

Original Article

Perception of subjective lived experiences of individuals with anorexia-cachexia in patients with advanced lung cancer

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ABSTRACT

Objective: Cancer cachexia (CC) is a frequent and debilitating syndrome in patients with cancer. It has serious implications for patients, extending beyond physical problems into psychological, and social domains. The objective of our study was to qualitatively understand the experiences related to CC in patients with advanced lung cancer.

Methods: Patients with advanced lung cancer with anorexia (≤ 37 points on Functional Assessment of Anorexia/Cachexia Treatment-ACS) and weight loss were eligible. Patients participated in semi-structured interviews prior to study treatment ($n = 19$). Qualitative analysis was conducted using interpretative phenomenological approach.

Results: Two super-ordinate themes emerged (anorexia and weight loss). Patients reported experiencing distress related to anorexia, weight loss, lack of social eating, worsening function, body image, and eating habits. The encouragement to eat by the family was often distressing to the patient. The treatment recommendations by their oncologist for anorexia and weight loss was felt inadequate. Patients felt that the treatment for CC should improve appetite and weight gain as well as their mood and be independent.

Conclusions: The findings of the study suggests that anorexia and weight loss results in high levels of distress due to their effects on physical and psychosocial domains. Further studies are needed to better understand the experience of anorexia and weight loss to develop strategies to effectively treat CC.

Trial registration: NCT03637816.

Introduction

Cancer cachexia (CC) is a frequent syndrome in patients with advanced cancer.¹ CC is associated with reduced physical function, reduced tolerance to anticancer therapy, and reduced survival.^{1,2} Currently, there are limited Food and Drug Administration (FDA)-approved treatments for CC.^{3,4} Recent American Society of Clinical Oncology guidelines (2020)⁵ suggests the need for effective therapies that target CC in patients with advanced cancer.⁶ Prior studies on CC mainly focused on the subjective and objective changes related to CC.^{7,8} However, studies by our team and others do suggest that patients and families have significant psychosocial distress due to lived experiences related CC and it was associated with loss of physical and social function due to decreased food intake, mobility, and the visual impact of weight loss on body image.^{9–14} This relationship is complicated: while for most

cancer patients the loss of weight is distressing and symbolic of end of life, some patients, especially those who are obese, perceive weight loss as beneficial in terms of their body image.^{13,15,16} Despite the high frequency of psychological distress there are limited studies to understand the lived experiences of cancer patients with CC.^{3,7,8,17–21} Understanding of the distressing experiences related to poor appetite and weight loss are therefore needed to develop of effective strategies against CC.

Non-small-cell lung cancer (NSCLC), which comprises 85%–90% of all lung cancer diagnoses and is the leading cause of cancer-related deaths in the United States.²² Most patients with NSCLC are diagnosed with advanced-stage disease. The median survival duration of patients with metastatic NSCLC is only 8–11 months,²³ and the 5-year survival rate is only 15%.^{24,25} Faced with a life-limiting illness, patients with advanced NSCLC develop multiple physical and psychosocial symptoms.^{26–30} One of the possible reasons contributing to poor

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outcomes including overall survival is the development of CC in patients with advanced lung cancer.^{3,7,31} Many patients with advanced NSCLC lose weight, have a poor performance status, and are unable to receive cancer treatment.^{3,31} Most of the focus of lung cancer research has been on targeting cancer treatment (e.g., cytotoxic therapy, targeted therapy, and immunotherapy).^{3,7,32} There are limited studies to qualitatively explore the patients' distress due to CC in advanced NSCLC patients.^{3,7,21} Therefore, the aim of our study was to qualitatively understand the lived experiences related to CC in patients with advanced NSCLC.

Methods

The results presented in this article are the secondary analysis of study to investigate the effects of anamorelin (a ghrelin receptor agonist) for anorexia/cachexia in patients with advanced NSCLC.

Patients

Consecutive patients were approached by a research coordinator at the thoracic oncology center in The University of Texas MD Anderson Cancer Center (UTMDACC) from November 27, 2018, to October 15, 2021. Patients with the following eligibility criteria were included in this study: (a) Diagnosis of advanced non-smallcell lung cancer (stage 4 disease), (b) presence of anorexia, defined as ≤ 37 points on FAACT A/CS domain, (c) history of $\geq 5\%$ of involuntary weight loss for body mass index (BMI) ≥ 20 kg/m² or $\geq 2\%$ of involuntary weight loss for BMI < 20 kg/m², over a period of 1 year, (d) adequate hepatic function, defined as aspartate transaminase and alanine transaminase levels $\leq 5 \times$ upper limit of normal, and (e) Life expectancy of ≥ 6 months. We excluded patients with BMI > 28 kg/m², pregnant or lactating women, or any relevant condition that would interfere with ability to understand and fully participate in the study.

A strict criterion for definition of CC was included to enroll patients in the study (eligibility criteria c), because not all advanced cancer patients have uniform weight loss. For example, some patients with BMI < 20 kg/m² and weight loss of $\geq 2\%$ have the CC syndrome.³³ Survival of ≥ 6 months was included in the eligibility criteria for this study in order assess the patients earlier in the trajectory of illness and were on active cancer therapy since in majority of these patients due to multiple other assessments and treatments, CC is usually not well addressed.

