

Symptoms of patients with incurable head and neck cancer: prevalence and impact on daily functioning

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ABSTRACT

Background. There is lack of research on symptoms in patients with head and neck cancer in the palliative phase. The aim of this study was to explore symptom prevalence and the impact of these symptoms on daily functioning in patients with incurable head and neck cancer. Also, discrepancies between patients and family caregivers are described.

Methods. Questionnaires were used to collect data about symptom prevalence (N=124) and symptom impact (N=24).

Results. We discovered that the symptoms with a high prevalence were fatigue, pain, weakness, trouble with short walks outside, and dysphagia. The symptoms with the greatest impact on daily functioning were dyspnoea, voice changes, trouble with short walks outside, anger and weakness.

Conclusions. Patients with incurable head and neck cancer experience a great number of different symptoms. Focus on these symptoms by healthcare professionals could further optimize symptom management. In future research, we recommend further validation of the used questionnaires.

INTRODUCTION

Head and neck cancer is known as a psychological highly traumatic cancer type¹. This is due to potential negative effects of the tumour itself and its treatment on various functions, such as swallowing, speaking, tasting, and smelling, as well as on the appearance of a patient. Head and neck cancer is the fifth most common cancer type worldwide and the most common neoplasm in central Asia². In the United States, head and neck cancer accounts for 3% of malignancies; in The Netherlands, it accounts for nearly 5%^{3,4}. The average age of patients affected with head and neck cancer is 63 years. More than two thirds of this patient group is men⁴. Significant risk factors for the occurrence of head and neck cancer are the use of tobacco and alcohol⁵.

Approximately 25 to 30% of patients with head and neck cancer will at a certain moment reach the palliative phase^{3,6}. Knowledge about experiences in the palliative phase of head and neck cancer is limited⁷. The palliative phase begins when cure is no longer possible or when curative treatment is refused and ends with the patient dying⁸. Earlier research among palliative patients with head and neck cancer showed a mean duration for the palliative phase of approximately 6 months⁷. During this phase, the number and intensity of symptoms can influence the quality of life of a patient negatively. Palliative care aims to improve the quality of life of patients and their family caregivers by adequately dealing with occurring symptoms, known as “symptom management”⁹. In this research, symptoms are defined as all complaints expressed by a patient as a result of a progressing disease or the consequences of the treatment for that disease. Patients with cancer in the palliative phase are frequently confronted with multiple and simultaneously occurring symptoms¹⁰⁻¹⁵. A systematic review of the literature (2007)¹⁶ about symptom prevalence in patients with cancer in general during the palliative phase, revealed 5 somatic symptoms occurring in more than 50% of patients during the palliative phase. These somatic symptoms were: fatigue, pain, lack of energy, weakness and appetite loss. However, this research only included a very small group of patients (5%) suffering from a head and neck tumour. Therefore, the possibility to generalize the results from this review to the entire population of patients with head and neck cancer patients is limited.

In another article (1997)¹³ on symptom prevalence, patients with head and neck cancer were included, however, this research focused on somatic symptoms only in the terminal phase. The 5 most frequently reported symptoms were: weight loss, pain, feeding difficulties, dysphagia and cough. Symptoms in the very last part of the palliative phase (the terminal phase), however, are not fully representative for the entire palliative phase. This is confirmed by a review of patients with cancer in general¹⁶, showing a difference between the prevalence of symptoms occurring in the last 2 weeks of living and symptoms that occur during the period prior to those weeks. Research among patient with head and neck cancer in general also indicates that, besides somatic issues, more than one third of patients are

also confronted with psychological problems¹⁷. In a recent study of surviving relatives of patients with head and neck cancer, two thirds of the relatives claimed that the patient was depressed and had a need for better psychosocial support during the palliative phase⁶. When it comes to symptom report, earlier research suggests that family caregivers in comparison with patients often over-estimate patient symptoms¹⁸⁻²¹. These studies, however, did not include patients with head and neck cancer.

In order to deliver good healthcare, it is important to know which symptoms occur during a specific disease or disease phase, as well as the extent of their impact on daily functioning. In this article, “symptom impact” refers to: “the impact that symptoms have on daily functioning of an individual patient.” The premise is that such an impact is either neutral or negative.

