

Original Research**Managing Cancer Cachexia: Multi-Disciplinary Healthcare Perspectives**Joanne Reid, PhD^{1*}; Aminah Jatoi, MD²; Elisa Enriquez-Hesles, BSc³; Samuel Porter, PhD⁴¹School of Nursing and Midwifery, Medical Biology Centre, Belfast, BT9 7BL, UK²Department of Medical Oncology, The Mayo Clinic, Rochester, MN, USA³Health Sciences Center, School of Medicine, Charlottesville, VA 22908-0395, USA⁴Department of Social Sciences and Social Work, Bournemouth University, Bournemouth BH1 3LT, England***Corresponding author****Joanne Reid, PhD**Professor, School of Nursing and Midwifery, Medical Biology Centre, 97 Lisburn Road, Belfast, BT9 7BL, UK; E-mail: j.reid@qub.ac.uk**Article information****Received:** March 17th, 2019; **Revised:** July 11th, 2019; **Accepted:** July 17th, 2019; **Published:** August 7th, 2019**Cite this article**Reid J, Jatoi A, Enriquez-Hesles E, Porter S. Managing cancer cachexia: Multi-disciplinary healthcare perspectives. *Palliat Med Hosp Care Open J.* 2019; 5(1): 14-22. doi: [10.17140/PMHCOJ-5-132](https://doi.org/10.17140/PMHCOJ-5-132)**ABSTRACT****Background**

Cachexia is a syndrome which is a common feature in more than 80% of patients with advanced cancer and globally accounts for over two million deaths per annum. At present there are no standard treatment guidelines for cancer cachexia management. Previous research conducted with the United Kingdom and Australia has highlighted different understanding and treatment practices of health care professionals in cachexia management, however, no study has elucidated the understanding and current practices of health care professionals in the United States.

Aim

The aim of this research was to explore the understanding and current practices of health care professionals in the United States when providing care to an individual with advanced cancer who has cachexia.

Methods

This is a qualitative study underpinned by symbolic interactionism. Face-to-face semi-structured interviews were conducted (n=17) with multi-disciplinary oncology staff and thematically analysed. Health care professionals were recruited from one large health care facility in the United States, until data saturation was reached. NVivo was used for data management. Criteria for upholding rigor (credibility, dependability, confirmability, transferability) were adhered to within this qualitative study. Full ethical approval was obtained prior to data collection commencing.

Results

Analysis determined four main themes related to (1) recognizing the signs and symptoms of cachexia; (2) the multidimensional impact of cachexia on both patients and families; (3) complexities when treating cachexia; and (4) future direction of care delivery for patients with advanced cancer who have cachexia.

Conclusion

Participants within this study recognized the multi-factorial pathophysiology of cachexia and its holistic impact which spanned biological, psychological and social domains. Additionally, they recognized the impact of cachexia on not only patients but also their family carers. In particular the feelings of helplessness family carers experience in trying to stop the progressive and involuntary weight loss associated with cachexia. Further research is required to examine how to best support the needs of patients with advanced cancer who have cachexia and their family carers and equip staff to optimize delivery of this.

Keywords

Qualitative research; Cancer cachexia; Symbolic interactionism; Multi professional care; Patients and carers.

BACKGROUND

Cachexia is a syndrome which is a common feature in up to 80% of patients with advanced cancer.¹ Despite the high incidence

of cachexia in advanced cancer, there is currently no standard of care for its management² and despite much research activity no clinical trials have led to treatment approval for the management of cancer cachexia.³ Patients with cancer cachexia experience re-

duced quality of life, reduced tolerance to treatments, and shortened survival.⁴ It is a complex metabolic abnormality that combines weight and muscle loss, anorexia, oedema, chronic nausea and fatigue.^{5,6} It has been consensually defined⁷ as a multifactorial syndrome characterised 'by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support.'^{7 (p 8)} Cancer cachexia encompasses three main stages: precachexia, cachexia and refractory cachexia.⁸ Refractory cachexia,⁷ which is the focus of much of the research conducted, refers to the 'stage where reversal of weight loss seems no longer possible.'^{7 (p 8)} Previous research has established that cachexia in advanced cancer has profound biopsychosocial consequences for patients and their families.^{9,10} Physically, the loss of muscle mass often leads to extreme weakness and decreased functional ability for the patient.⁶ 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.¹¹ 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.^{9,10,12}

