

# Healthcare Professionals' Response to Cachexia in Advanced Cancer: A Qualitative Study

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**C**achexia is complex syndrome seen in many chronic illnesses, including cancer. Until 2011, cachexia lacked an accepted definition, but work by a panel of experts has developed a consensus definition, which highlights that cancer cachexia is characterized by progressive lean muscle loss (with or without fat loss) that cannot be reversed by conventional nutritional therapy. The muscle loss is caused by multifactorial metabolic abnormalities, particularly in protein and energy balances because of the underlying illness (Fearon et al., 2011). Cancer cachexia is a major cause of global morbidity and mortality, affecting about 80% of patients with advanced cancer (Tisdale, 2002); in addition, cancer cachexia is the cause of two million deaths worldwide annually (Muscaritoli, Bossola, Aversa, Bellantone, & Rossi-Fanelli, 2006). Research has uncovered that cachexia in patients with advanced cancer has profound biopsychosocial consequences for patients and their families (Reid, McKenna, Fitzsimons, & McCance, 2009a, 2009b). Physically, the loss of muscle mass often leads to extreme weakness and decreased functional ability for the patient (Fearon, Voss, & Hustead, 2006). Psychosocially, cachexia is reported to have negative consequences for the patient's body image, which can result in social isolation and emotional distancing from family and friends (Hinsley & Hughes, 2007). In addition, the accompanying symptom of anorexia often creates tension and distress among patients and their family members, who focus on feeding in an attempt to reverse their loved one's decline (Holden, 1991; Reid et al., 2009b). This may lead to conflict between patients and families at an already emotional time, suggesting that the implications of cachexia extend beyond the patient and into the family unit. Although several treatment modalities for cancer cachexia have been tested (Berenstein & Ortiz, 2005; Dewey, Baughan, Dean, Higgins, & Johnson, 2007; Reid et al., 2012; Reid, Hughes, Murray, Parsons, & Cantwell, 2013), no effective treatment exists for this distressing syndrome.

**Purpose/Objectives:** To explore healthcare professionals' experience, understanding, and perception of the needs of patients with cachexia in advanced cancer.

**Research Approach:** A qualitative approach based on symbolic interactionism.

**Setting:** A regional cancer center in a large teaching hospital in the United Kingdom.

**Participants:** 34 healthcare professionals who had experience providing care to patients with cachexia in advanced cancer.

**Methodologic Approach:** Data collection consisted of two phases: focus group and semistructured interviews. Interviews were digitally recorded and transcribed verbatim for analysis. This article reports on findings from the second phase of data collection.

**Findings:** Analysis revealed that professional approaches to cachexia were influenced by three overarching and interthinking themes: knowledge, culture, and resources. Healthcare professionals commonly recognized the impact of the syndrome; however, for nonpalliative healthcare professionals, a culture of avoidance and an overreliance on the biomedical model of care had considerable influence on the management of cachexia in patients with advanced cancer.

**Conclusions:** Cachexia management in patients with advanced cancer can be difficult and is directed by a variable combination of the influence of knowledge, culture of the clinical area, and available resources. Distinct differences exist in the management of cachexia among palliative and nonpalliative care professionals.

**Interpretation:** This study presented a multiprofessional perspective on the management of cachexia in patients with advanced cancer and revealed that cachexia is a complex and challenging syndrome that needs to be addressed from a holistic model of care.

**Knowledge Translation:** Cachexia management in patients with advanced cancer is complex and challenging and is directed by a combination of variables. An overreliance on the biomedical model of health and illness occurs in the management of cachexia in patients with advanced cancer. Cachexia needs to be addressed from a holistic model of care to reflect the multidimensional needs of patients and their families.

Documented cachexia in patients is underestimated and under-recognized in clinical practice (Millar, Reid, Porter, 2009; von Haehling & Anker, 2010).