Data collection

Qualitative interview and analysis

Interviews were conducted by qualitative research trained coordinator either by person or telephone. During these interviews, we employed an inductive format and used open-ended questions. The questions were based on a semi-structured interview guide, which was further revised after the interview of the fourth patient to cover all topics missed in the initial interview guide (Supplementary Material, A1). The interviews were digitally recorded and transcribed verbatim for analysis. The transcripts were iteratively reviewed and analyzed using interpretative phenomenological analysis (IPA).³⁴ We coded (SY and ZL) separately the individual experiences and the meaning assigned to this experience using NVIVO 12 (QSR International, Melbourne, Australia) qualitative analysis software. We then developed themes based on the pattern of individual experiences across the patients in this study. The more frequent emergent themes ($> 50\%$ of participants) were used to develop the superordinate themes. Finally, we summarized the final set of themes with a references from the patient's transcript. Fig. 1 shows the flow diagram of the methods. For the IPA, a purposive sample of 19 patients was chosen as it was considered an adequate sample for the detailed description of each individual experiences to emerge.³⁵

The goal of our study was to understand the relationship between the two superordinate themes and the subthemes, as well as the connection between distress due to poor appetite and weight loss and lived experiences. Strategies to manage distress of poor appetite and weight loss is greatly needed, and this study was aimed to help to advance our understanding of which distressing experiences are related to poor appetite and weight loss so as to develop of effective strategies against them.

Secondary outcome measures

The research coordinator completed the patients' demographic characteristics and supervised the patients' completion of the Functional Assessment of Cancer Therapy—General (FACT-G), and its anorexia/cachexia scale, the FAACT-A/CS, and body composition (InBody 770) at the same time point as the qualitative interview. Laboratory studies related to CC including prealbumin, and C-reactive protein were also measured.

Subjective measures. FACT-G is a 27-item validated quality of life questionnaire and consists of general questions divided into four primary domains: physical well-being, social/family well-being, emotional well-being, and functional well-being.^{36,37} All items in the FACT-G scale use a 5-point rating scale (0 = Not at all, and 4 = Very much) with possible scores ranging from 0 to 108.

The FAACT A/CS domain is a 12-item symptom-specific domain designed to measure patients' additional concerns about their anorexia/cachexia during the previous 7 days on a scale of 0–4.³⁸ Possible scores for the 12-item A/CS range from 0 to 48, with 0 being the worst possible score and 48 the best. The optimal cut-off for the diagnosis for anorexia is ≤ 37 points.³⁹ The FAACT A/CS has an internal consistency and a reliability coefficient (Cronbach's alpha) of 0.88 for its 12 components, and a 4-point increase has been shown to be a clinically meaningful change/threshold.³⁸ We also assessed anorexia specific measures by using the 5-item anorexia symptom scale, which was obtained by summing the 5 anorexia symptom items derived from the FAACT A/CS domain: "good appetite," "interest in food drops," "food tastes unpleasant," "get full quickly," and "difficulty eating rich/heavy foods"; this shortened scale was validated to focus only the relevant anorexia-related symptom items contained within the FAACT A/CS domain.⁴⁰ The 4-item Anorexia Concerns Scale, which was obtained by summing the 4 anorexia concern items derived from the FAACT A/CS domain: "amount I eat to meet my needs," "worried about my weight," "concerned about how thin," and "family/friends are pressuring me to eat."⁴⁰

Objective measures

Body composition. Body composition (total body weight, BMI, lean body mass, body fat mass, skeletal muscle mass, total body water, basal metabolic rate, whole body phase angle, visceral fat area and visceral Fat level) was assessed using the InBody 770 body composition scale.^{41–43}

Ethical considerations

The UTMDACC Institutional Review Board (IRB No. 2017-1059-6-6-2018) approved this study, and all patients were provided written informed consent.

Results

Fig. 1 shows the study accrual, and analysis flow diagram. 20 of the 23 patients completed the subjective and objective assessments, and 19 patients completed the qualitative interview. Reasons for noncompletion of assessments and interviews were disease progression ($n = 2$) and lost in follow-up ($n = 2$).

Table 1 shows the patient's demographic characteristics, subjective and objective assessments.

Results of the qualitative analysis

Two superordinate themes emerged relating to patients with advanced NSCLC experiences of CC. These included: poor appetite, and weight loss. Each of the themes contained subthemes. Fig. 2 illustrates the relationship between the two superordinate themes and the subthemes, as well as the connection between distress due to poor appetite and weight loss and lived experiences. Table 2 shows distribution of themes among the study patients.

The details of the supraordinate theme and subthemes are provided below.

Poor appetite and weight loss

All patients perceived lack of appetite with weight loss to be central issue related CC. Patients with poor appetite experienced early satiety, nausea, constipation, and alteration in sense of smell, taste. Quotes from Patient 5, 9, and 12 illustrates challenges experienced by patients due to poor appetite, and weight loss.

“It is frustrating to know that I’m working so hard on my eating and yet I’m not seeing it in the weight gain. I haven’t gained any weight. I’ve only lost weight. The two times that I’ve been the sickest in the past few months I’ve lost weight.” – Patient 5

