

Fighting Over Food: Patient and Family Understanding of Cancer Cachexia

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Cancer cachexia is a complex chronic wasting syndrome in which muscle and fat are lost as a result of metabolic alterations brought about by interactions between the host and the tumor (MacDonald, Easson, Mazurak, Dunn, & Baracos, 2003). This syndrome is present in approximately 50% of patients with cancer (Tisdale, 2009). Cachexia-related weight loss is caused by more than reduced food intake. As a result of metabolic processes, cancer cachexia typically is characterized by nonintentional weight loss and wasting that is not responsive to conventional nutritional support (Tisdale, 1997). Cachexia has serious implications for patients with advanced cancer and can lead to increased risk of adverse events (Wiedenmann et al., 2008), reduced response to treatment modalities (Muscaritoli et al., 2006), and increased mortality (Wigmore et al., 1996). Therefore, this life-threatening syndrome often is debilitating, underdiagnosed, and undertreated in patients with advanced cancer.

Background

Cancer cachexia induces physiologic changes in appetite, thus affecting patients' ability to eat (Fearon, Voss, & Hustead, 2006). This is known to be a common source of concern for patients and their families (Hawkins, 2000; Hopkinson & Corner, 2006; Strasser, Binswanger, Cerny, & Kesselring, 2007). Because of concerns over eating, the potential for conflict over food between terminally ill patients and their family members has been reported (Hughes & Neal, 2000; Shragge, Wismer, Olson, & Baracos, 2007). A study conducted in

Purpose/Objectives: To investigate tensions over food that exist between patients with advanced cancer with cachexia and their families.

Research Approach: Heideggerian phenomenologic inquiry using unstructured interviews.

Setting: A regional cancer center in the United Kingdom.

Participants: 8 patients with advanced cancer living with cachexia and 8 family members.

Methodologic Approach: Singular unstructured interviews were recorded digitally, transcribed verbatim, and analyzed using thematic and interpretative phenomenologic analysis.

Main Research Variables: Cachexia and advanced cancer.

Findings: A fine line existed between offering food to a patient and forcing a patient to eat; often, conflict arose as a result. Contributors to that conflict focused on reduced dietary intake by the patient and the reaction to food refusal by the family, which frequently led to patients eating to please.

Conclusions: This study highlights the anxiety that surrounds eating and the distress it causes to patients and their families. This strain can escalate into arguments over food, causing negative repercussions for patients and their family members.

Interpretation: This is the first study to uncover tensions about eating as experienced by patients with advanced cancer and cachexia and their families. Nurses must consider this issue when designing and delivering effective care for this patient population.

the United Kingdom quantified anxiety resulting from reduced appetite in patients with advanced cancer and concluded that, as a result of their anxiety, family members can unwittingly pressure their loved one to eat (Hawkins). That resonates with a Canadian study that examined the nutritional care experiences in advanced

cancer from the perspective of patients, family members, and healthcare providers and identified social exclusion as a central strategy used by patients to avoid the potential for conflict over food from their family members (McClement, Degner, & Harlos, 2004). However, no study has formally investigated the experience of cachexia and its effect on food and feeding. Therefore, the current study sought to explore the experience of this phenomenon.

The data presented within this article are drawn from a larger study that explored patients' and family members' experiences of cancer cachexia (Reid, 2007; Reid, McKenna, Fitzsimons, & McCance, 2009). Findings illuminated six themes that reflected the complex dynamics in the experience of cancer cachexia. One theme focused exclusively on the tensions that exist over food in cachexia, Food Offering Versus Force Feeding. This article will articulate the research findings and shed light on this distressing and emotive issue in patients with advanced cancer with cachexia.

Methods

Research Design

Heideggerian phenomenologic research techniques underpinned the current study. Heideggerian phenomenology, which builds on the work of Husserlian phenomenology, reflected the interpretative aim of this research study, which was to enter into the life world of patient with advanced cancer with cachexia (and their family members) and, with the use of the hermeneutic process, interpret their illness events (Thorne, 1997). The assumptions and basic philosophic issues relating to interpretative phenomenology imply pre-understanding, which is linked to the process of interpretation. In using this approach, the study's aim was not merely to describe the research participants' lived experiences but to elucidate the personal meaning of cancer cachexia for each of the research participants.