Previous research revealed that healthcare professionals are missing opportunities to intervene and respond to the needs of patients with cachexia and their families (Reid, McKenna, Fitzsimons, & McCance 2010). Although attempts have been made to offer an explanation for why healthcare professionals miss such opportunities (Hopkinson, Wright, & Corner, 2006; Latham, 2001), no study has reflected the multiprofessional approach to the management of cachexia. Cachexia is a multidimensional syndrome and its management does not exclusively rest with the nursing profession. Given the devastating biopsychosocial impact of cachexia, the reason healthcare professionals are missing intervention opportunities must be investigated from a multiprofessional perspective. Research should aim to explore healthcare professional experience, understanding, and perception of needs of patients with cachexia and their families.

## Design

The current study focused on the attitudes and understandings of participants, indicating the appropriateness of a qualitative methodology. The theoretical underpinning of the research was provided by symbolic interactionism, a theoretical perspective concerned with examining the social context of interaction. Symbolic interactionism allows researchers to understand how individuals create and attach meaning to a particular phenomenon, and how the meaning influences their behavior and actions toward this phenomenon (Blumer, 1969). By approaching this study from a symbolic interactionism perspective, the research team could explore and understand how the participants attached meaning to cachexia in patients with advanced cancer and how this subsequently influenced their clinical practice response.

Given the absence of an agreed definition of cancer cachexia at the commencement of this study, a definition was agreed on by the research team that was considered reflective of its pathophysiology at the time, and which also acknowledged common features of already published definitions. For the purpose of this study, cancer cachexia was defined as a complex metabolic syndrome caused by an interaction between host and tumor. Cachexia is characterized by involuntary and progressive weight loss of 10% or greater of pre-morbid body weight, predominantly muscle mass (Davis & Dickerson, 2000; Fearon, 2008; Fearon & Barber, 2006; Muscaritoli et al., 2006; Skipworth, Stewart, Dejong, Preston, & Fearon, 2007; Tisdale, 2002). It cannot be reversed with nutritional intervention alone and

is associated with anorexia as well as increased morbidity and mortality (Bozzetti, 2008; Evans et al., 2008).

## Participants and Data Collection

Phase 1 of this study involved focus group interviews. Two focus groups were conducted in November and December 2009 and involved nine multiprofessional healthcare workers who had experience providing care to patients with cachexia. The purpose of the focus groups was to identify the most salient categories for exploration in the main stage of the research, which involved semistructured interviewing. Details of the results of the focus groups are reported elsewhere (Porter, Millar, & Reid, 2012). This article will focus on the main results from this study (phase 2).

Phase 2 of this research involved individual semistructured interviews conducted from February 2010 to September 2010 with 25 healthcare professionals involved in the care of patients with cachexia. A purposive sample was recruited from a large teaching hospital in the United Kingdom, which incorporates a regional cancer center. Purposive sampling was considered the most appropriate strategy because it allowed the selection of participants who had experience providing care to patients with cachexia and their families. Healthcare professionals met the inclusion criteria if they (a) were a dietitian, physician, RN, or clinical nurse specialist; (b) had an appropriate professional qualification in their field of work; (c) were working in, or in collaboration with, the regional cancer center; (d) were able and willing to be involved, and (e) were able to provide informed consent. Table 1 displays the profiles of the healthcare professionals who took part in this study. Participants took part in a single face-to-face interview. Interviews used open-ended questions facilitated by an interview guide, which was informed by the results of phase 1 of this research (see Figure 1). Interview times ranged from 30–85 minutes. Data saturation occurred once 25 interviews were conducted.

## Data Analysis

All interviews were digitally recorded and transcribed verbatim for analysis. Data analysis followed the iterative process outlined by Miles and Huberman (1994), who considered data analysis to consist of three processes: data reduction, data display, and conclusion drawing and verification. The first stage, data reduction, involved preparing the data for analysis. Statements that reflected the objectives of the study were assigned a label or code that was purely descriptive of what was represented in the text. Once data reduction were complete, the data display phase occurred, which involved entering the codes into a table with a verbatim quote to support the rationale for the code. Such visual representation assisted

the process of interpretive coding, which occurred in the conclusion drawing and verification phase of analysis to identify themes among the codes (Miles & Huberman, 1994). Then, the data were subjected to pattern coding, the process of identifying relationships and patterns in the data. Nvivo®, version 7.0, software was used to assist in the management and organization of the raw data. Analysis was carried out by the first author; however, all authors read a portion of the transcripts and contributed to ongoing analysis. Although this process did not yield any key changes, it helped to refine the final themes from analysis.