The current study focused on: (1) the prevalence of symptoms in patients with head and neck cancer during the palliative phase; (2) the impact of those symptoms on daily functioning of patients; and (3) discrepancies between patients and family caregivers with reference to how they individually score the occurrence of symptoms as well as their evaluation of the impact on daily functioning.

MATERIALS AND METHODS

Design

This cross-sectional descriptive study consists of a retrospective and a prospective element. The first research question was answered by making use of retrospectively collected data. The other 2 questions were answered by examining prospective data. This study was approved by the Medical Ethics Committee of the Erasmus Medical Centre Rotterdam.

Setting

At the Erasmus Medical Centre Rotterdam, a university medical centre in The Netherlands treating around 600 patients newly diagnosed with head and neck cancer every year, palliative care is given by a specialist palliative team for patients with head and neck cancer. This team consists of head and neck surgeons, specialized nurses, speech therapists, pain specialists, dietitians, social workers, and clergymen. Each year, approximately 130 new patients are registered by the palliative team. Since October 2006, as part of the standard working procedure, data is structurally gathered from patients with an head and neck tumour in the palliative phase. Since that date, all new patients are being requested by the specialized nurses to fill out a questionnaire, the Palliative Checklist (Pal-C), once during their palliative phase. In most cases, this happens shortly after receiving the diagnosis of their palliative status.

Follow-up of patients by the palliative team is done regularly, both in the outpatient clinic as well as by telephone. During about half of these medical telephone contacts, the family

caregiver speaks on the patient's behalf. This occurs because of issues such as difficulties with speech, pain and physical weakness of the patient.

Participants and procedure

Patients with a primary head and neck tumour in the palliative phase treated in the Erasmus Medical Centre Rotterdam were included. Patients who were younger than 18 years, unable to speak or write in Dutch, mentally incompetent or participating in another study at the same time were excluded. Participants were divided into 2 groups: the prevalence group and the symptom impact group.

The prevalence group

This group consists of all patients who completed a Pal-C (instrument described in detail below) between October 2006 and October 2008.

The symptom impact group

For this prospective part of our study, patient's main family caregivers were also included. Because of the limited number of available patients and the limited average life expectancy, a convenience sample was chosen. From February 2009 up to May 2009, patients were approached by the specialized nurses of the palliative team. After they had given written informed consent, participants were requested to separately fill out a questionnaire which is called the Palliative Symptom Impact list (Pal-SI), as mentioned below.

Data collection

The prevalence group

Sociodemographic data was gathered from the electronic patient file. Prevalence of symptoms was measured using the Pal-C. This questionnaire provides insight into the prevalence of 30 separate symptoms. The Pal-C was developed in 2006 by the Expert Centre of Palliative Care for Head and Neck Cancer of the department of Otorhinolaryngology and Head and Neck surgery of the Erasmus Medical Centre in Rotterdam. The instrument consists of 53 questions, of which the first 15 questions are from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15- Palliative (EORTC QLQ-C15-PAL)^{22,23}. The remaining 38 questions of the Pal-C are based on the Integral Checklist²⁴. The Integral Checklist is a questionnaire that was developed as an instrument for systematic screening of psychosocial and physical problems in ambulatory patients with cancer. The Pal-C is meant to obtain an impression of the situation as experienced by the patient during the past week. The Integral Checklist has been used previously in a study with patients with cancer in all phases of disease, including patients with head and neck cancer²⁴. Completion of the questionnaire requires approximately 20 minutes. The Pal-C, in its current form, has not been tested on validity and/or reliability. However, the Pal-C was primarily used to

support the gathering of information about the patient's health in a nonburdensome way and turned out to be a very practical instrument for that purpose and for referral to other specialists.

The symptom impact group

Sociodemographic data of patients was gathered from the electronic patient file. Caregivers sociodemographic data; sex, relationship to the patient, and age, were gathered by making use of questionnaires. Impact of symptoms was measured using the Pal-SI. This instrument was developed, for this study, by the Expert Centre of Palliative Care for Head and Neck Cancer of the department of Otorhinolaryngology and Head and Neck surgery of the Erasmus Medical Centre in Rotterdam. To enable comparison of data, the Pal-SI covers the same symptoms and uses equal formulation as in the Pal-C. The Pal-SI consists of 2 parts. Part A contains the 30 symptoms from the Pal-C. By answering "yes" or "no", the patient can indicate whether or not the specific symptom occurred in the previous week. In part B, the patient is asked to rate all symptoms present on an 11 point numeric scale (NMS), indicating the impact of a specific symptom on daily functioning. (0= "no impact", 10= "unbearable impact").

