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Title

Diet and weight management by people with non-metastatic colorectal cancer during chemotherapy: mixed methods research

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Wales NHS Ethics Committee 3 gave ethical approval for the study.

Abstract

Aim

To investigate self-management of dietary intake by colorectal cancer patients receiving chemotherapy.

Methods

A questionnaire was administered to 92 patients with non-metastatic colorectal cancer receiving chemotherapy treatment at a UK cancer centre in 2018-19. A maximum variation sample of twenty patients who completed the questionnaire were interviewed.

Results

More than three in five patients were at nutritional risk but fewer than one in five were concerned about dietary intake or weight. Self-management of diet and weight was inconsistent with achieving the nutritional intake recommended by clinical guidelines on nutrition in cancer.

Conclusion

There is potential for psychoeducation to support change in self-management of nutritional risk, with implications for better treatment tolerance and outcomes including quality of life.

Key words

Colorectal cancer, chemotherapy, nutrition, diet, weight, psychosocial, self-management, qualitative, mixed-methods, research

Summary points

- Malnutrition during cancer treatment is associated with poor treatment tolerance, survival and quality of life
- Self-management of dietary intake may be an important way to improve treatment tolerance and outcomes
- Little attention has been given to the facilitation of optimal dietary intake during cancer chemotherapy
- We found patients with colorectal cancer receiving chemotherapy to be at nutritional risk, but unconcerned about their dietary intake
- A minority self-managed by taking the healthy diet recommended to reduce risk of disease, whilst a majority sought to return to their pre-cancer dietary intake.
- Self-management of dietary intake was inconsistent with achieving the recommended nutritional intake for patients receiving chemotherapy
- There is potential for supportive nutritional care to potentiate chemotherapy in patients with colorectal cancer

Introduction

This research is about self-management of diet and weight by patients with non-metastatic colorectal cancer during chemotherapy treatment.

Background

Eating problems during cancer treatment are common and contribute to malnutrition. Weight loss, an indicator of malnutrition, has been observed in 40-92% of patients 65 years and older during chemotherapy [1]. Expert consensus is that all patients should have optimal nutritional care throughout the course of their cancer [2]. The aim is to prevent malnutrition, thus improving treatment tolerance, survival and quality of life [3]. Support for self-management of dietary intake and weight is a possible way to help patients maintain their nutritional status and therefore potentiate cancer treatment.

Research about eating and gastrointestinal cancer treatments

In 2011, Baldwin et al. [4] conducted a systematic review of oral nutritional interventions in malnourished cancer patients. The analysis of 13 studies with 1,414 patients, found improved nutritional intake and quality of life. The meta-analysis was of mixed cancer sites and stages, therefore did not reveal if sub-groups of patients are more likely to benefit from oral nutritional support. In the same year, 2011, Elia critically reviewed studies of oral nutritional support during treatment in patients with gastrointestinal cancer [5]. He concluded that the effect on survival and other outcomes is unknown because studies were of mixed cancer stages, compliance with oral supplements poor and groups of well nourished (who perhaps cannot benefit greatly from nutritional support) mixed with malnourished patients with sample sizes insufficient to conduct robust subgroup analysis. He draws attention to the proven difficulty in improving dietary intake in real-life situations, for example, when a patient becomes too unwell during treatment to adhere to recommended interventions. However, it is known that weight loss before or during cancer treatment can negatively influence treatment outcomes, even in people who are overweight [2].

Our own systematic search of the literature published since 2011, demonstrated that some sub-groups of cancer patients are more likely than others to benefit from nutritional support during cancer treatment. Patients with head and neck and gastrointestinal cancers are particularly likely to benefit [6].

In patients with gastrointestinal cancer, pre-operative oral nutritional supplements can reduce post-operative surgical site infection rate, post-operative weight loss [7] and serious complications [8]. Compliance with oral nutritional supplements in these patients is variable and independent of weight loss, appetite and comorbidity, but is dependent on information and education [9]. In patients with colorectal cancer followed up after radiotherapy for a median 6.5 years, those who received individualised nutritional counselling to maintain protein and energy intake experienced less treatment toxicity, better quality of life and lower mortality rate compared with patients randomised to either oral supplements and usual diet or usual diet [6, 10]. It is not known if nutritional care can achieve similar results for patients receiving chemotherapy for colorectal cancer.

Aim

To investigate self-management of eating problems in patients with colorectal cancer receiving chemotherapy to explore the potential for reducing the risk of malnutrition, which contributes to poor clinical and patient reported outcomes from treatment.

Question

What practical, social and emotional factors affect eating during chemotherapy treatment and how are they self-managed by patients?

Methods

The research was a mixed-methods qualitative study of sequential design to identify factors affecting diet and weight during treatment and how they were self-managed. It was conducted at a cancer centre in the UK serving a population of approximately 1.5 million people in 2018/19. The objectives were to refine an existing survey questionnaire to investigate the experience of eating and weight for patients receiving chemotherapy treatment for colorectal cancer. To administer the survey to all eligible patients attending clinics over a 30-week period (approximately 100 patients) and to conduct semi-structured exploratory telephone interviews with a sub-set of survey participants (max. 30 patients). (See Figure 1. Study design).

Eligibility criteria were:

- Adults (18 years or older)
- Colorectal cancer diagnosis, non-metastatic (stage I-III)
- Capacity to consent
- Receiving chemotherapy

Development of the survey questionnaire

We developed a bespoke questionnaire, selecting items from existing questionnaires, designed and evaluated for the identification of eating and weight problems in people with advanced cancer or mixed cancer sites. We utilized the knowledge from our previous systematic review of what is known about eating during cancer treatment [5] and development of a cachexia quality of life measure: the EORTC CAX24 [10]. We then added the Scored Patient Generated Subjective Global Assessment (PG-SGA), which includes the four patient-generated historical components (weight history, food intake, symptoms and activities and function – also known as the PG-SGA short form) for assessing nutritional risk [12, 13]. A score of 0-1 requires no intervention, 2 to 3 requires nutritional education by a dietitian, nurse or other clinician with pharmacology for symptoms, 4 to 8 requires intervention by a dietitian with support from nurse and other clinicians, and a score ≥ 9 indicates a critical need for symptom management and nutritional intervention. Questions about socio-demographics were also included. People affected by cancer (n=10) were invited to pilot the questionnaire using a think-aloud technique during completion, and their feedback informed the final version (see Appendix I).