## Rigor

Lincoln and Guba's (1985) criteria for assessing the trustworthiness of qualitative research was adopted in this study. They outlined four criteria for assessing trustworthiness: credibility, transferability, confirmability, and dependability. Credibility was established through the use of data triangulation, which provided a more complete understanding of the research topic because of the use of different disciplines of healthcare professionals in the study sample (Morse, 2001). Credibility also was established by the use of peer review. During the data analysis stage of this study, a selection of transcripts was reviewed by all members of the research team to ensure consistency between the data and the primary researcher's interpretation of it. Transferability was achieved by means of thick description, which required that the descriptions of the research setting, participants, and research design be made available to the reader, allowing them to decide whether the results could be transferred to their own setting. Confirmability and dependability also were enhanced through the use of an audit or decision trail that ensured all aspects of the research process were made explicit and communicated in detail.

## Ethical Considerations

Prior to the study's commencement, permission was obtained from the Research Governance Department of the Trust, and ethical approval was granted from the Office of Research Ethics Committees. Confidentiality and data protection procedures were applied. Each participant was given a personal identification number, and all data were stored on a password-protected computer. Any paperwork arising from the study was sorted in a locked filing cabinet. Information leaflets were provided to each potential participant, and written, informed consent was gained from each participant prior to interview.

## Results

Analysis revealed three overarching themes that reflected the participant experience, understanding,

**Table 1. Profiles of Semistructured Interview Participants**

Number	Pseudonym	Area of Work
1	Nurse 1	Hematology inpatient unit
2	Nurse 2	Hematology outpatient unit
3	Nurse 3	Oncology inpatient
4	Specialist nurse 1	Palliative care
5	Dietitian 1	Palliative care
6	Specialist nurse 2	Palliative care
7	Nurse 4	Hematology inpatient unit
8	Nurse 5	Hematology inpatient unit
9	Doctor 1	Consultant in palliative care
10	Doctor 2	Resident in oncology
11	Doctor 3	Resident in oncology
12	Doctor 4	Consultant in oncology
13	Doctor 5	Consultant in palliative care
14	Doctor 6	Consultant in palliative care
15	Dietitian 2	Oncology
16	Specialist nurse 3	Palliative care
17	Nurse 6	Oncology inpatient unit
18	Nurse 7	Hematology inpatient unit
19	Specialist nurse 4	Palliative care
20	Specialist nurse 5	Palliative care
21	Doctor 7	Intern in oncology
22	Dietitian 3	Oncology surgical ward
23	Nurse 8	Oncology
24	Nurse 9	Oncology inpatient unit
25	Nurse 10	Oncology inpatient unit

and perception of the needs of patients with cachexia and their families. These domains were interconnected, indicating the clinical complexities regarding management of this syndrome. In the following sections, these themes are presented using illustrative quotations from the participant transcripts.

## Theme 1. Knowledge

Knowledge refers to both formal knowledge of the causes and effects of cachexia and informal knowledge concerning the psychosocial impact of the syndrome on its sufferers and their families. Knowledge emerged as a prominent theme in the semistructured interview data. Analysis provided insight into participant understanding of cachexia and revealed marked variations in their knowledge of the pathophysiology of the syndrome. A subset of participants across all disciplines recognized that cachexia in advanced cancer and its associated weight loss was the result of an irreversible metabolic disturbance. However, among nursing participants, some based their understanding of the causes of cachexia on the outdated "energy steal" theory.

From a physiology point of view, the cancer needs growth, it needs food to survive and to thrive, and as it takes over more and more of the body, particularly in terminal phases . . . it just seems to use more and more of the energy, so it's as if it's almost like a fetus

that is taking the energy away from the mother and . . . the cancer almost becomes the primary source, or the primary destination of energy and nutrition and all the rest. So the person . . . doesn't get enough or any nutrition and they're just wasting away (nurse 5).

A range of explanations was offered from participants for the perceived causes of cachexia and the weight loss associated with it in advanced cancer. For some participants, incomplete knowledge resulted in a lack of recognition of the syndrome in clinical practice. Difficulties were reported by some participants in making the distinction between transitory weight loss in cancer and progressive weight loss from cachexia.

