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Educational needs of self-care in cachectic cancer patients and caregivers

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Educational needs of self-care in cachectic cancer patients and caregivers

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Abstract

Purpose of review

To give an overview of what is known about the educational component of supportive care for people with cancer cachexia and their family caregivers.

Recent findings

The educational needs for selfcare by people with cancer cachexia are largely unmet. There is potential for education to enable selfcare that i) mitigates cachexia-related distress with benefit to quality of life and ii) mitigates malnutrition/malnutrition risk with implications for treatment tolerance and outcomes. Theoretically informed approaches to cancer cachexia education for patients and their family members are needed if optimal methods for support of selfcare are to be identified. The cancer workforce also needs education to have the confidence and knowledge to play a role in the cancer cachexia education of their patients.

Summary

To address the educational needs of selfcare in cachectic cancer patients and their caregivers there is much work to do. Healthcare professionals need to know the best educational process and methods for cachexia for supporting quality of life and facilitate improving cancer treatment outcomes including survival.

Keywords: cancer, cachexia, education, patient, caregiver

Introduction

Cancer cachexia is characterised by involuntary weight loss, poor appetite, fatigue, and loss of muscle mass, with decreasing physical activity leading to increasing dependency as the syndrome progresses [1**]. Cancer is a leading cause of death worldwide with lung and colorectal cancers the most common cause of cancer mortality [2]. The prevalence of cachexia is high in these cancers and also in pancreatic, gastro-oesophageal, head and neck cancer and, more generally, in people with advanced cancer approaching end of life [3-4]. The experience of cancer and cachexia is common along with educational needs for self-care.

The cachexia-related problems managed by people with cancer and their caregivers

The problems experienced by people living with cancer cachexia and their family caregivers are wide ranging. They include declining physical function (physical health problems), eating- and weight-related distress (emotional problems), sense of helplessness and loss of control (psychological problems), social isolation (social problems), and dependency on others for help with everyday tasks such as shopping (practical problems) [5]. Cachexia can impact multiple domains of influence on health-related quality of life [6].

The experience of cachexia can be distressing for both patients and their family caregivers and also for healthcare professionals if they don't know how best to help [7]. Cachexia has proven to be a fiendish problem with three decades of research progressing understanding of the aetiology yet failing to develop an effective treatment [6]. The task of helping patients and their family members to live with cachexia is thus one of supportive care to minimise the disruption to everyday life of cachexia-related problems.

The WHO sets out an expectation of supportive care for all cancer patients to improve quality of life [2]. This is reflected in western government cancer policies, which place emphasis on support of patient engagement and empowerment for improved quality of life [8-10]. It also aligns with the Cancer Cachexia Society mission 'to empower patients with cachexia to live their lives to the fullest through education, awareness, and community' [11].

Best practice in supportive care of people with cancer cachexia

Current clinical guidelines for the management of cancer cachexia address supportive care from differing perspectives, which place greater or lesser emphasis on an holistic approach to the syndrome's management and patients' role in selfcare. Where the emphasis is on the biomedical management of disease, the focus is on successful cancer treatment and symptom management. For example, the American Society of Clinical Oncology (ASCO) clinical guideline [12**] states,

*The goal of identifying and treating cancer cachexia is to improve treatment tolerability, improve survival, and optimize the quality of life of patients with advanced cancer [12**].*

In comparison, the European Society for Medical Oncology (ESMO) clinical practice guideline [1**] in cancer cachexia places greater emphasis on an holistic approach. It recommends solutions to cachexia-related problems not only through disease control and symptom management but also through the management of psychosocial factors affecting illness experience,

Comprehensive treatment (of cachexia) requires a multitargeted and multidisciplinary approach aimed at relieving symptoms impacting on food intake, ensuring adequate energy and nutrient intake, minimising catabolic alterations, supporting muscle training and offering psychological and social support.