To date, research on the experience of cachexia has mostly focused on patients and their families.^{9-11,13,14} It is only in recent years that researchers have focused on healthcare professionals' perceptions of cancer cachexia. Qualitative research carried out in a regional cancer center in the United Kingdom (UK) provided a multi-professional perspective on the management of cachexia in patients with advanced cancer. This research revealed that cachexia is a complex and challenging syndrome that needs to be addressed from a holistic model of care.¹⁵ Further qualitative research conducted in a major teaching hospital in Australia indicated that contextual features of healthcare provision could influence professionals' responses to the challenge of cachexia. Specifically, the benefits of a dedicated cachexia clinic were noted.¹⁶

The differences identified in the UK and Australian studies underline the importance of conducting international research to identify both differences in how cachexia is understood and managed and to also identify best practice. In order to explore how the care of patients with cachexia is managed in the United States (US), the research reported here was conducted with professionals working in a major US medical practice and research group that is highly ranked for its cancer care. The aim of this research was to explore the understanding and current practices of healthcare professionals in the US when providing care to an individual with advanced cancer who has cachexia.

METHODS

This research uses interpretivist qualitative methodology.¹⁷ The theoretical foundations for this study are drawn from symbolic interactionism, a sociological perspective with origins in pragmatism, which builds on three main assumptions.¹⁸ First, people strive and act toward what represents meaning for them. Secondly, meaning arises out of social interaction. Finally, meanings are modified through an interpretative process.¹⁹ Therefore, a core tenant of

symbolic interaction is the inseparability of an individual and the context within which that individual exists.²⁰ This lends itself well to this research as it is exploring healthcare professionals understanding and current practices providing care to an individual with advanced cancer who has cachexia.

Sample and Recruitment

Given the specified aim and method of this study, purposive sampling was the most appropriate sampling strategy.²¹ This means that participants were selected because they had provided care to patients who had advanced cancer with cachexia. The appropriateness of selecting this sampling strategy is highlighted in the literature.²² Participants could be recruited into this study if they were a registered healthcare professional (pharmacist, medical doctor or nurse) currently working within the in-patient oncology directorate of the recruiting medical facility, who were able and willing to be involved.

To recruit participants, a clinical gatekeeper from the recruiting clinic approached staff either by email or verbally and asked them if they would like to participate. All participants who agreed to take part within the study undertook an interview. An information sheet was provided to all potential participants. If a care provider was interested, a mutually agreed time and venue was arranged for the interview to take place.

Data Collection

We recruited 17 healthcare professionals who worked within in-patient oncology in the recruiting institution to take part within this study from various disciplines (nursing=7; medical=9; and pharmacy=1). Data collection was *via* semi-structured interviews.²³ Due to the potential impact that could arise when an interview is conducted with a workplace colleague or peer, the interviews were conducted by a researcher (EEH) not involved in current patient care. Interview times ranged from 20 to 60-minutes. Data were collected from oncology practitioners (n=17) in the recruiting clinic. Within the interviews, the research team were cognisant of the importance of using open ended interview questions to facilitate communication to aid the research participants sharing their personal experiences.²⁴ Icebreaker questions were used to ease the participants into the semi-structured interviews, followed by main topic questions relating to the study, concluding with closing questions providing participants with the opportunity to raise any issues or air any concerns. When devising the interview agenda previous work in this area was acknowledged.²⁵ Such work advocates using an interview guide with five to seven broad areas of interest relating to the research topic. The interview agenda in this study contained a flexible format. This allowed room to phrase questions spontaneously, to probe, clarify and reflect. Table 1 below shows the five broad topic areas and example questions and prompts that were used with participants. Interviews and data analysis ran concurrently and interviews were completed when data saturation (i.e. no novel data) was achieved.²⁶

Table 1: Semi-Structured Interview Agenda

1) Interpreting cachexia

- Could you start by telling me what you think of when you hear the term 'cachexia'?
- What images come to mind when you think of someone as having cachexia in advanced cancer?
- Can you explain why these changes occur?