I wouldn't be able to recognize anybody that had cachexia. I'm sure I probably have nursed patients with it, but I can't think of any patients that I would have done. There's lack of knowledge out there about the difference between cachexia and just ordinary weight loss, maybe following just treatment (nurse 4).

A lack of distinct management approach toward cachexia resulted in some participants from nursing and

medical backgrounds over-relying on the role of nutrition in the care of this patient group. As outlined here, some participants continued to place an emphasis on optimizing nutrition despite recognizing the futility of it.

So, you know maximizing, although often it doesn't provide a huge benefit, maximizing their intake where possible so, obviously, getting dietitians involved to work out calorific requirements and making sure those are being met (doctor 7).

Formal tuition and training are not the only sources of information. Many of the participants displayed considerable experiential knowledge of the impact of the syndrome on patients and their families.

The other thing with cachexia that I would see, especially from their wife or partner, is that it can cause conflict, especially if [patients] don't want to eat because they see this person becoming more frail, more weak, muscle wasting, and they feel that this is their duty to try to get something, some kind of food, some kind of nutrition, and it can cause a lot of conflict because the person usually does not want to know. . . . It can cause, it can raise the, or add to, the emotional trauma of the whole journey (specialist nurse 5).

Although not all participants had an understanding of the pathophysiology of cachexia in patients with advanced cancer, this extract shows that they nonetheless had gained an understanding of the impact of living with the syndrome from their interactions with patients and families during the care process.

## Theme 2. Culture

The second theme that emerged was culture, referring to the commonly held assumptions about the appropriate ways to approach the problem of cachexia. Data revealed a reticence among nurses from a nonpalliative care background to recognize but not acknowledge or discuss weight loss with patients and their families.

Patients know themselves that they've lost weight because their pajamas are looser, their slippers aren't fitting, that kind of thing, and you can see it . . . when they look in the mirror every day, their cheeks are more sunken, maybe they've more hair falling out, or they can see their nails starting to deteriorate. So, I don't think they need the reminder from staff to say "your man [grim reaper] is knocking quicker" (nurse 5).

Many of the nonpalliative nursing and dietetic participants were concerned that acknowledgement of weight loss in this patient group would cause them additional distress.

### Understanding of Cachexia

- What comes to mind when I mention the word "cachexia" to you?
- Can you explain why these changes occur?
- Is it something you would see often in your practice?
- Previous education/training about cancer cachexia?

### Recognition of Cachexia and Its Management

- How do you recognize cachexia-induced weight loss?
- How would you assess a patient who has advanced cancer for cachexia?
- Are you aware of any interventions in place for patients with cachexia?
- What do they perceive is their role in cachexia management in advanced cancer?

### Impact of Cachexia on Patients and Their Families

- What sort of an impact does cachexia have on patients with advanced cancer?
- What sort of impact does it have on their families?
- Do patients and their families understand cachexia and reason for this weight loss?

### Communication and Avoidance Issues

- Problems with communication about cachexia in advanced cancer?
- Explore why. What are the particular areas of concern?
- What would you consider to be good quality cachexia management in advanced cancer? Any unmet patient and family needs?
- In your role, what do you perceive is your responsibility for management of cachexia in advanced cancer?

### Summing Up

- Anything else you would like to add to the discussion which we have not covered?

## Figure 1. Semistructured Interview Guide

You know, as far as weight and things go, I very seldom would weigh people unless they specifically ask me to weigh them. Because with somebody with cachexia, I mean they know, you know, and everybody can see that they've lost the weight and it's usually very distressing for them. . . . There's no point in me adding further to the distress by weighing them and saying "Well, yes, actually you've lost four stone from your normal weight" (dietitian 1).

The culture of avoidance additionally was created and maintained by the reported practice of some physicians telling patients with cachexia to "go away and build yourself up" (doctor 1).

Explanations for this practice and the reluctance to engage in such conversations also were uncovered in the data. For some physicians, it was the fear of taking away hope for the patient at this advanced stage of their illness. However, it was recognized across all disciplines that the desire of some to maintain hope may, in turn, provide false hope and expectations for patients and families about what could be achieved in relation to their weight loss.

