



Patients with cancer experience high impact of emotional consequences of reduced ability to eat: A cross sectional survey study

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Abstract

Objective: Patients with cancer can experience emotional consequences of reduced ability to eat, their impact is unknown. This study assesses the impact of these emotional consequences, and patients' satisfaction with healthcare professionals' (HCPs) support.

Methods: A cross-sectional survey was conducted among patients with head/neck, lung cancer and lymphoma, who experienced reduced ability to eat in the past year. Patients were recruited through patient organisations and hospitals. The questionnaire encompassed the impact of emotional consequences of reduced ability to eat (scale 1–10) and satisfaction with HCPs' support for reduced ability to eat (scale 1–10). The differences in patient characteristics between unsatisfied (Score < 6) and satisfied patients (score ≥6) were tested using independent *t*-tests and the chi-square or Fishers' exact tests.

Results: Overall, 116 patients (48%) responded and 98 were included in the analyses. The most impactful emotional consequences were as follows: disappointment (mean ± SD: 8.31 ± 1.49), grief/sadness (7.90 ± 1.91), and anger (7.87 ± 1.41). Patients were less satisfied when more time had passed since their diagnosis ($p < 0.002$) and when they expected no improvements regarding their eating problems ($p < 0.001$).

Conclusion: The impact of emotional consequences of reduced ability to eat is high. Support for emotional consequences is needed, especially for patients with reduced ability to eat, which persists in recovery and remission.

KEYWORDS

cancer, eating, patients focused care, psycho-oncology, surveys and questionnaires

1 | INTRODUCTION

Patients with cancer often experience nutritional problems, such as anorexia, taste and smell changes, dry mouth, swallowing problems and nausea (Arends et al., 2016), which can result in insufficient

nutritional intake and unintended weight loss (Baracos et al., 2018). Some types of cancer have a high prevalence of nutritional impact symptoms, such as head and neck cancer >90% (Crowder et al., 2018), and lung cancer 67–88% (Lin et al., 2020). In addition to these physical consequences, patients also experience psychosocial

consequences of reduced ability to eat. Lize et al. (2020) demonstrate that patients in different stages of the disease trajectory, including recovery and remission, experience a broad range of emotions. Patients mentioned experiencing feelings of anger, anxiety, disappointment, guilt, grief/sadness, powerlessness and shame. These emotions were evoked by patients' struggle with eating and by misunderstanding for this struggle from the people around them. Furthermore, patients experienced less pleasure in social activities because many are related to food and eating (Lize et al., 2020).

The effect of these emotions on patient's well-being is not yet clear. Although some research has been conducted, these studies were mainly conducted among cancer patient populations known to have a high prevalence of nutritional impact symptoms, such as patients in late advanced disease stages and patients with cancer cachexia. These studies show that the emotional consequences of reduced ability to eat can result in high levels of distress (Amano et al., 2019; Amano, Maeda, Morita, Okajima, et al., 2016; Amano, Maeda, Morita, Tataru, et al., 2016; Amano & Morita, 2018; Amano et al., 2018; Hawkins, 2000; Hinsley & Hughes, 2007; Holden, 1991; Hopkinson, 2007; Hopkinson & Corner, 2006; Hopkinson et al., 2006; Reid et al., 2009a, 2009b, 2010; Shragge et al., 2007; Souter, 2005; Strasser et al., 2007). Recently, Amano et al. (2019) coined the term 'eating-related distress' to explain the multiple and intersecting emotional and social consequences of nutritional problems among patients with cancer cachexia (Amano et al., 2019). Eating-related distress relates to the physical consequences of eating problems, patients' feelings about food and eating, their concerns regarding their diets, and the effect of eating problems on their relationships (Amano & Morita, 2018). Studies conducted among other patient populations with a high prevalence of nutritional impact symptoms such as patients with head and neck cancer, patients with hematologic cancer and patients receiving parenteral home feeding, also showed that the emotional consequences of reduced ability to eat can result in high levels of distress (Larsson et al., 2007a, 2007b; McGrath, 2002; Orrevall et al., 2004; Ottosson et al., 2013).

Patients with cancer cachexia generally receive intensive nutritional support for the treatment of their physical consequences (Arends et al., 2016). However, little attention has been paid to the emotional consequences of cancer cachexia (Amano & Morita, 2018; Oberholzer et al., 2013; Wheelwright et al., 2014). Healthcare professionals (HCPs) seem to avoid this topic, owing to feelings of uncertainty and the lack of a solution for the often-irreversible nutritional symptoms (Millar et al., 2013a, 2013b). In contrast, patients with cancer cachexia want their emotional consequences of reduced ability to eat acknowledged, and subsequently need information and support on how to manage this (Oberholzer et al., 2013; Wheelwright et al., 2014). Other studies conducted among patient populations with high prevalence of nutritional impact symptoms showed the same tendency; patients wanted HCPs to acknowledge their distress which is evoked by their nutritional symptoms. However, their HCPs tended to focus on the physical aspects of inadequate nutritional intake (Larsson et al., 2007a; McGrath, 2002).