2) Managing cachexia

- Can you tell me your experience of managing an advanced cancer patient with cachexia?
- Are you aware of any interventions in place for patients with cachexia in advanced cancer?
- How would you assess a patient with advanced cancer for cachexia?
- What are your priorities of care for an advanced cancer patient with cachexia and their families? Why these priorities?

3) Multi-professional working

- What support do you have in managing patients with cachexia in advanced cancer and their families?
- What do you consider is the most important part of your role in managing patients with cachexia and their families? Why?

4) Needs of patients and their families

- Do you consider cachexia in advanced cancer to be problematic for patients and their families? If so, why? If not, why?
- What do you perceive is the impact of cachexia in advanced cancer on patients and their families? Why is this?
- What do you think the needs of advanced cancer patients with cachexia and their families are? Why do you think this?

5) Quality management of cachexia

- How do you perceive the current care available for advanced cancer patients with cachexia?
- What would you consider to be good quality cachexia management?
- Can you think of anything else we should be doing?

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

Data Analysis

All interviews were digitally recorded and transcribed verbatim for analysis. Analysis was carried out using qualitative thematic analysis as outlined by Miles et al.²⁷ Analysis was led by two authors who are experienced in qualitative data analysis (JR and SP). Both authors read the transcripts independently and then coded each transcript by capturing common threads of information, in an iterative process.²⁸ Similar codes were clustered together, categories were then formed with groups of similar codes, and then the categories were grouped together to represent themes in these data.²⁷ All authors were involved in refining and agreeing the final themes. NVivo was used for data management. The two authors compared their individual coding until consensus was reached on final coding and themes.

Rigour

Transferability of the results was achieved through 'thick description'. Analysis revealed the diversity of viewpoints among participants and in this way thick description seeks to understand each participant's perspectives.²⁹ Transferability was enhanced by providing rich descriptions of the data from which conclusions have been drawn.³⁰ The dependability and confirmability of the study were achieved through the provision of a transparent audit trail in which every aspect of the research process is made explicit. By undertaking a systematic audit process and communicating the research process in detail, the quality, credibility and rigour of the work is demonstrated. This makes the analysis traceable and enables the investigators to verify that the conclusions have been clearly derived from the data.³¹

Ethical Consideration

Ethical approval was obtained from the Mayo Clinic Institutional Review Board. Fundamental principles of good practice including informed consent, voluntary participation, confidentiality and data protection procedures were applied as a minimum standard in the study.³² Verbal consent was gained from each participant and digitally recorded at the start of each semi-structured interview. All participants were informed of their right to decline to provide specific information or to withdraw from the semi-structured interview at any point without negative impact. No incentives were offered and the researchers did not engage in coercion of any kind. A participant identification number (PIN) was allocated to each participant. Only the researcher team had access to the list which identifies the PIN of each participant. All transcripts were anonymised and pseudonyms are used for verbatim quotations.

RESULTS

There were four main themes that emerged from the data. Each will be explored in turn with excerpts used to support theme development. The data presented displays the opinions of the participants who took part with this study, with excerpts selected to best display these opinions. Analysis sought to identify any negative case analysis, where for example one care providers opinion differed from the remainder of the sample. However, there were no negative cases within the findings presented within this paper.

Recognition of Signs and Symptoms of Cachexia

Clinicians interviewed were very clear about the symptomatology of cachexia in advanced cancer, providing narratives that accorded

closely with the literature. One interesting aspect of the accounts of cachexia was the inclusion by some respondents of signs and symptoms more associated with advanced chronic disease and its treatment in general rather than cachexia in particular, namely ascites and hair loss. Some were sceptical of using the term cachexia, preferring to treat associated symptoms individually on their presentation.