The patient is given that thread of hope, which you would have to argue is a little bit of false hope; there are other ways of giving hope, but the patient is given that thread of hope. The patient goes out feeling they've some chance and the oncologist or whatever clinician hasn't had to personally face the reality that this person is deteriorating and that they are going to continue to lose weight. . . . I think it leaves families and patients struggling to do the impossible and then possibly feeling that they've failed when they are not able to do it (doctor 1).

The impact of culture on the management of cachexia was uncovered further in relation to the influence of the biomedical model of health and illness within the clinical setting of this study. For those professionals from a nonpalliative care background, particularly the physicians, it was evident that their practice was influenced heavily by this model, which places an emphasis on cure and embodies attention to care of the physical aspects of disease.

I deal with things that I can deal with. I fix things that I can fix. Anything that's within my control and deal with. You know, at the end of the day if the patient initiated the conversation to me, "Oh I look awful and all," obviously, I'll naturally sit down and talk them through and talk with them about it; but I'll not sort of sit and actively seek to have a 40-minute discussion with them about the psychological impact of how their current appearance is affecting them because I don't have the time to, and I don't think that, I think that there might be

other things that I can do as a medical, just purely medically to try and actually reverse it or fix it and make them feel better (doctor 3).

The study also revealed that the practices of nursing and dietetic staff, who do not subscribe to the biomedical model, were heavily influenced nonetheless by the biomedical model of care.

I think I find working somewhere like this where it's a treatment center, you're trying your best to treat them and reverse everything and make it right, and I think even nursing and dietitians, we're all guilty of that, we're maybe not identifying all the time what's truly going on if somebody has cachexia and it's not necessarily about reaching a certain goal but trying to minimize side effects and things (dietitian 2).

Evidence suggested that cachexia management was relegated in priority in the clinical setting by the non-palliative care professionals because the tendency was to focus on symptoms that could be managed or treated more effectively.

We tend to sometimes concentrate more on other problems like pain or wounds or whatever. It probably could be better tackled, I think . . . they're more within our ability to treat, I suppose. I mean, you can always give something for pain relief or make somebody more comfortable in bed or whatever, but it's hard to think what you can positively do for someone with no appetite with a lot of weight loss (nurse 8).

In contrast, the participants who worked in a specialist palliative care team adopted a more holistic, biopsychosocial model of care.

You'd be looking at, not just from a physical perspective, that's obviously going to be done, but people would be expected to go into detail in terms of their bio-psychosocial assessment and . . . there should be triggers alongside that as to then to refer, who to refer onto (specialist nurse 2).

In addition, interviews with the palliative care professionals revealed a difference in how they perceived the priority of cachexia as a result of the influence of the holistic model of care. Their priorities of care were dictated by the patients and what they considered to be their main concerns.

I suppose in hospitals, as well, our conversations in our role tend to be led by the patient so whatever their concern is that day, we talk about. I mean, we might have a mental checklist in our head, you know, where you're sort of thinking, "the last time I came the main problem was pain or whatever,"

but if that's not what they talk about then you sort of talk about what they're talking about and then at the end you'll say, "Oh, last time this was a problem. How is that now?" so it tends to be led by the patients. You might go to the visit with objectives that you need to sort of do for that day but they might change when you walk in the house, you know? So, what they want to talk about, that's what we talk about (specialist nurse 3).

From the interviews with palliative care professionals, less evidence existed that they engaged in a culture of avoidance in relation to communicating with patients and families about the meaning of cachexia. They acknowledged that communication with this group of patients is challenging for all healthcare professionals, including themselves; however, participants still engaged in discussions with patients and families.

You have to start from the beginning and find out what the patient knows, how much the relative knows, who do they want to be involved . . . what the facts are, and then gently explaining the fact that you know in advanced disease, the body's requirements do go down and even in terms of fluid, its more common that in food, the amount that someone might need is a lot less, and the fact that if you try to overfeed somebody, especially artificially, they would have other problems like feeling sick, vomiting, and aspiration. . . . Most of the time, it would be gradually understood, sometimes there are battles but, I think, the fundamental problem is not realizing how extensive somebody's condition is and I think that's addressing the problem . . . not the fact that they're maybe not being fed or not eating properly, its why this is happening. And that's where we would spend a lot of time, addressing the fact (doctor 6).

