and their caregivers (12 (50%) patients died within 3 months of enrollment).	Psychoeducational intervention combined with a rehabilitative intervention for patient family carer dyads. Aim: to evaluate the feasibility of the intervention to treat cancer cachexia, assessed by completion rate.	Intervention delivered, in addition to standard care, by a nurse and a physiotherapist. The nursing role being to offer psychoeducation to help the patient and family carer cope with declining appetite and involuntary weight loss in the patient by strengthening individual and dyadic coping resources for the self-management of cancer cachexia. The physical activity component (not found feasible) facilitated enrollment to the nurse delivered psychoeducational intervention component.	Need for information, offered using a non-judgmental approach, to cope with involuntary weight loss and declining appetite.	Need for information, offered using a non-judgmental approach, to cope with involuntary weight loss and declining appetite in a family member.	During consultations once per week for three weeks, the trained nurse ($n = 3$) (1) used open questions to understand the viewpoints of patient and family carer of cancer cachexia, (2) mapped changing eating habits, (3) offered practical examples of different ways of managing food in the care of the patients, and (4) re-evaluated dyad's needs in the study period. The dyads were given an information booklet, which included a description of cancer cachexia and common emotional responses.	The psychoeducational sessions were evaluated to be feasible, as 20 dyads 83.3% (Confidence Interval, 62.6%–95.3%) received at least two sessions. For patients evaluated at 2 months follow-up (T3), there was no deterioration in patient quality of life or caregiver burden. Caregiver burden diminished between enrollment and T2 (4 weeks). Participants appreciated the booklet and the opportunity to talk about cancer cachexia, they were positive about a non-clinical intervention and considered it to offer a positive caregiver role, they also perceived a positive benefit for their relationship with respect to interactions over food. 12 (50%) completed the nurse-led intervention components (3 sessions). The dyads appreciated participation in a non-pharmacological cachexia study with their caregiver, with perceived positive impact on their relationship.
Buonaccorso et al.[23] Italy, 2022 (Conference abstract: Poster)	Mixed-methods single arm feasibility and acceptability study. 24 dyads: patients with cachexia and their caregivers (87.5% spouse)	Psycho-education combined with a rehabilitative intervention for patient family carer dyads. Aim: to evaluate (1) the feasibility of, (2) acceptability of the intervention and, (3) quality of life.	Intervention delivered by a nurse and a physiotherapist. The nursing role being to offer psychoeducation to help the patient and family carer to cope with cancer cachexia by strengthening dyadic coping resources for the self-management of cancer cachexia.	Need for information to self-manage the complex relational experience of cachexia.	Need for information to self-manage the complex relational experience of cachexia.	During consultations once per week for three weeks, the nurse (1) explained cachexia, (2) taught patients how to recognize its effects (e.g., weight loss), (3) facilitated discussion of the patient and family's perspectives, feelings about diet, and made suggestions of how to support each other in managing weight-and eating-related problems.	
Socratous et al.[13] Greece and Cyprus, 2021	Survey in 2018 119 nurse attendees, 8th Nursing Oncology Conference in Cyprus and 78 nurse attendees, 5th Symposium of Nursing Oncology in Greece.	Nurses' knowledge in relation to the Cancer Anorexia–Cachexia Syndrome (CACS) in cancer patients. Aim: to conduct a comparison of two European countries.	Participants named 23 different health care roles/people involved in management of CACS, which included nursing roles.	Not reported.	Not reported.	Discussion with the patient for his/her diet ($n = 1$ participant). Psychological support (unspecified) ($n = 7$ (4%) participants).	Not reported.

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Table 2 (*continued*)