The emotional impact of reduced ability to eat is mainly investigated among cancer patient populations with late advanced disease and cancer cachexia. Studies conducted among other patient populations with a high prevalence of nutrition impact symptoms only touched the subject but explored the topic among small patient populations with very specific complaints. Therefore, this study's aim is to assess the impact of cancer-related emotional consequences of reduced ability to eat among a broader and larger patient population. This study further assesses patients' satisfaction with HCPs support for their reduced ability to eat. Based on these insights, this study aims to formulate recommendations to improve HCPs support for the emotional consequences of reduced ability to eat.

2 | METHODS

2.1 | Design, setting and participants

This study conducts a cross-sectional survey to assess the impact of the emotional consequences of reduced ability to eat among patients with cancer, and patient satisfaction with the support of HCPs for reduced ability to eat. The data were collected in the Netherlands between September 2018 and July 2019.

Patients were eligible for inclusion if they (had) experienced reduced ability to eat due to cancer or its treatment in the past year, were ≥ 18 years, were diagnosed with head and neck cancer, Hodgkin or non-Hodgkin lymphoma or lung cancer and had signed an informed consent. We chose for head and neck cancer and lung cancer owing to their high prevalence of nutritional impact symptoms. We chose for patients with lymphoma owing to the relatively younger population and better prognosis. The rationale for including patients with one of these three types of cancer is that they differ in age, prognosis, onset and the cause of the nutritional impact symptoms and perspectives for recovery. These differences may influence the need for the support of HCPs for reduced ability to eat.

Patients were recruited through an online call posted via the channels of patient organisations for head and neck cancer (Patientenvereniging Hoofd/hals), lymphoma (Hematon) and lung cancer (Stichting Longkanker Nederland). This patient population was supplemented by recruitment by dietitians from four participating hospitals in the Netherlands: Leiden University Medical Center, Máxima Medical Center, Radboud University Medical Center and University Medical Center Utrecht. Patients were recruited through these two methods, because online recruitment can result in a self-selection bias of patients interested in health topics and with active information seeking behaviour (Eysenbach & Wyatt, 2002).

2.2 | Procedure

The participating patient organisations disseminated information about the study via online platforms. Regarding this information,

patients were invited to contact the research team via an online contact form, phone or email. Furthermore, dietitians in the participating hospitals assessed eligible patients, informed them about the study and asked them for permission to be contacted by the research team. Thereafter, the research team called the patients, informed them about the study comprehensively and answered their questions. All the patients that decided to participate could choose between a web-based survey or a paper survey sent to their home address. A web-based survey was hosted by a secure website. Patients were sent one reminder to complete the survey 3 weeks after subscription. After 6 weeks, the time frame for completion of the questionnaire was closed.

2.3 | Questionnaire

The questionnaire was developed in collaboration with a broad expert group that comprised two dietitians specialising in oncology care, one psychologist, and four representatives of patient organisations or patient information platforms. The questionnaire contained self-designed questions and statements regarding the impact of emotional consequences of reduced ability to eat and HCP support. The questionnaire was pilot tested among three patients to ensure that the questions were readable and understandable and participation would take patients a maximum of 30 min of their time. Based on their feedback, linguistic refinements were made. In particular, they found items that were worded negatively and were considered as too confrontational. These items were rephrased. Patients who did not experience reduced ability to eat currently or in the past year were excluded based on two selection questions at the start of the questionnaire: (1) Do you currently experience reduced ability to eat? (2) Did you experience reduced ability to eat in the past year? The reason to exclude those patients was that patients who do not experience reduced ability to eat cannot have emotional consequences of reduced ability to eat.

2.4 | Measurements

2.4.1 | Sociodemographic and clinical characteristics

Sociodemographic characteristics were self-reported in the questionnaire including gender, age, level of education (no education/primary school, lower general secondary education, vocational training, preuniversity education, university) and living situation (living together [with partner/children], living alone). Clinical characteristics were also self-reported in the questionnaire including primary cancer type (head and neck cancer, Hodgkin or non-Hodgkin lymphoma, lung cancer), time since diagnosis (<1 year, 1–5 years, ≥5 years), treatment phase (currently receiving treatment, not under treatment), intention of treatment (curative intent/palliative), treatment type (chemotherapy, immunotherapy or targeted therapy, radiotherapy,

surgery) and treatment frequency (no treatment, 1 treatment, ≥2 treatments).

2.5 | Nutrition and nutritional symptoms

The following questions were part of the questionnaire: 'Do you expect to eat well or better in the future' (yes/no) and 'Compared with what I ate before I got ill, I currently rate my food intake as' (more than usual, less than usual, unchanged). 'Did your weight change due to the disease' (yes I gained weight, yes I lost weight, no my weight did not change), medical nutrition (oral nutritional supplements, parenteral and tube feeding, no medical nutrition) and nutritional symptoms (anorexia or food aversion, diarrhoea, dry mouth, early satiety, emotional problems, fatigue, mucus formation in mouth, nausea and/or vomiting, obstipation, obstruction, pain while eating, taste and smell changes and an open field for other non-predefined symptoms).

2.6 | Impact of emotional consequences

Patients listed a top three of most impactful emotional consequences: 'Please indicate below which emotions, related to reduced ability to eat, you currently experience or experienced in the past year. You can list a maximum of three emotions'. The predefined list of emotions was based on previous qualitative research (Lize et al., 2020). The list included anger, annoyance, anxiety, concern, confrontation (with the disease), disappointment, grief/sadness, guilt, jealousy, less enjoyment, loneliness/social isolation, longing (for certain foods), misunderstanding (from others), powerlessness, rejection, reluctance (to eat) and shame and an open field for other emotions. Patients rated the impact of their top three of most impactful emotions on a scale ranging from 1 *no impact at all* to 10 *extreme high impact*.