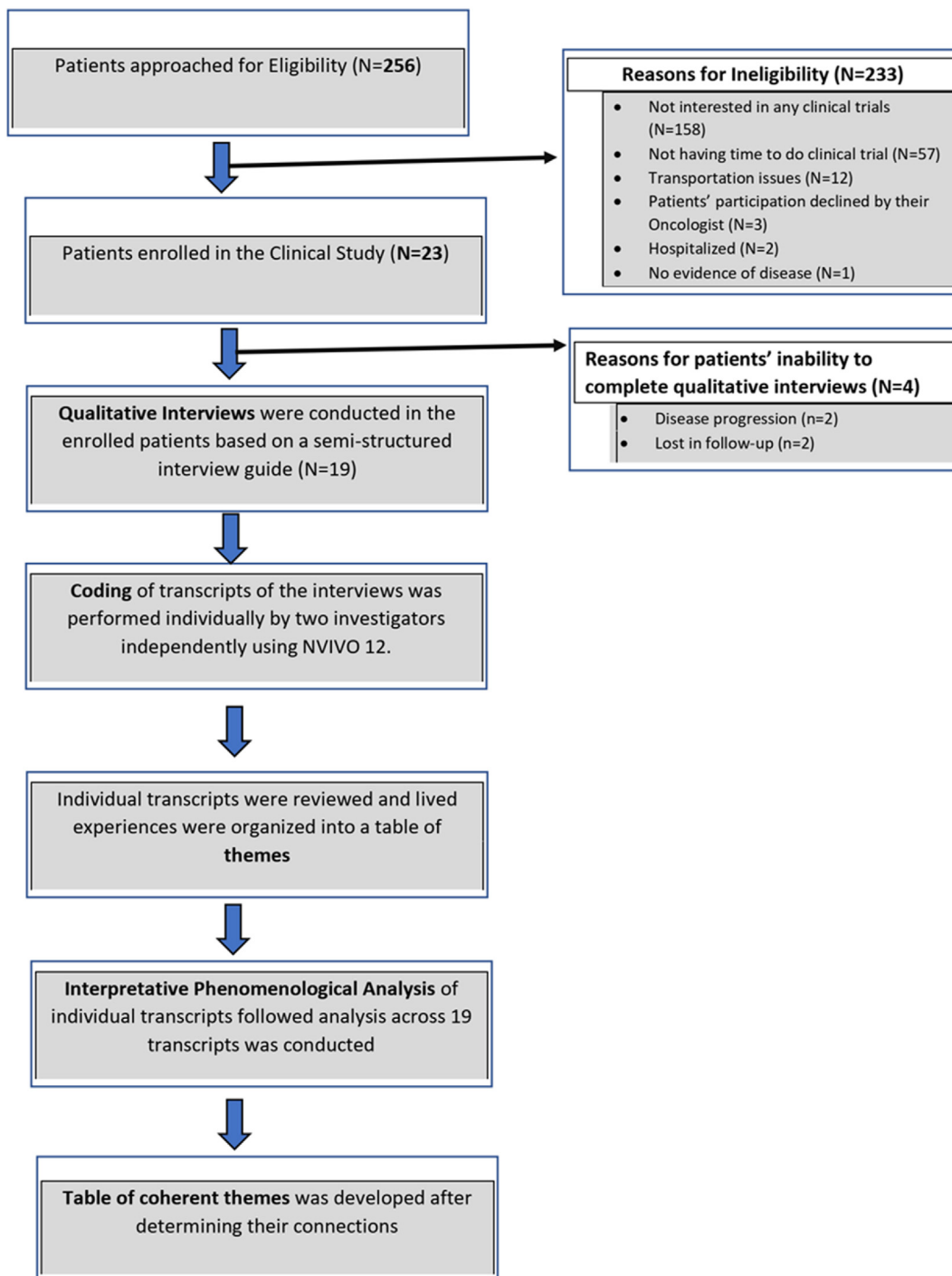


Fig. 1. Flow diagram of the study design.

Table 1

Demographic, clinical, body composition, and laboratory characteristics of advanced lung patients with anorexia-cachexia (N=20).

Characteristics	Data
Age, median (IQR), years	65 (56, 71)
Gender, n (%)	
Female	11 (55.0)
Race/ethnicity, n (%)	
Asian	3 (15.0)
Black or African American	5 (25.0)
White	12 (60.0)
Marital status, n (%)	
Married	15 (75.0)
Divorced/single	5 (25.0)
Education level, n (%)	
High school or less	7 (35.0)
Some college credits	4 (20.0)
College or above	9 (45.0)
Employment status, n (%)	
Employed (full-time or part time)	7 (35.0)
Medical leave of absence or unemployed	2 (10.0)
Retired	10 (50.0)
Homemaker	1 (5.0)
Occupation, n (%), n = 19	
Administrative/management	4 (21.1)
Laborers/workers	3 (15.8)
Professional	12 (63.2)
Zubrod performance status, n (%)	
0	3 (15.0)
1	10 (50.0)
2	6 (30.0)
3	1 (5.0)
FACIT-G, median (IQR)	
Physical well-being	20.5 (14.5, 24.0)
Social well-being	23.7 (20.0, 25.0)
Emotional well-being	17.5 (15.0, 22.0)
Functional well-being	16.5 (14.0, 21.0)
FACIT-G total	79.3 (64.5, 88.1)
FAACT A/CS, median (IQR)	
FAACT-A/CS	25.5 (18.0, 32.0)
5-IASS	10.5 (7.0, 14.0)
4-IACS	5.5 (3.5, 8.0)
FAACT total score	104.3 (85.5, 123.7)
FAACT trial outcome index	62.0 (49.5, 78.0)
Body composition assessment, median (IQR)	
Weight, kg	61.8 (55.7, 64.0)
Body mass index, kg/m ²	20.2 (18.7, 21.4)
Body fat mass, kg	11.3 (8.5, 13.5)
Lean body mass, kg	49.7 (40.4, 52.5)
Skeletal muscle mass, kg	26.6 (21.4, 28.2)
Total body water, kg	36.9 (32.5, 38.6)
Basal metabolic rate	1443 (1243, 1504)
Whole body angle, degree	3.8 (3.4, 4.3)
Visceral fat area, cm ²	60.4 (45.9, 73.2)
Laboratory measures, median (IQR)	
Pre-albumin, mg/dL	20.7 (16.9, 25.1)
C-Reactive protein, mg/L	6.2 (3.2, 17.0)

FACIT-G, Functional assessment of cancer therapy-general; FAACT AC/S, Functional assessment of anorexia and cachexia therapy-anorexia/cachexia scale; 5-IASS, 5-item anorexia symptom scale; 4-IACS, 4-item anorexia concerns subscale; TOI, Trial outcome index; PGIS, Patient global impression of severity; kg, Kilogram; m, Meter; cm, Centimeter; IQR, Interquartile; *Other, Jewish, None.

