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Food connections: A qualitative exploratory study of weight- and eating-related distress in families affected by advanced cancer

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ABSTRACT

Purpose: Weight loss and eating problems are common in cancer and have a profound effect on quality of life. They are symptoms of cancer cachexia syndrome.

This paper examines interdependency between advanced cancer patient and family carer experience of weight- and eating-related problems, leading to proposition of how weight- and eating-related distress might be alleviated in both patients and their family members.

Methods: The study was of cross-sectional design. Interpretive phenomenology informed the analytic process. Patient participants had advanced cancer and concern about weight and/or eating. Semi-structured interviews were conducted with 31 patient-spouse/partner dyads (62 interviews), which focused on weight loss and eating problems in the patient and how these had been managed.

Results: This study found change in weight and eating habits in advanced cancer to disrupt food connections. Food connects us with others physically by fuelling the body and sustaining physical activity and life, emotionally by communicating feelings about self and others, and socially by providing a reason for sharing time with others. The study found three dyadic responses to disruption in food connections; dual acceptance, dual resistance and mismatched resistance. They are of interest, because they can help discriminate between those patient-family carer dyads who might benefit from psychosocial interventions and those who will cope without such help.

Conclusion: The findings challenge clinicians and researchers to seek ways of aiding not only with concerns of the individual patients and carers, but also with interactions between distressed family members affected by symptoms of cancer cachexia syndrome.

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1. Introduction

Weight loss and poor appetite are common in people with cancer. They are symptoms of cancer cachexia syndrome (also known as cancer anorexia cachexia syndrome and cancer cachexia). It is defined as:

a multifactorial syndrome characterised by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. The pathophysiology is characterised by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism (Fearon et al., 2011).

The symptoms of cancer cachexia syndrome have a profound effect on quality of life and are associated with impaired physical function, reduced tolerance to treatment, and reduced survival. The current consensus amongst experts is that tumour-induced weight loss and anorexia can only be reversed by effective anti-tumour treatment (Fearon et al., 2011). There are currently no interventions known to be effective in arresting or reversing tumour-induced symptoms of the syndrome.

2. Background

Involuntary weight loss and other symptoms of cancer cachexia syndrome are the consequence of tumour-induced metabolic changes, such as inflammation, and secondary nutritional impact symptoms, such as nausea, that bring about a malnutrition component of the condition. The majority of people who die from cancer have involuntary weight loss (von Haehling and Anker,

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2014). In the past decade, studies have found that distressing problems caused by the symptoms of cancer cachexia syndrome include conflict over food in families, carer fear of patient wasting away, and carer perception of health professional neglect (Hopkinson, 2010). Family carers can experience greater distress than patients (Hawkins, 2000; Poole and Froggatt, 2002; Strasser et al., 2007). Witnessing the despair communicated by a tearful carer in words like 'he just won't eat' or the fear expressed by a patient who says 'I don't understand why I can't eat' can evoke powerful emotions such as feelings of helplessness (Hopkinson et al., 2006). Few health professionals assess or actively manage weight loss, poor appetite and other symptoms associated with cancer cachexia syndrome (Churm et al., 2009; Porter et al., 2012). This is perhaps unsurprising given the absence of medical treatment options and the distress and other negative emotions the symptoms can evoke.

In 2011, an international expert consensus statement acknowledged the importance of psychosocial support to the management of cancer cachexia syndrome (Fearon et al., 2011). Assessment by health professionals is important, as two different weight- and eating-related problems can be amenable to psychosocial intervention; weight- and eating-related distress (Hopkinson, 2010) and sub-optimal dietary intake when malnutrition co-exists with tumour-induced weight loss (Aapro et al., 2014).

This paper focuses on the negative emotions evoked by the symptoms of cancer cachexia syndrome. In particular, the alleviation of weight- and eating-related distress. The first psychosocial intervention tested for effect on weight- and eating-related distress in patients was the Macmillan Approach to Weight and Eating (MAWE). MAWE is a package of face-to-face education and emotional support provided to patients in their own homes by nurses (Macmillan Cancer Support, 2008). A finding from the MAWE trial was correlation in patient and family carer measures of weight- and eating-related distress. When interviewed, both patients and family carers described behaviours in the other member of the dyad that cause them distress and was in consequence of change in weight or eating habits (Hopkinson et al., 2008). These behaviours included talk and acts or omissions; interactions between patient and carer were important to the experience of weight loss and poor appetite. Furthermore, it seemed a system was operating where one interaction led to a responding interaction, intertwining the experience of both members of the dyad and creating interdependency in experience. Similarly, other researchers have found association between cancer patient and carer experience of distress, symptoms and quality of life (Harding et al., 2003; Hodges et al., 2005; Pitceathly and Maguire, 2003). In other disease states patient-family carer interdependency has been proposed as influential in health behaviour change (Lewis et al., 2006); patient decision making (Ransom et al., 2006); and emotional adjustment to illness (Mallinger et al., 2006). The form of interdependency in patient-family carer experience of cancer cachexia has not previously been studied. Understanding interactions between patients with cancer cachexia and their family members could be important for improving patient experience and clinical outcomes.

This study is based on the assumption that there is interdependency in patient and family carer experience of weight- and eating-related problems. It is the first study to examine the nature of this interdependency and consider the implications for clinical practice.

3. Aim

To examine interdependency in the experience of involuntary weight loss and poor appetite of patients with advanced cancer and

their family carers and to generate understanding that can inform clinical practice.

4. Methods

4.1. Primary study

All of the study participants were new referrals to one of two specialist palliative home care teams in the South of England from 2006 to 2007. They had agreed to take part in an exploratory trial of a psychosocial intervention for weight and eating-related distress (details of the primary research are reported elsewhere, see Hopkinson et al., 2010). The study recruited 65 patients (representing 28% (65/232) of new and eligible referrals during the data collection period.