2.7 | HCPs support for reduced ability to eat

Patients were asked about their experiences with the support of HCPs for emotional consequences of reduced ability to eat: 'Did you receive support for the emotional consequences of your reduced ability to eat from HCPs, or have you received this support in the past year?' If yes, the patients were asked to list from whom they received this support (general practitioner, physician, psychologist/therapist, dietitian, nurse, dental hygienist/dentist and others). Thus, more than one option was possible. If not, patients were asked if they felt the need for support at the time or in the past year. Furthermore, patients gave their opinions about a self-developed statement regarding their experiences with the support of HCPs for reduced ability to eat: 'Healthcare professionals support me well regarding my reduced ability to eat'. This statement was scored on a scale ranging from (1 *very strongly disagreed*) to 10 (*very strongly agreed*).

2.8 | Statistical analysis

Descriptive analyses were used to assess the sociodemographic and clinical characteristics of the patients, their experiences regarding nutrition and nutritional symptoms and the impact score of their top three emotional consequences with the highest impact. Patients were categorised into three subgroups, based on their primary cancer type (head and neck cancer, Hodgkin or non-Hodgkin lymphoma and lung cancer). Furthermore, we also compared patients based on their satisfaction with the support of HCPs, defining two groups by using the statement: 'Healthcare professionals support me well regarding my reduced ability to eat' (unsatisfied: score <6 [scale 1–10] vs. satisfied \geq 6). In the development of measures to assess patient satisfaction of Dutch patients, this 1–10 scale showed to be understandable and reliable (Moll van Charante et al., 2006). This rating system is similar to the Dutch grading system of primary and secondary schools. In this grading system, scores <6 were considered insufficient and scores \geq 6 were considered as sufficient. Differences in the sociodemographic and clinical characteristics and emotional consequences of patients between the satisfied and unsatisfied group were tested using independent sample *t*-tests (for age) and for all other variables Pearson's chi-square test or Fisher's exact test for categorical variables with respectively >5 and <5 expected numbers in cells. The missing observations were reported in the footnotes below the tables. Data were analysed using SAS (version 9.4) and a *p*-value <0.05 was considered statistically significant.

2.9 | Ethical considerations

The study protocol was reviewed by the Máxima Medical Center in Veldhoven, the Netherlands (METC N18.032), and was exempted from ethical review according to the Dutch Medical Research Involving Human Subjects Act (WMO). All the patients gave written informed consent and were informed that the survey would be analysed anonymously. To ensure that completing the questionnaire was not too confronting for patients the questions were not made mandatory and patients were assured that they could always withdraw without providing a reason.

3 | RESULTS

The overall response rate was 48%. More than two thirds of the patients recruited from the participating hospitals responded ($n = 88$; 69%). A lower response rate was observed among patients recruited by the patient organisations ($n = 155$; 35.5%). The reasons for non-response were unknown ($n = 114$). The known reasons were burden ($n = 4$), survey not applicable ($n = 4$), no interest in participation ($n = 3$) and patient died ($n = 2$). The reasons for excluding surveys after enrolment were: other or an unknown primary cancer type ($n = 13$), no eating problems ($n = 4$) and incomplete questionnaire ($n = 1$). In conclusion, the surveys of 98 patients were included in the analysis (Figure 1).