Data collection

Clinic staff identified eligible patients and introduced them to the researcher (CK) who offered a study pack comprising of a Study Brochure and the survey questionnaire. The researcher invited the patient to complete the survey during their clinic visit or to return it by post in a stamped addressed envelope. Completion of the questionnaire was taken as evidence of consent to participate [14].

Interviews

Semi-structured telephone interviews were conducted with a maximum variation sample of patients who complete the questionnaire (CK). The purpose was to explore the practical, social and emotional experience of eating through treatment and self-management of diet and weight. Interviews were performed until data saturation was achieved, defined as when three consecutive interviews produced no new issues [15].

Analysis

Survey data was entered into IBM SPSS for windows version 25 (CK) and analysed using descriptive statistics and graphical representations of data (JH) to determine the extent and pattern of eating and weight problems.

Interview data was audio-recorded and transcribed verbatim by a professional transcription company. Transcriptions were coded in NVivo computer software (CK), to assist with data management. Transcripts and coding were read and re-read, then categorised inductively by two researchers working independently (CK, JH). The researchers compared their analysis and agreed final categorisation of the data. Categorisation and the identification of relationships between categories conformed to Miles and Huberman's 'mixed strategy' for case-study analysis [16]. Themes relating the categories were identified (CK, JH) and then organised using an approach informed by hermeneutic phenomenology [17] to provide description of physical, social and emotional experience and management of weight and eating during chemotherapy treatment, which revealed possible explanations of the survey results (JH).

Wales NHS Ethics Committee 3 gave ethical approval for the study. Findings were shared with participants with consent. Anonymity was protected during reporting with patients denoted by P followed by their participant number.

Results

The survey questionnaire was returned by 52/92 patients (response rate 57%) with non-metastatic colorectal cancer, who were receiving treatment from November 2018 to June 2019. In this time period 132 eligible patients attended 70 clinics. Those not approached were, in clinic at a time the researcher was with another patient or not in attendance (n=27), did not speak English (n=2), were judged by a clinician as too unwell to approach (n=7), or declined to take part (n=4). Telephone interviews were then conducted with a maximum variation sample of 20 patients who completed the questionnaire to explore factors influencing nutritional self-care (see Table 1. Sample characteristics).

Eating problems and nutritional impact symptoms

Participants were asked if they were eating less or more than before the start of their treatment. 26/50 (52%) of the patients who provided a response were found to eat less and 12/51 (24%) found to eat more. When asked about the nature of any eating difficulty, more than half reported lack of interest in food, feeling full too quickly and feeling put-off eating by the amount of food on a plate, with nearly a third forcing themselves to eat and a fifth unable to eat although they wanted to (see Table 2. Experience of eating problems).

Participants were also invited to report nutritional impact symptoms. Overall, few symptoms were experienced and when they were, few patients reported severity to be 'quite a bit' or 'very much' (see Table 3. Nutritional impact symptoms). Nausea, dry mouth, lack of appetite, diarrhoea and

frequency of bowel movements were the most problematic. When asked if bowel movements had changed what was eaten, 42/50 (84%) reported 'little' or 'not at all' and when asked if bowel movements had resulted in eating less, 48/50 (96%) reported 'little' or 'not at all.'

Changes in weight

Fifty-one patients reported their weight at the time of questionnaire completion. The 32 men in the sample were mean weight 86kg (median 82kg, range 67kg to 121kg) and the 20 women were mean weight 78kg (median 75.5kg, range 51 to 122kg). Patients were also asked to report their weight six months prior to completing the questionnaire. Forty-eight patients reported their weight at the two time points. Weight gain was reported by 12/48 (25%), 32/48 (67%) reported weight loss and 4/48 (8%) were weight stable. Of the 19/48 (40%) patients who had lost more than 5% body weight, 11/19 (58%) had lost weight during their chemotherapy treatment.

Scored PG-SGA (nutritional risk screening)

31 men completed the scored PG-SGA, with a mean score of 4.2 (median 3.0, range 0-17) and 20 women completed the measure, with a mean score of 4.0 (median 3.0, range 0-11). In total, 33/51(67%) were at 'nutritional risk' with a PG-SGA score of ≥ 2 . 11 men (35.5%) and 7 women (35%) were in the category 'requiring no intervention.' Half of both the men 15/31 (48%) and women 10/20 (50%) were at nutritional risk with score 2-8, where nutritional care and symptom management by the oncology team are important, whilst 5 men (16%) and 3 women (15%) were in the category indicating 'critical need for intervention' (see Figure 2. Nutritional risk).

Emotional impact of changes in eating and weight

Despite more than two-thirds of participants being at nutritional risk, most were unconcerned about their eating or weight (see Figure 3.). When asked if they were concerned about eating, a high proportion, 40/51 (78%) responded no and similarly, when asked if they were concerned about their weight, 40/50 (80%) responded no.

Participants also rated the intensity of possible concerns. When asked if concerned about appetite, 51/52 (98%) reported 'not at all' or 'a little,' and when asked to rate worry about eating, 49/51 (96%) reported 'not at all' or 'a little.' Of the 33 participants who were at nutritional risk with a PG-SGA score 2 or greater, 33/33 (100%) reported 'not at all' or 'a little' concern about appetite, and 31/32 (97%) reported 'not at all' or 'a little' worry about eating.

Nutritional information and advice

A total of 19/51 (36.5%) participants had received information about diet and nutrition from a healthcare professional and more than half, 28/51 (54%), had gathered dietary information from other places (see Table 4.). However, there was no correlation between receiving or seeking nutritional information and PG-SGA score. A majority 41/50 (82%) responded 'not at all' to a question asking if more should be done to help them eat.

Interview findings

Sample

The interview sample (n=20) was selected to be representative of the whole sample (n=52). Similar proportions reported weight change, weight loss or weight gain during their chemotherapy

treatment, although a lower proportion had experienced >5% weight loss over six months (see Table 1.).

A range of practical, social and emotional factors influenced eating and the way in which people responded to change in eating habits and weight.

Practical factors affecting dietary intake

Common side effects

The participants spoke about chemotherapy side effects and disease symptoms affecting what they were able to eat and drink, consistent with the questionnaire responses;

“Even water tasted funny, I had a job to drink water, um so food just tasted absolutely dreadful....the first couple of days, I’d have a bit of constipation and then diarrhoea set in and it would be on and off for the rest of the cycle.” (P31)

However, side effects were fewer in number and less severe than expected:

“I get no sickness. Nothing. I think I’m one of the lucky ones.” (P2)

When asked about what they had eaten the day before the interview, more than half described their intake as ‘normal’ or similar to before their cancer diagnosis.