Specifically for family caregiver's, a family caregiver's version of the Pal-SI was available. This version differs from the original Pal-SI on 2 aspects: (1) to prevent missing values, the answer option "do not know" was added; and (2) all questions were formulated from the perspective of the family caregiver (i.e. instead of asking: "Have you had pain?", the family caregiver's version states "Do you think the patient had pain?". It took approximately 15 minutes to complete the Pal-SI.

Statistical analysis

The sociodemographic data, the prevalence of symptoms, and the impact of those symptoms were described by way of descriptive statistics. The sociodemographic data of patients from the prevalence group were statistically tested using the independent samples *t* test (age), chi-square test (sex, tumour location, and treatment) and the Mann-Whitney test (duration of palliative phase).

The sociodemographic data with reference to the patients from the symptom impact group were statistically tested using the Mann-Whitney test. In order to compare the prevalence and the symptom impact data of the patients and their family caregivers per pair, the Wilcoxon matched pairs test was performed.

Nonparametric tests were used when data was not normally distributed. With reference to the symptom impact group, this was the result of the limited number of cases. The significance level was set at 5%. For the analysis of the data, the statistics program SPSS version 14.0 was used.

RESULTS

Description of “prevalence group”

Between October 2006 and October 2008, 310 new patients were registered with the specialized nurses for palliative care. After exclusion, 220 patients were approached, of which 124 (56%) completed the Pal-C. Two percent of questions were not filled in. The reasons for exclusion and nonresponse are indicated in Figure 1.

Refer to Table 1 for sociodemographic data. Patients who completed a Pal-C (Pal-C+) were significantly different from those who did not complete a Pal-C (Pal-C \ominus) on 3 aspects. The Pal-C+ group (1) consisted of more men; (2) were subjected to more extensive palliative treatment; (3) their duration of the palliative phase was longer, with a median discrepancy of more than 100 days.

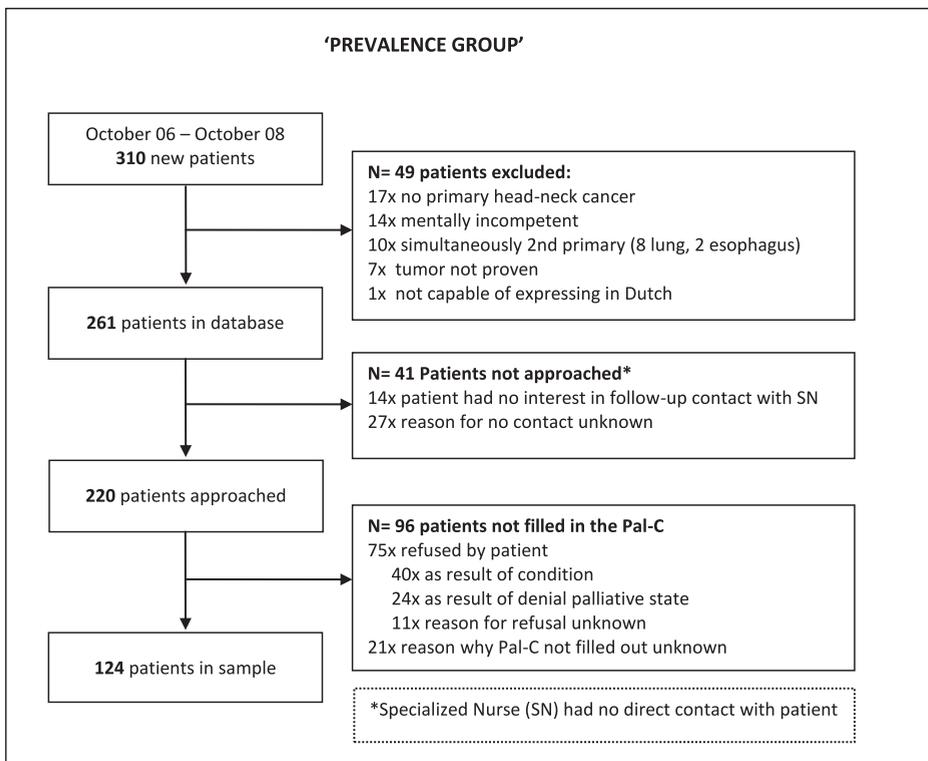


Figure 1. Prevalence Group

Description of “symptom impact group”