Empirical research							
Author, country, year	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Hopkinson[24] UK, 2018	Exploratory secondary analysis of qualitative interviews. 31 partner/spouse family carers of patients with advanced cancer and involuntary weight loss.	The nourishing role of family carers of patients with advanced cancer who have weight loss and eating problems. Aim: to explore unmet support needs.	Member of homecare multidisciplinary palliative care team.	Not reported.	Need for guidance in their nutritional care responsibilities as family carers, which included helping the patient to manage changing weight and fickle eating habits.	Education in the nourishing role to address food and eating-related uncertainties that are causing anxiety, distress, and/or conflict in the home and to help the family carer to know when they are offering appropriate food and fluid. Advice on eating well as a family carer, as their own eating habits can change when in the nourishing role putting them at nutritional risk.	Proposition that proactive education is most likely to be helpful when there is a mismatch in patient and family carer nutritional goals.
Reviews							
Author, country, year	Study design	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Oakvik et al.[25] Mexico, 2022	Narrative review.	CACS. Aim: to provide current evidence and updates in management.	CACS care is provided by an interdisciplinary team of nurses, dietary specialists, physicians, pharmacists, social workers, and specialists in pain and symptom management.	Not reported.	Not reported.	Nurses can provide nutritional education alongside dietitians. They can provide patients and caregivers with practical and safe advice for feeding, education on dietary management and advice against fad diets and other unproven or extreme diets.	Education provided by nurses can contribute to achieving optimal nutritional care for patients with cancer cachexia.
Sato et al.[26] Japan, 2021	Scoping review	Cancer cachexia management. Aim: identification of barriers to nursing practice in cancer cachexia.	In multidisciplinary interventions for cancer cachexia, nurses play an essential role in supporting self-care by encouraging and motivating their patients to engage in interventions.	Communication of information about cachexia and its associated physical and psychosocial problems that can cause distress.	Communication of information about cachexia and its associated physical and psychosocial problems that can cause distress.	Nurses (and other healthcare professionals) can provide patients and caregivers with the necessary Information (1) to understand the physical and psychosocial distress associated with cancer cachexia and, (2) to be aware of effective coping strategies.	The methodology of communication and educational interventions concerning cancer cachexia is not well developed. A practical guide is needed for aiding nursing management of cancer cachexia.
Zhao et al.[27] China, 2021	Narrative review.	Cancer cachexia management. Aim: to describe the	Interdisciplinary team, which includes nurses, is essential for cancer	Education to teach patients skills for symptom management.	Education in nutrition and hydration as end-of-life approaches.	Nurses have the knowledge and expertise to talk with patients and	Education as an important nursing role in the management of

(*continued on next page*)

Table 2 (*continued*)

Empirical research							
Author, country, year	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
		nature, cause, manifestations, treatment, and the role of nurse in the multidisciplinary management of cancer cachexia.	cachexia management. The nursing role includes nutritional management, symptom-control, and metabolic management.			families about nutrition and exercise. They can also provide psychosocial support to facilitate compliance. Nurses can teach skills for symptom management, such as, (1) modification of food texture to mitigate the pain of oral mucositis, (2) energy conservation techniques to help with cachexia-related fatigue (3) offering e-counseling to facilitate skills in coping with symptoms of cancer cachexia.	cachexia. Nurses are familiar with the health habits, socioeconomic statuses, and cultural mores of the patients they treat, which helps them to facilitate efficient communication that can help patients and their family carers to adapt to changes that accompany cancer cachexia.
Improvement projects							
Author, country, year	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Zhang et al.[28] China, 2022	Audit and feedback. 30 patients pre and 30 patients post service improvement.	CACS management. Aim: to implement an evidence-based practice in assessing and managing patients with CACS.	CACS care was provided by a multidisciplinary team who included, the department head nurse, clinical doctor, clinical nurse, nutrition nurse, pharmacist, psychologist, physiotherapist, senior dietitian, and social worker, who used a standardized CACS screening and assessment process.	Patients need to understand CACS and pre-improvement believed the information provided insufficient to help them better deal with cancer-related anorexia and weight loss.	Carers need to understand CACS and pre-improvement believed the information provided insufficient to help them better deal with cancer-related anorexia and weight loss.	The nutrition nurse, specialist nurse (and other team members) educated patients. The patient education programs, included strategies to be used for managing cachexia, health education, and home care of anorexia-cachexia. One-to-one bedside health education was supported by posters, health education prescriptions, and online videos uploaded to public websites.	Not reported.
Expert opinion							
Author, country, year	Source	Focus	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Granda-Cameron et al.[15] USA, 2018	Clinical experience.	Clinical framework for quality improvement of cancer cachexia.	Interdisciplinary model to assess and manage cancer patients at risk or with	Team approach and holistic care for cachexia extending beyond the	Not reported.	A master's prepared Oncology Nurse Navigator role includes	Cachexia Care Framework helps nurses to recognize, organize,

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Table 2 (*continued*)

Empirical research							
Author, country, year	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
		Aim: to report a Cachexia Care Framework, based on experience of a cancer cachexia clinic over 10 years.	cachexia. Core team comprised physician, nurse practitioner, nutritionist, physical therapist, speech pathologist, and clinic assistant with support available from social worker, chaplain, and psychologist.	Cancer Appetite and Rehabilitation (CARE) Clinic.		patient and carer education to overcome barriers to screening, intervention, and follow-up care for cachexia.	and decrease barriers to cachexia care across its stages, to include the education needed by patients and carers. (Although the education role is acknowledged as important, it is not detailed.)

approach to establish change in the patient's eating habits across the course of their cancer. This patient experience was then used to tailor information to raise awareness of common emotional responses to changing eating habits. A booklet was offered giving practical examples of how patients and family caregiver can manage eating problems.[22] A second study drew attention to the needs for cachexia education of family caregiver who might be uncertain of how best to manage the patient's loss of appetite or changing eating habits or be at risk of malnutrition themselves if aligning their food intake to the patient's.[24]