"We talk about appetite, weight loss, and probably the terminology that has most replaced "cachexia" is what we call "performance status" (Interview 3)

The importance of functional and psychosocial impairment of the syndrome and the impact that they had upon the quality of life of patients and their families was clearly recognized by respondents. In addition to having a comprehensive understanding of the signs and symptoms of cachexia, respondents also displayed an acute awareness of its deleterious consequences for patients and their families.

Recognition of the Impact of Cachexia

Impact on patients: The holistic impact of cachexia on patients was apparent to respondents, including biological, psychological and social impact.

"It's a huge burden and ultimately affects the quality of life and probably shorten their life as well". (Interview 14)

It was acknowledged that one of the hardest parts for patients themselves could be the fact that they were

"Doing everything and then everyone's telling them, "you're not maintaining your weight" (Interview 17)

Cachexia impacted both within and across the biopsychosocial domains and the presence of cachexia and its preferential loss of lean muscle mass was a visual reminder of the state of illness the patient was experiencing. The progressive nature of cachexia meant the assault it inflicted on patients was inexorable, defying often heroic efforts to combat it. This was often profoundly dispiriting for patients

"There are all these milestones that I think we're prone to try to get to. So anyway, they're frustrated by that and trying so hard to get to that and then they're working so hard to maintain their weight, to be healthy and then if they have to start struggling with cachexia.... "it's like no matter what I do I can't help myself". That helplessness I think is one of the hardest things that people have to deal with" (Interview 17)

Impact on families: Data highlighted how family members viewed the progressive weight loss and reduced appetite associated with cachexia as a barometer of overall health and related it to terminal decline. Cachexia was frequently seen to induce more stress for family members than patients.

"It seems to impact family members sometimes to a larger degree

than the patient. Because they are getting just constantly on their relatives, asking them to eat more. And sometimes, just...it can become really tense because a lot of times these people are dying and they just see it as a sign or a manifestation of their slow death" (Interview 3)

Often, family anxiety was observed to play out over the issues of diet and feeding. Having ceded most aspects of care and treatment to the professionals, the one area that many family members believed that they could contribute to the wellbeing of their loved one was in facilitating nourishment:

"I think sometimes that's what family members focus on because they can't control anything else and so I think sometimes that's hard for the cancer patient because they don't feel like eating but they feel like that's what their family is kind of focused on" (Interview 12)

It was recognized that the combination of family members' feelings of obligation to ensure that their loved ones are nourished and patients' experience of anorexia and early satiation could lead to the frustration of all parties involved:

"The family though can be pretty distressed and really trying to encourage family to eat and they're frustrated because the person can't eat what they think and the person's doing what they can and they're frustrated because other people are trying to force food on them. It's a very tough situation" (Interview 2)

Respondents observed that, unfortunately, this frustration can sometimes boil over into conflict between patients and family members, and even to coercion.

"And I think that for a family member, that's something they can control and so it becomes a bit of a pressure – like the patient will say, "well I eat meals a day because he forced me" or "she forces me" (Interview 16)

The futility associated with feeding in refractory cachexia and the progressive decline of the patients was evident to some respondents. The associated emotional turmoil that it induced in family members was apparent:

"It's not just the physical slow wasting, no matter what you do, but it's also that emotional frustration that these poor people have to deal with" (Interview 17)

Modalities of Treatment and Care

Notwithstanding the concerns recounted above about the deleterious consequence of family members' attempts to push nutrition on unwilling patients, the most common clinical strategy to mitigate the physical effects of cachexia was the promotion of caloric intake. That said, respondents reported that they adopted strategies that simultaneously attempted to meet family members' desires to provide their loved ones with nourishment while also taking into account the early satiety of patients. Thus, patients and family members were encouraged to adopt eating strategies that maximized the number of calories patients consumed within the

confines of cachexia-associated anorexia.