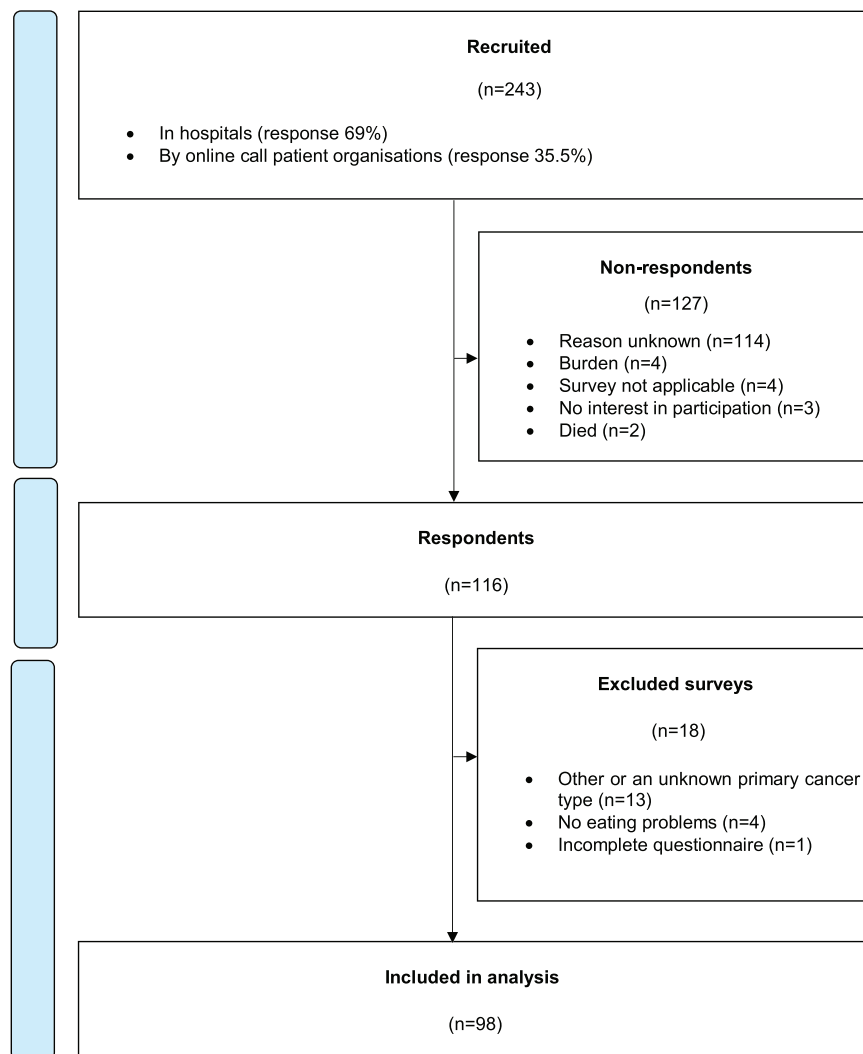
3.1 | Patients' characteristics

The mean age of the participants was 61.7, ranging from 24 to 91. Most patients were diagnosed with head and neck cancer (50%), followed by lung cancer (32%) and Hodgkin or non-Hodgkin lymphoma (18%). Most respondents received their diagnosis <5 years before participating in the study (85%), and most patients (had) received treatment with curative intent (63%). Almost three quarters of the population (71%) expected improvement in their reduced ability to eat in the future. Less than half of the patients with head and neck cancer had finished their treatments (45%), while most patients with Hodgkin or non-Hodgkin lymphoma and lung cancer were under treatment at the time of the questionnaire (62.5% and 80%). Patients with lung cancer received more often treatments with palliative intent (68%) compared with patients with head and neck cancer (12%) and Hodgkin and non-Hodgkin lymphoma (11%). More patients with head and neck cancer received two or more treatments (82%) compared with patients with Hodgkin or non-Hodgkin lymphoma (41%) and lung cancer (47%). Little over half of the patients with head and neck cancer expected to eat well or better in the future (59%), while most patients with Hodgkin and non-Hodgkin lymphoma and lung cancer expected to eat well or better in the future (89% and 80%) (Table 1).

Most patients had experienced weight loss (60%), 18% of the patients had gained weight and 22% of the patients had stable weight. In total, 30% of the patients did not use medical nutrition in the past year. The majority of the patients used oral nutritional supplements, and 34% of the patients used parenteral or tube feeding. Taste and smell changes were the most common nutritional symptoms reported by patients (63%), followed by anorexia and food aversion (51%) and dry mouth (47%). Patients with head and neck cancer more often experienced mucus formation in the mouth (61%) compared with patients with other primary cancer types. Patients with Hodgkin or non-Hodgkin lymphoma and lung cancer experienced more nausea and/or vomiting (50% and 52%) compared with patients with head and neck cancer (12%) (Table 2).

3.2 | Impact of emotional consequences of reduced ability to eat

Most patients (96%) reported one or more emotional consequences of reduced ability to eat, and 4% of the patient population experienced no emotional consequences. The impact of these emotional consequences was high, and emotional consequences with the highest impact scores were disappointment, with a mean impact of 8.31 (standard deviation [SD] 1.49) followed by grief/sadness (7.90; SD 1.91), anger (7.87; SD 1.41), confrontation with the disease (7.53; SD 1.91) and longing for certain foods (7.32; SD 2.12). The most often listed as one of the top three most impactful emotional consequences were: less enjoyment ($n = 44$), longing for certain foods ($n = 40$) and powerlessness ($n = 27$) (Figures 2 and 3).

FIGURE 1 Flowchart patients

3.3 | Support of HCPs for emotional consequences of reduced ability to eat

Almost half of the patients received support from one or more HCPs for emotional consequences of their reduced ability to eat (45%). The patients who received this support ($n = 44$), received support from a dietitian (89%), physician (36%), nurse (27%), dentist/dental hygienist (25%), psychologist/therapist (23%), general practitioner (20%) and speech therapist (4%). Of the patients who did not receive HCP support for emotional consequences (45%), 20% ($n = 9$) felt that they needed this support.

3.4 | Satisfaction of patients with the support of HCPs for reduced ability to eat

Overall, 66% of the patient population was satisfied with the support of HCPs for their reduced ability to eat. Patients who were satisfied did not differ in gender, age, level of education, living

situation, primary cancer type, treatment phase, intention of treatment, treatment type, treatment frequency, weight change or medical nutrition when compared with patients who were not satisfied. Patients who received support for the emotional consequences of reduced ability to eat from one HCP (1) and patients who received this support from more than one HCPs (>1), were equally satisfied. Patients who were diagnosed less than 1 year ago (<1) experienced higher satisfaction with HCP support for reduced ability to eat when compared with patients who were diagnosed 1–5 years or ≥ 5 years ago. Therefore, the more time passed since the patients' diagnosis, the less satisfied they were (<0.002). Furthermore, patients who expected to eat well or better in the future were more satisfied with HCPs support for reduced ability to eat than patients who did not expect to eat well or better in the future (0.001) (Table 3). Only the mean impact score of misunderstanding did differ between patients who were satisfied and those who were not satisfied, respectively mean 8.20 and 5.80 (0.03). The mean impact scores of the other emotional consequences did not differ.