“(food) ... I would shove it down anyway. But with this stuff here, I do not know if you ever smelt burnt feathers, you can imagine what they might taste like. It is hard to eat. You take a couple of bites, and it is yuck. Even coffee and I love coffee I cannot even drink coffee because it tastes bad. Everything you taste, tastes off. It is like your mouth tastes like burnt feathers all the time. The only thing that helps is water. I drink a lot of water that is the only thing it does not affect. Even coke tastes weird.” – Patient 9

“Guess it just seems as though I’ve lost a lot of will power to eat just because everything tastes so funny. And it seems as though I do get

full quicker, and my sense of smell has also increased quite a bit, so I could walk into anywhere and smell spices and things like that and it deters me from wanting to eat.” – Patient 1

Changes in eating habits

The patients in our study made changes in the eating habits, cooking, and meals to improve their appetite and weight loss.

Patient 2 illustrates strategies used to compensate for poor appetite: “I’m the cook, yeah. So, that’s hard. And even eating with the kids. It’s a big deal to have a family dinner. Now [After cancer diagnosis] I usually just sit them down and watch them eat and sometimes my husband will eat with them. If I’m going to eat anything, I can’t just scarf down something like I used to do. So, now I must be slower and more careful, or I’ll get nauseous.”

“Most of the time I just force myself to eat, which, you know if I can. If possible, I’ll try to eat something that’s easier, that’s not quite so strong. I’ll resort to soup or something like that or some broth at least or I’ve used those protein shakes before.” – Patient 2

Poor function

Loss of physical function was a concern among patients interviewed. The functional debility was distressful for the patients: “I haven’t been to the gym since I got sick. Can’t lift weights. I was a golfer, can’t play golf. The cancer has affected my daily activities because I was very active, healthy athlete type that now I can’t do any of that. Like today’s (activity) was a pretty good chore for me.” – Patient 10

“The hardest thing for me is not being able to provide for my family. Not being able to get up and go do dishes, get up and go do laundry. I do, I force myself to do it and I do it just to help my wife out because she’s taking care of me, and everything else. It’s just the fact that I just don’t have any strength, I don’t have any strength to do anything. It feels, I don’t know. It feels kind of helpless. You know?” – Patient 2

These were some important statements describing a significant loss of function that patients’ experience due CC. Patient often strive to be independent and play an important role as a family member including caring for their family. Due to the impact of CC, patients often felt weak and tired easily and therefore were unable to perform their daily activities. The loss of function was distressful for the patients as it made them feel dependent and diminished their role as a family provider.

Body image

CC resulted in obvious changes in physical appearance and their perception of body image. This altered body image was concerning to the patients as well as their family and friends. Their body image dissatisfaction made the patients feel depressed, self-conscious. They often made changes in their dressing and activity to reduce its impact. Some strategies included wearing loose clothes to make their weight loss less noticeable, exercise to gain muscle mass to look less emaciated and be more independent.

Patient 6 illustrates changes in dress fit due weight loss: “I feel like I’m beginning to look emaciated. I can’t wear any of the pants I used to wear, so I’ve had to buy much smaller sized ones. The clothes that I still have from my pre-weight loss days, slide off my hips. I think I carry most of my weight in my middle area. So, I don’t like the feeling of clothes that are too big. When I look in the mirror, I see the bony person with no muscle.”

CC has a negative effect on physical appearance resulting in significant impact of patient’s body image, but in a group of patients with obesity or overweight it may result in mixed emotions. On one hand it may be an accomplishment of one of their long-term goals of weight control, but on the other hand they are concerned about the negative impact of unintentional weight loss as it may suggest disease progression and possible death.

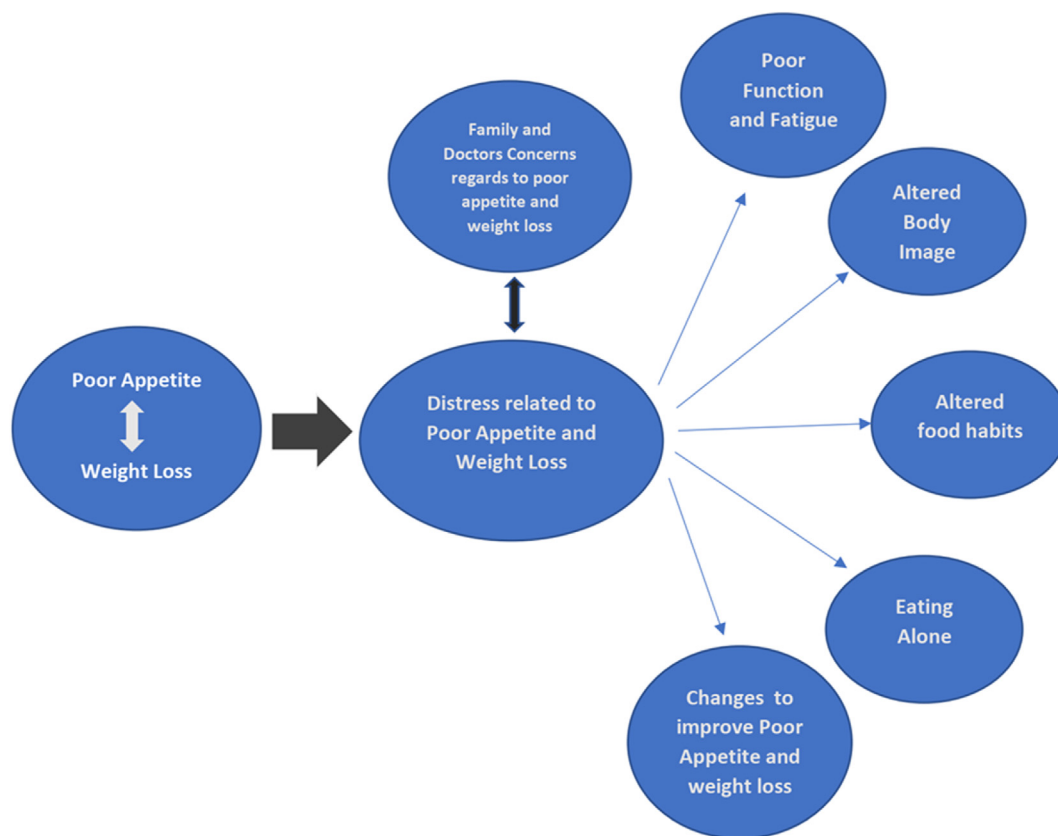


Fig. 2. Relationship between supraordinate themes and Subthemes. Arrows indicate the connections between distress due to poor appetite/weight loss and lived experiences.