"I'll tell them, I'll recommend that they eat small amounts frequently throughout the day; don't try to sit down to a big meal because that's not going to sit well in your stomach" (Interview 3).

More alarmingly, it was recognized that, in the desperation to do something to halt weight loss, the quasi-medicinal presentation of dietary supplements could prompt family members to pressurize their cachectic loved ones to consume them against their will.

"You have some ... relatives that insist that they want to do nutritional supplements and I'll say, 'well that's a good way to get calories but don't force it down – remember, this is quality of life and sometimes trying to get that in you and you don't feel for it might impact the quality of life as well'. So I do try to mediate a little bit between them" (Interview 16).

This quotation is an indication that some practitioners were aware that the use of ineffective treatments to bolster the psychological wellbeing of relatives could have negative consequences, and their consequent realization that orienting relatives to the reality of the situation and supporting them in developing strategies to make the best of it was an important aspect of the professional's role. The difficulty for professionals with this approach was that it almost inevitably entailed a candid conversation about approaching mortality. However, some recognized the benefits of having such a conversation:

"I think maybe helping families know that some of these things are normal and cachexia is part of the life process and understanding that this is maybe not something we can always reverse if it's... sometimes what happens toward the end of life" (Interview 2).

Another strategy reported by respondents was the prescription of hormonal and corticosteroid medication to stimulate appetite.

"Sometimes we can give steroids – low-dose steroids – that can help, appetite stimulant, they help just a little bit – Megace [megestrol acetate], Marinol [dronabinol]" (Interview 14).

However, as can be seen by the qualification in this quotation that 'they help just a little bit', respondents expressed considerable doubt about the efficacy of this strategy.

"The medications we have are relatively ineffective and relatively toxic so for example, megestrol acetate does work and sometimes works fairly well but has side effects. Patients are very, very worried about potential for blood clots. Steroids work a little bit in the short term, I think by causing water gain and then you have proximal myopathy and you're worse off than you started with. And that's probably it, and I think the rest of these are all unproven" (Interview 5).

Indeed, it was admitted that the purpose of prescribing appetite stimulants could be less about physiological benefits and more about reassuring anxious relatives that something was being

done to help the patient.

"When they can't seem to encourage the nutritional intake or tempt the person with the foods that they like, then it comes to the doctor and say, 'can you give him something to help his appetite?' You know, steroids can do that, but they have a lot of adverse effects. Progestational agents particularly, Megace, megestrol acetate, can boost the appetite, but again, you might be treating the family more than the patient" (Interview 3).

Recognition of lack of effectiveness of treatments to deal with the physiological effects of cachexia could be dispiriting for healthcare professionals:

"So what do we do for the family members? We basically provide information. We talk about like, 'this is the process and what's going on', we talk about measures that can be taken to help with that – both the patient and the family. There aren't really that many things. There's some research done but not a whole lot has been – or not a whole lot that can be done to actually help" (Interview 14).

It can be seen that respondents viewed cachexia as a problem that they currently have considerable difficulty in responding to in an effective manner.

"I think as oncologists we could do a lot better with measuring and quantifying cachexia. It's like a lot of it's gestalt and a lot of times we are, sadly, we just...don't pay attention to it. Or not at much as we should" (Interview 5)

Staff Perceptions for Future Improvements in Care

Participants discussed what might be done in relation to cachexia in patients with advanced cancer in order to improve their care. One aspect they identified was the need to improve scientific knowledge of the pathological processes involved:

"I think what we need to understand better, I think we need to understand the pathophysiology of cachexia better – the biology behind it. Which is probably going to be something really, really complicated. And what that tells me is there probably isn't going to be a single drug or a single intervention that works for all patients, it's just isn't going to work that way" (Interview 5)

Similarly, there was an appreciation that the evidence base for current therapies was inadequate.