In patients with cachexia, combining nutritional support with exercise training and psychological support is proposed. Anti-inflammatory interventions should also be considered [1].*

Premise of selfcare for health and wellbeing

An holistic model of healthcare provision invites consideration of illness experience in addition to managing pathological process. Psychosocial factors become relevant to helping a person manage their illness experience. Contemporary models of holistic care position the patient as an active decision maker and partner in clinical decision making [13]. The premise is that their involvement in illness management will support the achievement of optimal health and wellbeing outcome from treatment of disease, for example, by affording a sense of control [14, 15]. A patient-clinician partnership can facilitate clinical decisions consistent with the person's values [16] – important in situations of uncertainty such as how best to help a person living with cachexia when therapeutic options (beyond effective treatment of the primary cancer) are not available. Non-symptom related barriers to optimal nutrition in cachexia, such as beliefs about dietary intake, have been found of greater influence on nutritional intake than nutritional impact symptoms [17].

If people with cachexia are to engage in selfcare aligned with current clinical guidelines, then they have a need for education. They need to know about nutrition in cancer, safe exercise, and self-managing of cachexia-related problems.

This paper provides an overview of what is known about the educational component of supportive care for people with cachexia and their family caregivers. It focuses on literature published from January 2020 to December 2022.

The need for education in cancer cachexia: health care professionals

Patient education into what cachexia is, its common symptoms and its associated problems can mitigate distress [18*]. There is growing international consensus that education provided by a multidisciplinary team is important if patients are to successfully self-manage cachexia-related problems [19*].

Health care professionals need an understanding of cachexia and current best practice guidelines if they are to educate patients in selfcare. There is unmet need for this education [19*]. Surveys of healthcare professionals conducted in Australia, New Zealand, Japan, Italy, UK, Europe and North

America demonstrate limited knowledge of relevant guidelines on nutrition in cancer and/or cachexia and its management (see Table 1.). They also show that educated healthcare professionals are more likely to be aware of guidelines and to have the confidence to provide patients with nutritional advice [20]. However, education and training in cancer cachexia is reported to be inadequate [21, 22*, 23] despite being recognised for its potential to improve practice [22*, 24].

[Insert Table 1.: Study of need for education in cancer cachexia]

The need for education in cancer cachexia: patients and their families

Cachexia-specific education in selfcare that includes nutritional counselling is likely to be important throughout the cancer journey [19*], as the syndrome is dynamic [17]. Patient and family caregiver awareness of cachexia, its symptoms, progression and associated problems is thought likely to facilitate both acceptance of symptoms and the patient-clinician partnership that enables best supportive care [19*]. Multidisciplinary team and patient education in assessment and non-pharmacological management of cachexia can improve compliance with evidence based clinical guidelines [25]. It can affect the experience of cachexia, thus is recommended to mitigate distress [1**], and as part of nutritional interventions for improving nutritional status [12**]. For example, education in the self-management of a nutritional impact symptom, such as constipation, can make a difference to quality of life. Many factors affect quality of life of people living with cachexia (see Hopkinson, Amano, Baracos, 2022 [6] for a comprehensive list of known factors).

Meeting the need for education in cancer cachexia

Web-based education for clinicians and patients describes cancer cachexia as being a common and complex problem that presents as involuntary weight loss, loss of appetite, fatigue, weakness, and change in appearance [26,27] with impact on quality of life and activities of daily living [28]. It is explained as a 'biological systems disruption' [27] where weight loss cannot be reversed by eating [26]. Dietary counselling and treating the individual symptoms are recommended for improvement in quality of life [27], in the absence of any approved therapeutic option [28].

Clinical guidelines based on expert consensus are consistent in their recognition of cancer cachexia as being a complex syndrome requiring multimodal management to alleviate distress and improve quality of life [1**,12**] and/or mitigate specific related problems, such as malnutrition [29].

Multimodal interventions with education components

A scoping review published in 2021 found 19 multimodal interventions for cancer cachexia with one or more psychosocial components. Most of these interventions were intended to support selfcare. They were designed to bring about behaviour change for improved experience of cancer cachexia and quality of life. Although nine included an education, reports provided only limited information on the associated educational content and process [18*].

A framework for support of education in selfcare

It is possible that, *'a 5-minute dialogue may be more effective for relieving anorexia and/or cachexia-related distress in patients and caregivers than any 500-mg pill might be'* [30]. How can listening and offering counsel (advising/teaching) help with selfcare?