Strategies to eat and drink

An approach for managing chemotherapy side effects at home used by some was to follow rules. These might be personal rules but informed by information and advice given by oncology staff. Advice to eat before taking chemotherapy medication was an important influence on the pattern of eating or the decision to eat at all;

“My portion sizes are smaller, um, because of my medication, I have to eat before I have my medication. So, I have an alarm on my phone, to flash lunchtime, then I go oh right okay, I’ve gotta remember to eat something.” (P33)

Public health messages disseminated to the general population about what to eat and drink for health and well-being also influenced personal rules;

“We’ve always eaten healthily. Er, there’s no frying pan in this house. We don’t have sugar. We don’t use sugar. I had a weak coffee, but we usually drink boiled water. Both of us, yea, it’s all fresh vegetables or, frozen vegetables....We’ve always eaten healthy, healthy salads and fresh vegetables, fruit. We love our fruit, so it’s not much different to what it was before the cancer set in.” (P29)

A temporary thing

The side effects described as most hindering to eating were nausea and sickness, diarrhoea, loss of hunger/appetite, cold sensitivity to fluids and food leading to difficulty in keeping hydrated and also in handling food and drink. Any disruption to eating caused by chemotherapy side effects was ‘just one of these things you’ve got to put up with’ (P12) and expected to be temporary;

“It’s all part of the chemo, once chemo finishes, I think I will be a lot better.” (P38)

Social factors affecting dietary intake

Disruption of day to day activity

The change in day to day activity, particularly for those who had stopped working during treatment, was a factor influencing dietary intake. P5 was concerned about weight gain;

“Once I go back to work my diet is gonna change, because, obviously at home you do tend to pick and I don’t think that’s doing me any good. It’s just, probably, boredom and stuff like that, I mean if I go out and come back in, I’ll have a biscuit with a cup of tea, or a piece of cake and a cup of tea. It’s one of those things that I wouldn’t do in work.” (P5)

Physical activity or exercise were talked about along with dietary intake, as important for managing weight. Some participants spoke about physical activity or exercise to have been an important part of their lives. Concern was expressed because of the difficulty in remaining physically active during treatment and the implications, especially for those who did not want to gain weight;

“I should be doing a bit more exercise, but I can’t do it at the moment, I tried to walk a little bit, but it’s very, very tiring and I’m not very steady on my feet.” (P20)

A particular challenge for patients with a stoma who wanted to remain active, was concern about going out, because of the risk of a leak from the stoma bag. This affected their activity and also what they ate, with restriction of food and fluid intake being a way to manage the risk;

“I’ve got a colostomy bag....That’s kind of encouraged me to not eat very much.....If I’m going out in public, I won’t eat....If I’m going out, I’ll avoid eating whilst I’m out, and then I’ll eat when I get back home.” (P17)

Having another person either to feed, or who offered help with food preparation was helpful for those experiencing problems eating. To care for others, or care shown by others in providing food, was experienced as more than an offer of food for the body, but fuel for a sense of well-being. Patients who experienced the most difficulty finding the energy and motivation to attend to their nutritional intake were those who lived alone;

“Because it’s only me in the house....I try and cook, I cook dinner, that’s only once a week now, it used to be every day.” (P38)

A self-management routine

When disruption in day to day activity was recognised as a risk to either taking adequate nutrition or eating too much, a proactive approach could include establishing a routine. The routine might be to engage in a distracting activity to avoid overeating. For example, ‘doing jigsaws’(P33).

It might also include adapting an approach successful in managing a pre-cancer problem;

“What I always find helps with my weight, to go to class every week, to weigh myself.... I used to enjoy going to the Slimming World classes to get tips from other people and the support ‘oh, well done’ from the other people. My husband’s overweight, he’s gone to (the chemist) the last three weeks now to weigh there, which only costs us seventy pence, weigh and a little slip comes out, and I started that now last week...So, we are supporting each other that way.” (P33)

P33 has not only resuming an old activity that has previously enabled her to manage her weight, but also engaged her husband in her weight management plan. A mutually beneficial activity is established, as a helpful routine within their personal capabilities and financial resources.

Return to former activities, dietary habits and management of health was a recurring theme. The goal being to get back to normal;

"I just think keep going and trying to get back to normal and not sit around too much, you know, and get back to your normal activities." (P27)

Normal food and eating habits provided some reassurance of recovery;

"... it was the best I was feeling for, for ages...., I was able to eat normally" (P28)

Emotional factors affecting dietary intake

Getting better

Many patients were seemingly unconcerned about their diet, nutritional intake or eating habits. They gave accounts of improvement in what they were able to eat and drink, which assured them all was well, that additional information and advice on food, eating and nutrition was unnecessary and there was nothing more to be done;

"I'm sure I read somewhere, on one of the leaflets that you could ask for dietary advice. And...but I didn't really feel I needed it." (P8)

Factors described as evidence of being on a pathway of recovery were 'mind matters,' 'healthy eating,' and 'benefits of weight loss.'

Mind matters

Recurring were comments about positive thinking and having the right attitude for recovery;

"Although I've reduced my food, you know, for the bag and things, I don't let it get to me...I just think, oh well...I think a positive mind-set is the main thing....faith that everything is going to be okay." (P17)

Clinical staff were seen responsible for medical treatments to manage the disease and its symptoms. Personal responsibility was to have a positive attitude.

Healthy eating

Having the right attitude included eating the right foods for recovery and health. A small number of patients 'worried about the nutritional side of things' (P31). For these people, the right foods were believed to be the balanced diet recommended for the healthy population, to include fruit and vegetables every day. This proved challenging;

"I was concerned because, normally, my intake in nutrients and vitamins is normally quite high. I felt that because I was drawn to mainly just having lots of sandwiches and what I wanted, I was sort of fighting it at first, because I thought no I need to have my usual fruit and veg...in the end, I just thought, right, I just need to give in to how I'm feeling, because there is enough going on without me fighting myself over diet." (P7)

Benefits of weight loss

It was more often that the patients considered weight rather than nutrition. They spoke about their current weight and weight change evidencing improvement in health;

"I'm keeping to 11 ½ stone now. I'm happy with that. I needed to lose weight anyway, I was up to 14 ½ stone, that's no good, that's no good to anybody, but it's off now and I'm very pleased about it." (P29)

Most gave an account of their experience of surgery. Typically, this was of rapid weight loss followed by weight gain during the post-operative recovery period, which might be spontaneous or the result or effort of consciously '*building up again*' (P18). The benefits of weight loss were emphasised, particularly by those who had been overweight before the surgery, but also by patients who were not.

