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Cancer Cachexia Care

The Contribution of Qualitative Research to Evidence-Based Practice

KEY WORDS

Cancer cachexia
 Evidence-based practice
 Primary cachexia
 Psychosocial care
 Qualitative research evidence
 Refractory cachexia

Background: Despite its prevalence and prognostic impact, primary cachexia is not well understood. Its potential to cause considerable psychological stress indicates the need for qualitative research to help understand the perspectives of those affected. **Objective:** The aims of this study were to describe the perspectives of patients with primary cachexia, of their relatives, and of the healthcare professionals involved in their care and to demonstrate how this evidence can be applied in practice at 4 different levels of application ranging from empathy to coaching. **Methods:** A review of the qualitative literature and empirical qualitative investigation was used to understand the experiences of patients and relatives and the perspectives of professionals. **Results:** The main worries expressed by patients and relatives concerned appetite loss, changing appearance, prognosis, and social interaction. We also describe their coping responses and their views of professionals' responses. The main concerns of professionals related to poor communication, lack of clinical guidance, and lack of professional education. **Conclusions:** Understanding patients', families', and professionals' perspectives, and mapping that understanding onto what we know about the trajectory and prognosis of the condition, provides the evidence base for good practice. Qualitative research has a central role to play in providing the knowledge base for the nursing care of patients with cachexia. **Implications for Practice:** The evidence provided can improve nurses' insight and assist them in assessment of status, the provision of guidance, and coaching. There is a need for the development of a holistic, information-based integrated care pathway for those with cancer cachexia and their families.

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■ Introduction: Cancer Cachexia

Cancer cachexia is a complex metabolic syndrome predominantly characterized by severe weight loss resulting from loss of muscle mass. It is a devastating consequence of cancer and is associated with poorer response to cancer treatments, increased treatment side effects and toxicities, and greater psychological distress for patients and their families.¹ It has a powerful impact on patient survival, and it has been estimated that 20% of advanced cancer patients will die of cachexia rather than their primary disease.^{2,3} Cachexia is most frequently observed in patients with solid cancerous tumors of the pancreas, lung, and gastrointestinal system, with a lower prevalence in patients with breast cancer and hematological malignancies.^{4,5} It is not restricted to a cancer diagnosis, as it is also reported in other chronic diseases such as chronic obstructive pulmonary disease and end-stage renal failure. However, it is most prevalent in cancer, occurring in up to 86% of patients with a malignancy⁶ compared with just 24% of patients with chronic obstructive pulmonary disease.⁷

Weight loss is the most defining characteristic of cancer cachexia; however, not all weight loss in cancer is attributable to cachexia. Patients often experience weight loss from reduced nutritional intake as a result of cancer treatments or physical obstruction by a tumor mass. This type of weight loss can be reversed once its causes are corrected.⁸ However, many patients with cancer will have weight loss for no apparent reason. Unexplainable weight loss is the hallmark of primary, refractory cachexia.⁸ The fundamental difference between the weight loss in cachexia and that in secondary weight loss is the inability to reverse it with nutritional intervention alone. The weight loss experienced by patients with primary cachexia is involuntary and progressive, resulting in up to a 30% loss of pre-morbid body weight and, ultimately, death.⁹

The prevalence and the devastating effects of cachexia indicate that it should be an important focus for care. However, as we shall see, it has had less attention than it should. In this article, we seek to redress this imbalance by marshalling evidence from both quantitative and qualitative sources and combining this evidence with findings from two qualitative studies that described the experience of patients with primary cachexia¹⁰ and of the healthcare professionals involved in their care to provide recommendations for nursing care.

■ Literature Review Strategy

The literature search for quantitative data was carried out according to Cochrane Collaboration guidelines. Details of the search strategy used can be found in the published Cochrane Collaboration protocol.¹¹ For literature that fell outside the Cochrane parameters, including qualitative literature, a wider search strategy was adopted using the key words *cachexia*, *cancer cachexia*, *weight loss*, *terminal care*, and *advanced cancer* in the following databases: Medline, PubMed, Cumulative Index to Nursing and Allied Health Literature, British Nursing Index,

and Index to Theses in Great Britain and Ireland. The initial search generated 186 334 hits. Boolean phrases “AND” and “NOT” were used to refine the number of papers into a manageable amount for review. Of the results generated, the paper title was initially used to determine its appropriateness to the study, followed by a review of the abstract. If the abstract was deemed suitable, the full text was then sourced. Information was also obtained from reference lists of published papers. The review included opinion papers, clinical guidelines, clinical reviews, systematic reviews, 2 empirical quantitative studies, and 12 empirical qualitative research studies. The quality of the evidence in the papers reviewed varied considerably, ranging from soundly demonstrated empirical data to opinion papers, where it was difficult to ascertain the strength of evidence.

