

**Original Article**

# Helping Patients with Advanced Cancer Live with Concerns About Eating: A Challenge for Palliative Care Professionals

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**Abstract**

*This paper reports findings of an exploratory study of the eating habits of people with advanced cancer living in the south of England in 2003. The purpose of the study was to develop an understanding of why eating can be experienced as troubling and examine the potential for helping people live with the changes in eating habits that often accompany advanced cancer. Semistructured interviews were conducted with 30 patients, 23 lay caregivers, and 14 specialist nurses. The data were analyzed thematically. It was found that patients experienced eating-related concerns when the reality of eating differed from the expectations of eating. Patient response to concern ranged from acceptance to self-action. A subgroup of participants believed that they could have been helped by support for taking self-action. Eating-related concerns present nurses and other health care professionals with the challenge of supporting differing patient preferences for living with the symptom, which can include the expectation of support for self-action. J Pain Symptom Manage 2006;31:293–305. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Eating-related concern, good death, health promotion, self-action, end-of-life care, palliative care*

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**Introduction**

Many patients with cancer live with changes in eating habits that can be experienced as problematic, including loss of appetite, early satiety, food aversions, and declining food intake. The prevalence of anorexia in populations of people with advanced disease is reported within the range of 30–80%.<sup>1</sup> Previous studies of a diminished or lost desire to eat have focused on the development of pharmacological and nutritional interventions. These interventions have been found to be of limited value in stimulating appetite or increasing nutritional intake. Furthermore,

interventions have focused on arresting weight loss and enhancing nutritional status, without consideration of the issue of psychosocial support for people living with advanced cancer and eating-related problems.

A systematic literature search of electronic databases (PubMed 1966–2005/03; CINAHL 1982–2005/03; EMBASE 1980–2005/03; CancerCD 1990–2003/09) identified 10 studies that have investigated the experience of, and/or impact of, anorexia on patients with advanced cancer and their families.<sup>2–11</sup> These studies provide evidence that anorexia can precipitate distress. However, while there might be congruence between patient and caregiver assessment of appetite, they may have differing concerns about the symptom. Declining appetite may be of little importance to patients, yet troubling for caregivers. Caregivers have been found to admit to coaxing, nagging, pushing, and begging patients to eat, behaviors that can lead to family conflict.<sup>9,10,12</sup> To date, the focus of study has been on caregivers' concerns relating to anorexia in patients or comparison between patient and caregiver concerns in hospice inpatient settings. Little attention has been paid to the perspective of patients and how they might best be supported when living in their own homes managing the consequences of anorexia and other changes in eating habits.

This paper reports findings of an exploratory study conducted in the south of England in 2003. Multiple methods of data collection were used to collect information about the eating habits of patients under the care of two community palliative care teams. The focus of the work was the eating experience for patients with advanced cancer. Any change in eating habits perceived as problematic by the patient was taken as "the symptom" that the study sought to better understand. An understanding of experience that can precipitate concern was assumed an important foundation for any psychosocial intervention intended to help patients live with change in eating habits as they approach the end of life.

## Methods

An exploratory study was designed, in light of the scarcity of literature on the nature and cause of concern about eating in patients

with advanced cancer. The study aimed to develop an understanding of the manifestations, management, and meaning of eating changes in patients with advanced cancer and their families. The process of the study was informed by hermeneutic phenomenology. Although each study participant's perceptions were expected to be unique, it was assumed that they would be built from a shared reality.<sup>13</sup> The approach taken was one of gaining greater insight and understanding of this shared reality through the examination of multiple subjective perceptions of patients' eating habits.<sup>14</sup> Mixed methods of data collection were adopted to obtain information about eating. This paper reports the findings about eating habits derived from in-depth semistructured interviews.

Thirty patients with advanced cancer were interviewed under the care of two community palliative care teams in the south of England in 2003. Patient participants were asked to nominate both a health care professional and a family member/friend involved in their care. All patient participants nominated a nurse specialist, and 14 nurse specialists were interviewed about 30 patients under their care. The 14 nurse specialists had experience that ranged from 1 to 23 years in working with palliative care patients. In addition, 23 patient participants nominated a lay caregiver who was subsequently approached; all agreed to an interview. Of the 23 caregivers nominated, 15 were spouses, 4 were children, and 4 were friends/other relations. Of these caregivers, 14 were interviewed in the presence of the patient for pragmatic reasons. All interviews were semistructured and tape-recorded with the participants' consent.