TABLE 1 Patients sociodemographic and clinical characteristics (n = 98)

Characteristics	Number (%)			
	Total Group (n = 98)	Head and neck cancer (n = 49)	Hodgkin or non-Hodgkin lymphoma (n = 18)	Lung cancer(n = 31)
Gender				
Male	46 (48%)	28 (57%)	4 (25%)	14 (47%)
Female	49 (52%)	21 (43%)	12 (75%)	16 (53%)
Age (mean, range)				
	61.7 (24–91)	61.4 (24–91)	60.7 (26–80)	62.2 (43–78)
Level of education^a				
Low	23 (24%)	10 (20%)	6 (35%)	7 (24%)
Middle	41 (43%)	22 (45%)	6 (35%)	13 (45%)
High	31 (33%)	17 (35%)	5 (29%)	9 (31%)
Living situation				
Living together (with partner/children)	78 (82%)	36 (73.5%)	17 (100%)	25 (86%)
Living alone	17 (18%)	13 (26.5%)	0 (0%)	4 (14%)
Time since diagnosis				
<1 year	48 (51%)	21 (45%)	9 (53%)	18 (60%)
1–5 years	31 (33%)	17 (36%)	3 (18%)	11 (37%)
≥5 years	15 (16%)	9 (19%)	5 (29%)	1 (3%)
Treatment phase				
Currently receiving treatment	57 (60%)	22 (45%)	10 (62.5%)	25 (83%)
Not under treatment	38 (40%)	27 (55%)	6 (37.5%)	5 (17%)
Intention of treatment				
Curative intent	62 (63%)	42 (86%)	12 (67%)	8 (26%)
Palliative	29 (30%)	6 (12%)	2 (11%)	21 (68%)
Unknown	7 (7%)	1 (2%)	4 (22%)	2 (6%)
Treatment type				
Chemotherapy	56 (58%)	20 (41%)	14 (82%)	22 (73%)
Immunotherapy or targeted therapy	18 (18%)	4 (8%)	2 (12%)	12 (40%)
Radiotherapy	60 (62.5%)	47 (96%)	2 (12%)	11 (37%)
Surgery	33 (34%)	29 (59%)	2 (12%)	2 (7%)
Treatment frequency				
No treatment	3 (3%)	2 (4%)	0 (0%)	1 (3%)
1 treatment	32 (33%)	7 (14%)	10 (59%)	15 (50%)
≥2 treatments	61 (64%)	40 (82%)	7 (41%)	14 (47%)
Do you currently experience reduced ability to eat?				
Yes	80 (82%)	47 (96%)	13 (72%)	20 (64.5%)
No	18 (18%)	2 (4%)	5 (28%)	11 (35.5%)
Do you expect to eat well or better in the future?				
Yes	69 (71%)	29 (59%)	16 (89%)	24 (80%)
No	28 (29%)	20 (41%)	2 (11%)	6 (20%)
HCPs providing support for emotional consequences of reduced ability to eat (n = 44)				
1	11 (25%)	5 (19%)	3 (37.5%)	3 (33%)
>1	33 (75%)	21 (81%)	5 (62.5%)	7 (77%)

Note: Missing: gender 3, age 4, level of education 3, living situation 3, time since diagnosis 4, treatment phase 3, intention of treatment 7, treatment type 4, treatment frequency 2, Do you currently experience reduced ability to eat 0, Do you expect to eat well or better in the future 1. Percentages do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding.

^aLow educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = preuniversity education, high vocational training, university.

TABLE 2 Patients characteristics concerning nutrition ($n = 98$)

Characteristics	Number (%)			
	Total group ($n = 98$)	Head and neck cancer ($n = 49$)	Hodgkin or non-Hodgkin lymphoma ($n = 18$)	Lung cancer ($n = 31$)
Current nutritional intake				
More than usual	12 (12%)	6 (12%)	2 (12%)	4 (13%)
Less than usual	70 (72%)	39 (80%)	11 (65%)	20 (67%)
Unchanged	14 (14%)	4 (8%)	4 (24%)	6 (20%)
Weight change				
Weight gain	17 (18%)	8 (17%)	4 (22%)	5 (17%)
Weight loss	57 (60%)	27 (57%)	10 (56%)	20 (67%)
Unchanged	21 (22%)	12 (26%)	4 (22%)	5 (17%)
Medical nutrition				
Oral nutritional supplements	58 (60%)	36 (73%)	9 (50%)	13 (43%)
Parenteral and tube feeding	33 (34%)	23 (47%)	7 (39%)	3 (10%)
No medical nutrition	29 (30%)	8 (16%)	6 (33%)	15 (50%)
Nutritional impact symptoms				
Taste and smell changes	62 (63%)	32 (65%)	12 (67%)	18 (58%)
Anorexia or food aversion	50 (51%)	20 (41%)	12 (67%)	18 (58%)
Dry mouth	46 (47%)	32 (65%)	7 (39%)	7 (39%)
Mucus formation in mouth	43 (44%)	30 (61%)	5 (28%)	8 (26%)
Obstruction	41 (42%)	22 (45%)	9 (50%)	10 (32%)
Fatigue	38 (39%)	21 (43%)	5 (28%)	12 (39%)
Pain while eating	35 (36%)	22 (45%)	5 (28%)	8 (26%)
Nausea and/or vomiting	31 (32%)	6 (12%)	9 (50%)	16 (52%)
Early satiety	30 (31%)	11 (22%)	9 (50%)	10 (32%)
Emotional problems (i.e., fear)	12 (12%)	9 (18%)	1 (6%)	2 (6%)
Obstipation	11 (11%)	5 (10%)	3 (17%)	3 (10%)
Diarrhoea	10 (10%)	3 (6%)	3 (17%)	4 (13%)
Other symptoms ^a	3 (3%)	1 (2%)	2 (11%)	0 (0%)