■ Methodology: Qualitative Research in Evidence-Based Practice

One of the key debates concerning evidence-based practice (EBP) is the question of what constitutes appropriate evidence for the guidance of healthcare practice. Traditionally, the EBP movement favored a hierarchy of evidence founded on the capacity of research techniques to minimize the risk of bias in the results they produced.¹² On that criterion, the randomized controlled trial (RCT) was at the pinnacle of the hierarchy. Further down the ladder were various quasi-experimental strategies. Very close to the bottom, at best managing to creep ahead of consensus and opinion, was qualitative research.¹³ However, in recent years, this hierarchy has come under considerable challenge, not the least because of an increasing understanding of the limitations of RCTs.¹⁴

One of these limitations, which is especially concerning for evidence-based nursing, is the lack of focus in RCTs on the individual subjectivities of clients and their families. The concentration of RCTs on uncovering the average effects of an intervention means they have little or nothing to say about the individual experience of that intervention or of a person's experience of the condition that the intervention is designed to improve.¹⁵ This is a significant lacuna, because, as Grace and Powers¹³ observe, putting evidence to practice requires an understanding of patients' personal meanings, which influence their values and, therefore, their decisions. They go on to argue that this understanding of the meanings and values that people have in relation to health and healthcare, and the consequent responses that they make to healthcare situations, should be core to nursing knowledge. In other words, in addition to objective knowledge concerning biological functioning, pathology, diagnosis, and treatment, nurses need to attain an understanding of the subjective positions of the actors involved in those processes to respond adequately within the interactive processes of healthcare. The logical implication of acceptance of this argument is that there is a central place within nursing knowledge for qualitative research.¹⁶ The reason for this is that when dealing with meanings, quantitative strategies are of limited utility, in that meanings cannot be measured, only understood.¹⁷

In response to this critique of the deindividuating effects of quantitative research, 2 main approaches to the use of qualitative research have been adopted. One is to triangulate qualitative and quantitative methods to enable researchers to uncover both the effectiveness of an intervention and how it is experienced by those affected.¹⁸ This strategy of supplementing the insights of RCTs with those of qualitative approaches now enjoys considerable official approbation. Thus, for example, the British Medical Research Council's "Framework for Development and Evaluation RCTs for Complex Interventions to Improve Health"¹⁹ recognizes that at the stage of assessing feasibility, it is likely that a mixture of qualitative and quantitative methods will be needed. However, this "enhancement model"²⁰ is not the only role that has been posited for qualitative research. A more radical approach involves the advocacy of qualitative research's contribution to EBP independent of quantitative methods.²¹ Thus, for example, Morse et al²² described their use of theories generated from qualitative research data to develop patient assessment guides, arguing that the direct and exclusive application of qualitative methods provided a valid and useful means of patient assessment and intervention. Morse et al²³ have also developed "qualitative outcome analysis," which is a method of using qualitative strategies to evaluate the outcomes of nursing interventions.

The decision whether to use qualitative data to enhance quantitative research or to use qualitative research as an independent and self-contained research strategy should, like all methodological decisions, be based on which approach is best suited to the questions that require to be answered.¹⁵ In the case of cancer cachexia, efforts to develop effective interventions to alter the physiological processes involved have not been conspicuously successful to date. Given the limited capacity of physical approaches to the issue, efforts to minimize psychological distress caused by the condition are all the more important. As a consequence, the crucial research questions are those concerned with the perspectives and interactions of those affected by cancer cachexia, specifically patients, their family members, and the professionals caring for them. Because of this focus on human subjectivity, the use of qualitative research would appear to be the most appropriate strategy for providing an evidence base for nursing care of those with this distressing condition.

■ Quantitative Evidence: The Scientific Gap

Despite its prevalence and prognostic impact, primary cachexia is not well understood²⁴ and has been subject in the past to relative research neglect.^{25,26} Although a recent committed effort has been made toward furthering our understanding of cancer cachexia, research has so far been unsuccessful at unraveling the precise pathophysiological mechanisms of the syndrome. Advancement of our understanding has been further hindered by the previous lack of an agreed-upon definition and

classification criteria of the syndrome.²⁷ Indeed, it is only recently that an expert working group arrived at a consensus agreement that concluded that cancer cachexia is a multifactorial syndrome, defined by loss of muscle mass that is not responsive to nutritional support and characterized by a negative protein and energy balance as a result of reduced food intake and abnormal metabolism.²⁷

A universally agreed-upon definition benefits clinical practice by enabling the development of guidelines for the management of cancer cachexia.²⁸ The previous lack of definitional clarity and the absence of practice guidelines hindered health-care professionals' ability to identify and effectively manage patients with cachexia in advanced cancer. Consequently, in clinical practice, cancer cachexia remains underestimated²⁹ and underdiagnosed.³⁰ Management has been further complicated by lack of effective treatment to halt or reverse the cachexia syndrome. Pharmacological and nutritional interventions have proved of little benefit for refractory cachexia,^{31,32} and indeed, an optimal treatment for cachexia in advanced cancer has yet to be developed.³³ As for psychosocial interventions, there has been progress with the development of European clinical guidelines,²⁸ which identify communication and information as important components of care. However, they provide little detail about the specific psychosocial or informational strategies that would be most appropriate. This lack of detail is, at least in part, a consequence of the guidelines' reliance on the standard EBP approach, which is predominantly based on the quantitative analysis of the efficacy of putative treatments.