"Yeab. So that we can support – because patients are finding all kinds of stuff on the internet and they're trying it, and they believe in it, and if it's doing them more harm, then it would be nice to have evidence to show. Or if it's a positive, it would be nice to have evidence to show. And just let them know that we're here to support them in what their choices are, but we also want to have it evidence-based" (Interview 7).

Another common proposal was for the incorporation of specialists in the care of cachexia into the clinical team.

"It will be nice to have a...I wouldn't say a 'cachexia clinic' but

some...well maybe we have it to some extent – to have a palliative medicine clinic where there is a team that’s really interested and focused on that” (Interview 5)

In particular, the need for close coordination with multidisciplinary colleagues was emphasized to provide ‘holistic’ care for those with the syndrome:

“I think there has to be multidisciplinary care. It’s not going to be a drug. I think all of us realize that. ... I think at the end of the day, it has to be a multidisciplinary, multidimensional approach with several different teams. And I think really the team that probably will and should play the largest role is palliative medicine” (Interview 5)

There was also an understanding that patients’ and relatives’ understanding of cachexia and how best to respond to its challenges could be improved if educational support was not confined to the clinic, but was sustained after they left the hospital environment:

“Where if we had somebody to go visit them while they’re back there – could you imagine how huge that would be? How many more people we could help? That’s what we need” (Interview 17).

Another approach to ensuring that information could be accessed by patients and relatives after consultations was the provision of information materials for them to take home with them:

“It would be nice if we were thinking of hey, I have a really good video or specific information that would be tailored to what we’ve spent half of this visit discussing, I want you to review it and let me know what you think at your next visit” (Interview 9).

Participants spoke about the need to provide educational material on cachexia to help inform both patient care carers

“Educational material... just to educate them period on: What is cachexia? What are the harms of it? Is it as bad as we think? You know, to kind of reassure them – I think that would help...if we had that [understanding] in an educational material booklet, stuff like that they could read and feel empowered with, I think it would go a long way actually” (Interview 16).

Nor was it just patients and family members who were seen as potential beneficiaries of educational material. Healthcare professionals also needed continuing professional development in relation to cancer cachexia.

“Maybe even educate oncologists because that’s something we may not do the best job of” (Interview 14)

DISCUSSION

Findings from this study show healthcare professionals’ insights in to the multi-dimensional ramifications of cachexia for patients with advanced cancer and their families. They also acknowledge the current lack of approved treatment regimes for this syndrome of advanced cancer and highlight the need to develop educational

resources to assist them in helping patients and their families understand cancer cachexia and cope with its impact.

Lack of recognition of cancer cachexia has previously been reported within the literature as a barrier to effective management of this syndrome.^{33,34} However, the participants in this study, all of whom are experienced in oncology, were very clear about the signs and symptoms of cachexia. They were also aware of the limitations of current treatment options, specifically the ineffectualness of interventions involving nutritional supplementation or stimulation (which involved the additional jeopardy of unwanted side effects). Most importantly, they recognized that cachexia must be seen as more than just weight loss, a view that is consistent with the current evidence based on the pathophysiology of cachexia.³

It is encouraging to see from the findings that participants within this study recognized the multi-factorial pathophysiology of cachexia and their role as a provider of holistic care. Participants discussed how the impact of cancer cachexia spanned physical, social and psychological domains which were interconnected and recognized the holistic impact that cachexia had on both patients and carers. In particular, it was noted that cachexia was a great cause of anxiety for both patients and their carers and reflective of previous research¹⁵ participants highlighted how this impacted on family functioning, for example when there was conflict over food. This aligns with previous studies which have delineated the negative consequences of struggles between patients and their families over food or food supplement intake and the helplessness that family carers of individuals with cancer cachexia can experience in relation to coping with this syndrome.^{9,34-36} This level of insight influenced the desire of professionals to provide supportive interventions not only to patients but also their families, the importance of which is outlined in the literature.^{6,33}

Unfortunately, despite their understanding of the physiology, treatment, and biopsychosocial effects of cachexia, many respondents continued to report difficulties in its management. Specifically, they recognized that they had not solved the problem of acquiescing to relatives’ requests to prescribe ineffectual or potentially harmful interventions to boost calorific intake, thereby colluding with assumptions they knew to be erroneous about the relationship between nutrition and cachexia.