Between February 2009 and May 2009, 116 new patients were registered with the specialized nurses. Of the total of 56 patients who met all the inclusion criteria, 24 patients (43%)

Table 1. Socio-demographic data Prevalence Group

Characteristic	% (no. of patients) by group*		P value			
	Pal-C+ group (n=124)	Pal-CØ group (n=137)				
Age, average (interval)	68 (39-90 y)	66 (28-98 y)	.203			
Sex						
Male	73 (91)	61 (83)	.019			
Female	27 (33)	39 (54)				
Location of Tumour						
Oral cavity	24 (30)	20 (28)	.724			
Oropharynx	26 (32)	30 (41)				
Larynx	11 (14)	13 (18)				
Hypopharynx	13 (16)	14 (19)				
Nasopharynx	2 (3)	2 (3)				
Nasal fossa	11 (14)	6 (8)				
Other †	12 (15)	15 (20)				
Treatment	All phases	Palliative phase	All phases	Palliative phase	A	P
No treatment	8 (10)	50 (62)	17 (23)	70 (96)	.067	.017
Surgery	2 (3)	2 (2)	3 (4)	0 (0)		
Radiotherapy (RT)	32 (39)	35 (43)	19 (26)	22 (30)		
Chemotherapy (CT)	0 (0)	7 (8)	0 (0)	6 (8)		
Surgery + RT	35 (43)	2 (2)	33 (45)	0 (0)		
Surgery + CT	1 (1)	0 (0)	0 (0)	1 (1)		
Surgery + RT + CT	7 (9)	1 (1)	15 (21)	0 (0)		
CT + RT	15 (19)	5 (6)	13 (18)	2 (2)		
Time interval between start of pall phase and Pal-C median (interval)	61 days (0-1682)		X			
Duration palliative phase	169 days (9-2621) ‡		62 days (1-652)§		.000	

Abbreviation: Pal-C, Palliative Checklist; CT, chemotherapy; RT, radiotherapy.

* Except as otherwise stated.

† Tumours of the skin, salivary glands, ear, and trachea.

‡ Based on 109 patients.

§ Based on 128 patients.

and 24 family caregivers completed a Pal-SI. For 3% of the questions, no answer was given. The reasons for exclusion and nonresponse are indicated in Figure 2.

Refer to Table 2 for sociodemographic data. Patients from the Pal-SI+ group were not significantly different from the patients of the Pal-SIØ group. Family caregivers were, on average, 60 years old (32-77 years). Their relation to the patient was that of the husband/wife (17), daughter/son (5), friend (1) and brother (1).