■ Qualitative and Psychosocial Literature Review

In addition to their physical effects, symptoms such as weakness, weight loss, and anorexia associated with cachexia have been reported as having devastating psychosocial consequences for those affected by the syndrome.³⁴ Loss of muscle mass often leads to extreme weakness and loss of functional ability for patients, which has a negative impact on their overall quality of life.³⁵ In addition, weight loss is reported as having negative consequences for a patient's body image, which can result in social isolation and emotional distancing from family and friends.³⁶ The psychological effects upon family members are also considerable.³⁷⁻³⁹ Indeed, Strasser et al⁴⁰ found that partners may be more concerned about patients' weight loss than the patients themselves.

The literature also indicates that loss of appetite is a common source of concern for patients and their families,^{37,40,41} with the declining oral intake of patients with advanced cancer being of great emotional and social significance for all family members.⁴² Patients' and families' concerns can be manifested in conflict over food consumption^{42,43} and may result in family members putting pressure on their loved ones to eat.^{39,41} These pressures can lead patients to adopt strategies of social self-exclusion to avoid conflict.⁴⁴ These tensions are exacerbated by the tendency for patients and their families, and

indeed healthcare professionals, to regard weight loss as an unmentionable, taboo subject.³⁴ Professionals' lack of acknowledgment of weight loss in advanced cancer has also been reported by Dewey and Dean,⁴⁵ who concluded that it was only acknowledged by nurses if patients and families took the initiative and voiced their concerns about it, resulting in a reactive approach to its management.

Evidence suggests that cachexia in advanced cancer is poorly managed and not well understood,^{12,46} with healthcare professionals often missing intervention opportunities to meet the needs of patients and their families.⁴⁷ These conclusions echo the identification of Hopkinson et al³⁴ of a weight loss taboo among specialist nurses and their reluctance to acknowledge its presence with patients and families. These responses to weight loss in advanced cancer are concerning, given its profound biopsychosocial impact, thus highlighting a fundamental gap in care provision for patients with cachexia and their families.

Attempts have been made to explain why healthcare professionals are missing opportunities to intervene and provide effective care for patients with cachexia in advanced cancer and their families. It has been suggested that a lack of understanding of the syndrome has hindered effective management in the clinical setting.⁴⁸ The findings of Latham⁴⁹ support this, as the nurse participants in her study demonstrated limited understanding of the pathophysiology and management of the syndrome. But it is not just a matter of an incomplete understanding or a lack of definitional clarity. In addition to these problems of knowledge, the fact that no therapeutic intervention has proved successful at reversing or halting the progression of cachexia in advanced cancer may have led professionals to put less emphasis on its management. Thus, Hopkinson et al³⁴ reported that the participants in their study perceived there was little that could be done to help patients and families manage their weight loss.

Existing qualitative and psychosocial evidence indicates that the current management of cachexia leaves a lot to be desired, both in terms of the stress and conflict that it generates in patients and families and the lack of knowledge and motivation on the part of professionals. However, what have not been fully explored are the lived experiences of patients and families and the reasons why professionals are currently unable to provide adequate psychosocial support. The next section reports on 2 empirical studies that focus on these issues.

■ Applying Qualitative Evidence to Clinical Practice

In this section, we summarize the findings of 2 qualitative studies. The first, which addresses the experiences of patients with cachexia and their families, has been previously reported on.¹⁰ The second, on healthcare professionals' perceptions and understandings of cachexia, is novel to this article. We then take these empirical data and, in combination with the knowledge gained from reviewing the literature, we apply it to a framework designed to facilitate the application of qualitative knowledge to practice.⁵⁰

Both studies involved an interpretive focus aimed at understanding the experiences of those involved. Both received research governance permission from the healthcare institutions involved and ethical approval from the regional research ethics committee. Written consent to participate and to allow anonymous publication of data was obtained from all participants.

The first study used purposive sampling to select advanced cancer patients with cachexia from a regional cancer center in the United Kingdom. All participants were older than 18 years and able to provide informed consent. Patients were eligible for inclusion if they had a confirmed diagnosis of advanced, incurable cancer; had weight loss greater than 10% in the last 6 months; perceived weight loss as a problem; and were living at home. Any patient who experienced secondary causes of cancer cachexia was excluded from the study. Patients were asked to nominate a family member to take part in the study. A total of 15 patients and 12 family members were interviewed. All interviews were transcribed. Thematic analysis was conducted across all interviews.⁵¹ This analysis of transcripts was supplemented by an Interpretative Phenomenological Analysis⁵² of 8 interview sets (8 patients and their family members).

In the second study, 2 multiprofessional focus group interviews were conducted with 4 and 5 participants, respectively, with the aim of uncovering the main themes and issues in cachexia management. The focus group interviews were digitally recorded and transcribed. Thematic content analysis was undertaken according to the framework of qualitative analysis developed by Miles and Huberman.⁵³ This involved reading the transcripts and condensing the data into codes and categories to reflect the main themes emerging from the data.

Results 1: Cachexia From the Perspective of Patients and Families

The fundamental qualitative knowledge required to develop effective EBP for the psychosocial care of those with cachexia and their families is that which can tell us how it affects these groups. Our interpretative phenomenological study explored the experience of cachexia for patients with advanced cancer and their family members, providing an in-depth understanding of the lived experience of cancer cachexia. Four main worries were identified, and issues surrounding how they coped with these worries and how professionals dealt with them were also highlighted.

Worries about appetite loss: Analysis established that 2 of the most serious manifestations of cancer cachexia articulated by both patients and family members were early satiety and reduced appetite.