### Theme 3. Resources

Analysis established that the availability of resources in the clinical area had a considerable impact on the management of cachexia in advanced cancer. Data revealed that lack of time and staff were frequently cited by participants across all disciplines as barriers to its effective management. For physicians, it was recognized that patients and families need time to discuss nutritional concerns; however, they reported a lack of sufficient time in clinical practice to address these.

Obviously, the problem with clinics, for us as physicians, time is limited. You haven't got all day, you know to take a full complete dietary history, and you've also got other issues like working out the appropriate systemic therapy, getting that right, so the problem is we're actually quite limited in

what we can do, the time we can spend. Although, obviously, more time should be spent by us and probably dietetic staff to be honest (doctor 2).

In relation to dietetics, the impact of understaffing was revealed by dietitian 2, who recognized that it placed limitations on the amount of support provided to patients who were at risk of developing cachexia.

In an ideal world, if we had more staff, you know, it would be great and you could see patients, all patients, or you could see everybody early on if it was a specific, maybe if it was a specific patient group like lung or pancreatic who you know were going to go through some degree of weight loss as soon as they are diagnosed; but, at the minute, it doesn't happen unfortunately. And it's not possible, we wouldn't be able to cope with it and then maybe patients who really, really need us, you know, who are really in the throes of treatment and losing weight, then we wouldn't be able to see them for enough time. So, it's trying to prioritize, we're trying to prioritize at the minute but ideally, if it ever changes, it would be great to see them earlier on (dietitian 2).

Conversely, the benefit of having time to manage cachexia in advanced cancer was revealed in the interviews with some of the specialist palliative care professionals. Evidence suggested that dedicated time with patients and families allowed for a more effective approach to management of the syndrome as it allowed for more effective communication with patients and families.

I think, yeah, perhaps we have a bit more time to do it [explore the meaning of weight loss in advanced cancer] in say at the palliative medicine clinic or in the hospice as an inpatient (doctor 6).

### Thematic Combinations

The overarching themes of knowledge, culture, and resources did not influence practice in isolation. For example, a lack of education and training resources also was revealed as a barrier to effective management of cachexia in advanced cancer. Some of the nursing participants reported a lack of professional education about cachexia in their preregistration training.

Because of lack of knowledge, lack of knowledge and understanding because it's something I certainly haven't been aware of in my [preregistration] training (nurse 4).

This lack of education also could provide a rationale for the reticence of healthcare professionals to provide an explanation and meaning for cachexia in advanced cancer.

If they know a bit more, they can talk to the families about it and they feel then, they don't feel so under

pressure when a family member comes and says “You’re not giving them food” or “You’re not doing enough about their nutrition.” They don’t feel then, instead of trying to give nutrition, they feel then that they can then explain why they’re not doing that or what the process is (nurse 7).

As acknowledged by doctor 7, at times their teaching program can be ad hoc and, therefore, cachexia in advanced cancer management was excluded.

Yeah, if you’ve got a tight teaching session and you want to get through as much as possible, then you probably would prioritize other things above it. That’s sort of in the ad hoc teaching that we would do (doctor 7).

The link between culture and resources is highlighted as it is evident that the influence of the biomedical model of care has extended into teaching priorities for physicians. In a treatment-focused clinical setting that subscribes to the biomedical model of care, this naturally resulted in an emphasis on physical aspects of care in teaching.

Probably it’s [cachexia] not as maybe high profile as maybe other aspects of terminal care, so whenever you’re doing any teaching on terminal care you’ll maybe focus on the areas you feel more comfortable with and just in general, culturally within medicine, it’s not as high profile and that always impacts on teaching. You know people always teach about things they’re familiar with and confident with, so does that make sense? (doctor 7).

## Discussion

This study demonstrates that cachexia management is complex and challenging for healthcare professionals. As the findings revealed, its management is not just reliant on one strategy. The domains of knowledge, culture, and resources highlighted in the findings are not mutually exclusive, but instead intersect. Many of the management challenges revealed by the participants were complex and influenced by elements from all three themes, which reflect the multidimensional nature of cachexia management in advanced cancer.