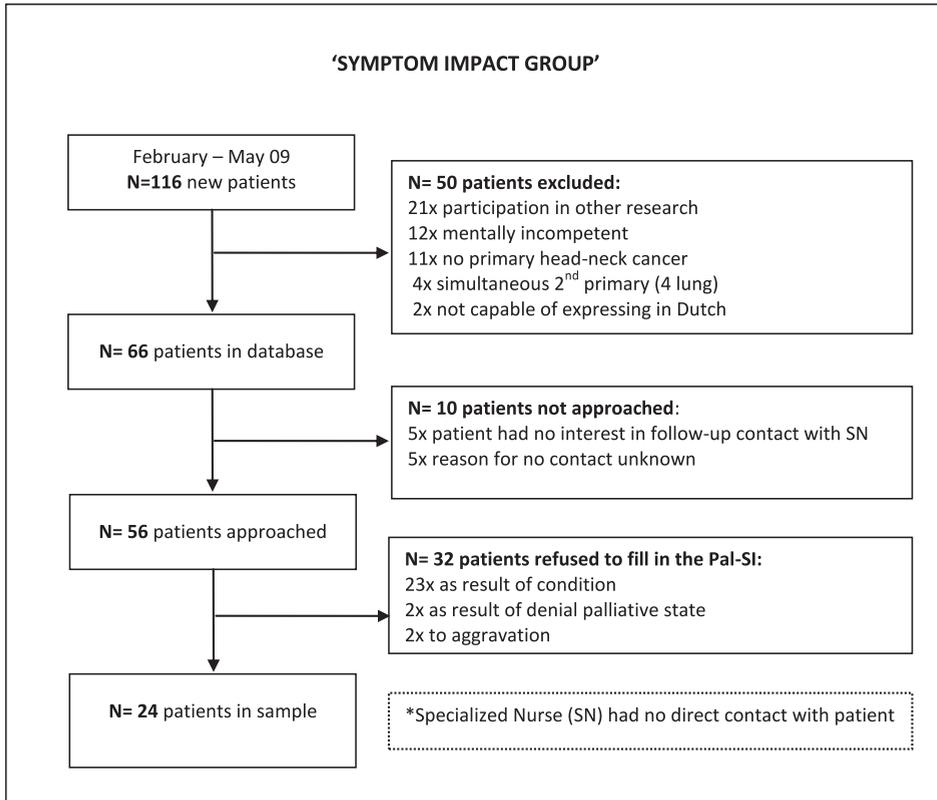


Figure 2. Symptom Impact Group

Prevalence of symptoms in “prevalence group”

All results obtained from the Pal-C are described in Table 3. Patients reported an average of 14 different symptoms (interval 0-26), of which there were 10 somatic symptoms and 4 psychosocial symptoms. Fatigue had the highest prevalence (81%), followed by pain (75%), weakness (75%), trouble with short walks outside (65%) and dysphagia (59%). Frequently reported psychosocial symptoms were worrying (61%), sadness (57%), tenseness (52%), depressed mood (52%) and powerlessness (50%).

Prevalence of symptoms in “symptom impact group”

All results obtained from the Pal-SI are described in Table 4. The patient and his/her family caregiver differed significantly from one another for the occurrence of 4 symptoms: difficulty sleeping (patient 29% vs caregiver 13%; $p = .046$), dyspnoea (21% vs 42%; $p = .025$), powerlessness (75% vs 46%; $p = .046$) and anxiety (29% vs 50%; $p = .034$).

Table 2. Socio-demographic data Symptom Impact Group

Characteristic	% (no. of patients) by group		P value			
	Pal-SI + group (n=24)	Pal-SI⊖ group (n=42)				
Age, average (interval)	66 (29-90 y)	67 (38-98 y)	.957			
Sex						
Male	50 (12)	64 (27)	.260			
Female	50 (12)	36 (15)				
Tumour location						
Oral cavity	33 (8)	21 (9)	.823			
Oropharynx	17 (4)	19 (8)				
Larynx	8 (2)	14 (6)				
Hypopharynx	4 (1)	12 (5)				
Nasopharynx	0 (0)	5 (2)				
Nasal fossa	17 (4)	12 (5)				
Other *	21 (5)	17 (7)				
Treatment	All phases	Palliative phase	All phases	Palliative phase	A	P
No treatment	4 (1)	38 (9)	10 (4)	45 (19)	.797	.615
Surgery	4 (1)	4 (1)	2 (1)	2 (1)		
Radiotherapy (RT)	21 (5)	42 (10)	21 (9)	38 (16)		
Chemotherapy (CT)	0 (0)	13 (3)	0 (0)	10 (4)		
Surgery + RT	42 (10)	0 (0)	41 (17)	0 (0)		
Surgery + CT	0 (0)	0 (0)	2 (1)	0 (0)		
Surgery + RT + CT	17 (4)	4 (1)	12 (5)	0 (0)		
CT + RT	13 (3)	0 (0)	12 (5)	5 (2)		
Time interval between start of pall phase and Pal-SI, average (interval)	270 days (17-1024)		X			

Abbreviation: Pal-SI, Palliative Symptom impact list; CT, chemotherapy; RT, radiotherapy.