Note: Missing: current nutritional intake 2, weight change 3, medical nutrition 1, nutritional impact symptoms 0. Percentages do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding.

^aSocial problems ($n = 1$), bloating and flatulence after eating ($n = 1$) pain in stomach ($n = 1$).

4 | DISCUSSION

Our study shows that patients with cancer-related reduced ability to eat experienced high impact of emotional consequences. The most impactful emotional consequences of their reduced ability to eat were disappointment, grief/sadness and anger. The most frequently mentioned emotional consequences were less enjoyment, longing for certain foods and powerlessness. The majority of the patients who received HCPs support for the emotional consequences of reduced ability to eat, received this support from a dietitian (89%). Of the patients who did not receive such support, 20% felt they still needed this support. Most patients (66%) who received support from HCPs for their reduced ability to eat were satisfied with this support. Patients 1–5 years and ≥ 5 years after diagnosis experienced lower satisfaction with the support of HCPs for reduced ability to eat compared to patients diagnosed < 1 year. Therefore, the more time passed

since the patients' diagnosis, the less satisfied they were with the support of HCPs (< 0.002). Furthermore, patients who expected no improvements in their reduced ability to eat in the future were less satisfied with the support of HCPs than patients who expected to recover (< 0.001).

Previous research shows that patients with advanced cancer and cancer cachexia experience high levels of distress owing to disease-related eating problems. Amano et al. (2019) demonstrate that many advanced cancer patients had eating-related distress and that patients with cancer cachexia had significantly greater eating-related distress than those without cachexia (Amano et al., 2019). Overall, Amano et al. (2019) indicate that food and eating is not only related to nutrition and the nutritional intake of patients, but also concerns the emotional and social well-being of patients. Our study underscores this idea and adds to the findings of Amano et al. (2019) stating that reduced ability to eat can have high emotional impact, not only among