"I had the operation.... that just knocks back your appetite, erm, whether there's some other more medical reason why I lost, I don't know, but the result was I lost 8 or 9 kilos. It wasn't a problem because, although I not overweight at all, it possibly didn't do me any harm to lose that." (P23)

Family members reinforced beliefs about the benefits of weight loss;

"... my family are very pro me losing weight. I have that pressure." (P20)

Patients who were gaining weight but who did not want to return to or become overweight, spoke about weight being out of their control during treatment. This might be because of the advice given to eat before taking oral chemotherapy to minimise treatment side effects;

"I'd rather not put on any more weight butI guess I'm between a rock and a hard place really. I mean, I do need to eat so as I can take my chemo drugs." (P16)

Or, it was explained that steroid treatment '*does increase your appetite*'; (P25) and change in everyday activity, for example '*not being in work*' (P25) had impact on dietary intake and weight.

Nothing to be done and taking control

Although there was a dominant shared narrative of weight and weight gain being out of control during cancer treatment – partly because of the disease treatment and treatment side effects – there was a competing narrative. This was the dominant narrative throughout six interviews with patients across the spectrum of nutritional risk, assessed using the PG-SGA, three of whom were weight gaining and three weight losing. It was of overtly taking control to aid recovery, in spite of this being difficult;

"I make myself eat, even when I don't want to. I try and keep it to three or four reasonable health meals a day, cos, as far as I can concentrate on good quality food as well than just getting something into me, and I do as much exercise as I can tolerate....It's you know, taking control and sometimes not feeling like it, but knowing that it, in the long run it's what my body needs and how I'm gonna recover.... A bit of control over what's going on with me, I suppose, it's keeping myself in the best condition that I can while I can't exercise and eat what I would normally, I want to try and maintain at least a part of it. It gives you focus." (P18)

The two narratives of being 'out of control' versus taking control, may be intertwined within a patient's story. This was evident in accounts of internet use. P23 is an example of someone who talks about the internet as a source of information for managing diet and weight but who has confidence in his existing knowledge of diet and nutrition, so considers there is nothing to be done;

"One is able to Google....what's good to eat, which is probably not very clever. It's best to ask people, but err, no try and have a reasonable diet, you know, the reasonable fruit and vegetables." (P23)

5 patients actively avoided searching the internet for information about diet and weight 'you get into a lot of misinformation' (P9). It was considered a worrying or frightening thing to do. Thus, to do nothing was a passive way of taking control;

"I specifically avoided that, um, I know if you look something up on the internet, generally you just worry yourself to death, so I made a particular point of not looking stuff up." (P25)

Talking about the internet revealed the intertwined narratives of actively taking control by managing nutritional intake and physical activity through rules, routine and self-help, as compared to a more passive approach of drawing on existing knowledge and experience to find one's own way and wait for treatment-related problems to pass. For those taking control passively, the intention was always to 'just do things normally really' (P17) or return to normal;

"I was never really a big eater; my normal standard weight is seventy kilos (....) I'm trying to get my weight back to normal." (P25)

Making sense of the survey results and interview findings

The majority of patients were at nutritional risk, but unconcerned about diet, eating and weight. An explanation for this lack of concern is the sense of control gained from taking the same diet as prior to their cancer diagnosis or from a belief in being on a pathway back to normal. This belief is reinforced by the improvement in dietary intake and recovery of weight loss post-surgery and prior to commencing chemotherapy, accompanied by fewer than expected side effects of chemotherapy. The assumed return to eating normally equated with recovery, contributed to ambivalence about actively managing dietary intake and the decision that there was nothing to be done until after chemotherapy treatment. A minority of patients gained a sense of control and well-being during chemotherapy treatment by actively seeking information and self-managing nutritional intake and weight. This minority spanned all categories of nutritional risk and included those who were both weight gaining and weight losing. Education to disrupt the goal of eating as normal (pre cancer) may be a way to facilitate change in self-management. There is potential for disruption of the belief that eating as normal is good, to enable a greater number of patients to actively self-manage, whether they are weight losing, weight gaining or at any level of nutritional risk.

Discussion

In this study, a majority of patients with non-metastatic colorectal cancer reported changes in eating habits during chemotherapy treatment and two-thirds were assessed to be at nutritional risk. Malnutrition can lead to weight loss or weight gain. Twenty five percent had gained weight and 67% had lost weight over a six-month period (37% after starting chemotherapy treatment). Concern regarding eating was reported by one in four (25%) who had gained weight and one in five (19%) who had lost weight, over six months. Thus, there was a large group of patients who had no eating concerns despite being at nutritional risk.

The interviews revealed a dominant narrative of confidence in self-management of eating and weight, reinforced by weight gain accompanying recovery following surgery, which led to a belief that further dietary information or advice was unnecessary. Experience of overcoming eating problems and regaining weight lost pre- and immediately post operatively, plays an important role in

how people go on to manage eating whilst on chemotherapy. Confidence that recovery was in progress was further reinforced by the experience of fewer and less intense nutritional impact symptoms than were expected whilst on chemotherapy. Also, important to note, is that some patients welcomed weight loss. Of these, some welcomed weight loss because they had been overweight, as has previously been reported [18]. However, others did so despite having been underweight.

Interest in nutritional care

An on-line survey of 96 patients, most living in south or south-east England, 1/3rd with advanced disease, and 1/3rd with breast cancer, reported dissatisfaction with nutritional care and wanted additional advice on diet and nutrition during treatment to help them manage side-effects of chemotherapy, weight changes and what they eat [19]. Interview based studies evidence that patients find eating problems distressing and lack appropriate dietary instructions [20,21]. Yet there is competing evidence. Patients have also been found reluctant to engage in nutritional care. A study conducted in Turkey of mixed cancer sites reported that more than a third of patients declined participation because of fatigue or disinterest in nutritional support [22]. Our study demonstrated that diet and nutrition was of concern to only a minority of patients, despite the fact that it should have been of concern to all at nutritional risk. A majority were content with the nutritional advice and information available to them. The sample demographic was typical in terms of age, gender, ethnicity and domestic status of patients receiving treatment for colorectal cancer when compared with 857 colorectal cancer patients from 29 centres across the UK [23]. Lack of concern surrounding dietary intake and nutrition during chemotherapy for colorectal cancer may manifest beyond the study centre location in South Wales, UK.