The patient interview schedule was developed from the findings of the systematic literature review and the expert opinion of the project steering group members. Each interview began by the researcher stating her particular interest in weight loss and eating, and then inviting the participant to talk about their illness. The pattern of the interview followed the aspects of the illness experience relating to weight and eating that were of importance to the patient. At the end of the interview, patients were asked what had helped them live with any described changes and concerns. The caregiver and nurse interviews

were conducted using a similar approach. Findings relating to weight loss are reported elsewhere.<sup>15</sup>

### *Sampling and Recruitment*

Patient interviewees were identified from a survey of 232 people with advanced cancer living in their own homes, but under the care of two community palliative care teams (the survey findings are reported elsewhere).<sup>16</sup> Sampling from potential participants was purposive. It was informed by reference to the survey data, medical records, and details of the patients' eating-related issues reported by clinicians. The intention was to recruit a diverse group of patients across age, gender, diagnostic group, and experience of changes in eating habits. The inclusion criteria were as follows: (1) having a diagnosis of advanced cancer; (2) reporting a change in eating habits since they first perceived that they were unwell (which could precede diagnosis); (3) not receiving radiotherapy, chemotherapy, enteral, or parenteral feeding; and (4) being able and willing to participate.

The participants were 16 men and 14 women whose ages ranged from 43 to 85 years (median age 70 years). The primary site of cancer included the following groups: breast cancer,  $n = 5$ ; lung cancer,  $n = 4$ ; prostate cancer,  $n = 4$ ; head and neck,  $n = 4$ ; gastrointestinal,  $n = 6$ ; other,  $n = 7$ . The survey found that 29 of the interview participants were eating less than before they first perceived that they were unwell; 16 of these patients were concerned about eating less. Patient records revealed that four of the participants were referred to a specialist palliative care team because of anorexia. Two of the participants came from minority ethnic backgrounds. Within 7 months of the interview, 19 participants had died; the median time to death for this subgroup was 2 months.

The researcher made initial contact with the participants by telephone. If agreeable, the patient was mailed a letter of introduction and an information sheet explaining the nature and purpose of the study. They were given a minimum of 24 hours to consider their decision prior to interview. Of the 32 patients approached, one decided not to take part and a second died before the agreed interview date. The patient interviews were conducted

in the participant's own home ( $n = 27$ ) or at one of two hospice day care units. The duration of the interviews ranged from 20 to 90 minutes. Interviews were audio-recorded and transcribed verbatim.

### *Analysis*

The study question was as follows: "what are the manifestations, current management, and meanings of changes in eating habit for people affected by advanced cancer?" The data were interrogated with the study question, which enabled categories, and then themes, to be derived inductively. Interview data were managed and retrieved using a computer-based qualitative data analysis package (NUD\*IST6 QSR).

The two-staged process of firstly analyzing the data through coding and categorization, then secondly, interpreting the data by mapping and modeling was informed by Wolcott's (1994) framework for qualitative data analysis and conforms to Huberman and Miles' (1994) "mixed strategy for cross-case analysis." Hence, an understanding of the experience of eating, represented by a "model of the patient experience of living with change in eating habits and advanced cancer," was a creative product devised within a structured approach. The rigor of this interpretive work was then established through dialogue with cancer patients, clinicians, and academics and through a search for disconfirming evidence.<sup>14,17</sup>

The research had the approval of local research ethics committees and conformed to the research governance processes of the relevant National Health Service hospital trusts. All participants' names have been changed for reporting purposes to protect their anonymity.

### *Findings*

The interviews revealed many ways in which the experience of eating differed for the participants with advanced cancer, as compared with when they had last considered themselves to be well. These changes in what was eaten and what happened in the environment around the person while eating, were captured by a theme labeled the "reality" of eating. In

this paper, the theme is presented from the patient's perspective.

### *Reality*

*Change in What Can Be Eaten.* Changing eating habits was found to be part of what it was to live with advanced cancer. Collectively, the patients were experiencing changes that included early satiety ( $n=5$ ), loss of hunger/enjoyment ( $n=14$ ), food aversions ( $n=22$ ), eating as a chore ( $n=6$ ), and physical changes, including other symptoms, that made eating, chewing, or swallowing difficult ( $n=11$ ). For some, experiencing the need to stop eating occurred after just 2–3 mouthfuls of food ( $n=4$ ). Table 1 details physical change in desire for food described by the nine participants who agreed that their carer could participate in the study and whose carer interview was performed in the absence of the patient. The data presented are typical of all participants involved in the study.

*Environment Influencing What Can Be Eaten.* Eating alongside other people was usual for most of the patients. The presence or absence of other people could determine what was eaten. This was because of the feelings generated when it became impossible to eat similar foods, in similar amounts over the same time period, as family/friends. Table 1 lists examples of environmental factors that shaped feelings about eating.

Paula considers her eating habits to be anti-social, because she is only able to take liquefied food through a straw, which takes her a long time and is accompanied by dribbling. Her solution was to eat alone.

Taking liquidized food is not the sort of thing you want to do with family and friends. (Paula)

When family or friends were present their comments and behavior might increase or decrease the amount that could be eaten. Frank explains that the presence of his family was one of the main reasons he ate anything.