“I kind of liked the fact that I was losing weight initially, but then became a little bit of an irritant because nothing fit. And I still don’t worry about the fact that I’m down to 140 (pounds). I don’t notice that as much as people notice it who see me and say, you’ve really lost a lot of weight. I don’t feel malnourished, or I don’t feel that I’m starving myself, but obviously I’m not eating enough to maintain my weight” – Patient 9

Distress to maintain food intake and weight

Distress related to food intake despite lack of desire to eat is an important issue among patients with CC. Patients 10, 17 and 7 illustrates the distress related to maintain food intake and weight.

Table 2
Distribution of themes^a.

Themes	Patient interview numbers
Change in eating habits and meal preparation	1, 5, 7, 10, 12, 18, 19
Eating alone or with family/friends	1, 3, 5, 6, 7, 8, 9, 11, 13, 14, 16
Distress and response due to anorexia	1–3, 5, 9–15, 17, 19
Patients’ perception and response to family, friends, and doctors’ concerns of poor appetite and weight loss and response	1–13, 16, 17, 19
Function (activity, work, fatigue)	1–4, 6–8, 10–12, 16, 19
Distress and response to weight loss	1, 4, 6, 7, 9, 10–12, 15
Body image	1, 6, 8–9, 11–13
Spirituality	1, 11, 12, 19
Weight loss and prognosis (importance of anorexia cachexia treatment)	2, 5, 8–11, 14, 19
Expectation from treatment for anorexia with weight loss	1, 11, 17, 19
	1–4, 6–12, 14–16, 18–19

^a Themes of poor appetite and weight loss were found in all patient interview transcripts.

“It (Eating) was a problem and then it gets to be a chore when you’re not hungry. You know you got to eat, so it starts to affect you that you must eat, but you’re not hungry. So, you get to force yourself. Because you know you have to get calories in, or you’ll get sicker. So, anyways, then I’d get weight gain. I was not a body builder, but I worked out a bunch, I was very healthy, 190 (pounds) and you get down to 140 (pounds). Probably effects your self-esteem some too.” – Patient 10

“I don’t have the desire, don’t be hungry. It’s hard to eat when you’re not hungry. It’s hard to be forced to eat when you’re not hungry. And my water intake is not very good. It takes me two days to get through one of these [gestures to mini water bottle], so with all the medicine I take I just take a sip of water, take my medicine, which is about 10 or 15 pills, I take so much.” – Patient 17

“I guess people bother me all the time. It’s a visible thing (weight loss) they can actually see. So, I guess that’s the most bothersome. People are like, oh man you lost all that weight, you need to eat more, and all of that. It bothers me.” – Patient 7

These are some of the profound statements regards to the impact of CC. Patients perceive the need to eat to be important for their ability to be walk, be independent, and fight cancer. The need to eat despite no desire to eat often creates a very challenging situation. This struggle often results in low self-esteem and emotional distress to the patient.

Distress of lack of social eating

Patients felt eating with family/friends was an integral part of their lives and social functioning and well-being. They found that inability to eat with them very distressing.

Patient 2 illustrates the importance of eating as a family brings pleasure to patients.

"We like to eat so, its missing some of the stuff that we we're doing. We have places we like to go out to eat and little traditions, that's what we do and when I don't have an appetite, he's (spouse) like, hey lets go to, you know. And it's one of our favorite restaurants and it's like, I really don't want to eat. You know, it's like, I want to go, but I know I'm going to sit there and not be able to eat it. Or it won't be worth going out to eat because I'm going to eat three bites and be like, if I eat any more, I'm going to be sick. You kind of lose it, instead of wanting to go out to eat and go have fun or go somewhere fun with the kids, I just want to stay home and nibble on something, or, so, losing that, that's rough, I don't like that. We're kind of foodies. We like international cuisine, and we like food, so it's no fun to not be able to enjoy it anymore. And it's something that we enjoy doing together as a family." – Patient 2

"I don't like to go to restaurants with people because I'm self-conscious about the fact that it's difficult for me to eat. And my friends with whom I would be going with are also conscious of the fact that it's going to be difficult for me to eat whatever is at a normal restaurant. Other than soup." – Patient 6

CC not only results in poor appetite, but patients often cannot tolerate being present near food as it may cause them to be more nauseous. This is very distressing to patient as it effects the important time they would like to spend with family and friends. This often forces the patient to social isolation which in turn results in further distress.

Family, friends, and treating oncologists concerns and encouragement to eat

CC due its easily visibility due to patients' poor appetite and physical appearance elicit concern about the patients' well-being among family and friends. The family and friends' encouragement to eat more to manage their weight loss was often distressing to the patient. As patients feel it's challenging because despite this encouragement, patients' efforts to eat more is often not successful resulting in conflict between patients and their family/friends. This dynamic of expression of support and love may negatively impact the patients in terms of the psycho-social distress and often may result is patient being socially isolated.