Clinical guidelines

Nutritional counselling is the most often used intervention for patients with cancer who have a functioning gastrointestinal tract and are malnourished [24]. It can improve nutritional status in patients receiving chemotherapy [25]. In China, patients with gastric cancer receiving chemotherapy were randomised to intensive nutritional counselling or usual nutritional care (n=144). The intervention group had improved calorie and iron intake throughout treatment and fewer treatment interruptions compared to the usual care control. [26]. Critical components of nutritional counselling are to explain reasons for and agree goals of nutritional recommendations and to motivate the patient to adapt to the nutritional demands of their cancer [2]. These components are consistent with behavioural change theories and strategies known to facilitate food behaviour change beyond the context of cancer care [27].

Personalised nutritional counselling and support for physical activity is recommended by the ESPEN Clinical Guideline on nutrition in cancer, to stabilise weight and prevent loss of muscle mass and function [2]. Counselling is recommended to support dietary adaptation using regular foods, fortified foods and oral food supplements [24] to achieve an intake of 25-30 kcal/kg/day and 1.2-1.5g protein/kg/day (or intake based on an estimate of energy needs) [24]. However, this knowledge alone may not change self-management of eating during treatment. Beliefs surrounding eating, such as perceived health benefits, not just symptoms such as taste change, constrain and enable management of eating problems [28]. Our study reveals participants were unconcerned about eating and mostly unaware of nutritional risk, and nutritional considerations influenced diet of only a minority. This minority were concerned to take control by eating the healthy diet promoted to prevent or reduce risk of disease. Dietary management has similarly been found an important way of feeling in control for breast [29] and prostate [30] cancer patients on treatment.

For a majority of our study participants, food and fluid intake was influenced by a desire to either continue as normal, or the hope of returning to normal. Thinking and behaviour was driven by normal symbolising recovery and thus giving comfort. It was feeling not fuelling that was important to self-management of diet, eating and weight during treatment. This suggests that, for care to be effective in supporting self-management of nutritional risk during chemotherapy treatment, it should focus not only on fuelling the body, advising the best nutrient intake, but also create a feel-good factor.

A personal reference point

Normal eating habits or usual dietary intake prior to receiving a diagnosis of colorectal cancer was used by a majority of patients, as the reference point for recovery and indicator of health. This has implications for nutritional care during chemotherapy treatment. It seems likely that to be effective, nutritional counselling should advise adaptations as close as possible to the patient's normal intake and eating pattern, as has previously been recommended to support patients receiving radiotherapy [10]. It also raises a question about the potential for psychoeducation to change the reference point. For example, if the advised reference point was stable weight through treatment, as recommended by ESPEN, this may facilitate a guideline compliant dietary intake for patients receiving chemotherapy. In other words, it may encourage dietary intake, which can reduce the risk of interruptions to treatment schedule and improve quality of life through improved nutrition [24]. The approach may be particularly helpful for patients who self-manage eating during chemotherapy treatment by creating personal rules informed by healthcare professional advice.

Limitations

This research was a single centre study in the UK and was about nutritional care of patients receiving a single treatment modality, chemotherapy. Almost all patients with Stage I disease are treated by surgery alone, therefore it is likely that the analysis and conclusions are based on data collected from patients with Stage II-III colorectal cancer. The transferability of the findings to other disease stages, cancer treatments and other geographical locations in the UK and beyond, should be investigated with a larger sample size. This would permit robust statistical tests of the propositions generated by the analysis and stratification to enable comparison of rectal and colon cancers and comparison of weight losing, weight gaining and weight stable patient groups.

Data collection was performed by a social scientist who then conducted the analysis in partnership with a nurse academic. The findings have been tested for credibility through discussion with service users, cancer clinicians, clinical academics and researchers practising in England and Wales. Evaluation of credibility should be extended to include multidisciplinary cancer teams across all four nations in the UK and beyond.

Conclusion and future perspective

Patients with non-metastatic colorectal cancer receiving chemotherapy treatment were at nutritional risk, but few were concerned about dietary intake or weight. A minority sought to take control of their nutritional intake by striving to consume the healthy diet recommended to reduce risk of disease in the healthy population. A majority took comfort from continuing to eat normally or striving to return to normal pre-cancer dietary intake. Neither approach to self-management of eating and weight was consistent with achieving the nutritional intake recommended by the ESPEN Clinical Guideline on nutrition in cancer [24]. There is potential for psychoeducation to support change in self-management of nutritional risk, with the implication of a future with better chemotherapy tolerance and outcomes, including quality of life.

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Table 1. Sample characteristics