Participants

Purposive sampling was used to select patients with advanced cancer with cachexia from inpatient and outpatients units in a regional cancer center in the United Kingdom. All participants were older than 18 years and had the ability to provide informed consent and read and write in English. Patients were eligible for inclusion if they had a confirmed diagnosis of advanced, incurable cancer; had weight loss greater than 10% in the previous six months; perceived weight loss as a problem; and were living at home. Any patient who experienced secondary causes of cancer cachexia (e.g., gastrointestinal obstruction, prolonged nausea or vomiting) was excluded from the study. Patients were asked

to nominate a family member to take part in the study. Family members were eligible for inclusion if they had face-to-face contact with the patient more than five times per week and were identified by the patient as his or her significant other.

Procedures

The study was approved by the Regional Research Ethics Committee, and governance was gained from the Health Trust where the study was conducted. All participants signed a written consent prior to taking part in the study. Patients were referred to the study by multidisciplinary staff within the regional cancer center. Single unstructured interviews were conducted with each participant in his or her home. Participants were asked to talk about their experience of cancer cachexia. Interview probes included, "What are your thoughts about the weight loss you have experienced?" and "How has your weight loss affected your everyday life?" When a participant mentioned a topic related to cachexia, the primary author, who conducted the interviews, asked follow-up questions, such as, "Can you tell me a little bit more about that?"

The data collection and analysis procedures were stringently monitored to ensure rigor within the study. Specific approaches to uphold rigor included digital recording and verbatim transcription of all interviews. In addition, the interviewer took thorough handwritten field notes of each interview. Those notes were especially relevant because they illuminated the direction of questioning within each interview and provided the necessary context for analysis. The analysis and interpretation of data should be "thick" in that they include the complexities in the data set (Lincoln & Guba, 1985). Therefore, the analysis presented in this study endeavors to display the diversity of viewpoints among the participants.

Data Analysis

All interviews were transcribed and checked against the original voice file and field notes for accuracy before being read and reread several times. Thematic analysis was conducted across all interviews (Van Manen, 2001). The preliminary analysis of transcripts confirmed the decision to perform interpretative phenomenological analysis (IPA) with eight interview sets (eight patients and their family members) (Smith, Jarman, & Osborne, 1999). Although all themes generated from thematic analysis were identical to those generated from IPA, the aim of conducting IPA was to uncover the depth and nuances of the experience of cancer cachexia by selecting a subsection of transcripts on which to conduct a detailed analysis. The process of conducting IPA involved identifying statements that reflected the participants' experience of cachexia, which were recorded and then arranged

into themes. Emerging themes were listed and any connections between them were established. Next, a table of themes was developed. The themes that emerged from the first interview formed the framework for subsequent interviews, and newly emerging themes were added to the table as they emerged. An iterative approach to data analysis was taken so that all new themes were clarified with prior transcripts and work continued back and forward between the cases in this way. Analysis continued across the data until no new themes emerged.

Results

Interviews ranged from 42–128 minutes. In total, eight patients and eight family members were interviewed. Participants' (patients and family members) characteristics are displayed in Table 1.

Reduced Dietary Intake Causes Conflict

Data suggested that reduced dietary intake frequently became a source of conflict between patients and their families, resulting in patients feeling like they were constantly in an environment focused on food from which they could not escape.

Well I'm never hungry as I was telling you, but [my wife and daughter always are] saying, "Eat this now, eat this now." [Looks away and then down to the floor.] A quiet life, love, that's all I need now, so I just eat what I can when they give it to me. It's never enough anyhow; sure, the weight's going off, and the rows [arguments] is going on.

The degree of helplessness evident in the previous account portrays the futility of the situation that patients perceived to exist over food. More notably, the nonverbal communication helps to convey the personal emotional state of this participant. Changes in food preferences and eating habits created conflict. Indeed, in many cases, the family members' focus on food exerted unnecessary pressure on patients to conform and eat. "When his appetite went down . . . we gave off and he started eating then, [but] that was for us. Really I think we were forcing him to eat."