"My sister would call me, I think you need to be eating, I think you need- and I was like no, I'm going to try this. So, it was mixed feelings about it, and I'm thinking, am I going to have to eat like this the rest of my life? I don't know if I can make it." "Because my husband, still eating what he wants to eat. A lot of time I'll just tell him to go eat, don't even sit at the table with me, or the bar, wherever I was, because I just didn't want to have to watch him eat stuff that, you know." – Patient 1

There was relative lack of support perceived by the patients from the oncologist regards to their poor appetite and weight loss. The prescription for management of CC provided by oncologist includes diet changes in terms of calories and protein intake, as well as medications and physical therapy may not adequately address all the psychosocial distress related to CC in most of the patients.

"Oh man he would say just try to eat something; oh my god is there something you can give me to make me eat. He kind of make me mad when I tell him I am not eating, oh he would say just try to eat something." – Patient 17

Treatments to improve appetite and weight loss

Patients felt the treatment for CC should improve their appetite, weight as well as address other important detrimental effects of CC including improvement in their depressed mood, exercise capacity, so that they are independent and tolerate cancer treatment.

"I'm hoping that it's going to help me eat. I still don't have that desire, that hunger, that I got to eat now. And I don't know if this pill is going

to do that. It's going to say, oh you're hungry now you need to eat something or its time for a snack. I mean, not time for a snack, but you know what I'm saying. It's just, I'm hoping that my appetite continues to increase. More than what it is now." – Patient 1

"I think just stimulating appetite would stop the weight loss. And I think if I could exercise more and eat more, I would be happier with how I look." – Interview 08

"... It (treatment) would look like ... help me eating, maybe exercising, first I got to get there mentally. If I can't get there mentally, I can't get there. I may sit and think about it. I go and look at my bike and maybe dust off the monitor and stuff and go about my business, but weight gain would look ..." ".... gain weight and muscle will make me happy and to have more positive attitude and have less depression ... energize to do anything on my own." – Patient 11

"I would like to have a treatment that I could consistently cause me to gain weight but also to maintain that gain. To be able to gain enough weight to ensure that I can take chemo." – Patient 19

Discussion

In our study, patients reported that their poor appetite was associated with severe distress due to changes in taste, nausea, and diminished desire to eat. The weight loss resulted in severe decrease in energy levels, physical activity, and diminished body image, self-esteem, and mood. Patients felt their weight loss was most easily visible to their family, which made them feel stressed, and they made changes in their eating habits, meals, cooking, and were eating alone, as well as wearing loose clothes. Patients' family were concerned by the patients' poor appetite and weight loss. The encouragement to eat more by family was often distressing to the patient. The treatment recommendations by their oncologist for CC was often felt inadequate by the patients. Regards to the expectation of benefit from a treatment for CC, the patients felt that the medication should help with improvement in appetite and weight gain, as well as benefit their mood, and be independent.

The findings of our study were consistent with the other qualitative CC studies in that CC negatively affects them and results in poor appetite, weight loss but also impacts their psychological and functional experience. Rhondali et al. found that weight loss was associated with significant body image dissatisfaction in patients with advanced cancer.¹³ Hopkinson et al. found that weight loss and change in eating habits cause significant distress and disrupt food connections.⁴⁴ Cooper et al. found that CC was viewed by patients as a multidimensional experience encompassing physical, psychosocial, and existential components.⁴⁵ They found that patients and their caregivers were actively involved in coping efforts.⁴⁵ Another qualitative study of patients' CC experience found the following themes similar to our study: physiological changes in appetite; visibility of CC; weight loss interpreted as a bad sign; response from health care professionals; conflict over food; and coping responses.¹⁹ However, our study differs from other studies in that: (1) Our study was based on Fearon et al.'s consensus report. The Fearon's criteria is the most accepted definition of CC, and it uses both subjective and objective markers so that patients with CC are accurately diagnosed.³³ (2) We included only advanced NSCLC patients who had at least 6 months of prognosis as per the eligibility criteria. (3) We have included patients who are on cancer treatment. These factors are more pertinent as many patients now are on some form of cancer treatment until late in advanced lung cancer.^{7,46} The definition of CC and patients with prognosis of 6 months were included in the eligibility criteria to limit capturing the experiences of patients due to terminal illness in last few weeks of life. (4) Interestingly in our study, we found that patients with CC would like to overcome CC by specific treatment targeting CC that would overcome the distress and debilitation due to CC, more specifically they would like the medication to improve their appetite,

and weight, help them to tolerate cancer treatment, improve their depressed mood, exercise more, and help them to be able to perform their activities independently.

There are several limitations of the study. The patients were enrolled from a single tertiary cancer center, and therefore the findings may not be generalizable. While CC in cancer patients is considered a significant psychosocial stressor for the family as a unit, only patients were interviewed in this study. Our study was conducted from November 2018 to October 2021, however recent studies suggest that issues discussed in our study regards to livid experiences of cancer patients with CC would be still applicable to the current economic and social landscape based on the recently published studies.^{7,47,48} Hence, we anticipate the relevance of our findings have not changed overtime.^{47,48}

Conclusions

The findings of this study suggest that anorexia and weight loss results in high levels of distress due to their effects on physical and psychosocial domains. Further studies are needed to better understand the experience of CC so as to develop strategies to effectively treat CC.

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CRedit author statement

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Declaration of competing interest

The authors have none to declare.

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Ethics statement

The study was approved by the Institutional Review Board of the University of Texas MD Anderson Cancer Center (IRB No. 2017-1059), and all patients were provided written informed consent.