Models to aid understanding of educational process and to structure education

The Capability, Opportunity, Motivation leads to Behaviour (COM-B) model of behaviour change (see Figure 1.) can provide a framework for education of people affected by cancer cachexia. It is an evidence based and theoretically informed framework of behaviour change. Opportunity and capability influence motivation to change behaviour. Opportunity lies in the circumstances that make a change possible (or not), such as the ability to buy different foods. Capability comprises personal resources to make a change, such as knowledge of what might be a beneficial change. Motivation originates in the belief in a change being of value and the willingness to engage in the change [31, 32].

[Insert Figure 1. COM-B: a model for framing patient and family caregiver education]

Enabling capability

If education is important for knowledge acquisition, how can we enable capability? Using a story telling method is one approach to sharing knowledge [33]. It is an indirect method of sharing information likely to be experienced as less challenging by a person with cachexia and more likely to be remembered than statements of fact. For example, raising awareness of the importance of nutrition and how attention to eating and drinking can improve patient experience and quality of life,

Exemplar: My colleague told me an interesting story about a person with advanced and progressing lung cancer who was losing weight fast. He was thought to be in his last days or weeks of life. His daughter moved him into her home to provide care. The local community team offered education in the fortification of foods. For example, adding cream to soup. Much to everyone's surprise this person with cancer started gaining weight and feeling stronger, gaining the ability to do more independently. Clearly there was a malnutrition component to the cachexia, which when addressed, improved his symptoms and quality of life.

Stories can draw on past clinical experience and be adapted to the patient's individual circumstance, such as disease status, geographical location, and culture. Education for cachectic cancer patients may need adjustment for individuals, if it is to be accessible, acceptable, and informative for all who might benefit. Disparities in cancer treatment outcomes, including survival, are associated with low levels of education, poor health literacy, low income, and low levels of social support [27,34]. Tailored education may be important to enable understanding, motivate selfcare and facilitate access to resources and social support, if it is to address health inequity in people with cachexia.

Motivating selfcare

Considering the process of education may be important if we want to know how to motivate selfcare. Learning theory consistent with an holistic approach to cachexia management can provide understanding of how education can motivate selfcare. It can inform the content and process of education for enabling selfcare of cachexia-related problems.

Social learning theory provides an explanation of learning and behaviours [35]. It posits that they are the outcome of the person-environment interaction and that self-efficacy, the confidence to complete

a task, is important for motivation in learning and for change to happen. Relating this to the case of cachexia, self-efficacy to selfcare is the confidence to manage symptoms and other cachexia-related problems. Bandura (1971) [35] identified factors affecting self-efficacy. They include, the experience of success, for example, following skill training, and vicarious experience, such as seeing others succeed. Encouragement/discouragement of others is also influential. Clinicians have an authoritative voice, attended to by patients and thus influential. Family members and friends also have influence. Feedback from others is an important motivator of learning that supports selfcare.

How to educate, a missing ingredient in multimodal cancer cachexia management

There have been positive results from evaluations of multidisciplinary clinical services for cancer cachexia [36*,37*] and from exploratory trials of multimodal interventions with psychosocial components to address cachexia and its related problems [38*,39*]. The complex interventions have been found feasible to deliver and acceptable to patients and their family members [38*, 40]. Improvement has been shown in symptoms [36*], protein and energy intake [39*], weight [37*, 38*], emotional wellbeing and quality of life [36*,39*]. Whilst the multimodal interventions are reported, there is limited attention to how they might work - their mechanisms of action. Limited or no information is provided on the nature and process of education components, or how they are modified in response to non-adherence, for example, to dietary advice, or adjusted to address individual need, such as economic and cultural diversity.

In conclusion

The challenge now is to better understand how to optimise multimodal interventions. Explanatory theories, such as social learning theory and behavioural change theory, can inform the content and process of educational components of multimodal interventions. They can also help with understanding of how the interventions work (or not), which can assist in establishing best practice in meeting the educational needs of selfcare in cachectic cancer patients and their family caregivers.

In conclusion, education is an under exploited and researched mechanism supporting selfcare by people living with cancer cachexia. Education for selfcare in cachexia is important. It can facilitate the adoption of behaviours consistent with those recommended by clinical practice guidelines for best

health and wellbeing outcomes in patients living with cancer cachexia. Thus, education can help to reduce the risk of malnutrition, help to limit dependency, and facilitate understanding and adaptation mitigating cachexia-related distress with benefit to quality of life.