Variations were revealed across all disciplines in the extent of participants’ knowledge of the causes and management of cachexia in advanced cancer. Although all participants recognized that cachexia was associated with tumor presence, only some recognized the metabolic pathophysiology of the syndrome in line with the most recent explanation offered in the literature (Fearon et al., 2011). Others still believed in the outdated metabolic steal theory, which has been refuted in the literature

(American College of Physicians, 1989). This incomplete understanding about the causes of cachexia in advanced cancer confirms previous work by Latham (2001) and Churm, Andrew, Holden, Hildreth, and Hawkins (2009), who reported a lack of knowledge about the syndrome among healthcare professionals in community and hospital settings. Patients and their families want information on the causes and implications of cancer cachexia (Reid et al., 2010); therefore, a lack of knowledge on the part of healthcare professionals will compromise their ability to provide such information and leave the patient and family isolated to cope with the syndrome alone.

Failure to provide information was compounded further by the difficulties in recognizing cachexia reported by some nursing participants. Muscle wasting and anorexia, two of the hallmarks of cancer cachexia (Fearon & Barber, 2006), were not always associated with the syndrome. This lapse was despite recognition from participants across all disciplines of the impact that cachexia and anorexia had on patients and their families. The body of literature suggests that patients and families may experience eating-related distress at the end of life (Holden, 1991; Reid et al., 2009b; Strasser, Binswanger, Cerny, & Kesselring, 2007); however, the lack of appropriate response from some healthcare professionals uncovered in this study denotes a fundamental gap in care provision for patients with cachexia in advanced cancer and their families.

The missed opportunity for intervention that arose from a lack of knowledge of the syndrome contributed to an overall culture of avoidance about cachexia that was uncovered in this study. The culture of avoidance about cachexia uncovered in this study adds further evidence to the prevalence of a weight loss taboo at the end of life that was reported (Hopkinson et al., 2006). Receipt of experiential knowledge of the inevitability of the syndrome in advanced cancer further contributed to this culture of avoidance. Evidence suggested that some healthcare professionals from a nonpalliative care background were reluctant to acknowledge cachexia given the prognostic significance of weight loss at the end of life. They believed that it was the imparting of such information that would cause distress to patients and families; however, as confirmed by Innes and Payne (2009), the failure to disclose such information can cause distress. A lack of acknowledgement by healthcare professionals of weight loss in patients with cachexia has been reported previously by Reid et al. (2010) and resulted in a perceived lack of patient and family insight into treatment intent and plans of care. This culture of avoidance was exacerbated by a reported reluctance of some physicians to engage in conversations about the presence and meaning of cachexia in patients with advanced cancer. Research findings have consistently reported the importance of open and honest conversations with patients and families about end-of-life

concerns to allow time to prepare for impending death (Parker et al., 2007; Quill, 2000). However, data from this study confirm the findings of a body of literature that suggests that some medical staff experience difficulties engaging in end-of-life conversations (Amiel et al., 2006; Dosanjh, Barnes, & Bhandari, 2001).

The influence of models of health and illness on the management of cachexia in advanced cancer provided an explanation as to why there was less evidence that palliative care professionals contributed to the culture of avoidance about cachexia. The dominance of the biomedical model of health and illness prevailed in the clinical setting of the research, which is characterized by a central focus on cure (Wade & Halligan, 2004). This relegated the importance of cachexia given the absence of an effective treatment intervention; despite recommendations in the literature that optimal management of the syndrome in patients with advanced disease should be directed at managing its psychosocial implications (Radbruch, Elsner, Trottenberg, Strasser, & Fearon, 2010; Reid et al., 2009a). In contrast, palliative care professionals practiced under a holistic model of care that embodied attention to the psychosocial needs of patients and families, as well as the physical needs (Wade & Halligan, 2004). Subsequently, this allowed for the delivery of more patient-focused care rather than the task-orientated care dictated by the biomedical model. Central to this was holistic assessment as it was recognized that patients with cachexia need a multidisciplinary approach to their care that addresses the complex biopsychosocial impact of the syndrome (Reid et al., 2009a). This holistic assessment by healthcare professionals is essential given the conclusions of Detmar, Aaronson, Muller, and Schornagel (2000), who suggested that patients and families only discuss their psychosocial concerns if the issues are raised by their healthcare professional. Therefore, failure to adequately engage in holistic assessment could risk the full multidimensional impact of the cachexia being under recognized.