* Tumours of the skin, salivary glands, ear, and trachea

Impact on daily functioning from “symptom impact group”

According to the patients, dyspnoea, voice changes, trouble with short walks outside, anger, and weakness, all had, in decreasing order, a large impact on daily functioning. The score for the symptom impact on daily functioning of the patient differed significantly between the patients and their family caregivers on 5 symptoms: trouble with short walks outside (patient NMS 5,5 vs caregiver NMS 6,7 $p = .047$), difficulty sleeping (4,7 vs 5,3; $p = .042$), powerlessness (4,4 vs 3,8; $p = .031$), trouble expressing oneself (3,3 vs 4,9; $p = .014$) and anxiety (5,1 vs 4,5; $p = .015$).

Table 3. Prevalence of symptoms n=124 from the Pal-C

Symptoms	% of patients	(no./total no. of patients)	Symptoms	% of patients	(no./total no. of patients)
Fatigue	81	(101/124)	Dyspnoea	41	(51/123)
Pain	75	(93/123)	Coughing after eating/ drinking	38	(47/122)
Weakness	75	(93/123)	Need for help with everyday functioning	30	(37/123)
Trouble with short walks outside	65	(81/123)	Nausea	29	(36/121)
Dysphagia	59	(73/123)	Wound in neck or face	22	(27/124)
Difficulty speaking	57	(71/123)	Unpleasant smell/ stench	19	(24/123)
Difficulty sleeping	56	(70/124)	Worrying*	61	(75/118)
Head and Neck oedema	56	(69/122)	Sadness*	57	(71/118)
Daily activities restricted as result of pain	53	(66/121)	Depressed mood*	52	(65/123)
Weight loss	53	(66/124)	Tenseness*	52	(65/122)
Voice changes	52	(64/123)	Powerlessness*	50	(62/117)
Constipation	48	(60/123)	Anger*	39	(48/116)
Shortness of breath	48	(59/123)	Anxiety*	32	(39/117)
Need to stay in bed/ chair during day	48	(59/123)	Trouble expressing oneself*	24	(30/118)
Appetite loss	53	(66/119)	Feelings of shame*	12	(15/118)

Abbreviation: Pal-C, Palliative Checklist. * Psychosocial symptoms.

DISCUSSION

In the first part of this research, we explored symptom prevalence in 124 patients with incurable head and neck cancer. Within this sample, “fatigue” was the somatic symptom most prevalent (81%), followed by pain (75%), weakness (75%), trouble with short walks outside (65%) and dysphagia (59%). To our knowledge, no comparative figures are known for symptom prevalence in patients with incurable head and neck cancer. Prior studies among head and neck cancer survivors, a few years after their curative treatment, indicate diverging percentages for the prevalence of fatigue (33 to 48%)²⁵⁻²⁶, pain (10 to 43%)²⁵⁻²⁸, and dysphagia (17 to 76%)²⁵⁻²⁸. For the prevalence of weakness and trouble with short walks outside, no comparative figures were found. We hypothesize that symptoms experienced by patients in the palliative phase are not consistent with those experienced by cancer survivors because of the difference of disease phase, location/ presence of the tumour, and tumour treatments.

The 4 most prevalent symptoms experienced by patients with head and neck cancer in the palliative phase are consistent with the results of a systematic review in 25,074 patients with cancer in general, during the palliative phase.¹⁶ Despite a probable difference in aetiol-