I take soups but I don't enjoy anything. I try for the sake of my family who are getting all stressed about it. I have no feeling of hunger at all and no appetite. (Frank)

However, in trying to encourage eating, family members could unintentionally be discouraging. Emma explains how her mother discourages her from eating.

Mum will go through, would you like this? Or would you like that? The end product is that it is even harder for me to try and stomach something. (Emma)

Tension around food and eating was described by members of one-third of the family groups studied. For some patients, mealtimes had become difficult or even dreaded events.

### *Expectations*

The "reality" of eating was experienced against a backdrop of ideas and beliefs about what should be eaten, captured by a theme labeled "expectations" of eating. Table 1 gives examples of the ideas and beliefs held by patients, caregivers, and nurse specialists about the patient participants' eating habits.

*Patients' Ideas About How They Should Behave.* The patient participants' stories told of how they believed a sick person should behave. Their comments revealed that it was thought important for a sick person to try to eat or be seen to be trying to eat.

I try. (Sid)

Some held beliefs that it was important to try to eat certain "good" foods, such as fruit, vegetables, or a low-fat diet. These ideas were often linked to beliefs about maintaining health and a sense of well-being.

Stella talks about the whole issue of culturally accepted good dietary habits from the perspective of someone with advanced cancer. She explains not only her concern to eat healthily, but also about the barriers to this being, not only her poor appetite, food aversions, and difficulty preparing food, but cost. She feels that the books that she has been given offering dietary advice to cancer patients have been unhelpful, because they imply that she is not doing all in her power to optimize her health.

I am not eating vegetables, I am not eating fruit. It scares me (....) Somebody loaned me a cancer book and it talked of foods—what to eat and what you could eat, which is very difficult, because my body is

telling me one thing, but the information is telling me a different thing. (...) Organic is the best, but organic is too expensive.

I feel that as well as the cancer, I am abusing my body, too. (...) I've always been one for looking after myself. It just makes me very frustrated. (Stella)

In a society that values behavior that demonstrates personal responsibility for health, changing eating habits could lead to feelings of being misunderstood and, in part, responsible for illness experiences.

*Caregivers' Ideas About How They Should Behave.* In parallel, the families and friends of the patient participants expressed ideas about how they should behave as caregivers. The caregiver behavior described by patients was consistent with the caregivers' own accounts. During the interviews, caregivers were not asked directly about their caregiving role, yet evidence of how they thought they should behave emerged. Good caregivers were believed to encourage a patient to eat. Rita's caregiver is a close friend. She considers it very important that she motivates Rita to eat:

If somebody is not well and there's nobody to encourage them to eat, they just don't bother to eat. I think Rita would be like that. (Rita's friend)

*Nurse Specialists' Ideas About Being a Good Health Care Professional.* Some patient and caregiver participants spoke about their nurse specialist's approach to an eating-related concern. Described approaches were consistent with the nurses' accounts of management. A majority of the nurse specialist participants expressed a concern to move people toward acceptance of eating (or not eating) for enjoyment and comfort. Claire explains her goal for patients who have concerns about eating:

I don't want them to have anxiety around eating and drinking.

I want them to eat and drink when they are hungry and for enjoyment. (Claire)

Overall, the nurses had low expectations of being able to help alleviate the difficulties patients and their families faced in consequence of changed eating habits.

### *The Source of Concern*

Living with changing eating habits could become of concern to patients not only because of their own expectations, but also those held by their family/friends or their nurse specialist. These expectations comprise understandings of what it is to be a good patient with good eating habits, a good caregiver, and a good health care professional. When the reality of eating contradicted these encultured values and expectations, it could cause concern.

Patients could blame themselves for not meeting the expectation that they would try to eat and try to work toward caregiver's goals. The nature of Terry's cancer meant that it was advisable for him to avoid certain foods. He explains:

All (nurses, doctors and my wife) do is moan. 'I told you not to eat that'. It is good advice. They know I'm stupid and I eat stupid things. I shouldn't do it. (Terry)

To lose the desire to eat could lead not only to feelings of inadequacy and self-blame but also guilt. Isaac expressed guilt:

Knowing that (my wife) is trying...It upsets me a bit to refuse these foods... I just can't help it. (Isaac)

So as a patient with advanced cancer, it was difficult to provide one of the rewards that caregivers sought. This reward was the acceptance of and enjoyment of food, thus providing evidence of good caregiving. Failure to meet this caregiver expectation could be a problem because of its impact on family relationships, as explained by Ron:

Because I can't be persuaded to eat anything else, there is an atmosphere in this house. (Ron)

### *Patient Response to Concerns*

When the reality of eating differed from expectations of eating and led to concern, a response was initiated. Responses were on a continuum. The continuum ran from coming to accept the concern as something to be lived with, through to taking self-action. Self-action was a conscious decision to manipulate either reality or expectations, thus mitigating eating-related sources of distress.