Key points

There is growing recognition of the need for patients and their family caregivers to receive education in cachexia and its management to mitigate the negative impacts of the syndrome

The cancer workforce need education in cancer cachexia if they are to have the knowledge and confidence to provide education for selfcare in cachexia

Patient education for selfcare in cachexia should be informed by learning theory with embedded techniques, such as storytelling, known to support health behaviour change

Evaluation of methods of education for selfcare in cachexia is needed to enable refinement of multimodal interventions.

If education in cancer cachexia is to support the agenda for health equity, then attention is needed to adjustments to education provision for groups with differing support needs to selfcare.

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Conflicts of interest

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Table 1.: Study of need for education in cancer cachexia

Author	Country	Method	Sample	Knowledge and confidence in cachexia management	Educational need and/or impact	Author conclusion
Murphy et al. 2021	UK	Survey: Provision of nutritional care in cancer	n=610, 31% nurses, 25% dietitians, 31% doctors	20% completely confident in giving nutritional advice 39% (n = 226) aware of nutritional guidelines for cancer patients Significantly more HCPs who were aware of guidelines were found to be completely confident in providing nutritional advice (n = 100, 44.4%; $\chi^2 = 149.50$, df = 4, p= 0.001) and to always discuss nutrition with patients (n = 177, 79.0%; $\chi^2 = 79.28$, df= 3, p= 0.001).	HCPs with a greater awareness of guidelines had received training (p = 0.001) and were more likely to report complete confidence in providing nutritional advice (p = 0.001)	To ensure consistency of practice and improvements in patient care, there is scope for enhancing the provision of appropriate nutrition education and training.
Ellis et al. 2021	Australia and New Zealand	Online survey: Management of CACS	n=192, 90% doctors or nurses	85% unaware of any guidelines 56% neutral or not confident in managing CACS	93% believed formal training in CACS would benefit their clinical practice	This study exemplifies the urgency for training and a structured CACS management plan for HCPs
Muscaritoli et al. 2021	Italy	Online survey (self or interviewer completed): nutrition and cachexia	n=300, 100% medical oncologists	99% aware of nutrition-metabolic problems in cancer 71% aware of guidelines 60% agreed nutritional status affects feasibility and tolerance of antineoplastic treatment 49% agreed nutritional management has a relevant role carried out only occasionally	Almost half attributed undertreatment of nutritional problems in cancer to insufficient training of HCPs	Progressively increased knowledge about the pathogenesis of cancer cachexia has not been accompanied by effective strategies aimed at improving the approach to the syndrome
Amano et al. 2022	Japan	Self-report questionnaire: knowledge, perceptions, and practices in cancer cachexia management	n=1320 HCPs (58.5% response rate) in 451 cancer designated hospitals	<50% of physicians, nurses, and dietitians used a clinical practice guideline for the management of cachexia. Half of participants reported no relationship between cachexia and life expectancy Physicians, nurses and dietitians considered their roles to be important in the management of cancer cachexia	No profession reported adequate training and confidence in cancer cachexia management 20% of participants reported educating patients and their family members on cancer cachexia. One third of these HCPs were able to provide people affected by cachexia with sufficient nutrition and exercise interventions and evidence-based information	HCPs are not regularly providing education and emotional support for people affected by cancer cachexia. HCPs need education to enhance implementation of holistic multimodal interventions
Baracos et al. 2022	Japan, Europe and North America	Mixed-methods educational needs assessment (electronic survey and focus groups): knowledge and management of cancer cachexia	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 Most participants (>84%) identified weight loss as a red flag and identified potential causes Half of participants offered patient education materials to those at nutritional risk Participants who did not routinely screen for nutritional risk thought weight loss an expected side effect of treatment and/or did not have the	All respondents reported limited general nutritional information at all levels of education and even less education in cancer cachexia.	HCPs need to better understand the pathophysiology, identification of and treatment of cancer cachexia. They need concise pragmatic guidelines and affordable education that is easily accessible and can be delivered where they are practising.

				knowledge or tools to screen and/or did not see it as a priority		
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HCP = Health Care Professional CACS = cancer anorexia cachexia syndrome

Figure 1. COM-B: a model for framing patient and family caregiver education