Table 4. Results Symptom Impact Group n=24 from the Pal-SI

Symptoms	Prevalence, % (n)		P value	Symptom impact, average (interval)		P value
	Patients	Close relatives		Patients	Close relatives	
Somatic						
Trouble with short walks outside	25 (6/24)	38 (9/24)	.083	5,5 (2-9)	6,7 (3-9)	.047
Need to stay in bed/chair during day	21 (5/24)	25 (6/24)	.317	3,8 (1-6)	4,8 (1-8)	.102
Need for help with everyday functioning	13 (3/24)	13 (3/24)	1.00	4,0 (3-5)	5,0 (5)	.180
Shortness of breath	38 (9/24)	33 (8/24)	.705	3,4 (1-7)	4,5 (2-8)	.561
Pain	54 (13/24)	58 (14/23)	.317	4,9 (2-10)	5,5 (1-10)	.109
Difficulty sleeping	29 (7/24)	13 (3/24)	.046	4,7 (1-10)	5,3 (2-10)	.042
Weakness	42 (10/23)	50 (12/22)	.705	5,2 (1-10)	4,6 (1-10)	.476
Appetite loss	21 (5/23)	13 (3/23)	.059	5,0 (1-8)	6,0 (2-8)	.414
Nausea	25 (6/24)	17 (4/22)	.317	3,4 (1-5)	2,0 (1-3)	.223
Constipation	21 (5/24)	25 (6/22)	.564	4,8 (2-10)	4,8 (2-10)	.102
Fatigue	92 (22/24)	79 (19/23)	.317	4,5 (1-10)	4,8 (1-10)	.796
Daily activities restricted as result of pain	33 (8/24)	25 (6/23)	.317	5,0 (1-10)	4,5 (2-6)	.313
Head and Neck oedema	25 (6/23)	29 (7/22)	.655	4,3 (1-7)	4,9 (1-10)	.465
Wound in neck or face	13 (3/24)	17 (4/23)	.564	5,0 (5)	5,3 (3-9)	.102
Unpleasant smell/ stench	4 (1/24)	17 (4/24)	.083	5,0 (5)	4,3 (2-6)	.068
Dyspnoea	21 (5/24)	42 (10/24)	.025	7,0 (3-10)	4,6 (1-8)	.234
Difficulty speaking	54 (13/24)	54 (13/24)	1.00	4,9 (2-10)	4,7 (1-9)	.648
Dysphagia	54 (13/23)	42 (10/22)	.405	5,0 (1-10)	6,2 (3-10)	.813
Coughing after eating/drinking	33 (8/23)	42 (10/24)	.666	4,1 (1-7)	5,0 (1-10)	.055
Voice changes	38 (9/24)	50 (12/24)	.257	5,9 (1-10)	4,8 (1-10)	.698
Weight loss	25 (6/24)	29 (7/23)	.317	3,8 (1-8)	4,9 (1-8)	.131
Psychosocial						
Tenseness *	38 (9/24)	33 (8/23)	1.00	3,9 (1-10)	4,1 (2-6)	.858
Depressed mood *	46 (11/24)	38 (9/21)	.317	3,9 (2-7)	3,1 (2-5)	.088
Powerlessness *	75 (18/24)	46 (11/21)	.046	4,4 (1-10)	3,8 (2-7)	.031
Worrying *	63 (15/24)	63 (15/21)	.083	4,4 (1-8)	4,4 (1-8)	.368
Trouble expressing oneself*	25 (6/24)	42 (10/23)	.157	3,3 (2-7)	4,9 (2-8)	.014
Feelings of shame*	13 (3/24)	4 (1/24)	.317	2,3 (1-5)	2,0 (2)	.461
Anxiety *	29 (7/24)	50 (12/21)	.034	5,1 (2-8)	4,5 (2-8)	.015
Anger *	29 (7/24)	42 (10/23)	.180	5,3 (3-7)	4,2 (1-8)	.609
Sadness	71 (17/24)	54 (13/24)	.102	4,6 (1-9)	6,0 (2-9)	.338

Abbreviations: Pal-SI, Palliative Symptom impact list.

* Psychosocial symptoms.

ogy of various symptoms as a result of different primary diagnoses, it seems that the most prevalent symptoms during the palliative phase are independent of the primary diagnosis.

In this study, a distinction was made between somatic and psychosocial symptoms. Despite the assumption that psychosocial symptoms occur less frequently in palliative patients with cancer in general¹⁷, it has been shown that these symptoms play an important role in the assessment of quality of life in patients with head and neck cancer²⁹⁻³³. The 5 most frequently reported psychosocial symptoms in our study were: worrying (61%), sadness (57%), tenseness (52%), depressed mood (52%) and powerlessness (50%). The prevalence figures for psychosocial symptoms found in our study are higher for the symptoms: worrying, sadness, tenseness, and anxiety compared to the findings of 2 other studies. The article by van den Beuken et al.³⁴ studied a subpopulation of 25 patients with incurable head and neck cancer during their treatment and found a prevalence of 25% for worrying, 17% for tenseness, and 8% for anxiety. In the overall incurable oncological population, Teunissen et al.¹⁶ found a prevalence of 36% for worrying, 39% for sadness, and 30% for anxiety. These discrepancies between our findings compared with other studies could be explained by the use of different terminology, measuring instruments and sample selection. For example, van den Beuken (2009) included patients who were all still receiving some form of (palliative) treatment aimed at symptom control, such as surgery, radiotherapy, or chemotherapy during the palliative phase of their illness. Whereas we studied a group of patients of which only a small portion was receiving such treatment and the larger portion was not. Receiving treatment, even if this treatment is of a palliative nature, can place patients more in a fighting mode and less open to feelings and negative emotions such as worrying. Teunissen et al.¹⁶ used a brought population of patients in the palliative phase, which could also lower the prevalence of these results because we know that patients with head and neck cancer psychologically suffer more¹ and have been associated with higher levels of depression and anxiety.