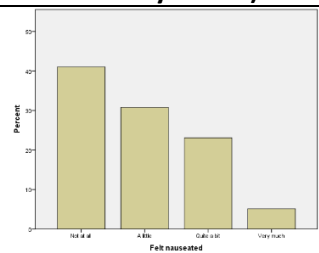
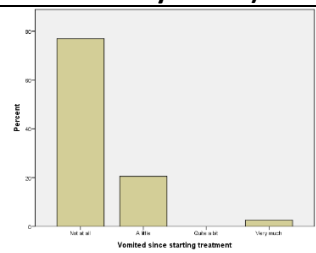
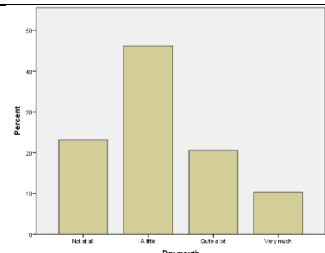
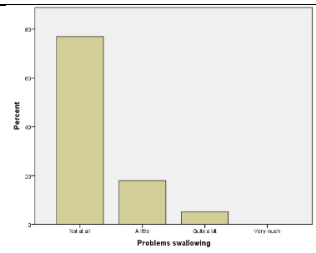
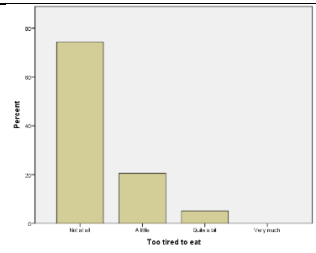
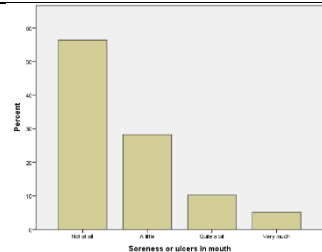
Sample characteristics		
	Survey sample	Interview sample
Gender (n (%))		
Female	20 (38.5)	9 (45)
Male	32 (61.5)	11 (55)
Age (years)		
Mean	67	64
Median	68.5	62
Range	36 to 86	48 to 84
Ethnicity (n(%))		
White British	51/52 (98)	19/20 (95)
Education		
No formal qualification	10 (19)	0 (0)
Trade qualification	8 (15)	3 (15)
Higher degree	10 (19)	6 (30)
Living with (n(%))		
Partner/spouse	38 (73)	16 (80)
Family	4 (8)	0
Alone	10 (19)	4 (20)
Cancer treatment (n(%))		
Surgery	48 (92)	20 (100)
Stoma	19 (38)	8 (44)
Chemotherapy	52 (100)	20 (100)
Time on treatment in weeks (median, mean (range))	8.5, 11.6 (1 to 49)	6.0, 11.2 (4 to 28)
Comorbidity (n(%))		
None	19 (36.5)	8 (40)
Diabetes	6 (11.5)	3 (15)
Heart disease	6 (11.5)	3 (15)
Multiple	6 (11.5)	2 (10)
PG-SGA (median, mean, (range))	3.00, 4.12 (0 to 17)	3.00, 4.1 (0 to 11)
Nutritional risk score ≥ 2 (n(%))	33/51 (67)	13/20 (65)

Visual Analog Scale (VAS) (median, mean, (range))		
Eating-related concern	0.5, 1.8 (0 to 9.5)	0.95, 2.31 (0 to 7.5)
Eating-related distress	0.45, 1.1 (0 to 9.5)	0.50, 1.41 (0 to 7.5)
Weight-related concern	1.2, 2.3 (0 to 10)	1.45, 2.44 (0 to 7.5)
Weight-related distress	0.5, 1.5 (0 to 9.5)	0.50, 1.41 (0 to 7.5)
Eating change (n(%))	36/51 (71)	12/20 (75)
Eating more	12/51 (23.5)	6/19 (32)
Eating less	26/50 (52)	8/18 (44)
Weight in kg (median, mean, (range))	78.0, 100.44, (50.8 to 121.6)	82.9, 84.94 (57.2 to 121.6)
Weight change over 6 months based on self-report of actual weight (n (%))		
Stable	4/48 (8)	3 (15)
Weight loss <5%	13/48 (27)	7 (35)
Weight loss >5%	19/48 (40)	3 (15)
Weight gain	12/48 (25)	7 (35)
Weight change since commencing SACT based on self-report of YES/NO (n(%))		
Weight has changed	36/52 (70)	12/20 (60)
Weight less	18/50 (35)	5/18 (28)
Weight more	18/50 (35)	6/18 (33)

Table 2. Experience of eating problems

Problem	A little, Quite a bit, Very much n,n,n=n/N(%)	Not at all n(%)
Put off by too much on plate	21,5,1 = 27/50 (54)	23/50 (46)
Feeling full too quickly	19,3,4 = 26/50 (52)	24/50 (48)
Lack of interest	16,8,2 = 26/50 (52)	24/50 (48)
Trouble eating	15,4,1 = 20/49 (41)	29/49 (56)
Problems with liquids	8,6,2 = 16/51 (32)	35/51 (69)
Problems with solids	14,1,1 = 16/50 (32)	34/50 (68)
Forced self to eat	11,2,2 = 15/50 (30)	35/50 (70)
Put off by smell	8,4,2 = 14/49 (29)	35/49 (71)
Food texture unpleasant	5,4,2=11/49 (23)	38/49 (78)
Want to eat but unable	8,1,1 = 10/50 (20)	40/50 (80)

Table 3. Nutritional impact symptoms

Most problematic nutritional impact symptoms (<10% experienced them 'quite a lot' or 'very much')		Least problematic nutritional impact symptoms (>10% experienced them 'quite a lot' or 'very much')	
	Nausea		Vomiting
	Taste change		Teeth
	Dry mouth		Swallowing
	Lack of appetite		Pain
	Tiredness		Mouth ulcers
	Bowel symptoms		