For patients, eating often became a chore. The well-intended behavior of family members frequently had negative repercussions on patients, who typically became upset and angry by the continual focus on food.

They try to feed me everything. It doesn't matter if I want it or not; they'll still make me eat it, and I, that's just, they start me off, I just have to say, "I don't want it." [Lowers verbal volume.] You've no idea, no idea. [The patient sighs and lowers head.]

The desperation and emotional suffering inherent in this situation is particularly distressing, given that this is occurring during the final months of the patient's

Table 1. Participant Characteristics

Variable	n	%
Patient gender (N = 8)		
Male	4	—
Female	4	—
Caregiver relationship to patient (N = 8)		
Husband	2	—
Wife	4	—
Sister	1	—
Daughter	1	—
Mean weight loss by cancer diagnosis		
Lung cancer	—	18
Prostate	—	17
Acute myeloid leukemia	—	30
Bile duct	—	13
Cystadenocarcinoma	—	18
Mesothelioma	—	17

life. The defining characteristic of cachexia is that no matter what foods patients consume, they still lose weight. However, family members failed to see weight loss as an inevitable consequence of cachexia. For example, even after changes in the patients' appetite, they continued to encourage maximum oral intake as a means of resolving this crisis: "She still puts a full, full plate down in front of me, you know [shakes head from side-to-side]. I say, 'Well I can only eat what I can eat and that's it.'"

Patients and their family members alluded to patients removing themselves from situations in which the potential for conflict was evident—when food was offered that they did not want or would turn down: "She's right. Sometimes I don't want it and if she goes on then, I'd say, she'd be giving it to you, and I'd say, 'I'm away to bed.' Don't want it, you know." Social isolation and, therefore, avoidance of conflict was a strategy used by some patients as a means of evading disagreements over food. In addition, further action was taken by patients to prevent conflict over eating.

Y'know you're saying to yourself, here [family members] come again. They're going to start again about me eating. Then I'd say to . . . [my husband], you tell them I had such and such, and he'd say okay. I'll tell them. Then they come in and then he tells them the truth.

The desperation experienced from conflict over food was vast for this patient. Indeed, in an effort to avoid further conflict in her family situation, she tried to encourage relatives to collude with and lie for her about what she had eaten throughout the day. While patients often felt dejected and harassed because of this conflict, family members also suffered.

And then when we did have [arguments over food], you felt terrible in yourself [participant's eyes

welled up, looks to the side, clears throat, and then re-establishes eye contact] . . . because you know why should we be having these bust ups?

This account provides insight into the anguish experienced by family members when arguments over food arose. Bickering with a loved one over food was extremely difficult for family members. They expressed their guilt and remorse verbally and nonverbally.

Eating to Please

Patients described eating as a way of pacifying their family members. They often intimated that they ate, not because they wanted food, but because they wanted to satisfy their family members who were encouraging them to eat: "I do my best to eat it, to please them; it's just to please them like . . . it's hard [to eat]. I never, never feel hungry." Furthermore, patients acknowledged that they did this as a way of avoiding or resolving conflict over food: "I eat something to shut them up. I'll go and take maybe a digestive biscuit or a bit of toast. I'm not hungry; it's just to please them really." Patients wanted to maintain harmony with their family and eating food provided by their family members was a way of achieving that. The focus on food was fundamentally important for family members. The provision of food and nutrition had symbolic significance for patients and their families.

They're constantly on at me [about food]. Constantly, no matter what, anytime they're here; you know, they're just constant. I know they're just worried about me and all. I know that's why they do it.

For patients, family members' focus on food was a sign of their love, concern for their well-being, and compassion toward their ailing health. For family members, the symbolism of giving food mirrored the patients' feelings and the act of buying, preparing, and offering foods that the patients liked was how the family members demonstrated their love and concern for the patients' well-being.

Sometimes he'd take a tin of rice or custard. I always have it in the house now, he enjoys them, and he only has half a tin. I always make sure I have tins of them in the cupboard.