*Acceptance.* For some participants, to live with eating change did not demand any conscious

Table 1

**Eating Changes Identified by Patients and Ideas and Beliefs About Eating Held by Patients, Their Lay Caregiver, and Their Nurse Specialist**

Patient <sup>a</sup>	Reality		Expectations		
	Physical Change	Environmental Influence	Patient Ideas/Beliefs	Caregiver Ideas/Beliefs	Nurse Specialist Ideas/Beliefs
Vera	<ul style="list-style-type: none"> <li>-Feels full all the time.</li> <li>-Never feels like eating.</li> <li>-Forces herself to eat.</li> <li>-Can eat a maximum of three mouthfuls at any meal.</li> <li>-Has an aversion to meat.</li> <li>-Has a dry mouth.</li> </ul>	<ul style="list-style-type: none"> <li>-Husband becomes angry when she does not eat.</li> <li>-Dread of mealtimes.</li> <li>-Weakness causing inability to prepare food.</li> </ul>	<ul style="list-style-type: none"> <li>-I'm unable to eat because my husband is "not much of a cook."</li> <li>-I'm unable to drink as advised by nurses, but they don't know.</li> </ul>	<ul style="list-style-type: none"> <li>-It's difficult to get my wife to take any food.</li> <li>-We don't chat, she just sleeps; I don't know if it's because she's not eating.</li> <li>-She doesn't want to eat because she's frightened it will get stuck and she'll be sick.</li> </ul>	<ul style="list-style-type: none"> <li>-Vera is unable to eat but her husband feels she does not make an effort.</li> <li>-It's important to go with what Vera wants to eat and when she wants to eat.</li> <li>-Vera's weakness contributes to eating-related difficulties.</li> </ul>
Terry	<ul style="list-style-type: none"> <li>-Feels full quickly.</li> <li>-Binge eats until he vomits and/or experiences pain.</li> <li>-Food fancies change hour by hour.</li> </ul>	<ul style="list-style-type: none"> <li>-Wife becomes angry and upset in consequence of food refusal, binge eating, and rapidly changing food fancies.</li> </ul>	<ul style="list-style-type: none"> <li>-I want to gain weight by eating more.</li> </ul>	<ul style="list-style-type: none"> <li>-I find it difficult to know what to give Terry to eat.</li> <li>-I feel responsible for what he eats.</li> <li>-Terry often fancies things he ought not eat or he knows will cause him problems.</li> <li>-I fear giving him too much solid food that might block his stent and lead to his death.</li> </ul>	<ul style="list-style-type: none"> <li>-Terry resists admitting that his cancer is causing him problems and that he should take smaller meals more frequently.</li> <li>-His food fancies create work for his wife.</li> <li>-Terry uses eating as a measure of the control he has over his illness.</li> <li>-Terry's wife tries to restrict his dietary intake.</li> </ul>
Paula	<ul style="list-style-type: none"> <li>-Physical effort to eat.</li> <li>-Can take liquidized food through a straw.</li> <li>-Swallowing difficulties.</li> <li>-Taste changes leading to a preference for bland foods.</li> <li>-Eats "out of necessity" not enjoyment.</li> <li>-Dry mouth.</li> <li>-Dribbling.</li> </ul>	<ul style="list-style-type: none"> <li>-Embarrassed when taking liquidized food in the presence of others.</li> </ul>	<ul style="list-style-type: none"> <li>-I want to try to take enough calories to give my body the "best chance"/help with healing.</li> <li>-I think advice from a speech therapist and dietician would be helpful.</li> <li>-I am socially isolated due to the embarrassment of eating and drinking with others.</li> </ul>	<ul style="list-style-type: none"> <li>-Paula wants to eat but is unable to swallow.</li> <li>-It is important that she has enough calories to boost her energy level.</li> <li>-Advice from a dietician would be helpful.</li> <li>-Paula should restrict her social activity to conserve energy.</li> </ul>	<ul style="list-style-type: none"> <li>-Paula has a swallowing problem.</li> <li>-It is important not to cause concern by discussing what Paula is eating, thereby putting pressure on to eat more.</li> <li>-There are obstacles to making referrals to a speech therapist and a dietician.</li> <li>-She is unable to go out because of her swallowing problem.</li> </ul>

Table 1  
(Continued)