4.2. Design

Of the 65 patients in the primary study, 31 were supported by a husband/wife/partner who also gave consent to participate. The secondary analysis reported here is of trial baseline semi-structured interviews conducted with these dyads (62 interviews, as patient and family carer were interviewed separately). The interviews focused on the experience of weight loss and eating habits in the patient and perception of how any related problems had been managed. Interview durations were 12–89 min for patients (determined by the patient's condition and concentration) and 15–62 min for carers (determined by competing demands for their time). They were conducted by the author, a cancer and palliative care nurse with 20 years clinical experience plus 10 years experience as a nurse researcher, who was not involved in the delivery of clinical services to participants. Measures of weight-related distress and eating-related distress were taken, using visual analogue scales ranging 0–10 (zero representing no distress and ten extreme distress). For example, patients were asked, 'Over the past three days, how much distress has eating caused you?'

4.3. Sample/participants

Patients were eligible for participation if they:

- had cancer but were no longer receiving potentially curative treatment,
- were 18 years or older,
- had self-reported weight loss and/or eating problems,
- had concerns or had reported that a family member had concerns about their weight and/or eating,
- were receiving usual care, which was nurse managed care (the most complex cases were managed by medics),
- assessed to have no clinical reason for exclusion, such as cognitive impairment or severe uncontrolled pain where the planned interview would be inappropriate,
- cachexia (>5% loss of body weight over six months) or high risk of cancer cachexia syndrome by virtue of advanced disease state and reduced food intake.

Patients were informed about the study during the first telephone contact made by their palliative care nurse that followed their referral to the palliative care service. During this phone call, the nurse sought permission to mail a study information sheet with a short eligibility questionnaire. On receipt of the patient-completed questionnaire, the researcher contacted all eligible patients by phone to seek permission to conduct an interview in their own home and to contact a family carer.

4.4. Ethical considerations

There is much sensitivity around the conduct of research with people who are approaching the end of life. Access is difficult and recruitment challenging (Ewing et al., 2004). One of the main concerns for both researchers and gatekeepers is burden on sick patients and their carers. Analyses conducted for the parent study identified that distress was, in part, dependent on the behaviour of other family members. Secondary analysis of the existing data set was judged to offer the opportunity to gain insight and understanding of this interdependency, without burdening additional patients with a data collection process. This opinion was supported by the Southampton and South West Hants Local Research Ethics Committee B (Project ref: 08/H0504/190) which granted approval for the study.

4.5. Analysis

The researcher checked transcriptions for accuracy against the interview audio-recordings, a process which enhanced familiarity with the data. The secondary analysis was then conducted in three stages using an interpretive phenomenological approach informed by the work of van Manen (1990). The first step in the analysis was to examine the meaning of weight, food and eating for each patient and carer independently. Data was identified that detailed the patient's experience of weight and eating and their carer's experience of the patient's weight and eating. These data extracts were then further analysed for each individual but within the wider context of their entire interview. Codes that emerged were; messages communicated through weight and food, perceived changes in weight and eating, the impact of these changes, interpretation of and response to the changes, and contradictions and uncertainties.

The second step in the analysis was to examine the meaning of weight, food and eating within each dyad. Shared and competing understandings from the first stage of the analysis were used to generate a summary description of interactions within each dyad, thereby locating the nature of interdependency in response to involuntary weight loss and eating problems. Finally, a thematic cross-case analysis was conducted (Miles and Huberman, 1994), where each dyad was considered as being a case. The thematic analysis sought patterns in dyadic response. This enabled the construction of a conceptual model of the dyadic experience of involuntary weight loss and change in eating habits in the patient.

The discovered patterns of dyadic response were then considered in the context of the wider related academic literature about adaptation, coping and collective coping. This led to an explanation of weight- and eating-related distress in families and generation of theoretical propositions of how it may be alleviated. Consideration was also given to the influence of the personal and professional history of the researcher on the analytic process. This consideration was aided by clinical supervision provided by a counsellor who is also an experienced nurse and researcher.

4.6. Rigour

Establishing the rigour of this interpretive work has been an ongoing process. A detailed log was maintained of decisions, a decision trail, and issues arising explored during both monthly academic supervision and monthly clinical supervision with a counsellor independent of the research (Koch, 1994). Disconfirming evidence of emergent themes and their interpretation has been sought within the dataset analysed. The emerging concepts, propositions and interpretation were further evaluated in focus group style meetings and one-to-one discussions with the study user involvement group members, who included consultant

dietitians, clinical psychologists, family therapists, nurses, medics, academics, psychological therapists and patients (Van Manen, 1994; Miles and Huberman, 1994).

5. Findings

Twenty seven of the thirty one patients and four of their carers were men. Patients and carers were of similar age (mean patient age 71 years and mean carer age 68 years). The patients had metastatic cancer of mixed primary sites, 19 had lost more than 5% of their body weight in the six months prior to interview, 29 had died within 13 months of interview and median time to death from interview was 2.7 months. (See Table 1 for patient and carer characteristics.)

[In the following analysis, patient quotes are followed by the letter P and their original trial number and carer quotes with the letter C followed by their partner's trial number. The quotes are those that best illustrate reported findings.]

5.1. Everyday interactions: the importance of food

Food and eating are an important part of our everyday lives. These everyday meanings of food, eating and weight were present in the study participants' accounts and formed the backdrop of their experience of weight and eating problems. Offering food represented connection with others and was recognised as a caring act:

She's always putting nick nacks in front of me 'there's a bowl of sweets up there' and I find a couple of chocolate bars on the side table. I quite like it, because I know she's looking after me. (P69)

Eating was also spoken about as a social activity, something done with others:

So we're all going out to eat (C31)

Some foods were considered of greater value than others:

I'm very anti package foods. I like to eat good home-made wholesome food (P43)

The preparation of certain foods and meals was important for sustaining relationships with friends:

My wife is famous for her roast dinners on Sundays, she really is! (P72).

Food was not just about fuelling the body, it had emotional meaning and social value.