Family members typically kept the patient's favorite foods on hand in an attempt to gain the most benefit from any occasion when their loved one had a craving.

Reaction to Food Refusal

Family members focused heavily on encouraging patients to regain their health through eating and, when food was rejected or refused by patients, family members offered a variety of responses, including anxiety.

He's our father and we love him and we were panicking because he wasn't eating and we didn't know what to do.

The previous example helps to convey the affection and devotion to their loved one that was evident from all family members. In this study, only patients recognized the futility of eating in relation to cachexia. In contrast, family members viewed food as a vehicle to aid recovery. Thus, when food intake diminished, the family members' natural reaction was one of apprehension and worry as they related the patients' weight loss to reduced oral intake. Interestingly, when food was rejected by patients, the female family members talked most about how this affected them. They responded in two ways. First, they experienced guilt as they described how they continually offered food, even though it was refused; they believed that not offering food might have been viewed as neglect on their part: "I felt it was our fault you know, because he wouldn't eat and we couldn't get him to eat." Second, family members described feeling angry when patients declined food that they prepared: "I made the dinner, made what he liked, always liked and would have always eat, and he said he didn't like it, didn't want it, which I was quite angry at."

Patients' rejection of food was viewed by their family members as a refusal of their provision of support and nourishment. When prepared food was rejected, family members saw it as much more than a refusal of food offered. Family members often experienced feelings of personal rejection of the affection, concern, and consideration they put into the preparation and offering of food.

Discussion

This study uncovers the complex and emotive situations that surround eating for patients with advanced cancer who have cachexia and their families. In this study, care for patients by their family members centered on the provision of food. Patients explained how that often manifested in a way that their family members exerted unnecessary pressure on them to eat, Food Offering Versus Force Feeding. The "will to nourish" (Hughes & Neal, 2000) appeared to dominate in many families, with members conforming to a perceived nutritional and caring mandate in which the provision of food and the act of feeding were expressions of love and care. The lack of understanding regarding cachexia and the continual focus on food often led to conflict within the patient's family.

Conflict culminated when family members tried to encourage their loved one to eat. To avoid conflict, patients used tactics such as social isolation and lying. These findings mirror and expand on previous research (McClement et al., 2004); they also confirm Holmes's (2001)

theory on conflict resolution, which highlighted four strategies for resolving conflict, including avoidance. That was evident within this study as patients socially isolated themselves when the potential for conflict over food was present. Although previous research has suggested that conflict over food can occur between patients and their families (Holden, 1991), results from the current study outline the negative implications of conflict for patients and their families.

Participants stated that patients ate not because they wanted food, but because they wanted to satisfy their family members and avoid further conflict. This finding supports Stephany's (1991) discussion on terminal illness that suggested that patients eat because they desperately want to please their caregivers. Furthermore, these data are in line with Holmes's (2001) Framework of Conflict Resolution that outlined accommodation as one of four strategies to avoid conflict. In the current study, that was evidenced by patients being willing to sacrifice their needs and give in to family to avoid conflict. The symbolic importance attached to food was evident; food was a sign of the family members' affection and anxiety for the patient's well-being. However, because family members did not understand the physiology and nature of cachexia, they experienced feelings of guilt when they could not persuade their loved one to eat.

Lawrence (1984) proposed that food is the medium through which women demonstrate their love; interestingly, within this study, female family members discussed the emotional connotations linked with their role in food preparation and food offering. Therefore, they often experienced feelings of frustration when food was rejected and felt personally rejected in their attempt to provide nourishment and support their loved one. Holmes (1998) suggested that a patient's failure to eat evoked feelings of anxiety in their family members. In the present study, family members reacted to patients' failure to eat with mixed transitory emotions, including anxiety and despair. In their theory of emotion, Plutchik and Kellerman (1980) suggested that transitory emotions can affect and often drive behavior, an opinion previously confirmed in the cancer literature (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004).