Data availability statement

The data that support the findings of this study are available from the corresponding author, SY, upon reasonable request.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

Appendix A. Supplementary data

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References

- Bachmann J, Heiligensetzer M, Krakowski-Roosen H, Buchler MW, Friess H, Martignoni ME. Cachexia worsens prognosis in patients with resectable pancreatic cancer. *J Gastrointest Surg*. 2008;12:1193–1201. <https://doi.org/10.1007/s11605-008-0505-z>. Epub 2008 Mar 18. PMID: 18347879.
- Dewys WD, Begg C, Lavin PT, et al. Prognostic effect of weight loss prior to chemotherapy in cancer patients. Eastern Cooperative Oncology Group. *Am J Med*. 1980;69:491–497. [https://doi.org/10.1016/s0149-2918\(05\)80001-3](https://doi.org/10.1016/s0149-2918(05)80001-3).
- Kimura M, Naito T, Kenmotsu H, et al. Prognostic impact of cancer cachexia in patients with advanced non-small cell lung cancer. *Support Care Cancer*. 2015;23:1699–1708. <https://doi.org/10.1007/s00520-014-2534-3>.
- Srdic D, Plestina S, Sverko-Peternac A, Nikolac N, Simundic AM, Samarzija M. Cancer cachexia, sarcopenia and biochemical markers in patients with advanced non-small cell lung cancer-chemotherapy toxicity and prognostic value. *Support Care Cancer*. 2016;24:4495–4502. <https://doi.org/10.1007/s00520-016-3287-y>.
- Roeland EJ, Bohlke K, Baracos VE, et al. Management of cancer cachexia: ASCO guideline. *J Clin Oncol*. 2020;38:2438–2453. <https://doi.org/10.1200/JCO.20.00611>.
- Jafri SH, Prevgliano C, Khandelwal K, Shi R. Cachexia index in advanced non-small-cell lung cancer patients. *Clin Med Insights Oncol*. 2015;9:87–93. <https://doi.org/10.4137/CMO.S30891>.
- Morita-Tanaka S, Yamada T, Takayama K. The landscape of cancer cachexia in advanced non-small cell lung cancer: a narrative review. *Transl Lung Cancer Res*. 2023;12:168–180.
- Watanabe H, Oshima T. The latest treatments for cancer cachexia: an overview. *Anticancer Res*. 2023;43:511–521. <https://doi.org/10.21873/anticancer.16188>.
- Bruggeman AR, Kamal AH, LeBlanc TW, Ma JD, Baracos VE, Roeland EJ. Cancer cachexia: beyond weight loss. *J Oncol Pract*. 2016 Nov;12(11):1163–1171. <https://doi.org/10.1200/JOP.2016.016832>.
- Parmar MP, Swanson T, Jagoe RT. Weight changes correlate with alterations in subjective physical function in advanced cancer patients referred to a specialized nutrition and rehabilitation team. *Support Care Cancer*. 2013;21:2049–2057. <https://doi.org/10.1007/s00520-013-1762-2>.
- Porter S, Millar C, Reid J. Cancer cachexia care: the contribution of qualitative research to evidence-based practice. *Cancer Nurs*. 2012;35:E30–E38. <https://doi.org/10.1097/NCC.0b013e31823d52b7>.
- Reid J, McKenna HP, Fitzsimons D, McCance TV. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer Care*. 2010;19:682–689. <https://doi.org/10.1111/j.1365-2354.2009.01124.x>.
- Rhondali W, Chisholm GB, Daneshmand M, et al. Association between body image dissatisfaction and weight loss among patients with advanced cancer and their caregivers: a preliminary report. *J Pain Symptom Manag*. 2013;45:1039–1049. <https://doi.org/10.1016/j.jpainsymman.2012.06.013>.
- Waterfield K, Andrew I, Macnaughton J, Hawkins C. A qualitative study exploring patients experience of ACS and a structured approach to its management. *BMJ Support Palliat Care*. 2012;2:A51.
- Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs*. 2006;54:304–312. <https://doi.org/10.1111/j.1365-2648.2006.03818.x>.
- Hutton JL, Martin L, Field CJ, et al. Dietary patterns in patients with advanced cancer: implications for anorexia-cachexia therapy. *Am J Clin Nutr*. 2006;84:1163–1170. <https://doi.org/10.1093/ajcn/84.5.1163>.
- Hopkinson JB. Psychosocial impact of cancer cachexia. *J Cachexia Sarcopenia Muscle*. 2014;5:89–94. <https://doi.org/10.1007/s13539-014-0142-1>.