Patient <sup>a</sup>	Reality		Expectations		
	Physical Change	Environmental Influence	Patient Ideas/Beliefs	Caregiver Ideas/Beliefs	Nurse Specialist Ideas/Beliefs
Thelma	-Amount eaten has declined over time. -Able to take sips of cold clear fluid. -Nauseated.		-My family stresses that I ought to eat. They "get on my wick."	-Thelma will get upset if urged to eat. -Its difficult to try not to show concern when she doesn't eat.	-Nausea is due to constipation.
Frank	-No appetite. -No feeling of hunger. -Does not look forward to meals. -Takes toddler-size portions. -Dribbling.	-Takes food to please family. -Embarrassed by the size of his portions. -Cooking food smells unpleasant.	-I'm puzzled as to why I should have a poor appetite. -I force myself to eat and drink to prevent hospitalization and abate my wife's distress.	-I hate listening to Frank trying to take food and fluids. -I fear him choking on food, as I would feel responsible. -I wonder if medications are suppressing his appetite. -I have trouble thinking of social outings that won't include food. -I don't believe Frank would eat/drink unless encouraged.	-Frank's family is "brutal" in saying that he's got to eat: he only eats because they expect it. -He has problems with saliva and swallowing causing the family to complain about "grunting." -Frank should eat what he fancies.
Arthur	-No taste. -Periods of no desire for food. -Fluctuating appetite. -Unstable blood sugar levels.		-My wife thinks I'm being awkward when I refuse food.	-Its important to encourage ill people to take nutrition. -Maintaining energy levels through the use of food supplements is one way of improving quality of life. -Morphine suppresses appetite.	-Arthur's wife is anxious about his diabetic control but eating what he wants is more important than stable blood sugar levels. -His wife takes control of food and medications.

(Continued)



Table 1  
(Continued)

Patient <sup>a</sup>	Reality		Expectations		
	Physical Change	Environmental Influence	Patient Ideas/Beliefs	Caregiver Ideas/Beliefs	Nurse Specialist Ideas/Beliefs
Steven	<ul style="list-style-type: none"> <li>-Chore to eat.</li> <li>-Does not enjoy anything.</li> <li>-Dribbling.</li> <li>-Preference for sweet things.</li> <li>-Potato causes belching, hiccups, and retching.</li> <li>-Cannot face a "proper" meal.</li> <li>-Two doughnuts might sustain him for a whole day.</li> </ul>	<ul style="list-style-type: none"> <li>-Can't eat out because people stare.</li> </ul>	<ul style="list-style-type: none"> <li>-When I eat it feeds the tumor.</li> <li>-Healthy people don't understand that your food needs differ from theirs.</li> <li>-I feel guilty that my mother has to prepare special meals.</li> <li>-Dieticians don't tailor advice to your particular needs and preferences.</li> </ul>	<ul style="list-style-type: none"> <li>-It's a waste of time cooking, but I would feel guilty if I hadn't prepared a meal.</li> <li>-Smoking may be suppressing his appetite.</li> <li>-I don't think giving Steven what he wants is the best thing to do, as it might not be enough to keep him going.</li> </ul>	<ul style="list-style-type: none"> <li>-Steven wants to eat but can't, yet functions fairly well in spite of this.</li> <li>-I've not been able to refer to a dietician, but I have sought her advice.</li> <li>-It's not always possible to improve someone's situation, but it is possible to walk alongside.</li> <li>-Medications are artificial and short-term help.</li> </ul>
Jimmy	<ul style="list-style-type: none"> <li>-Loss of interest in eating.</li> <li>-Nausea at the sight of food.</li> <li>-Declining food intake over time.</li> <li>-Forces himself to eat.</li> </ul>	<ul style="list-style-type: none"> <li>-Cooking food smells "weird."</li> </ul>	<ul style="list-style-type: none"> <li>-It's important to eat, in particular protein, in order to maintain strength.</li> </ul>	<ul style="list-style-type: none"> <li>-I find it difficult to know what to give Jimmy to eat.</li> <li>-He must be suffering through not eating.</li> <li>-If he ate, he would get stronger.</li> <li>-I don't know if I've done all I can to help him eat.</li> <li>-Protein supplements are expensive.</li> </ul>	<ul style="list-style-type: none"> <li>-Its important to make eating and drinking as pleasurable as possible and not putting pressure on to eat.</li> <li>-Jimmy sees diet as a way to overcome effects of cancer.</li> <li>-It's difficult sustaining hope, yet aiding acceptance of reality.</li> </ul>
Ron	<ul style="list-style-type: none"> <li>-No appetite.</li> <li>-Able to take fluids and porridge-consistency solids.</li> <li>-Intermittent nausea.</li> <li>-Fluctuating ability to eat.</li> </ul>	<ul style="list-style-type: none"> <li>-Constant tension between family members around food and eating.</li> </ul>	<ul style="list-style-type: none"> <li>-There is an "atmosphere in this house" because I'm unable to eat.</li> <li>-I want to try to eat something to maintain my "mental energy."</li> <li>-My wife forces me to eat.</li> </ul>	<ul style="list-style-type: none"> <li>-Ron won't try his favorite foods; I have to force him to eat.</li> <li>-My son says I must make him eat.</li> <li>-He says he doesn't want to eat, but I'm not sure, because he eats sometimes.</li> </ul>	<ul style="list-style-type: none"> <li>-There is not a lot to offer for eating problems.</li> <li>-Ron is unable to accept that his eating difficulties are a natural consequence of his cancer.</li> <li>-Nausea reminds him of his illness.</li> <li>-Ron's wife does not understand that his eating difficulties are the consequence of his cancer, but believes he needs a better attitude.</li> </ul>

<sup>a</sup>The nine patients from the total sample where patient and lay caregiver were interviewed independently.



plan of action or management per se. To live with eating changes was to trust one's body to be self-regulatory, as before illness.