5.2. Involuntary weight loss and/or change in eating habits

All of the patient participants had experienced involuntary weight loss and/or change in eating habits. Examples described by most included no desire to eat, 'I don't fancy anything. Just no appetite' (P24); change in the taste of food, 'Things don't taste as you expect them to taste, and that puts me off' (P69); reduction in the amount eaten, 'He is eating about half of what he used to' (C73); and a shift from eating as being enjoyable to being unpleasant, 'Now I just hate eating. I wish I could get by without any eating at all. At the end of a meal I think to myself 'I'm glad that's all over.' It's a sort of punishment' (P17). Change in appearance was also spoken about by a minority, 'I've gone ever so thin' (P57).

Table 1
Participant characteristics.

	Patient group (n = 31)	Carer group (n = 31)
Age (mean (range))	71 (44–83)	68 (47–84)
Gender (n)		
Men (husbands/partners)	27	4
Women (wives/partners)	4	27
Diagnosis (n)		
Lung	8	
Breast	1	
Renal	2	
Upper gastrointestinal	5	
Colorectal	1	
Prostate	2	
Bladder	2	
Pancreas	2	
Other	8	
Medication for symptoms (n (%))		
Anti-emetic	9	
Analgesia	27	
Aperients	15	
Steroid	10	
Quality of life (mean) ^a	4	
Malnourished: >5% loss body mass in six months prior to interview (n) ^b	19	
Time to death (median months) ^c	2.7	
Eating-related distress ^d (mean(range))	29 (0–90)	48 (0–100)
Weight-related distress ^d (mean(range))	20 (0–90)	47 (0–100)

^a Measured using EORTC QLQ-C15 (range 0–7).

^b Information not available for three patients who did not wish to be weighed.

^c Within 13 months of interview 29 participants had died.

^d Measured using a visual analogue scale (range 0–100).

5.3. Anxiety and distress

Anxiety is uncertainty arising from threat to well-being and experienced as concern, worry, apprehension or unease (Lazarus, 1999). Changes to patients' weight and/or eating habits could cause anxiety for both patients and carers.

Patients and carers did not actually describe themselves as anxious. They chose to talk about bother, worry or concern (concern was the term used by the researcher to enquire about emotional experience of changing eating habits and involuntary weight loss). But their thoughts and feelings can be understood as anxiety. Anxiety was expressed through thoughts of the impact of changing eating habits on nutritional status and health:

I think at this point the lack of appetite is a concern because of the ultimate effect it is going to have, not the immediate effect. So it's something I am not that concerned about in terms of weight loss at the moment. I am more concerned about the adverse effect it's having on me in terms of body nutrition and the long term effect of that (P43)

Anxiety was also articulated by identifying death as being the consequence of not eating:

It worries me because I'm not eating. I know if I've got to last any time at all, you know, another year or whatever, I need to be eating. I don't want to throw my life away (P1)

Similarly, carers described troubling thoughts about other consequences of eating less, in particular the impact on physical activity, with concern expressed about weakness and dependency.

It does worry me because he was so solid before, and he's so weak now, that he can't do anything (C17)

Anxiety is a negative emotion. The American Cancer Society (2014) defines distress as unpleasant feelings or emotions that

cause problems in coping with cancer and its treatment. For the purpose of this study, distress was understood in this way, as anxiety that disrupts daily living (physical, social and/or emotional). Whilst cancer brings uncertainty for everyone, the degree of anxiety experienced differs, becoming distressing for some, but not everyone.

Some study participants spoke about distress. They understood that changes in weight and eating habits were a threat to the patient's physical well-being, leading to physical weakness and, ultimately, to death. Hence, the patient's physical appearance could cause distress.

He looks so terribly thin without any clothes on. It's distressing (C20)

Most carers were unable to talk about why witnessing wasting was distressing or how it interfered with their everyday life. Simply thinking about appearance led to tearfulness and sobbing. C30 was someone able to explain why witnessing physical wasting is upsetting.

When he undresses, I'm not used to seeing him with what I call wrinkly skin. And I suppose it's another sign of what's going on inside I suppose. Well, I don't like being reminded! (C30)

C63 explains that physical contact with her husband has become distressing.

I am frightened to touch him, 'cause he is so bony. I am frightened to touch him in case I hurt him by touching him (C63)

Change in appearance and eating habits can also be distressing because it disrupts relationships. C1 explains:

He said he didn't want to eat with us, he didn't want to upset the children, he was adamant he didn't want to eat with us, so I gave him a small meal in here (sitting room) and when I came in he'd

only eaten half. At first it infuriated me, then I thought afterwards that was stupid because as long as he was eating something... (C1)

P1 volunteered to talk about his decision to eat apart from the family. His weight loss had prompted mealtime talk that challenged his autonomy in deciding what to eat and reminded him of his illness.

They start this 'you've got to eat otherwise you are going to be ill' so I say 'I am already bloody ill.'...they (family) are trying to help by saying 'come on you've got to eat something because you are losing weight all over the place' and I am embarrassed then (P1)

When talking, C1 focuses on physical changes. She says it is the choice to eat apart from the family and the small amount eaten that was infuriating. Perhaps it is also the emotional meaning that is infuriating. P1's decision to eat separately had been understood to be rejection of the family's attempts to help him delay death and demonstrate their care. Many of the other carers and patients, described feeding and related activities as demonstrating a caring relationship, such as C34.

I cannot force him to eat so we just do the best we can. ...trying to select the things that he really fancies, which isn't a lot and then of course I feel better because I have tried to do something (C34)

Physical changes in weight and eating can disrupt patterns of physical connection with others, as described by C63. They also disrupt emotional and social connections, which is perhaps what C1 talks about. Below, is an extract from a detailed account by C43 of difficulty eating evoking anxiety, which disrupted social life and disrupted relationships including her own relationship with her husband. Reduced appetite had disrupted emotional and social connections.