Worries about changing appearance: For many patients, the experience of this visible weight loss became a distressing and embarrassing aspect of their life.

Worries about prognosis: Both the rate and degree of weight loss were perceived as indicators of the patients' state of health, and as such, it was a source of concern for both patients and their family members. Indeed, it was family members, more often than patients, who expressed the most severe concern over their loved one's weight loss.

Worries about social interaction: Reduced dietary intake frequently became a source of conflict between patients and their families. Even when meal times were consciously used as fora to reinforce familial bonding in this time of stress, conflict over food was still experienced between family members who insistently encouraged their sick relatives to consume food to aid their recovery and patients who were incapable of complying with their family's desires.

Coping responses: Both patients and their family members discussed the overt strategies that they used to cope with the implications of cachexia. Although most participants were aware of the terminal nature of the patient's illness, data suggested that some patients could not process this information and escaped its enormity by denying the inevitable truth. Alternatively, some patients accepted the inevitable reality of their situation but tried to keep a positive attitude. However, an alternative response to facing the inevitability of death was despair.

Frustration with the response of healthcare professionals: The symptoms of cancer cachexia were frequently brought to the attention of healthcare professionals by both patients and their family members, who frequently found their response to be inadequate or inappropriate. Participants within this study identified 3 main barriers to successful cancer cachexia management. These were lack of acknowledgement, lack of information, and lack of intervention.⁵⁴

Results 2: Cachexia From the Perspective of Healthcare Professionals

That patients and their families perceived the approach of healthcare professionals to cachexia management as unhelpful, often ignoring it and its attendant problems, strongly indicates the existence of problems with those professionals' perspectives on the experience of cachexia. It reminds us that patients and their families are not the only actors in the processes that we have been examining. Thus, in addition to taking cognizance of the experience of those affected by the disease, effective EBP also needs to take account of the understandings and interpretations of the various professionals who deliver care. Consequently, the second focus of our research program has been to use qualitative research to uncover professionals' perspectives.

Although there is established evidence that healthcare professionals are not adequately managing cancer cachexia,^{10,34,45} explanations for this are based largely on anecdotal accounts, as no formal investigation has been conducted into its management in clinical practice. This suggests that there is an urgent need to gain the perspectives of those involved in care delivery for patients with advanced cancer who have cachexia to identify the clinical complexities in managing cachexia in advanced cancer.

To gain this insight, we used a general interpretive methodology to explore how healthcare professionals respond to cachexia in advanced cancer. Analysis of focus group interviews with ward nurses, specialist nurses, dietitians, and medical staff working in a regional cancer center identified 3 themes: poor

communication with patients and families, lack of clinical guidance, and lack of professional education.

Communication with patient and family: Poor communication was acknowledged as a barrier to effective cachexia management by the focus group participants. They reported that patients and their families often did not demonstrate an awareness of their terminal prognosis and suggested that this was because it had not been discussed between them and the medical team. This lack of insight created difficulty for healthcare professionals when trying to explain cachexia, given that it is a powerful prognostic indicator. Healthcare professionals suggested that they were reluctant to enter into such a conversation, for fear of raising end-of-life issues, which the patients and their families may not have been prepared for. This failure to adequately communicate with patients and families about their prognosis helps explain the lack of acknowledgement and information perceived by patients and relatives.

Lack of clinical guidance: Lack of clinical guidance for professionals also emerged as a challenge in managing cachexia in advanced cancer. Participants were aware of the multifaceted pathology of cancer cachexia and also the difficulty in making the distinction between weight loss from cachexia and secondary factors, realizing that each has very different interventions and outcomes. Data suggested the participants felt a sense of frustration at the lack of guidelines to aid assessment and diagnosis of cachexia.

Lack of professional education: This difficulty in recognizing refractory cachexia was frequently associated with the lack of professional education as perceived by healthcare professionals within this study. The focus group participants reported a lack of preregistration and postregistration education about the causes and care of cachexia and a subsequent lack of knowledge on the subject. This lack of knowledge compromised the healthcare professionals' ability to educate patients and their families about cachexia, even though the professionals recognized the need to do so. The provision of this information and education is vital if patients and their families are to understand cachexia and accept it as part of natural terminal decline. However, without sufficient knowledge on the causes and management of cachexia, the healthcare professionals in the focus groups felt ill-prepared to undertake such a task, providing another cause of the lack of information reported by patients and family members.

Summary

Our evidence paints a very concerning picture. On the one hand, those people with cancer cachexia and their family members are beset with profound worries about their lack of appetite, their change in appearance, and the suspicion that these changes are harbingers of death. These anxieties, in turn, generate conflict between family members who seek to deal with these worries through the encouragement of eating and their sick loved ones who simply cannot eat. The tragedy of


this situation is compounded by the fact that in many instances, they find little succor or support from the professionals looking after them. This inadequacy of care is confirmed by professionals who cite 3 main reasons for it—the fear of having to openly confirm that the presence of secondary cachexia indicates poor prognosis; the lack of explicit guidelines for action; and ignorance about cachexia and its causes and effects, resulting from poor education. All of these indicate the need for changes in professionals' approach across a broad range of attitudes, knowledge, and behavior.