Participants also reported lack of professional education and training to equip them with the knowledge and skills required to meet the information needs of this patient population, further adding to the culture of avoidance and confirming previous findings by Reid et al. (2010), who reported a lack of information from healthcare professionals on the causes and implications of cachexia.

## Implications for Practice

General nurses, clinical nurse specialists, physicians, and dietitians all have a role to play in the delivery of care and, therefore, improve the experience of cancer cachexia for patients and their families. Healthcare

professionals need to educate patients and families about the causes and implications of cachexia. This should be done prospectively to prepare patients and families for the potential of weight loss and anorexia so they are not left struggling to cope and understand it in the already emotive end stage of their disease. Incomplete understanding of the causes of cachexia and difficulty recognizing cachexia highlight the need for an educational intervention for healthcare professionals at undergraduate and postgraduate levels to give them the formal knowledge required to educate patients and families about the syndrome. Patients with advanced cancer and their families also need to better understand the role of food in cachexia management and the futility of maximizing nutritional intake at the end stage of the disease trajectory. Healthcare professionals are in a key position to help educate patients and families about the biologic processes responsible for cachexia and help them recognize it as a natural part of terminal decline. This engagement with patients and families about the meaning of cachexia may help shift their focus away from the perception of food as a means of survival, and dissociate the connection between their loved one's decline and their lack of nutritional intake. The existence of a culture of avoidance about discussing the presence of cachexia in patients with advanced cancer, therefore, needs to be addressed urgently and indicates the need for intervention for healthcare professionals to help them manage challenging communication issues. Finally, patients with cachexia have complex multidimensional needs; therefore, the provision of holistic, multiprofessional care is vital for effective management. A move away from the dominance of the biomedical model of health and illness toward a more holistic approach to care will realign the lack of priority given to cachexia in advanced cancer.

Results of research into the experience of cachexia in advanced cancer for patients and their families (Reid et al., 2009a) and from this study need to be combined to inform the development of a psycho-educational intervention for patients with cachexia in advanced cancer and their families. Patients with cachexia in advanced cancer and their families want their weight loss acknowledged, they want information on its causes and implications, and they want an intervention to help manage it (Reid et al., 2010). The psycho-educational intervention would, therefore, involve the provision of information about the typical aspects and concerns associated with the presence of cachexia in advanced cancer, such as weight loss and loss of appetite, with the aim of reducing stress and improving coping in this patient and family group by increasing understanding about the nature and impact of the syndrome. The current study provided an insight into the context and challenges of care provision to this patient group, which had not been previously explored, and which is essential to the development of a sustainable

and feasible intervention for the management of cachexia in patients with advanced cancer. Future research should be directed at the development, testing, and evaluation of this intervention.

## Limitations

The findings presented in this article must be interpreted taking into account the study's limitations. It could be argued that only those who had a strong interest or knowledge of cachexia in advanced cancer would volunteer to take part in this study, given the need to participate in discussion about cachexia. This could have potentially skewed the results and provided an inaccurate representation of the response of healthcare professionals to cachexia. However, the data suggest otherwise, given the variable combination of responses from healthcare professionals and the overt acknowledgement by some of their lack of understanding of cachexia and its management.

## Conclusions

This study is novel as it presented a multiprofessional perspective on the management of cachexia for patients and their families. The findings reveal that the manage-

ment of cachexia is directed by a variable combination of the influence of knowledge, the culture of the clinical area, and available resources. It identified distinct differences in the management of cachexia in patients with advanced cancer between those professionals from a nonpalliative care background and those from a palliative care background. Among all disciplines of the nonpalliative care professionals involved in this study, an over reliance on the biomedical model of health and illness occurred in the management of cachexia in contrast to a holistic model of care that tended to be adopted by palliative-trained healthcare professionals. Healthcare professionals need to not only recognize the impact of cachexia, but also have the necessary knowledge, culture, and resources to allow them to respond to it in an effective manner.

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