Of course you get his family saying 'oh come on try and eat a little bit more' and he's 'No, no, I'm OK'. But then of course when we talk about it 'Oh everybody keeps on going on at me.' Do they not think that I want to eat? Everyone moans at me.' And I try to say, as much as I possibly can, 'people are only saying these things because they are concerned. They know how you used to eat and they see how you are not eating now and it is a concern.' ... And I say to him 'do you think I like seeing what's happening at the moment, knowing how you used to eat? And how as a couple we used to enjoy going out for meals?...It has affected us. It's one of the things that we used to enjoy; we'd say let's go and have a meal somewhere.' Or a friend would say 'come in and have a meal with us.' ... He can't go out for a meal and I think it's having an overall effect on us. (C43)

Similarly, C19 explains how his wife no longer enjoys food and how this has changed the conversations they have, disrupted their social life, caused arguments and left him feeling inadequate in his role as carer.

She doesn't enjoy (eating). Doesn't look forward to it, whereas before she became ill, it was one of the things we both enjoyed...We used to go out for meals. It was a great pleasure and we used to have friends round for dinner parties, very enjoyable...She won't after any meal say 'I enjoyed that.' I might, she won't...I might from time to time get annoyed that she hasn't eaten as much as I like her to eat. And in the end I feel I shouldn't have said that and I'm sorry for doing it. Because the

condition she's in, she's not very well and I feel awful about it afterwards...It worries me so much because I feel I'm not looking after her.

In summary, food, eating and weight were found important for connecting with others; physically, emotionally and socially. Food fuels the body giving the physical strength to sustain every day activities, giving and receiving food can communicate feelings that establish and sustain relationships, sharing food is important for establishing and sustaining a social network. Weight and eating represent physical, emotional and social connectivity. Unintentional weight loss and change in eating habits provoke anxiety and other negative emotions, such as anger, fear, embarrassment, and regret, manifesting as distress when connections essential to everyday activity are disrupted.

5.4. Response to anxiety evoked by change in weight and eating habits

Two different approaches were adopted in response to changing weight and eating habits: acceptance or resistance, although there were elements of both approaches present in the majority of accounts. For each individual, the dominant approach informed their response to the anxiety provoked by changing eating habits and weight loss. This response could calm the anxiety. It was a combination of thoughts and behaviours either supporting acceptance that the food connection was lost, or supporting activity to bring about change to sustain the food connection in the case of resistance.

5.4.1. Thoughts and behaviours supporting acceptance

'Nothing can be done' was a theme running through most explanations of change in weight and eating where the person was adopting a predominantly accepting approach.

You know, you can't do anything about (weight loss). Not really. So I suppose one has to gently chuck it into the back of one's mind and think 'get on with life girl.' I can be very practical. (C30)

The weight loss and eating problems were attributed to cancer, which was believed to be beyond control.

I wonder why he's losing so much weight. But then I realise that he's got this cancer and I think that's why he's losing the weight....He doesn't eat as much as he used to ... I can't make him eat (C18)

5.4.2. Thoughts and behaviours supporting resistance

Most explanations of changing weight and eating habits supported resistance. This resistance included the explanation of changes as being reversible, temporary or something that could be arrested if managed appropriately. Both patients and carers described various forms of self-help or observations that evidenced a belief in the possibility of a return to a former state of normality.

An example of a self-help response is the belief that contaminants in food had caused disease and elimination of such contaminants would lead to a solution.

I can't help but feel that things like DDT that they scattered around the fields didn't do anybody any favours, I mean there's all sorts of drugs go back into the water system through urine and the rest of it. So, that all worries me, that all we do is recycle the same old things. So we do try and concentrate quite heavily on getting organic food stuff (C31)

This is an example of active resistance: a deliberate attempt to change dietary intake to improve health and take control over life's course. Alternatively, a more passive resistance could be adopted. In these examples, emphasis was not on doing anything differently, but on the cause of weight loss and eating change being a passing problem that could be overcome, such as a symptom or comorbidity that could be effectively treated.

I'm not eating half as much as I used to. Less than half probably. I blame it on the chest infection I had. I was really bad. It took months and months to get rid of it. (P4)

I ate an apple today ... I did have a tin of sardines a couple of weeks ago ... sardines and apples, so I might get back to what I used to eat, yeah. (P69)

5.4.3. Response to anxiety involving other: disruption to everyday interactions

Both patient and carer could explain a weight or eating problem and solution to be, in part or entirely, within the control of the other member of the dyad. In this situation, interactions around food, eating and weight could include attempts to influence the others' behaviour.

... every meal you're looking at him and saying have you had enough to eat? 'Are you sure you've had enough to eat? (C74)

Failed attempts to resolve weight and eating problems, by changing the other person's behaviour, led to distress. For example, C69 is described by her husband as becoming distressed when her latest food idea does not tempt him to eat.

Sometimes I force food down. It's hard to force it down. I know she gets upset about it. I know she goes and has a little weep sometimes. She's put everything into it and I don't eat. (P69)

When active resistance includes attempts to change the behaviour of another person and these attempts fail, then anxiety is not alleviated and past connectivity is not restored. It is when active resistance fails, rather than the actual change in weight and eating, that is the source of the distress. It is the meaning of the change that is distressing, anticipation of increasing loss of strength, independence and ultimately death accompanied by loss of emotional and social connections. Interactions with the other person can be a reminder of the meanings of the change in weight and eating, hence sustaining the anxiety underlying the distress.

5.4.4. Interdependency

The primary purpose of this study was to examine and understand the interdependencies between patient and carer weight- and eating-related distress. The analysis so far presented allows some propositions about patient-carer interdependency in weight- and eating-related distress.

1. Disruption of food connectivity causes anxiety, which can manifest as distress
2. Weight- and eating-related distress in patient-carer dyads is interdependent when one (or both) respond to anxiety evoked by weight loss and changing eating habits with an expectation of behavioural change in the other member of the dyad.

5.5. Patterns in dyadic response

Three patterns in dyadic response to the anxiety evoked by involuntary weight loss and changing eating habits in the patient

were found in the data set. These were dual acceptance, dual resistance and mis-matched resistance. These patterns are evidenced below.