■ Putting Qualitative Evidence Into Practice

Having identified the concerns that arise from the experience of cancer cachexia and the inadequacy of professional responses to these concerns, the question becomes one of the manner in which that information can be used to help all parties to manage this illness in such a way that distress and discomfort are minimized. Kearney⁵⁰ has suggested that qualitative evidence can be applied directly to practice in at least 4 ways. The first is to provide insight or empathy to allow clinicians to better understand the experiences of those under their care. The second is to inform the assessment of status or progress, providing information about the trajectory of illness experience. This information, in turn, can be used as the basis for formal assessment tools to aid clinicians in identifying likely responses of individuals at different points in the illness trajectory. The third way is to constitute the knowledge base for anticipatory guidance, which involves sharing qualitative data with clients, allowing them to anticipate and prepare for the experiences that have been identified through the research, and for clinicians and clients to negotiate what resources and support they will require to deal with these. Of course, in line with the general philosophy of qualitative research, the data should not be seen as unproblematically generalizable. Rather, clients should be given the opportunity to assess the degree to which their particular experience is consonant with the experience of the research subjects from which the data were gleaned. Finally, the most active mode of application is coaching, whereby clinicians advise clients about what they can do to reduce distress or improve adjustment. We wish to suggest here that an adequate approach to the care of those with cancer cachexia and their families requires the inclusion of all 4 of these modes of application. We will demonstrate this by mapping the concerns summarized in the Table onto each mode.

Insight or Empathy

This mode of application involves using qualitative research findings to help healthcare professionals to better understand the experience of living with an illness, from the perspective of either the person with the disease or those who are close to them, and thus to offer support in a more sensitive, empathetic manner. It allows the professional to respond to cues in a more informed manner, to recognize whether the responses

 **Table • Summary of Issues and Psychosocial Consequences Associated With Cachexia**

Issue Associated with Cachexia	Experiential and/or Behavioral Consequences
Patients	
Weakness and loss of function and mobility	Reduced quality of life
Concerns over loss of appetite	Anxiety
Altered appearance because of weight loss	Distress and isolation
Realization of implications of cachexia	Coping responses of denial, positive acceptance or despair
Families	
Patient weight loss and anorexia	Concern and distress
Belief that the patient needs to eat to recover	Distress, conflict, and social isolation of patient
Patients and families	
Knowledge or suspicion of prognosis	Concern and anxiety
Lack of professional acknowledgement	Exacerbation of the negative consequences of the experience of cachexia
Lack of professional information	Exacerbation of the negative consequences of the experience of cachexia
Lack of professional intervention	Exacerbation of the negative consequences of the experience of cachexia
Professionals	
Lack of priority because of no effective physiological intervention	Poor support and management
Reluctance to raise end-of-life issues	Poor communication
Lack of guidelines to help identify cachexia	Difficulty in identifying the presence of cachexia
Limited knowledge because of lack of professional education	Professionals feel unprepared to educate patients and families
Patients, families, and professionals	
Weight loss taboo	Isolated worry of patients and families

are typical or atypical, and to design and implement support accordingly. However, it is important that this knowledge is used appropriately and that individuals are not shoehorned into the norms of response identified by qualitative research.

That caveat aside, it is not difficult to see how an understanding of the psychological and social disruption and tensions that cachexia can cause those affected by it is essential information. To provide appropriate care, professionals need to be aware of the challenges faced by patients confronting weakness, loss of appetite, altered appearance, and the poor prognostic implications of cachexia. They need to understand

families' concerns about their loved one's anorexia and weight loss and to appreciate how they might conclude that recovery depends upon eating. They also need to reflect on their own position and to realize that the absence of effective interventions makes nursing care more rather than less important. They need to break the taboo of discussing weight loss, notwithstanding the sensitivities of raising end-of-life issues. They also require a greater understanding of cachexia, and that in turn places an onus on nurse educationalists to ensure that such knowledge is imparted.

Assessment of Status or Progress

Essentially, this application of qualitative evidence adds to empathetic understanding of the factor of time. By taking the trajectory of illness experience into account, it allows professionals to provide more nuanced modes of care that relate to cachexia. There are a number of critical stages in the trajectory of cancer cachexia and its diagnosis and care. The European Palliative Care Research Collaborative's guidelines²⁸ identify 3 stages of cachexia. The first stage of "precachexia" involves weight loss of less than 5%, whereas the second stage of "cachexia" is characterized by weight loss greater than 5%. The final stage of "refractory cachexia" involves cancer disease that is procatabolic and unresponsive to anticancer treatment, accompanied by low performance status and a life expectancy of less than 3 months.

Whereas the recommended treatment for stage 2 is proactive, including vigorous nutritional support and anti-inflammatory treatment, in stage 3, the primary treatment goal is not the reversal of weight loss but alleviation of symptoms and increase in well-being.

Careful medical diagnosis is required to distinguish between these stages and between cachexia and secondary weight loss caused by anatomic or iatrogenic factors.²⁸ However, what we are concerned with here are the experiential responses elicited by each stage and the support strategies required to meet them. Specifically, the evidence presented relates to the illness experience of the final, refractory stage, which will be considerably different from the second stage, when active efforts are still being made to maintain weight.