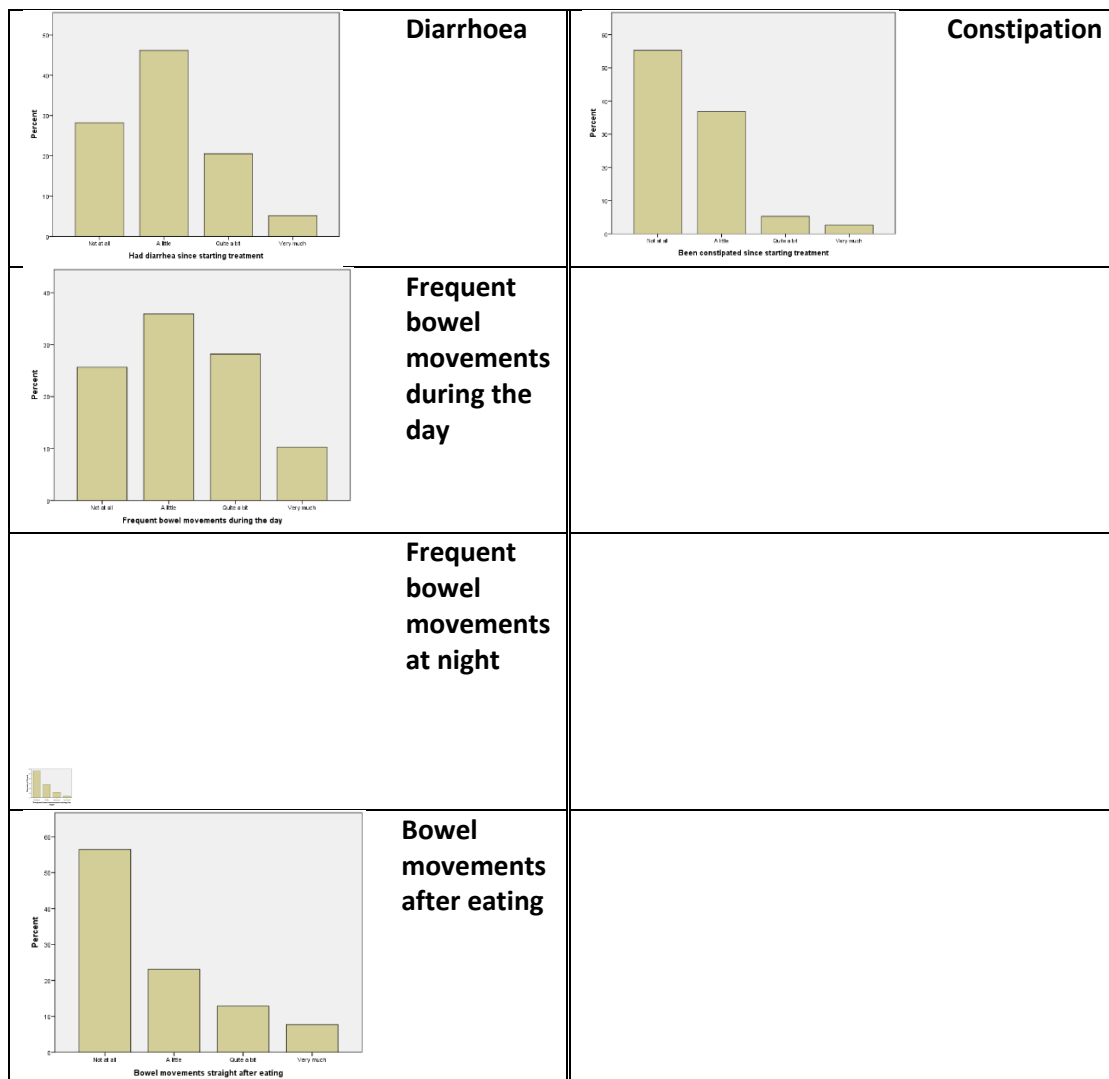


Table 4. Sources of nutritional information and advice

	Information from a healthcare professional	Information from other places	PG-SGA score between 2 and 8 offered healthcare professional advice	PG-SGA score ≥ 9 offered healthcare professional advice
Men	12/32 (37.5%)	17/31 (53%)	6/15 (40%)	3/5 (60%)
Women	7/19 (35%)	11/19 (55%)	4/10 (40%)	1/3 (33%)
Total	19/51 (36.5%)	28/51 (28%)	10/25 (40%)	4/8 (50%)

Figure 1.: Study design

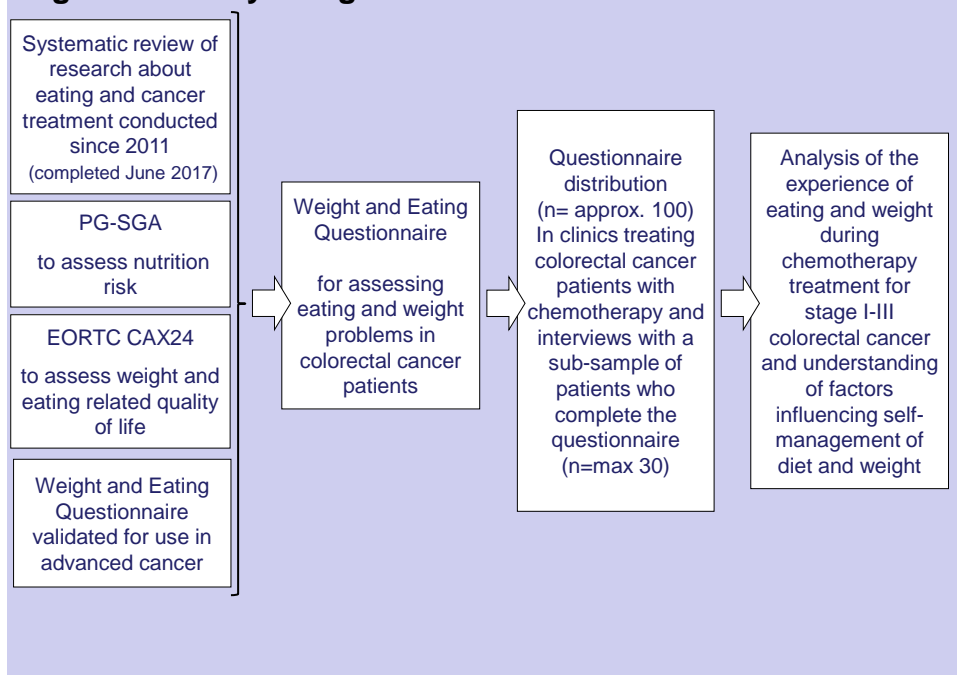


Figure 2. Nutritional risk

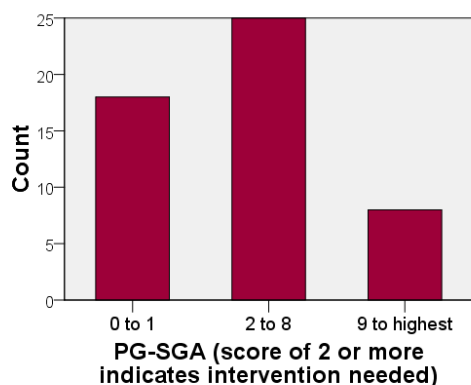
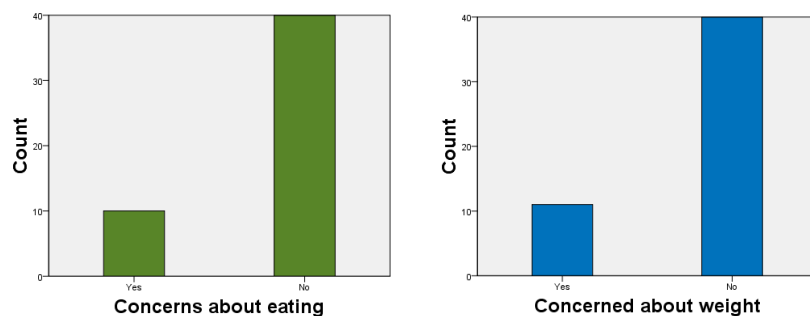


Figure 3. Concern about eating and weight



Appendix 1.: Questionnaire

Section 1: About you

Please insert or tick the answer that best applies to you:

1. I am:

☐

Male

☐

Female

☐

Other

☐

Prefer not to say

2. My date of birth (DOB) is:...../...../.....

3. I am currently receiving (please tick all that apply):

☐

Chemotherapy

☐

Immunotherapy

☐

Hormone Therapy

☐

Other (please state)

4. I have had surgery:

☐

YES

☐

NO

5. I started Chemotherapy in: Month..... Year.....

I started Immunotherapy in: Month..... Year.....