5.5.1. Dual acceptance: adjustment to disrupted food connections

Despite being aware of weight loss and eating problems, five of the patients and family carer pairs seemed untroubled. Both members of these dyads scored zero, or close to zero, for both weight- and eating-related distress. They made no attempt to change each others' behaviour or engage in any other resistance to changing weight and eating habits.

P42 was housebound and living in a downstairs room. He seemed very contented.

I'm quite happy with what I'm eating. (P42)

His wife was confident that everything possible was being done to manage his weight loss and poor appetite:

He used to have quite a big appetite, but now – well he has no more than a child's meal... (The weight) is just going to come off anyway, what can I do? I mean, I feed him, I try and exercise him and that's it. I can't do nothing about it, if the weight comes off. It's just going to come off and that's it.

Interviewer: Why do you think it comes off?

Because of the cancer. (C42)

5.5.2. Resistance to disrupted food connections

The patients and family carers who reported distress about the patient's weight loss or eating problems were more resistant to the changes. Either both patient and family carer were resisting changes; dual resistance. Or just one member of the dyad seemed to be working at arresting or reversing changes; mismatched resistance.

5.5.2.1. *Dual resistance.* In the eleven dual resistance pairs both patient and family carer reported high distress in consequence of the patient's weight and changing eating habits. They were partners in a shared effort to restore a past experience of everyday interactions around food, eating and weight. Both experienced distress when this resistance was unsuccessful in restoring food connectivity. Their stories were the same, that is, disruptive change and a fight to reverse the change thus restoring life to 'normal' in relation to food. Both P72 and his wife were working together at increasing his food intake.

I'm not eating enough. It's as simple as that. I mean yes, I feel I ought to eat more. I have just got to eat more. (P72)

If I don't feed him that's it! He's going to fade away I'm not waving a big stick, but I encourage him to eat. (C72)

They both reported eating-related distress because of lack of success in changing P72's eating behaviour to sustain his life.

5.5.2.2. *Mismatched resistance.* The most frequent presentation amongst the 31 dyads was a mismatch between patient and carer response. In this situation, one partner in the dyad engaged in more resistance in trying to restore a past normality than the other.

5.5.2.3. *Mismatched resistance: patient resistance outweighing family carer resistance.* Ways that seven patients were observed to work at alleviate anxiety included actively fighting to reverse the

change in their weight and eating habits, for example by manipulating their diet or trying to force food.

I am eating more puddingsTo try to gain weight. (P57)

In contrast, C57 was less resistant to changes and described the situation differently:

We don't do puddings now. Well, he does a little bit (C57)

Another form of patient resistance was to claim that their partner had responsibility for feeding or weight management:

My food input has been pretty reasonable. I don't know why I've lost 2lb (this week)discuss that with my wife to find out what my true weight is. She knows what my weight is better than I do (P34)

When a carer considered the patient's approach to weight loss and changing eating habits to be unrealistic, then they reported high levels of distress. They found themselves in a place of tension. They wanted to help without undermining the patient's hope of recovery yet could see recovery was unlikely. P24 was forcing foods, seeking information about diet and cancer from healthcare professionals, and monitoring his level of physical activity.

I was ten times worse 2 months ago than I am now. I feel more like food. I can face it better (P24)

C24 felt 'there is nothing more now they can do' and was watching and waiting.

Some days he'll say 'I feel more me self today. I'm getting better.'You want to be optimistic with him when you feel he's like that. So, at the moment I don't think he perhaps realises that it is slowly terminal. And you wouldn't want to bring the subject up if he was going to be upset about it. So we've got to go along with it. (C24)

Despite seeming to have accepted that 'he can't eat' C24 remained troubled. It was becoming increasingly difficult for her to feed her husband, which she described as 'awkward trying to find something he will eat a bit of.' This example illustrates that anxiety may be evoked in an accepting person who is living alongside resistance. Such anxiety prevails when it is not possible or seems unwise to challenge the behaviour of the resistant other. The carer can feel anxious in the struggle to maintain normality and not undermine hope.

5.5.2.4. Mismatched resistance: carer resistance outweighing patient resistance. In eight cases it was the carer who believed that disrupted food connectivity could be reversed and normality restored. The patient had accepted that they were no longer able to eat as previously, that their weight loss was irreversible and that they were on a trajectory approaching the end of life. They typically recognised the carer's resistance, perhaps making themselves eat or electing to eat alone to try to sustain the carer's hope of restoring a past normality. The patient was in a place of limbo waiting for the carer to recognise the futility of feeding and move towards greater acceptance of impending separation. This waiting could be accompanied by petitioning health professionals to challenge the carer's behaviour. P54 had sought the help of a dietician in gaining permission from his wife to eat chocolate.

If I'm going up (in weight) I feel quite pleased. If I am going down I think 'oh my goodness!' But I don't worry about it I must sayI eat as much as I can. (P54)

When I see him eating a chocolate bar, I think, 'crumbs you wouldn't have done that cause of your heart conditions.' So, it's just you sort of think 'well that may not be doing him a lot of good.' (C54)

5.6. Adjustment and aided adjustment to disrupted connections

In a few cases, the patient or the family carer spoke of either adapting to change over time or intervention by a healthcare professional that had helped them to work with resistance. C1 spoke of successfully meeting the challenge of adapting to her husbands changed food choices:

He would never eat a pudding when he was healthynow he will eat pudding and love it. That, I found, took me quite a while to get used to. (C1)

Help from a healthcare professional could take the form of information about what to eat when living with weight loss and a small appetite. Alternatively, it could be advice about how to behave and reassurance that everything possible was being done to for weight loss and poor appetite. C15 described how a nurse had helped when her husband was experiencing her poor appetite as distressing:

My husband was very concerned at first, because I wasn't eating what he thought was enough. But (nurse) spoke to him about it ... 'don't pile her plate up and don't give her a lot of food if she doesn't want it.'It seems as though she was saying 'don't force food on me.'