Patients for whom healthy eating was unimportant and who did not hold themselves personally responsible for their food intake were accepting of their eating changes. This was the case for Arthur:

I just accepted that I couldn't eat. (Arthur)

*Self-Action.* Others were more reflective about the changes that they experienced. They stepped back and considered choices in living with eating changes. These patients were carefully managing their eating habits. Their concern was to use eating as a way of mitigating existing problems and averting future anticipated problems. These activities were captured by a theme labeled self-action.

Stella understood that her cancer could not be cured, yet wanted to do all that was possible to optimize her health in spite of her disease. It was a way of continuing to feel in control of her life and cope with her illness.

You know, you are doing something yourself, as well as other people helping. It enables you to keep going. You know you are looking after yourself. (Stella)

Of the patients interviewed, 18 were found to be manipulating their dietary intake. Foods were found to be used to help people live with other symptoms, such as weakness and fatigue. For example, Albert believes that his Fortisip drink provides him with the energy that he needs to continue his daily activities:

One thing that (my specialist nurse) put me on to was this energy drink. That's absolutely magic. (...) I feel as though I couldn't do without it. I have one of those every day. (Albert)

Manipulation of diet as a way of life with advanced cancer did not always mean changing what was eaten. It could also involve making a choice not to eat, so as to try to control the cancer. Two patients were found to be restricting their dietary intake in an attempt to limit the growth of their cancer.

Few of the self-help dietary changes used by patients were described as having been recommended by health care professionals, and mostly had not been discussed with them. It seemed that there was little expectation of health care

professionals advising on how diet might help people live with advanced disease. For example, Paul wanted information on the consequences of choosing not to eat, as he was considering regaining control over his future by electing to refuse food and hasten the end of his life. He wanted to know if this would increase or decrease his pain. However, he had felt unable to discuss the potential choice with his specialist nurse, as he believed that she would neither find it an acceptable topic for discussion nor would she support it as a reasonable course of action:

(I would like to ask my specialist nurse) what would happen if I were to go on hunger strike? (...) I cannot get rid of these chains of events that I am condemned. (Healthcare professionals) have to follow the rules of the game. You cannot do anything on your own because you are condemned by society to react in a very established way. (Paul)

When patients did seek support for their self-action from health care professionals, they could be disappointed with the response. Steven had been referred to a dietician much earlier in his disease course but had found the approach taken to his eating problems unhelpful. He believed that optimizing nutritional intake was very important to being able to "fight" cancer, but felt able to eat only a limited variety of food.

Interviewer: What would you have preferred (the dietician) to do?

Sit down and talk to me properly.... Talk to me about my eating habits, rather than saying right we've got these nutritional supplements; try these (...) There's things you learn... You know your own body, your likes and dislikes. So surely they can say 'Lets start from what you like.... Start with a survey of my life?' (Steven)

Caregivers, like patients, expressed a range of views about the most appropriate way to live with eating-related issues. Similarly, their views spanned a continuum from acceptance to self-action.

#### *Nurse Specialist Response*

The specialist nurses who took part in the study believed their role to be one of acting to ameliorate problems. They collectively expressed uncertainty about how to help people

with eating difficulties. The majority suggested the symptom was something for which they could do little to help. Belief that little could be done led to feelings of frustration and helplessness. Jenny talks about the palliative care team as “fixers” and eating difficulties leading her to feel discomfort because they cannot be fixed.

I feel quite uncomfortable because we like to try and fix everything and be able to offer something. We can't do that with eating problems. We can't do anything to make that better. (Jenny)

Eating was considered something that might be best not discussed with patients and caregivers, out of concern that this could generate rather than alleviate problems, as explained by Rachael.

She can only eat what she can eat, we don't want her to worry. We don't want to put more pressure on or anxiety. (Rachael)

When patients or caregivers spontaneously expressed concerns about eating, a typical approach was to try to help with acceptance of any change.

We try to encourage (patient and caregiver) to go with what she wants rather than what she feels she should be having. That's been perhaps the hurdle to get over. (Anna)

Helping people across what Anna calls a “hurdle” was recognized as difficult by nurses who described people passing through a period of time to acceptance. Other terms and phrases used to describe the hurdle included a “transition,” a “phase,” “coming to terms with,” and “facing up to.” Claire describes what it can be like trying to help people accept change in eating habits.