The impact of nurse-led education

Psychoeducational sessions are feasible for nurses to deliver, with more than 80% of patients and their family caregivers attending at least 2/3 sessions and expressing appreciation of the opportunity to talk about cachexia.[22] The sessions were perceived to set out a positive role for family caregivers who were found to experience less caregiver burden at 4 weeks from baseline (pre-sessions).[22] The patient and family caregivers also reported benefit for their relationship through improved interactions relating to food and eating.[22–24] Proactive psychosocial intervention is proposed to be most likely of benefit when there is a mismatch between patient and family caregiver nutritional goals.[24]

Nurse-led education has also been reported to support improved nutritional intake of patients with cancer cachexia.[24,25,27] Nurses are familiar with the culture and health habits of the patients they care for and can use this knowledge to adjust their education to help patients adapt to life with cachexia.[27] A large number of potential nurse-led interventions for symptoms are reported, for example, for dry mouth.[23,25,27] However, the nurse contribution to cachexia education is, in the main, overlooked in the literature and the nature and methods of education with benefit are not well described. There are calls for a practical guide to aid the communication and education component of nurse-led cachexia care.[15,26]

Discussion

The scoping review found only 9 publications[13,15,22–28] that included description of the nurse role in cachexia education for patients and their family caregivers. Of these, only 3 were empirical research (four publications)[13,22–24] and just one testing a nurse-led intervention.[22] The contribution of nurses to the multimodal management of cancer cachexia through the offer of patient and family caregiver education has received little attention in the literature. All cancer patients meet nurses and patient education in the management of disease and symptoms is a recognized important therapeutic activity within the cancer nursing role.[6]

This review found that the educational role of the nurse in meeting the needs of a patient with cancer cachexia and their family caregiver can be to:

- raise awareness of cancer cachexia syndrome and its causes,
- share knowledge of symptoms and related problems, which can aid patient understanding to support adherence to interventions and to support emotional coping,
- offer dietary information and advice to mitigate risk of malnutrition,
- teach skills in the self-management of nutritional impact symptoms,
- adjust information, advice, and skill training to cultural and social context and
- offer and signpost educational resources about management of cancer cachexia.

The review supports an argument that this educational offer should be tailored according to stage of cachexia, symptoms, emotional response, and social circumstance—it should be personalized.[1] This personalization might include adjusting advice and goals negotiated with patients and families according to stage of cachexia, with focus on screening and addressing risk of malnutrition in the pre- and early stages

of cachexia,[15,25] focus on maintenance of muscle mass and optimal nutritional status during active or palliative treatment,[25–27] and negotiating goals that focus on quality of life with patients who are approaching end of life with refractory cachexia.[22,24,27]

Nurse cancer cachexia education with impact

The review has found interaction among patient, family caregiver, and nurse a central feature of nurse-led patient education in cachexia.[13,22,24,26–28] Cancer cachexia and its symptoms can be a sensitive topic of conversation with patients and their family caregiver. The methods for initiating discussion, sharing information, and promoting self-management are an important consideration.[5] Knowledge of health behavior change can be applied to an evidence-based approach for engaging patients and their family caregivers in conversation and for supporting uptake and adherence to advice for self-care.[5] Nurses have been found able to offer dietary advice with beneficial effect in other contexts, such as the management of diabetes.[29,30] If nurses offer dietary advice to patients with cancer cachexia, they can contribute to the management of malnutrition risk. They can teach self-care for nutritional impact symptoms, to include teaching skill in modifying foods to increase protein intake for those with poor appetite and involuntary weight loss.[31] Feedback that evokes positive emotion (positive sense of self) may be important for cachexia education with health benefit for the patient and for positive impact on quality of life for the family caregiver.[32] Audit using clinical practice guidelines for cancer cachexia[1,2] to set a standard of best practice, can have a role to play in feedback to support service improvement in the management of cachexia, to include feedback on the patient education and patient/family caregiver adoption of advocated self-care practices.[28]

Patient education in self-care, which adopts methods known to support behavior change such as goal setting,[33,34] cannot stand alone from a knowledge of the causes of cachexia, its symptoms, and natural progression.[35] Nurses work with people on the boundary of treatment for disease and support of their everyday life. They help with adjustment to disease symptoms and treatment for best possible health and well-being outcome. This involves working in a biopsychosocial space requiring understanding of disease process and emotional coping to include influence of social context on adaptation.[18] Nursing knowledge spans disease, treatment, emotional adaptation and coping. The how, when and what of sharing this knowledge and understanding with patients and family caregivers affected by cancer cachexia—the nurse educational role in cachexia—has been little studied, as shown by the dearth of literature identified for this review. Exploratory and pilot trials of multimodal interventions for people with advanced cancer and symptoms of cachexia that include an educational component delivered by a dietitian or physiotherapist and have been found acceptable to patients and their family caregivers. Benefits have been found to include improved emotional well-being and improved nutritional intake.[32,36,37] The potential contribution of the nurse educational role in cachexia has been, in the main, overlooked and is thus little studied. Nurses need to know how to deliver patient education in cachexia for positive effect on patient and family caregiver health and well-being.