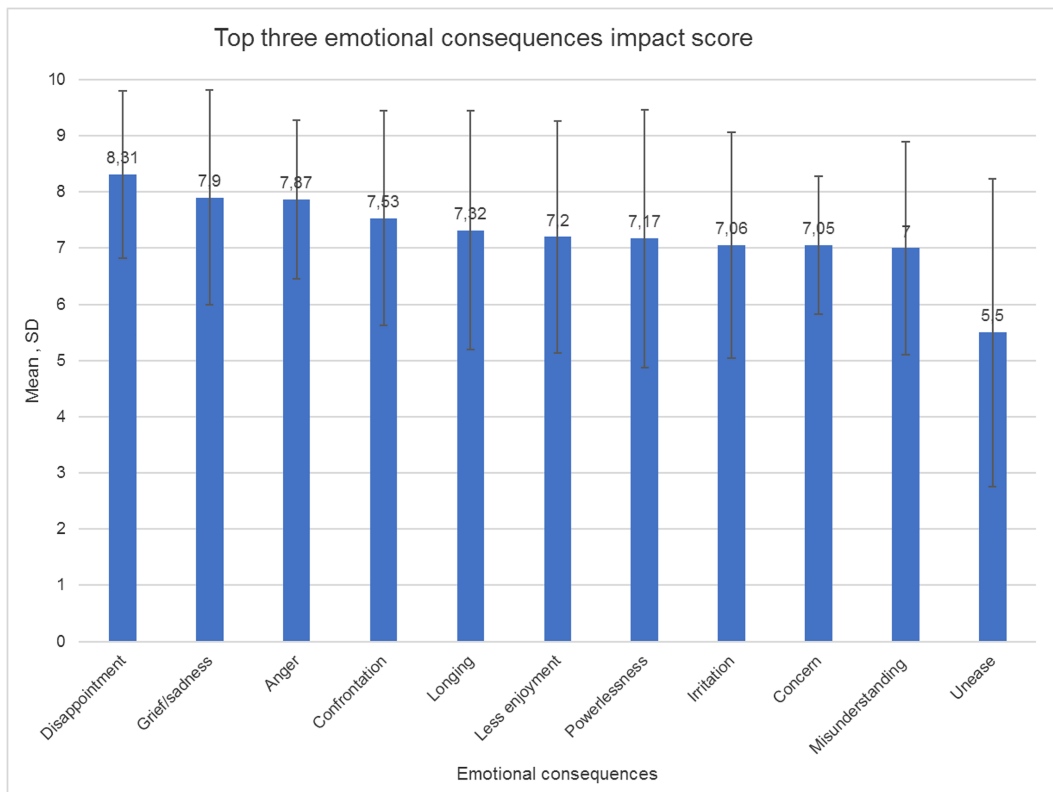


FIGURE 2 Top three emotional consequences impact score

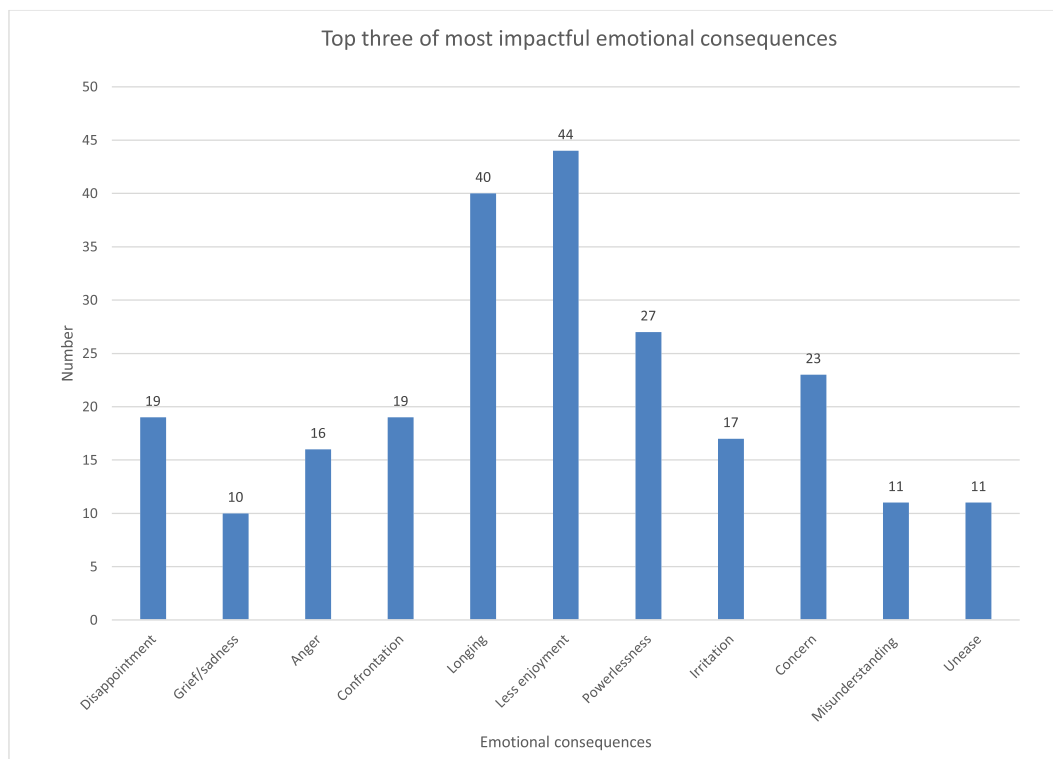


FIGURE 3 Top three of most impactful emotional consequences

TABLE 3 Patients characteristics and satisfaction with HCPs support for reduced ability to eat (n = 96)

Characteristics	'Healthcare professionals support me well regarding my reduced ability to eat'		p value
	Not satisfied <6 33 (34%)	Satisfied ≥6 63 (66%)	
Gender			
Male	15 (33%)	31 (67%)	0.77
Female	17 (35%)	31 (65%)	
Age (mean, range)	61.6 (37–75)	61.16 (24–91)	0.86
Level of education^a			
Low	8 (36%)	14 (64%)	0.67
Middle	16 (39%)	25 (61%)	
High	9 (29%)	22 (71%)	
Living situation			
Living together (with partner/children)	26 (33%)	52 (67%)	0.43
Living alone	7 (44%)	9 (56%)	
Primary cancer type			
Head and neck	18 (37.5%)	30 (62.5%)	0.79
Hodgkin or non-Hodgkin lymphoma	6 (33%)	12 (67%)	
Lung	9 (30%)	21 (70%)	
Time since diagnosis			
<1 year	8 (17%)	39 (83%)	<0.002
1–5 years	15 (48%)	16 (52%)	
≥5 years	9 (60%)	6 (40%)	
Treatment phase			
Currently receiving treatment	22 (39%)	35 (61%)	0.25
Not under treatment	10 (27%)	27 (73%)	
Intention of treatment			
Curative intent	19 (31%)	43 (69%)	0.15
Palliative	13 (46%)	15 (54%)	
Treatment type^a			
Chemotherapy	19 (34%)	37 (66%)	0.83
Immunotherapy or targeted therapy	6 (33%)	12 (67%)	0.89
Radiotherapy	21 (36%)	38 (64%)	0.83
Surgery	13 (41%)	19 (59%)	0.39
Treatment frequency			
No treatment	1 (33%)	2 (67%)	0.62
1 treatment	9 (28%)	23 (72%)	
≥2 treatments	23 (38%)	37 (62%)	
Weight change			
Weight gain	7 (47%)	8 (53%)	0.57
Weight loss	18 (32%)	38 (68%)	
Unchanged	7 (33%)	14 (67%)	
Medical nutrition			
Oral nutritional supplements	16 (28%)	41 (72%)	0.09
Parenteral and tube feeding	10 (31%)	22 (69%)	0.06
No medical nutrition	13 (46%)	5 (54%)	0.12
Do you currently experience reduced ability to eat?			
Yes	30 (38%)	48 (62%)	0.08
No	3 (17%)	15 (83%)	