Anticipatory Guidance

This mode involves openly sharing the results of qualitative research with clients and their families. The purpose is to enable users to understand their situation and to anticipate how it might develop, thus helping them to appreciate the strategies and resources they can use to deal with the problems that they are facing or are likely to face in the future. It has the additional benefit of helping users to feel less solitary and unique in what they are going through.

Patients and families need to be aware that beyond a certain stage, loss of appetite is not something that can be overcome by willpower or persuasion. Families especially need to understand that the patient's illness is likely to make them feel weak and self-conscious about their emaciated appearance, thus requiring considerable comfort and support to help them cope

with their concerns. Moreover, families should be made aware of the human and technological resources that can be accessed to assist those whose weakness may become profound enough to compromise their mobility and capacity to perform the activities of daily living.

Anticipatory guidance is, of course, a very delicate issue in relation to cancer cachexia. Specifically, it is closely connected with the intimation of a terminal prognosis, one that is in all likelihood accelerated by the presence of cachexia. Notwithstanding the difficulties for both the deliverers and recipients of this message, we need to consider the problems that arise from the alternative of ignorance, which tends to encourage futile attempts to persuade or even coerce patients to eat their way back to health. If these attempts were merely futile, the option of maintaining ignorance might be more acceptable, but the fact that the futility is often accompanied by distress and discomfort makes it less easy to defend.

Coaching

The final mode of using qualitative research evidence is also the most active. Here, not only do professionals share evidence with users, but also, they use that evidence as the basis for advice on how clients and carers can adjust to their situation and minimize distress. The evidence can be used to illuminate those approaches and strategies that reduce distress, and those that exacerbate it, and thus to provide clients and their relatives with an understanding of the courses of action that are most likely to provide the best experiential outcomes.

The significance of coaching in the care of cancer cachexia cannot be underestimated. As we have seen, much of the distress caused by the syndrome is the result of the misunderstandings of family members about its amenability to reversal by means of feeding. By explaining the futility of force-feeding and by showing evidence that the experience of cachexia is less traumatic if the person suffering does not feel coerced into trying to eat, along with talking through how care and nurturing can be carried out in ways other than food preparation, healthcare professionals can provide family members with skills to enable them to deal with the very difficult situation they are facing in a way that minimizes conflict and distress.

Families can also be coached in relation to strategies that compensate for weakness and loss of mobility and that encourage social interaction without embarrassing their sick relative. They should also be reassured that, for most people, it is more fulfilling to discuss uncomfortable issues than to pretend they do not exist.

Discussion

From the outset of the presentation of cachexia, nurses are in a key position to prepare patients and their family members for the changes that will follow. Open communication and education provide the potential to alter how the weight loss associated with cachexia is viewed. The patients' altered appetite

may certainly contribute to their weight loss; however, nurses should help family members to distinguish between alterations in appetite that can be explained in terms of secondary causes and those that are an expected consequence of cachexia over which the patient has minimal control. On the basis of imparting this understanding, nurses can provide families with information about what they can do to help their loved one through this illness journey. Part of this understanding would entail an acceptance that weight loss is a poor prognostic indicator. Although this is a very difficult message to impart, it is hoped that through a realistic understanding of what is happening, both patients and their families would be helped to come to terms with the fact that the patients' progressive and involuntary weight loss signals their movement toward death.

The alternative to candidness is not kindness. Our research participants found the "silence" of clinicians when confronted with cancer cachexia extremely distressing. Healthcare professionals need to acknowledge cachexia and provide information on its nature and impact. By providing those affected with insight into its workings and what can be done to ameliorate its negative effects, professionals can prevent a lot of avoidable grief. Furthermore, fully explained supportive healthcare interventions addressing the holistic needs of both patients and their families would help empower them to deal with cachexia and to move toward acceptance of the patients' impending death. Such interventions must not only entail but also move beyond the provision of information and should focus on patients and their families establishing, addressing, and coping with their fears and anxieties in relation to this phenomenon.

It should of course be admitted that the use of qualitative research evidence to generate specific practical approaches to care is contentious. Without the checks and balances concerning validity and reliability that are part and parcel of using quantitative data to ground interventions, how can we be confident that the information on which interventions are based is accurate or appropriate? Notwithstanding the mechanisms that exist for the rigorous review of qualitative evidence,^{55,56} the use of experiential data to ground healthcare actions is one that does not sit completely comfortably with established interpretations of the relationship between evidence and practice. However, as Kearney⁵⁰ observes, experiential knowledge in the form of clinicians' own storehouses of exemplars is continually used to inform clinical assessments. Nevertheless, this objection reminds us that it is inappropriate to universalize from the experience of research subjects to all the individuals whose situation is similar to those subjects. Once again, it is essential for practitioners to use their clinical judgment to ascertain whether the qualitative evidence they have to hand fits with the experiences of the particular clients and families for which they are caring.

■ Conclusion

The purpose of this article was to contribute to the knowledge base required to develop adequate models of care for cancer cachexia. Given the inexorable and distressing nature

of cachexia, we have shown how understanding both users' and professionals' perspectives, and mapping that understanding onto what we know about the physiological trajectory and prognosis of the condition, provides an important evidence base for good practice.