Cancer cachexia care must be multidisciplinary if it is multimodal

Publications have called for guidelines and presented models for nurse-led cachexia care.[26,31] However, all nine publications included in this review positioned the nurse as being a member of a multidisciplinary team supporting patients with cancer cachexia. Multimodal cachexia care is delivered by a team of people with complementary expertise. Whilst the contribution of some team members is clearly defined, for example the physiotherapist supports physical activity/exercise, the role of the nurse has not been clearly differentiated. It has been reported that it can include screening patients for risk of cachexia and initial assessment[38–41] and coordination of cachexia care.[42] This review draws attention to the important patient and family caregiver educational component of the nursing role within the multidisciplinary team. What is perhaps needed is not a model for nurse-led cachexia care but a wider model for cachexia care with clearly defined embedded roles to include a nursing role with patient education component. The reported patient and family caregiver acceptance of booklets, videos, and posters to support nurse-led cachexia education[22,23,28] suggests they are needed to support the multidisciplinary team offer of cachexia care. They can act as boundary objects facilitating talk about technical and sensitive topics,[43] such as involuntary weight loss and conflict in the home over food. Investigation is needed of how to tailor electronic and hard copy educational resources to meet the needs of people from different cultures and socioeconomic backgrounds thus accommodating variability in the meanings of food, eating, diet, and weight.[44]

Limitations

A single nurse researcher conducted this rapid scoping review with implications for the reliability of selection and data extraction. The risk of error through omission of relevant papers was addressed in three ways. First, by running multiple parallel searches (multiple databases and multiple searches within each database). Second, by screening the reference lists and searching for citations of included publications. Finally, by cross-checking with reruns January 2015 to February 2023 of related published peer reviewed searches by the author.[7,18]

The review focused on a nursing contribution to cancer cachexia care, namely the education that can be provided by nurses for patients with cancer cachexia and their family members. Whilst the multifaceted problems associated with cachexia require a multimodal approach delivered by a team with diverse expertise, the expert contribution of the nurse can be difficult to delineate. The nursing role in the management of cachexia has been reported to screen patients, identify cachexia and related problems, then coordinate interventions delivered by other team members.[1,38] Whilst these are valuable tasks completed by nurses within multidisciplinary cancer care teams, nurses can make other contributions to holistic cachexia care.[27,45] Education in cachexia for the support of self-care is one. The focus on this topic has detracted from other possible learning from the review and is a bias arising from the professional background and clinical experience of the author. A second reviewer, with different history and experience, or consultation with patients, caregivers, and clinicians, may have enabled additional insights.

Conclusions

Nurse-led education may be important for any successful multimodal intervention in cancer cachexia. However, little attention has yet been paid to this potential mechanism of successful intervention. Understanding the teaching content and methods that can be used by nurses to provide effective education in self-care by people with cancer cachexia could make an important contribution to improvement in clinical outcomes and quality of life of patients and their family caregivers.

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Declaration of competing interest

The author has none to declare.

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Ethics statement

Not required.

Data availability statement

The data that support the findings of this study are available from the corresponding author, JBH, upon reasonable request.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

Appendix A. Supplemental data: MEDLINE searches

SEARCH EXAMPLE

Database: Ovid MEDLINE(R) ALL <1946 to February 22, 2023>
Search Strategy:
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1 (nutrition* or dietary counseling or dietary advice or nutritional counseling).mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] (459802)
2 (education or teaching or training).mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] (1505433)
3 Nurses/(45017)
4 nurs*.mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] (801905)
5 3 or 4 (801905)
6 1 and 2 and 5 (4450)
7 limit 6 to (english language and humans and yr = "2015 -Current") *(1073)
8 cachexia.mp. or Cachexia/(11168)
9 weight loss.mp. or Weight Loss/(117877)
10 Wasting Syndrome/or Wasting Disease, Chronic/(1983)
11 8 or 9 or 10 (128370)
12 7 and 11 *(40)
13 2 and 5 (225070)
14 11 and 13 (458)
15 limit 14 to (english language and humans and yr = "2015 -Current") *(133)

* = abstracts screened.

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