(Continues)

TABLE 3 (Continued)

Characteristics	'Healthcare professionals support me well regarding my reduced ability to eat'		p value
	Not satisfied <6 33 (34%)	Satisfied ≥6 63 (66%)	
Do you expect to eat well or better in the future?			
Yes	14 (21%)	54 (79%)	<0.001
No	19 (70%)	8 (30%)	
HCPs providing support for emotional consequences of reduced ability to eat (n = 44)			
1	1 (9%)	10 (91%)	0.21
>1	9 (27%)	24 (73%)	

Note: Missing: gender 2, age 3, level of education 2, living situation 2, primary cancer type 0, time since diagnosis 5, treatment phase 2, intention of treatment 6, treatment type 4, treatment frequency 1, weight change 3, medical nutrition 1, Do you currently experience reduced ability to eat 2, Do you expect to eat well or better in the future 1. Percentage do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding.

^aLow educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = preuniversity education, high vocational training, university.

patients receiving palliative treatments, but also among those receiving curative treatment and those whose reduced ability to eat persists in recovery and remission.

This study emphasises the findings of previous research that patient populations in less advanced disease stages might need support regarding reduced ability to eat, which is often left unaddressed by HCPs. Patients with head and neck cancer undergoing radiotherapy expressed that they needed to remain in continuous contact with an HCP who was familiar with the eating challenges that head and neck cancer and its treatment entail. Patients felt "Left to One's Own Devices" (Larsson et al., 2007a, p. 329) when the HCPs did not respond to their needs. Head and neck cancer patients in the Netherlands, mentioned that emotional support from the general practitioner during aftercare is crucial, because the support from HCPs from the hospital decreased after treatment (van Overveld et al., 2018). In this study, 20% of the patients who did not receive support from HCPs for the emotional consequences of reduced ability to eat felt they needed support. Considering the high impact of emotional consequences of reduced ability to eat, also found in this study, it is important to gain more insight into the patients that might need more support from their HCPs regarding these problems. The more time passed since patient's diagnosis the less satisfied patients were, and patients who expected no improvement regarding their reduced ability to eat were less satisfied with support of HCPs. These findings can serve as a starting point to improve future support of HCPs and as a starting point for future research.

4.1 | Strengths and limitations

To the best of our knowledge, this is the first study to assess the impact of emotional consequences of reduced ability to eat and satisfaction with the support of HCPs among patients with cancer throughout the disease trajectory and in recovery and remission.

Other studies only touched upon this topic. However, it has not yet been studied comprehensively as a primary research aim.

This study has some limitations that need to be addressed. First, we used a self-developed questionnaire because no validated measures were available. The recruitment of patients through patient organisations and participating hospitals limits the generalisability of the study results. Recruiting patients through patient organisations might have resulted in a selection bias favouring patients with a relatively good health status (Eysenbach & Wyatt, 2002). The study results show that patients' satisfaction with HCPs declined after diagnosis; therefore, recruitment through patient organisations might have resulted in a selection bias of patients who were less satisfied. Recruiting patients in hospitals can result in more patients who probably received (nutritional) counselling at the time of the survey, and patients who expect their reduced ability to eat to improve. This might have skewed the patient population to a population more satisfied with the support of HCPs. In conclusion, information (recall) bias needs to be considered, as we also asked patients to think back about the support they received in the last year.

4.2 | Implications for practice and future research

As suggested in the international guidelines (Arends et al., 2016), nutritional and psychosocial screening are integrated into oncological care in Dutch hospitals. However, screening for the emotional consequences of reduced ability to eat requires more attention. Dietary treatment often ends when nutritional requirements are met and a steady nutritional state is reached. Medical follow-up visits after treatment are mainly focused on the (recovery from) physical side-effects of treatments and screening for residual tumour and cancer recurrence. Further research is needed to determine what patients need from their HCPs regarding follow-up care for their reduced ability to eat. For future care, it is important that HCPs recognise and assess the needs of patients for the emotional support for reduced ability to

eat in all stages of the disease and in recovery and remission. The use of screening instruments such as the distress thermometer and problem list (Tuinman et al., 2008) can serve as a starting point for early recognition and assessment of emotional consequences of reduced ability to eat throughout the care process.

In conclusion, most patients with cancer reduced ability to eat due to their cancer and its treatment experience a broad range of emotional consequences, including disappointment, grief/sadness and anger. Moreover, the impact of these emotional consequences was high. The more time passed since the patients' diagnosis, the less satisfied they were with the support of HCPs for reduced ability to eat. Additionally, patients who expect no improvements in their reduced ability to eat in the future are less satisfied with the support of HCPs. Clearly, more attention and support from HCPs for the emotional consequences of reduced ability to eat, its emotional impact and need for supportive care for these problems are needed. To improve future care, early recognition and assessment of the emotional consequences of reduced ability to eat by HCPs are important, both during and (long) after treatment.

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CONFLICT OF INTEREST

All authors have no relevant commercial or other relationships to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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