Interviewer: And was he?

In a way, yes. YeahHe doesn't do it anymore. (C15)

6. The relationship between the concepts: a model of patient and family experience of involuntary weight loss and changing eating habits

In everyday life food is about more than fuelling the body, it has emotional and social meaning. The meanings connect people physically, emotionally and socially. Cancer can change what can be eaten and when it can be eaten. In addition to the anxiety provoking threat this presents to physical function, physical independence and survival, it can disrupt emotional well-being, relationships and social life. Cancer disrupts food connections.

Study participants found change in weight and eating habits 'worrying', 'annoying', 'a punishment', 'upsetting'. These descriptions reveal the anxiety and other negative emotions that can be evoked. Change in the physical, emotional and social experience of life evokes not only anxiety but a response. The change can either be accepted or resisted. Both acceptance and resistance have a shared purpose of alleviating anxiety. When acceptance or resistance fails to ameliorate anxiety, then anxiety disrupts everyday life and manifests as distress.

Interdependency between patient and family-carer weight- and eating-related distress arises when unsuccessful attempts to change, defend or protect the behaviour of the other person fail to alleviate anxiety and disrupt everyday life precipitating distress. However, thoughts and behaviours can adjust, or a healthcare professional can aid adjustment, so that anxiety is alleviated and distress dissipated.

When both members of a patient-carer dyad are accepting of changing eating habits, then neither experience distress. When

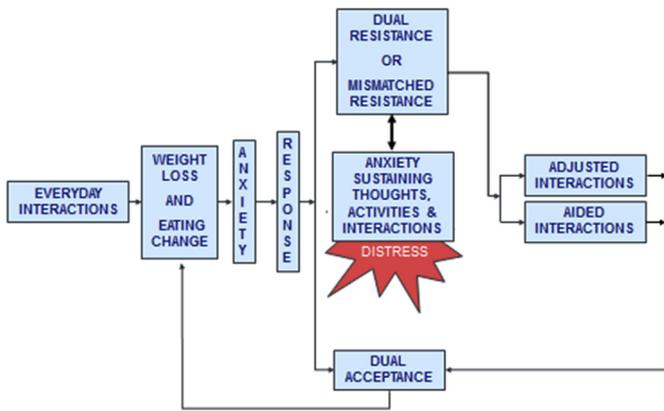


Fig. 1. Conceptual model of patient and family carer experience of weight loss and changing eating habits.

resistance to changing eating habits fails, then distress is experienced. When both patient and carer are resisting changing eating habits, then they can both experience distress. Only when resistance includes unsuccessful attempts to influence the behaviour of the other partner in the dyad is there patient-carer interdependency in weight- and eating-related distress (Fig. 1).

7. Discussion

This study has found the change in weight and eating habits that accompany advanced cancer disrupt food connections. Weight- and eating-related distress are indicators of this disruption. Food connection is the way food contributes to an understanding of self as a physical, social and emotional being. Food connects us with others in ways that we are not always aware; physically by fuelling the body and sustaining physical activity and life, emotionally by communicating feelings about self and others, and socially by providing a reason for sharing time with others.

Studies of healthy populations evidence the symbolic meanings of food, which include expressions of care through giving and receiving of food and social value placed on certain food types (Caplan, 1997; Dovey, 2010; Lupton, 1996). Our first interactions in this world are concerned with the creation of connections that ensure our need for food and nurture are satisfied (Marvin and Britner, 2008). The people in this study made comments such as, 'I want to get back to normal (weight, energy and activity) (P57)' and 'he's got to eat (C10)' which can be seen as a wish to restore past connections. No one spoke about their need for food connections driving troublesome thoughts, feelings and behaviours. However, theorising that disruption to food connections evokes anxiety and a response to this anxiety, can help us understand difficulties that patient-carer dyads encounter. It leads to the proposition that people who resist change in their food connections strive to re-establish or sustain an old balance of separation from and connection with others, important to their sense of well-being. The resistance to disrupted food connections is a defence against feelings of isolation and abandonment; an innate drive evoked by the symptoms of weight loss and eating problems.

7.1. Adaptation and coping

Lazarus (1991) theory of emotion and adaptation can help us understand the behaviour observed in this study. It proposes that we are all in a constant dynamic process of adapting to the

environment motivated by an innate drive to achieve a sense of well-being. Negative emotion is experienced, such as distress, guilt, and fear when the person-environment appraisal is of threat to well-being. If weight loss and anorexia are consciously or unconsciously perceived to be a threat to connections then well-being will be threatened and negative emotion evoked. Coping responses will then operate to restore subjective well-being. This response may include the thoughts and behaviours identified as resistance in the accounts of participants in this study.

Within patient-carer dyads, the behaviour of the carer was observed to be important to the experience of resistance as either calming anxiety or sustaining anxiety. In recent work about coping and adaptation, the coping possibilities for each partner in a dyad are recognised, in part, to be shaped by the nature of their relationship created through interactions, and have come to be described as dyadic coping (Bodenmann, 2005).

The implication of understanding weight- and eating-related distress through the lens of both Lazarus' theory of emotion and adaptation and dyadic coping theory is that intervention should include support for both individual and dyadic coping resources.

7.2. Implications for the management of cancer cachexia syndrome

Unintentional weight loss and poor appetite are symptoms of cancer cachexia syndrome. Multimodal therapies are now thought to be necessary to manage the syndrome. It is anticipated that future management will combine a pharmacological agent for tumour-induced metabolic change, nutritional support to address the malnutrition component of the syndrome, exercise to maintain muscle mass and psychosocial support (Fearon et al., 2011; Aapro et al., 2014). Psychosocial support is argued important given the evidence that both patient and family can become distressed by the syndrome. Reid et al. (2010) has proposed that symptoms of cachexia evoke anxiety because of lack of information and understanding of the syndrome. Other studies of the psychosocial effects of cancer cachexia syndrome have led to the proposition that weight- and eating-related distress might be mitigated through the combination of information, support for coping and attention to patient-carer-healthcare professional interactions (Hopkinson, 2014). This study has identified the nature of patient-carer interactions that contribute to weight- and eating-related distress in patient and carer: interactions that are futile attempts to change the behaviour of the other member of the dyad.