Meares (1997) suggested that the degree of anxiety in relation to reduced food intake was related to the caregiver's level of understanding of the terminal nature of the patient's illness. Interestingly, family members expressed the most concern over the patient's failing appetite and did not understand the nature and effect of cachexia. All participants in this study were aware of the terminal nature of the patients' illness. Faced with the image of their loved one fading away, family members appeared to rationalize the patients' weight loss and viewed food as a vehicle to aid recovery. Freud (1936) suggested that rationalization is a defense mechanism

used to prevent the overwhelming anxiety of a situation. Therefore, perhaps family members' defense reaction was to discuss, buy, prepare, and offer foods in a manner usually associated with recovery from illness, rather than acceptance of the terminal nature of cachexia in advanced malignancy. That may help to explain the distressing tensions and disputes that existed around food within this population.

Study Limitations

The sampling procedure for recruiting family members into this study was dependent on the patients identifying and giving consent for their chosen family member to participate. Patients may have been inclined to select a family member whose beliefs concurred with their own. Thus, the views expressed by the family members in this study may not be generalizable to the wider family circle. However, data suggest that although similarities were identified between patients and significant others, overt and distinct differences also existed.

Nursing Implications

In advanced cancer, palliation of cachexia is recognized as a formidable task for nurses (Dewey & Dean, 2008). Data from this study suggest that arguments over food may affect quality of life for the time remaining for patients and may have negative repercussions for family members. Supportive informational interventions are needed for family members to understand that, for patients, food is a means of social enjoyment, rather than a treatment used to help arrest cachexia. Interventions should focus on helping families understand how the patient's altered appetite may contribute to weight loss. However, interventions should help family members distinguish between alterations in appetite that can be explained physiologically and those that are an expected consequence of cachexia over which the patient has minimal control. Emphasis needs to be placed on what family members can do to help a loved one through the illness trajectory. Furthermore, the futility of feeding a patient with cancer cachexia must be understood and is especially pertinent when dealing with the perceived role of food in cachexia. Information interventions should reinforce the ineffectiveness of feeding in cachexia and explain the difference between starvation and cancer cachexia. That would enable family members to understand the characteristics of this phenomenon and acknowledge that the patient's progressive and involuntary weight loss confirms the poor prognosis and movement toward death. As a result, family members may be able to shift their focus from food, thus reducing tension. Such interventions may contribute to patients eating for pleasure and increasing their social interaction rather than to satisfy their family members. In

addition, if family members do not experience feelings of guilt or distress when patients can eat only a small amount of food, patients may be encouraged to socially engage more with their friends and family, particularly at meal times. Most importantly, if family members are informed about the patient's inability to eat, alongside the irreversibility of the weight loss, they may adapt their response to cachexia (focus on food) and move toward acceptance of the terminal nature of the advanced cancer. The incidence and affect of cachexia underscore the value of sensitizing nurses to such issues.

Conclusion

This study is novel in that it provided the opportunity to be present and interact with patients with advanced cancer experiencing cachexia and their family members. Talking to participants about their experiences of cachexia provided insight into the tensions that exist over food between patients and their families. The focal point of the arguments centered on the quantity of food eaten and were fueled by a lack of understanding

about the role of food in cancer cachexia management. Further research providing supportive informational interventions to patients and their families needs to be conducted. The research should focus on the nature and effect of cancer cachexia and the role of food in cachexia management to evaluate the effectiveness of reducing the conflict over food experienced by this client group.

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Journal Club Questions

This article has been chosen as particularly suitable for reading and discussion in a Journal Club format. The following questions are posed to stimulate thoughtful critique and exchange of opinions, possibly leading to changes on your unit. Formulate your answers as you read the article. Photocopying of this article for group discussion purposes is permitted.

1. How frequently do we care for patients who are cachectic?
2. How often do we have problems with patients who do not or cannot eat?
3. Given the principles covered in this article, what are some of the ways in which we can encourage intake even if the patient is having difficulty with eating?
4. How can we support family members in their struggle to get the patient to eat?
5. This article raises wider issues regarding conflict between patient behavior and family desires. What are our options for addressing these situations? What approaches have worked and which have been less effective?

At the end of the session, take time to recap the discussion and make plans to follow through with suggested strategies.