Sometimes you feel you are banging your head against a wall—trying to focus on the enjoyment and eating, and not focus on trying to sustain life. (Claire)

The specialist nurses who were willing to support patients who sought help with self-action were uncertain of the appropriateness of this course of intervention. They also found it could be difficult to access the expertise of other health care professionals, such as dietitians.

### *A Model of the Patient Experience of Living with Changing Eating Habits*

The themes that emerged from the data and the relationships between them enabled the development of a conceptual model. This model provides an understanding of the patient experience of living with eating difficulties (Fig. 1). The reality of eating and expectations of eating are represented as counterbalanced. To maintain the balance and therefore not experience concern, patients respond to changes in reality and expectation.

Patients respond to the challenge of expectation differing from reality on a continuum ranging from acceptance of the changes as being outside of their control to self-action, as discussed previously. Nurses and other health care professionals may be able to mitigate eating-related concern through the provision of support that aids patients in regaining a balance between eating reality and eating expectations.

## **Discussion**

### *Helping Patients Live Well with Changing Eating Habits*

A key finding that emerged from the development of the Model of the Patient Experience of Living with Eating Changes and Advanced Cancer is that patients have differing preferences for living with eating-related concerns. Preferences range from acceptance to engaging in self-action.

The conceptual model provides an understanding of the experience of living with changing eating habits from the perspective of a patient with advanced cancer who lives in a context of often competing streams of ideas about eating held and expressed by those in their social network. However, it is limited in scope. The patients selected were a diverse group, in terms of age, gender, cancer site, social circumstances, and proximity to death. However, only two patients were from ethnic minorities and in view of the finding that cultural context was important to the experience of eating changes, it seems likely that the framework does not capture all experience across ethnicity, geography, and time. Furthermore, all patient participants nominated nurse specialists as the health care professionals

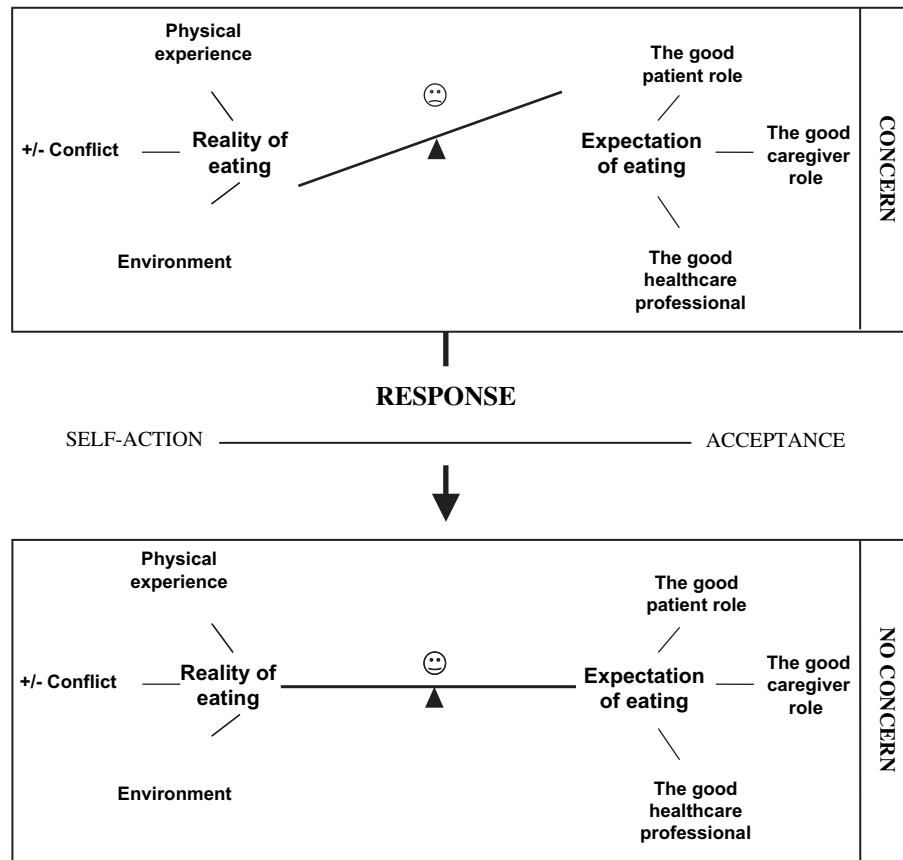


Fig. 1. Patient experience of living with changing eating habits and advanced cancer.

whom they agreed could be approached and invited to participate in the study. The perceptions of nurses may not represent those of all members of the interdisciplinary team.