This indicates that, while adequate knowledge and resources are necessary conditions for holistic cachexia care, they are not sufficient. What is also required is a culture that is supportive of openness about mortality and the processes associated with it.³³ Undoubtedly, Annas³⁷ exaggerates when he states of American Society that *‘we are a death-denying culture that cannot accept death as anything but defeat. This means we... are utterly unable to prepare for death.’*³⁷ (p 12) Nonetheless, the findings here are in marked contrast to those found in a study of cachexia care in Australia, where the initiation of candid conversations about cachexia with patients and their carers was seen as therapeutically important.¹⁶ We might ask to what extent does having to practice within a culture that discourages open discussion about death and dying limit clinicians’ ability to provide holistic care.

In fairness, the generalized comparison of American and Australian culture probably over-emphasizes American uniqueness and Australian freedom from death taboos. On the one hand, the Australian results relate to the specific phenomenon of the influence of a dedicated cachexia clinic, rather than a nationwide approach to cachexia care. On the other hand, the overreliance on treatment-oriented approaches to cachexia is far from an exclusively American phenomenon. Thus, an Italian review of three global surveys of healthcare professionals' perspectives on cancer cachexia (CC)³⁸ found that *'the ability to promote total weight gain was rated by participants as the most important factor in selecting a therapy for CC treatment. This was closely followed by the ability to maintain current total weight/prevent further weight loss, lack of side-effects, and improvement of fatigue'*.^{38 (p 2232)} Quality of life (QoL) was identified as a goal, but its achievement was largely confined to symptom management. While this included improving mental strength and lifting patient mood, no mention was made of the need to support patients and close others in confronting the existential challenge of cachexia, or of avoiding the relational traumas that lack of understanding of the syndrome can generate.

CONCLUSION

This study has provided insights from an in-depth analysis of interviews with 17-experienced healthcare professionals in relation to patients who have advanced cancer and are experiencing cachexia. Despite understanding the physiology, treatment, and biopsychosocial effects of cachexia, difficulties in its management still prevail and this is reflective of the international literature within this area which highlights the paucity of attention to the existential and relational ramifications of cachexia.

An indication of the way forward is to be found in the example of the dedicated Australian cachexia clinic¹⁶ which, through practice, research and education successfully cascaded effective therapeutic approaches to the existential and relational challenges raised by cachexia. This suggests that it is important to consider the educational and procedural mechanisms that could be used to counter lack of cultural attention to these crucial aspects of end-of-life care. But the difficulties inherent in effecting such a cultural shift should not be underestimated, given deeply ingrained occupational mores that militate towards reliance on technical solutions. As Gawande³⁹ has noted, *'medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. Yet – and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days'*.^{39 (p128)}

The respondents in this study displayed a close understanding of the physiology of cachexia; a holistic appreciation of the challenges it presents; and an acute grasp of the limited technical options available to respond to it. Yet they still had difficulty in confronting directly the impending mortality of their patients, as did many of the patients' relatives. This in turn inhibited clinicians' capacity to provide optimal psychosocial care, even though they appreciated the need for that type of care. However, this cognitive dissonance may well provide the key to a new approach. This gulf between theory and practice in professionals striving for excellence

can be an important driver for changes in practice that realigns it with their beliefs about what will optimize their patients' wellbeing.

LIMITATIONS

The findings presented in this paper must be interpreted in light of the study's limitations. Most importantly, the selection bias, as this data has come from one institution in the US. Additionally, all staff interviewed had clinical oncology experience. However, many patients with cancer cachexia encounter an array of healthcare professionals, many with generalist training and perspectives from staff such as community nurses/dietitians/medics were not within the remit of this research.

AVAILABILITY OF DATA AND MATERIALS

The data of this study are available from the corresponding author on reasonable request.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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