The proposed model of weight- and eating-related distress implies that acceptance of changing weight and eating habits will mitigate weight- and eating-related distress in both patient and carer. Acceptance of death by clinicians and acceptance of death by patients and families are integral to understandings of contemporary good death (Zimmerman, 2012). However, acceptance may not always result in best clinical outcomes. Understanding of what can and cannot be changed for the better is difficult for patients and carers when the patient's clinical condition is changing. Clinical expertise is needed to aid decision making. There is a need for involvement of clinicians educated in current best practice in the management of cancer cachexia syndrome (Aapro et al., 2014).

This study found three dyadic responses to weight loss and changing eating habits; dual acceptance, dual resistance and mismatched resistance. They are of future interest, because they can help clinicians with expertise in the management of cachexia to recognise patient-family carer dyads with particular needs and tailor psychosocial interventions accordingly.

7.3. The future of psychosocial support for people affected by cancer cachexia syndrome

The findings give hope for improving the experience of weight loss and eating problems in advanced cancer patients and their family carers. Tools and techniques from family and couple therapy may have a role to play in aiding adaptation and coping in patient-carer dyads where there is interdependency in the experience of distress. Investigation of the effect of intervention to support the patient-carer relationship indicates that it is possible to improve relationships and reduce overall distress; for example, for couples affected by breast cancer (Manne and Badr, 2008) and couples where the patient is approaching the end of life (McLean et al., 2008; 2013). It may be possible to tailor existing couple and family focused interventions to support the patient-carer relationship in dyads where there is interdependency in the experience of symptoms of cancer cachexia syndrome.

7.4. Limitations of key findings

The study was conducted in just two locations in the South of England. The sample comprised solely white British dyads who had agreed to take part in a larger intervention study. Of all new referrals to the two community palliative care services who took part in the study, approximately half of those with involuntary weight loss and/or eating difficulties agreed to take part. The majority of the family carers were women and whilst in this study there were no gender differences in the findings, the four male participants may be atypical of a wider population of male family carers. It is not possible to know how similar or different volunteers are from those who declined participation and therefore the transferability of the findings to other populations of patient-carer dyads affected by advanced cancer, involuntary weight loss and eating problems. Yet the problems described by the participants have been reported by qualitative studies conducted across the western world (Oberholzer et al., 2013; Wheelwright et al., 2014).

Whilst the credibility of the model of the experience of involuntary weight loss and eating problems in families affected by advanced cancer has been discussed with 32 UK experts, the study user involvement group, not all disciplinary groups or relevant experts were represented, for example no one from the social work community contributed. Further empirical work is required to test its transferability to other settings and populations of people affected by cancer.

The lead researcher is a cancer and palliative care nurse by background. The interpretation is influenced by a concern to generate understanding that might inform clinical practice. This focus may have obscured competing or complementary explanations of the patient family-carer dyad experience. For example, one could focus on how the socio-economic status of the family might influence the availability of foods and be important to coping with the experience of eating problems in cancer.

8. Conclusion

Weight loss and change in eating habits in advanced cancer disrupt food connections. This disruption can cause distress, in not only patients, but also their family members. Patient-carer interactions can either sustain or ameliorate this distress. The pattern of interaction between members of a patient-carer dyad should be taken into account when offering psychosocial support. This insight challenges researchers and clinicians to seek psychosocial interventions that support both individual and dyadic coping in distressed family members affected by symptoms of cancer cachexia syndrome.

Conflict of interest statement

Jane Hopkinson is a member of the Scientific Board, Cachexia Hub, Helsinn Healthcare.