6. I have the following (please tick all that apply):

- ☐ Diabetes
- ☐ Heart Disease/ Heart attack/ High blood pressure
- ☐ Stroke
- ☐ Lung disease/breathing problems
- ☐ Gastrointestinal disorders (Crohn's/ Irritable Bowel Disease IBD)
- ☐ Arthritis
- ☐ Other (please state).....

7. I currently live with:

- ☐ Spouse/partner
- ☐ Other family members
- ☐ Alone
- ☐ Other
- ☐ Prefer not to say

8. I have the following (please tick highest):

- ☐ Trade/NVQ
- ☐ GCSE/O Level
- ☐ A level or Equivalent
- ☐ Degree/Higher Degree
- ☐ No Formal Qualification
- ☐ Other
- ☐ Prefer not to say

9. I am:

- ☐ White British
- ☐ White Other
- ☐ Mixed/Multiple Ethnic Groups
- ☐ Asian/Asian British
- ☐ Black/African/Caribbean/Black British
- ☐ Other
- ☐ Prefer not to say

Section 2: Your Eating Experience

We are interested in your experience of eating since you started your current Chemotherapy. Please read the questions below and circle the answer that best applies to you. There are no right or wrong answers.

Please **circle one answer** per question.

Since starting my current Chemotherapy:

- | | |
|---|----------|
| 1. My eating habits have changed | YES / NO |
| 2. I eat more now than before I started treatment..... | YES / NO |
| 3. I eat less now than before I started treatment..... | YES / NO |
| 4. I have made changes to the way I eat..... | YES / NO |
| 5. I have concerns about eating. | YES / NO |

6. My family is concerned about my eating habits..... YES / NO
7. I have been given advice about eating by a healthcare professional..... YES / NO
8. I have found dietary information from other places e.g. internet, leaflets, books..... YES / NO

Some people have problems eating during their treatment.

Since starting your current Chemotherapy:

	Not at all	A little	Quite a bit	Very much
9. Have you had trouble eating?	1	2	3	4
10. Have you lacked appetite?	1	2	3	4
11. Has food tasted different from usual?	1	2	3	4
12. Have you found the texture of food unpleasant?	1	2	3	4
13. Have you been put off eating by the smell of food?	1	2	3	4
14. Have you been put off eating by having too much food on your plate?	1	2	3	4
15. Have you felt full too quickly after beginning to eat?	1	2	3	4

Since starting your current Chemotherapy:

	Not at all	A Little	Quite a bit	Very much
16. Have you lacked interest in eating?	1	2	3	4
17. Have you had problems drinking liquids?	1	2	3	4
18. Have you had problems eating solid foods?	1	2	3	4
19. Have you been unable to eat despite wanting to?	1	2	3	4
20. Have you forced yourself to eat?	1	2	3	4

Some people have symptoms or treatment side effects that interfere with their eating.

Since starting your current Chemotherapy:

	Not at all	A little	Quite a bit	Very much
21. Have you vomited?	1	2	3	4
22. Have you felt nauseated?	1	2	3	4
23. Have you had soreness or ulcers in your mouth?	1	2	3	4
24. Have you had a dry mouth?	1	2	3	4
25. Have you had problems with your teeth?	1	2	3	4
26. Have you had problems swallowing?	1	2	3	4
27. Have you been in too much pain to eat?	1	2	3	4

28. Have you been too tired to eat?	1	2	3	4
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Some people have bowel problems that interfere with their eating.

Since starting your current Chemotherapy:

	Not at all	A Little	Quite a bit	Very much
29. Have you been constipated?	1	2	3	4
30. Have you had diarrhea?	1	2	3	4
31. Have you had frequent bowel movements during the day?	1	2	3	4
32. Have you had frequent bowel movements during the night?	1	2	3	4
33. Have bowel movements occurred straight after eating?	1	2	3	4
34. Have you felt embarrassed because of your bowel movement?	1	2	3	4
35. Have your bowel movements changed what you choose to eat?	1	2	3	4
36. Have your bowel movements made you eat less?	1	2	3	4
37. Do you have a stoma bag (colostomy/ileostomy)?	Yes		No	

Some people have concerns about eating.

Since starting your current Chemotherapy:

	Not at all	A little	Quite a bit	Very much
38. Have you felt concerned about your appetite?	1	2	3	4
39. Have you felt embarrassed when eating?	1	2	3	4
40. Have you felt guilty when eating?	1	2	3	4
41. Have you felt pressured by other people to eat more?	1	2	3	4
42. Have you had trouble eating in front of other people?	1	2	3	4
43. Have you felt other people disapprove of what you eat?	1	2	3	4
44. Have you felt troubled by advice about eating from family and friends?	1	2	3	4
45. Have you felt troubled by advice from healthcare professionals?	1	2	3	4
46. Have you felt more should be done to help you eat?	1	2	3	4
47. Have you worried about eating?	1	2	3	4

For the following questions please rate how you have felt about your eating habits since starting your current treatment. **Please mark the line with an X.**

How much **concern** has eating caused you?

No concern										Extreme concern

--	--	--	--	--	--	--	--	--	--

--	--	--	--	--	--	--	--	--	--

How much **distress** has eating caused you?

**No
distress**

**Extreme
distress**

We are also interested in some things about your weight since you started your current Chemotherapy. Please read the questions below and circle the answer that best applies to you. There are no right or wrong answers.

Please **circle one answer** per question.

Since starting my current Chemotherapy:

- | | |
|--|------------|
| 48. My weight has changed..... | YES / NO |
| 49. I weigh less now than before I started treatment..... | YES / NO |
| 50. I weigh more now than before I started treatment..... | YES / NO |
| 51. I am concerned about my weight. | YES / NO |
| 52. My family is concerned about my weight. | YES / NO |
| 53. I currently weigh about | Don't know |
| 54. Six months ago I weighed about | Don't know |

For the following question please rate how you have felt about your weight since starting your current treatment. **Please mark the line with an X.**

How much **concern** has your weight caused you?

No concern												Extreme concern

How much **distress** has your weight caused you?

No distress												Extreme distress

Section 3: Nutritional Risk Assessment

Scored PG-SGA (Patient Generated Subjective Global Assessment)