*Facilitating the Transition to Good Death.* The practice of the specialist nurses studied was consistent with reports in the limited available literature that looks at how patients can be supported when living with eating-related problems. This literature conceptualizes living with changing eating habits as a transition as the end of life approaches.<sup>12</sup> It identifies the purpose of intervention to be the facilitation of acceptance and comfort.<sup>5,18-20</sup> This approach, of enabling a transition to acceptance of eating changes is consistent with a professional ideology of good death, which focuses on facilitating a death where patient acceptance is achieved.

Patients involved in this study did not talk of, or allude to, being in or having passed through a transitional phase to acceptance of their eating changes. Becoming unable to eat the same

foods at the same times and places as previously was something that just happened. Those patients who accepted the changes as a normal and irreversible accompaniment to progressing illness, conceded to moving further into a liminal state that is induced by a cancer diagnosis.<sup>21</sup>

A liminal state is one where previously transparent physical and mental phenomena become nontransparent, leading to a sense of difference from others.<sup>21</sup> Behavior becomes distinguishable from those in one's social network, as contrary to that which is normal and valued. Liminality can be excluding and isolating. Hence to accept eating changes is to accept one is becoming different from one's social network. It is to move away from shared goals, hopes, and aspirations for the future, as expressed by Frank's wife:

It's the future that I find strange. We're planning for separate things even though we're together... Different futures for the first time in 36 years. (Frank's wife)

To facilitate acceptance of eating changes is to aid further movement into the liminal state. Patients living with eating changes in an accepting way could find this approach supportive. It enabled them to live, as death approached, without guilt or self-blame relating to eating. But for those whose well-being was dependent on retaining a sense of autonomy and control of health and illness, seeking ways of self-acting to limit experience of liminality was important. This study found a small cohort of patients who, although they knew that they were dying, wished to engage in self-help and health promotional activities. These patients expressed disappointment at the support that they had received in response to their endeavors to optimize their health and well-being using dietary manipulation.

*The Potential for Promoting Health Until Death.* Increasingly, onus is being placed on healthy individuals to take responsibility for their health and well-being.<sup>22,23</sup> Yet health promotional activities have been found to be adopted most often in response to experienced and anticipated ill health.<sup>24</sup> Hence, it seems unsurprising that some patients with advanced cancer express an interest in how they might act to promote their own health and well-being. Yet, little is known about which health behaviors lead to optimal outcomes in terms of quality of life for patients known to be approaching the end of life. In the case of eating, while there is no evidence that activities such as dietary manipulation are of benefit, there is also no evidence of adverse outcomes.<sup>25,26</sup> There may be as yet unproven psychosocial benefits of dietary manipulation and other self-actions.

The evidence from this study demonstrates that, even having accepted the inevitability of death with advanced cancer, some patients have a desire to engage in self-help and health promotional activity to enable them to live with eating-related concerns. This finding challenges nurses and other health care professionals to consider whether their personal ideology of good death includes the facilitation of self-action. The challenge is to find practical ways of helping patients who, in spite of knowing that they are terminally ill, have a desire to manage their illness experience using a proactive approach, which complements conventional palliative treatments and care.

In this study, the infrastructure was found not to be in place for those who wished to engage in self-action in relation to their eating. Access to dieticians, speech therapists, and information about how to help oneself were at best ad hoc, and at worst absent. In part, this might be because of a failure to recognize the potential benefits to patients' psychological well-being of feeling enabled to optimize their health in spite of imminent death. This approach is perhaps founded on an absence of evidence around the benefits or otherwise of supporting people who adopt a proactive approach to living with advanced cancer. Further work is needed to establish outcomes from interventions that support self-action as death approaches. It might be that aiding a transition to acceptance of eating changes is the most appropriate approach to managing patients with advanced cancer. However, it could equally prove that patients who resist movement toward acceptance may be adopting different, but equally effective, ways of living with eating troubles.

#### *Can Self-Action Be Consistent with Good Death?*

If facilitating a good death is understood as supporting the patient-selected approach to living with their illness, then self-action can be consistent with a good death. However, facilitating living well with advanced disease is not to assume that the patient knows best and concede to "good enough death."<sup>27</sup> It is to recognize that there are different ways of living well and that expert knowledge should be tailored according to the goals or preferences of the patient. To nourish becomes to care for using science and art,<sup>28</sup> guided by what it means to the patient to live well with advanced cancer.

### **Conclusion**

Change in eating habits is often of concern to patients with advanced cancer. The majority of the palliative care nurses involved in this study were found to work toward facilitating acceptance of the symptom. This approach may not be the only way of helping patients live with eating-related concerns as the end of life approaches. Some patients were found to live with their eating troubles by engaging in self-action and expressed concern about lack of support for this behavior. Eating-related concerns present nurses and other health care

professionals with the challenge of supporting differing patient preferences for living with the symptom, which can include the expectation of support for self-action.

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