Implicit in this assertion is an argument for the centrality of qualitative research in providing the knowledge base for holistic care. That contribution is especially important when care is aimed at ensuring that the distress caused by the experience of illness is minimized. In conditions such as cachexia, where the degree to which healthcare can contribute to physiological improvement is limited, qualitative evidence to guide practice is indispensable. In making this observation, we are not gainsaying future developments of therapies that will be able to physically ameliorate or even reverse the condition of cancer cachexia. Nor are we saying that psychosocial care of patients with treatable conditions is unimportant. What we are saying is that, given the limitations of current knowledge, it is the responsibility of healthcare professionals to ensure that people affected by cachexia are given the best tools available to help them deal as well as they can with something that is not susceptible to cure or significant amelioration.

The development of supportive tools requires the operationalization of pertinent qualitative knowledge in such a way that it can inform practice effectively. We examined how qualitative information could be used within each of the 4 modes of application identified by Kearney: insight, assessment, anticipatory guidance, and coaching. However, we have framed all these in terms of the responsibilities and actions of individual practitioners. In consonance with the tenets of EBP, it is important to ensure that decisions based on best evidence should be as widely adopted as possible. This in turn implies the need for the inclusion of this information in appropriate clinical guidelines. In particular, the development of a holistic, information-based integrated care pathway for those with cancer cachexia and their families would be a significant step toward optimizing care for those affected by this distressing affliction. Perhaps, ironically, the efficacy of such a pathway would require valid and rigorous testing, which implies the need to subject it to an RCT, once again demonstrating the point that research strategies should be chosen to meet the question at hand, rather than according to an a priori hierarchy of knowledge.