18. Oberholzer R, Hopkinson JB, Baumann K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manag.* 2013;46:77–95. <https://doi.org/10.1016/j.jpainsymman.2012.06.020>.
19. Reid J, McKenna H, Fitzsimons D, McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud.* 2009;46:606–616. <https://doi.org/10.1016/j.ijnurstu.2008.10.012>.
20. Son W, Lin J, Puppa M. Nutritional interventions in cancer cachexia prevention and treatment. *OBM Integr Complement Med.* 2020;5:44. <https://doi.org/10.21926/obm.icm.2004044>.
21. Setiawan T, Sari IN, Wijaya YT, et al. Cancer cachexia: molecular mechanisms and treatment strategies. *J Hematol Oncol.* 2023;16:54. <https://doi.org/10.1186/s13045-023-01454-0>.
22. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2022. *CA A Cancer J Clin.* 2022;72:7–33. <https://doi.org/10.3322/caac.21708>.
23. Ramalingam SS, Owonikoko TK, Khuri FR. Lung cancer: new biological insights and recent therapeutic advances. *CA Cancer J Clin.* 2011;61:91–112. <https://doi.org/10.3322/caac.20102>.
24. Siegel R, Ma J, Zou Z, Jemal A. Cancer statistics, 2014. *CA Cancer J Clin.* 2014;64:9–29. <https://doi.org/10.3322/caac.21208>.
25. Bar J, Urban D, Amit U, et al. Long-term survival of patients with metastatic non-small-cell lung cancer over five decades. *J Oncol.* 2021;2021:7836264. <https://doi.org/10.1155/2021/7836264>.
26. Delgado-Guay M, Yennurajalingam S, Parsons H, Palmer JL, Bruera E. Association between self-reported sleep disturbance and other symptoms in patients with advanced cancer. *J Pain Symptom Manag.* 2011;41:819–827. <https://doi.org/10.1016/j.jpainsymman.2010.07.015>.
27. Denollet J, Schiffer AA, Spek V. A general propensity to psychological distress affects cardiovascular outcomes: evidence from research on the type D (distressed) personality profile. *Circ Cardiovasc Qual Outcomes.* 2010;3:546–557. <https://doi.org/10.1161/CIRCOUTCOMES.109.934406>.
28. Meyer T, Buss U, Herrmann-Lingen C. Role of cardiac disease severity in the predictive value of anxiety for all-cause mortality. *Psychosom Med.* 2010;72:9–15. <https://doi.org/10.1097/PSY.0b013e3181c64fc0>.
29. Teunissen SC, Wesker W, Kruitwagen C, de Haes HC, Voest EE, de Graeff A. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manag.* 2007;34:94–104. <https://doi.org/10.1016/j.jpainsymman.2006.10.015>.
30. Wang XS, Shi Q, Williams LA, et al. Inflammatory cytokines are associated with the development of symptom burden in patients with NSCLC undergoing concurrent chemoradiation therapy. *Brain Behav Immun.* 2010;24:968–974. <https://doi.org/10.1016/j.bbi.2010.03.009>.
31. Zhu R, Liu Z, Jiao R, et al. Updates on the pathogenesis of advanced lung cancer-induced cachexia. *Thorac Cancer.* 2019;10:8–16. <https://doi.org/10.1111/1759-7714.12910>.
32. Pirker R. Treatment of advanced non-small-cell lung cancer: from chemotherapy to chemoimmunotherapy. *J Oncol Pract.* 2018;14:537–538. <https://doi.org/10.1200/JOP.18.00474>.
33. Fearon K, Strasser F, Anker SD, et al. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol.* 2011;12:489–495. [https://doi.org/10.1016/S1470-2045\(10\)70218-7](https://doi.org/10.1016/S1470-2045(10)70218-7).
34. Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qual Res Psychol.* 2004;1:39–54. <https://doi.org/10.1191/1478088704qp0040a>.
35. Tindall L, Smith JA, Flower P, Larkin M. Interpretative phenomenological analysis: theory, method and research. *Qual Res Psychol.* 2009;6:346–347, 2009.
36. Cella DF, Tulskey DS, Gray G, et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol.* 1993;11:570–579. <https://doi.org/10.1200/JCO.1993.11.3.570>.
37. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcome.* 2003;1:79. <https://doi.org/10.1186/1477-7525-1-79>.
38. Ribaldo J, Cella D, Hahn E, et al. Re-Validation and shortening of the functional assessment of anorexia/cachexia therapy (FAACT) questionnaire. *Qual Life Res.* 2000;9:1137–1146. <https://doi.org/10.1023/a:1016670403148>.
39. Blauwhoff-Buskermolten S, Ruijgrok C, Ostelo RW, et al. The assessment of anorexia in patients with cancer: cut-off values for the FAACT-A/CS and the VAS for appetite. *Support Care Cancer.* 2016;24:661–666. <https://doi.org/10.1007/s00520-015-2826-2>.
40. Gelhorn HL, Gries KS, Speck RM, et al. Comprehensive validation of the functional assessment of anorexia/cachexia therapy (FAACT) anorexia/cachexia subscale (A/CS) in lung cancer patients with involuntary weight loss. *Qual Life Res.* 2019;28(6):1641–1653. <https://doi.org/10.1007/s11136-019-02135-7>.
41. Hui D, Bansal S, Morgado M, Dev R, Chisholm G, Bruera E. Phase angle for prognostication of survival in patients with advanced cancer: preliminary findings. *Cancer.* 2014;120:2207–2214. <https://doi.org/10.1002/cncr.28624>.
42. Dalal S, Hui D, Bidaut L, et al. Relationships among body mass index, longitudinal body composition alterations, and survival in patients with locally advanced pancreatic cancer receiving chemoradiation: a pilot study. *J Pain Symptom Manag.* 2012;44:181–191. <https://doi.org/10.1016/j.jpainsymman.2011.09.010>.
43. Del Fabbro E, Parsons H, Warneke CL, et al. The relationship between body composition and response to neoadjuvant chemotherapy in women with operable breast cancer. *Oncologist.* 2012;17:1240–1245. <https://doi.org/10.1634/theoncologist.2012-0169>.
44. Hopkinson JB. Food connections: a qualitative exploratory study of weight- and eating-related distress in families affected by advanced cancer. *Eur J Oncol Nurs.* 2016;20:87–96. <https://doi.org/10.1016/j.ejon.2015.06.002>.
45. Cooper C, Burden ST, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. *J Cachexia Sarcopenia Muscle.* 2015;6:99–111. <https://doi.org/10.1002/jcsm.12010>.
46. An A, Hui D. Immunotherapy versus hospice: treatment decision-making in the modern era of novel cancer therapies. *Curr Oncol Rep.* 2022;24:285–294. <https://doi.org/10.1007/s11912-022-01203-5>.
47. Amano K, Hopkinson J, Baracos V. Psychological symptoms of illness and emotional distress in advanced cancer cachexia. *Curr Opin Clin Nutr Metab Care.* 2022;25:167–172. <https://doi.org/10.1097/MCO.0000000000000815>.
48. Amano K, Morita T, Miyashita M. Potential measurement properties of a questionnaire for eating-related distress among advanced cancer patients with cachexia: preliminary findings of reliability and validity analysis. *J Palliat Care.* 2020;37:107–112. <https://doi.org/10.1177/0825859720951356>.