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References

- Aapro, M., Arends, J., Bozzetti, F., Fearon, K., Grunberg, S.M., Herrstedt, J., Hopkinson, J., Jacquelin-Ravel, N., Jatoi, A., Kaasa, S., Strasser, F., 2014. Early recognition of malnutrition and cachexia in the cancer patient: a position paper of a European School of Oncology Task Force. *Ann. Oncol.* 25 (8), 1492–1499. <http://dx.doi.org/10.1093/annonc/mdu085>. Epub 2014 Feb 25.
- American Cancer Society, 2014. Distress in People with cancer. Available at: http://www.cancer.org/treatment/treatmentsandsideeffects/emotional_sideeffects/distressinpeoplewithcancer/distress-in-people-with-cancer-toc (accessed 31.3.15).
- Bodenmann, G., 2005. Dyadic coping and its significance for marital functioning. In: Revenson, T.A., Kayser, K., Bodenmann, G. (Eds.), *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*. American Psychological Association, Washington, pp. 33–50.
- Caplan, P., 1997. Approaches to the study of food, health and identity. In: Caplan, P. (Ed.), *Food, Health and Identity*. Routledge, New York, pp. 1–31.
- Churm, D., Andrew, L., Holden, K., Hawkins, C., 2009. A questionnaire study of the approach to anorexia-cachexia syndrome in patients with cancer by staff in a district general hospital. *Support. Care Cancer* 17, 503–507.
- Dovey, T.M., 2010. *Eating Behaviour*. Open University Press, Maidenhead.
- Ewing, G., Rogers, M., Barclay, S., McCabe, J., Martin, A., Todd, C., 2004. Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliat. Med.* 18, 452–459.
- Fearon, K., Strasser, F., Anker, S.D., Bosaes, I., Bruera, E., Fainsinger, R.L., Jatoi, A., Loprinzi, C., MacDonald, N., Mantovani, G., Davis, M., Muscaritoli, M., Ottery, F., Radbruch, L., Ravasco, P., Walsh, D., Wilcock, A., Kaasa, S., Baracos, V.E., 2011. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol.* 12 (5), 489–495.
- Harding, R., Higginson, I.J., Donaldson, N., 2003. The relationship between patient characteristics and carer psychological status in home palliative cancer care. *Support Care Cancer* 11, 638–643.
- Hawkins, C., 2000. Anorexia and anxiety in advanced malignancy: the relative problem. *J. Hum. Nutr. Dietetics* 13, 113–117.
- Hodges, L.J., Humphris, G.M., Macfarlane, G., 2005. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc. Sci. Med.* 60, 1–12.
- Hopkinson, J.B., Wright, D.N.M., Corner, J.L., 2006. The experience of weight loss in people with advanced cancer. *J. Adv. Nurs.* 54 (3), 304–312.
- Hopkinson, J.B., Fenlon, D., Nicholls, P., Wright, D., Okamoto, I., Roffe, L., Scott, I., Foster, C., 2008. Helping People Live with Advanced cancer: an Exploratory Cluster Randomised Trial to Investigate the Effectiveness of the 'Macmillan Approach to Weight Loss and Eating Difficulties' (MAWE). Macmillan Cancer Support, London.
- Hopkinson, J.B., 2010. The emotional aspects of cancer anorexia. *Curr. Opin. Support Palliat. Care* 4254–4258.
- Hopkinson, J.B., Fenlon, D.R., Okamoto, I., Wright, D.N.M., Scott, I., Addington-Hall, J., Foster, C., 2010. The Macmillan Approach to Weight loss and Eating difficulties (MAWE): a Phase II cluster randomised exploratory trial of a psychosocial intervention for weight and eating related distress in people with advanced cancer. *J. Pain Symptom Manag.* 40 (5), 684–695.
- Hopkinson, J., 2014. Psychosocial impact of cancer cachexia. *J. Cachexia, Sarcopenia Muscle* 5, 89–94.
- Koch, T., 1994. Establishing rigour in qualitative research: the decision trail. *J. Adv. Nurs.* 19, 976–986.
- Lazarus, R.S., 1991. *Emotion and Adaptation*. Oxford University Press, Oxford.
- Lazarus, R.S., 1999. *Stress and Emotion: a New Synthesis*. Free Association Press, London.
- Lewis, M.A., McBride, C.M., Pollak, K.I., Puleo, E., Butterfield, R.M., Emmons, K.M., 2006. Understanding health behaviour change among couples: an interdependence and communal coping approach. *Soc. Sci. Med.* 62, 1369–1380.
- Lupton, D., 1996. *Food, the Body and the Self*. SAGE, London.

- Macmillan Cancer Support, 2008. *Macmillan Approach to Weight Loss and Eating*. Available at: <http://learnzone.macmillan.org.uk/> (accessed 20.12.14.).
- Mallinger, J.B., Griggs, J.J., Shields, C.G., 2006. Family communication and mental health after breast cancer. *Eur. J. Cancer Care* 15, 355–361.
- Manne, S., Badr, H., 2008. Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112 (11 Suppl. 1), 2541–2555.
- Marvin, R.S., Britner, P.A., 2008. Normative development: the ontogeny of attachment. In: Cassidy, J., Shaver, P. (Eds.), *Handbook of Attachment Theory and Research*, second ed. The Guilford Press, New York, pp. 269–294.
- McLean, L.M., Jones, J.M., Rydall, A.C., Walsh, A., Esplen, M.J., Zimmerman, C., Rodin, G.M., 2008. A couples intervention for patients facing advanced cancer and their spouse caregivers: outcomes of a pilot study. *Psycho-Oncology* 17, 1152–1156.
- McLean, L.M., Walton, T., Rodin, G., Esplen, M.J., Jones, J.M., 2013. A couple-based intervention for patients and caregivers facing end-stage cancer: outcomes of a randomized controlled trial. *Psycho-Oncology* 22, 28–38.
- Miles, M., Huberman, A., 1994. *Qualitative Data Analysis*. SAGE, Thousand Oaks, California.
- Oberholzer, R., Hopkinson, J., Aurelius, O., Baumann, K., Fearon, K., Strasser, F., 2013. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J. Pain Symptom Manag.* 46 (1), 77–95. E-pub 15th November.
- Pitceathly, C., Maguire, P., 2003. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur. J. Cancer* 39, 1517–1524.
- Poole, K., Froggatt, K., 2002. Loss of weight and loss of appetite in advanced cancer: a problem for the patient, the carer, or the health professional? *Palliat. Med.* 16, 499–506.
- Porter, S., Millar, C., Reid, J., 2012. Cancer cachexia care. *Cancer Nurs.* 35 (6), E30–E38.
- Reid, J., McKenna, H.P., Fitzsimons, D., McCance, T.V., 2010. An exploration of the experience of cancer cachexia: what patients and families want from healthcare professionals. *Eur. J. Cancer Care* 19 (5), 628–689.
- Ransom, S.M.A., Sacco, W.P., Weitzner, M.A., Azzarello, L.M., McMillan, S.C., 2006. Interpersonal factors predict increased desire for hastened death in late-stage cancer patients. *Ann. Behav. Med.* 31 (1), 63–69.
- Strasser, F., Binswanger, J., Cerny, T., Kesselring, A., 2007. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat. Med.* 21, 129–137.
- Van Manen, M., 1994. *Researching Lived Experience*. The Athlone Press, Canada.
- von Haehling, S., Anker, S., 2014. Prevalence, incidence and clinical impact of cachexia: facts and numbers - update 2014. *J. Cachexia, Sarcopenia Muscle* 5, 261–263.
- Wheelwright, S., Darlington, A., Hopkinson, J.B., Fitzsimmons, D., White, A., Johnson, C.D., 2014. A systematic review to establish health-related quality of life domains for intervention targets in cancer cachexia. *BMJ Support. Palliat. Care*. <http://dx.doi.org/10.1136/bmjspcare-2014-000680>.
- Zimmerman, C., 2012. Acceptance of dying: a discourse analysis of the palliative care literature. *Soc. Sci. Med.* 75 (1), 217–224.