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References

1. Bruera E. ABC of palliative care: anorexia, cachexia, and nutrition. *BMJ*. 1997;315:1219-1222.

2. Tisdale MJ. Cachexia in cancer patients. *Nat Rev Cancer*. 2002;2:862–871.
3. Muscaritoli M, Bossola M, Aversa Z, Bellantone R, Fanelli FR. Prevention and treatment of cancer cachexia: new insights into an old problem. *Eur J Cancer*. 2006;42(1):31–41.
4. Tisdale MJ. Biology of cachexia. *J Natl Cancer Inst*. 1997;89:1763–1773.
5. Inui A. Cancer anorexia-cachexia syndrome: current issues in research and management. *CA Cancer J Clin*. 2002;52:72–91.
6. Teunissen SCCM, Wesker W, Kruitwagen C, de Haes HCJM, Voest EE, de Graeff A. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage*. 2007;34(1):94–104.
7. Wagner PD. Possible mechanisms underlying the development of cachexia in COPD. *Eur Respir J*. 2008;31(3):492–501.
8. Davidson AJ, Chasen MR. Managing cancer cachexia: a guide to current therapy. *Oncol Exchange*. 2008;7(3):8–11.
9. Mak RH, Cheung WW. Mechanisms of cachexia. In: Fantuzzi G, Mazzone T, eds. *Nutrition and Health: Adipose Tissue and Adipokines in Health and Disease*. Totowa, NJ: Humana Press; 2007:255–264.
10. Reid J, McKenna H, Fitzsimons D, McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud*. 2009;46(5):606–616.
11. Reid J, Donnelly M, Cantwell M, Cardwell CR, Mills M, Murray LJ. Thalidomide for managing cancer cachexia. *Cochrane Database Syst Rev*. 2010;(9): Art. No.: CD008664. doi: 10.1002/14651858.CD008664.
12. Akobeng A. Understanding randomised controlled trials. *Arch Dis Child*. 2005;90:840–844.
13. Grace J, Powers B. Claiming our core: appraising qualitative evidence for nursing questions about human response and meaning. *Nurs Outlook*. 2009;57:27–34.
14. Britten N. Qualitative research and the take up of evidence based practice. *J Res Nurs*. 2010;15(6):537–544.
15. Blackwood B, O'Halloran P, Porter S. On the problems of mixing RCTs with qualitative research: the case of the MRC framework for the evaluation of complex healthcare interventions. *J Res Nurs*. 2010;15(6):511–521.
16. Noyes J. Never mind the qualitative feel the depth! The evolving role of qualitative research in Cochrane intervention reviews. *J Res Nurs*. 2010;15(6):525–534.
17. Bhaskar R. *The Possibility of Naturalism: A Philosophical Critique of the Contemporary Human Science*. 3rd ed. London, England: Routledge; 1998.
18. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311:42–45.
19. Medical Research Council. *Developing and Evaluating Complex Interventions: New Guidance*. London, England: Medical Research Council; 2008. www.mrc.ac.uk/complexinterventionsguidance. Accessed September 20, 2010.
20. Popay J, Williams G. Qualitative research and evidence-based healthcare. *J R Soc Med*. 1998;35(suppl):32–37.
21. Sandelowski M. Using qualitative research. *Qual Health Res*. 2004;14(10):1366–1386.
22. Morse J, Hutchinson S, Penrod J. From theory to practice: the development of assessment guides from qualitatively derived theory. *Qual Health Res*. 1998;8(3):329–340.
23. Morse J, Penrod J, Hupcey J. Qualitative outcome analysis: evaluating nursing interventions for complex clinical phenomena. *J Nurs Scholarsh*. 2000;32(2):125–130.
24. Millar C, Reid J, Porter S. The challenges of managing cachexia in advanced cancer. *Cancer Nurs Pract*. 2009;8(4):24–27.
25. Poole K, Froggatt K. Loss of weight and loss of appetite in advanced cancer: a problem for the patient, the carer, or the health professional? *Palliat Med*. 2002;16(6):499–506.
26. Steer TE. Report of a Joint Cancer Research UK/Medical Research Council workshop on cancer cachexia research at the Royal College of Physicians, Tuesday, 2 December 2003. *Br J Cancer*. 2005;92(10):1830–1833.
27. Fearon K, Strasser F, Anker SD, et al. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol*. 2012;12(5):489–495.
28. Radbruch L, Elsner F, Trottenberg P, Strasser F, Fearon K. *Clinical Practice Guidelines on Cancer Cachexia in Advanced Cancer Patients With a Focus on Refractory Cachexia: European Clinical Guidelines*. Aachen, Germany: Department of Palliative Medicine/ European Palliative Care Research Collaborative; 2010.
29. Oi-Ling K, Man-Wah D, Kam-Hung D. Symptom distress as rated by advanced cancer patients, caregivers and physicians in the last week of life. *Palliat Med*. 2005;19:228–233.
30. Fox KM, Brooks JM, Gandra SR, Markus R, Chiou CF. Estimation of Cachexia among Cancer Patients Based on Four Definitions. *J Oncol*. 2009; Article 693458:1–7. doi: 0.1155/2009/693458.
31. Berenstein G, Ortiz Z. Megestrol acetate for treatment of anorexia-cachexia syndrome. *Cochrane Database Syst Rev*. 2005;(2). Art. No.: CD004310. doi: 10.1002/14651858.CD004310.pub2.
32. Dewey A, Baughan C, Dean T, Higgins B, Johnson I. Eicosapentaenoic acid (EPA, an omega-3 fatty acid from fish oils) for the treatment of cancer cachexia. *Cochrane Database Syst Rev*. 2007;(1). Art. No.: CD004597. doi: 10.1002/14651858.CD004597.pub2.
33. Harle L, Brown T, Laheru D, Dobs AS. Omega-3 fatty acids for the treatment of cancer cachexia: issues in designing clinical trials of dietary supplements. *J Altern Complement Med*. 2005;11(6):1039–1046.
34. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs*. 2006;54(3):304–312.
35. Tisdale MJ. Protein loss in cancer cachexia. *Science*. 1999;289(5488):2293–2294.
36. Hinsley R, Hughes R. The reflections you get: an exploration of body image and cachexia. *Int J Palliat Nurs*. 2007;13(2):84–89.
37. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage*. 2006;31(4):293–305.
38. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncol Nurs Forum*. 1997;24:1751–1757.
39. Holden CM. Anorexia and terminally ill cancer patients: the emotional impact on the patient and the family. *Hospice J*. 1991;7(3):73–84.
40. Strasser F, Binswanger J, Cerny T, Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat Med*. 2007;21(2):129–137.
41. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *J Hum Nutr Diet*. 2000;13(2):113–117.
42. Shragge JE, Wismer WV, Olson KL, Baracos VE. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med*. 2007;21(3):227–233.
43. Hughes N, Neal RD. Adults with terminal illness: a literature review of their needs and wishes for food. *J Adv Nurs*. 2000;32(5):1101–1107.
44. McClement SE, Degner LF, Harlos MS. Family responses to declining intake and weight loss in a terminally ill relative. Part I: fighting back. *J Palliat Care*. 2004;20(2):93–101.
45. Dewey A, Dean T. Assessment and monitoring of nutritional status in patients with advanced cancer: part 1. *Int J Palliat Nurs*. 2007;13:258–265.
46. Delmore G. Cachexia—quo vadis? *Support Care Cancer*. 2000;8:165–166.
47. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum*. 2009;36(4):439–445.
48. MacDonald N, Easson AM, Mazurak VC, Dunn GP, Baracos VE. Understanding and managing cancer cachexia. *J Am Coll Surg*. 2003;197(1):143–161.
49. Latham D. How the district nurse cares for the terminally ill patient with cachexia. *Br J Community Nurs*. 2001;6(1):5–10.
50. Kearney M. Levels and applications of qualitative research evidence. *Res Nurs Health*. 2001;24:145–153.
51. Van Manen M. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. 2nd ed. London, Ontario: Althouse Press; 1997.
52. Smith JA, Jarman M, Osborne M. Doing interpretative phenomenological analysis. In: Murray M, Chamberlain K, eds. *Qualitative Health Psychology*. London, England: Sage; 1999:218–240.
53. Miles MB, Huberman MA. *Qualitative Data Analysis*. 2nd ed. London, England: Sage Publications; 1994.
54. Reid J, McKenna H, Fitzsimons D, McCance T. An exploration of the experience of cancer cachexia: what patients and their families want from health care professionals. *Eur J Cancer Care*. 2010;19:682–689.
55. Porter S. Validity, trustworthiness and rigour: reasserting realism in qualitative research. *J Adv Nurs*. 2007;60(1):79–86.
56. Freshwater D, Cahill J, Walsh E, Muncey T. Qualitative research as evidence: criteria for rigour and relevance. *J Res Nurs*. 2010;15(6):497–508.