The least occurring psychosocial symptom (12%) was “feelings of shame”. We find this remarkable because head and neck cancer and its treatment can lead to mutilations and disfigurement, and therefore one would expect a higher prevalence for this specific symptom. It could be possible that patients already coped with these consequences when they occurred earlier on during the curative phase. Another reason for the low prevalence of feelings of shame may be related to the specific characteristics of the majority of patients with head and neck cancer; men over 60 years of age, generally with a lower socioeconomic background. Especially sex and age might influence the importance of appearance. Our findings are consistent with a study of patients after a laryngectomy, in which 14% of patients reported experiencing feelings of shame³⁵.

In the second part of this research we explored the impact of symptoms on daily functioning of patients with incurable head and neck cancer. We also looked at discrepancies between patients and their family caregivers with respect to how they score symptom occurrence and symptom impact on daily functioning. The symptoms dyspnoea, voice

changes, trouble with short walks outside, anger, and weakness, all have, according to the patients in the symptom impact group, a significant impact on daily functioning.

Furthermore, we found that family caregivers of patients with head and neck cancer during the palliative phase frequently overestimate the occurrence of somatic symptoms as well as the impact from those symptoms on daily functioning of patients. In two thirds of cases, although not always significant, the prevalence and the symptom impact score for somatic symptoms were systematically estimated higher by the family caregivers compared to patients. However, when it comes to psychosocial symptoms, we see a reverse trend. Both symptom prevalence as well as symptom impact are underestimated by family caregivers. Approximately 50% of the symptom prevalence and the symptom impact score are indicated higher by the patients compared with family caregivers. These findings are not consistent with studies in patients receiving oncology treatment during the palliative phase, in which family caregivers more frequently overestimated psychosocial symptoms compared to somatic symptoms¹⁹⁻²¹. Research indicates that the degree of consistency between patients and their caregivers depends on the health condition of the patient in question. Just a slight consistency can be found when the health of the patient is very good or very bad³⁶. A potential explanation for the discrepancy between patients and family caregivers could be underreporting of symptoms by patients. Patients do not wish to worry their caregivers and hence are very careful when communicating about their symptoms and/or the intensity of those symptoms^{18 20 21 37}. Whether or not the discrepancy between patients and their family caregivers in our study can be explained by this is unclear and requires further investigation. It is remarkable that family caregivers indicated that dyspnoea was present, twice as often as the patients did. In case of a head and neck tumour, dyspnoea is a potentially realistic threat. It is likely that fear of suffocation makes the family caregivers more aware of possible signs of dyspnoea. In addition, a lot of patients with head and neck cancer trivialize their dyspnoea because the progression happens gradually. Our result is consistent with prior research among patients with lung cancer during the palliative phase¹⁸.

Limitations

The cross-sectional method of current study is inapt to obtain a definite conclusion about the entire palliative phase. Practical achievability of a longitudinal approach within a palliative population, however, is limited, and hence very difficult to realize^{38 39}. Despite the fact that the Pal-C and the Pal-SI are well used and practical instruments for gathering information in the least possible intrusive way, the lack of validation is a limitation. Another limitation was the 44% nonresponse within the prevalence group. Nonresponding patients had a significant shorter life expectancy and seemed to have a much worse condition than responding patients. Generalization of the results from the prevalence group should therefore be done carefully. The large number of nonresponse (more specifically, patients that dropped out because of their weak condition) within this group, however, also confirms

how vulnerable this specific cancer population group is. Finally, the option to work with an occasional random sample for investigating the symptom impact group means that patients were selected. The number of patients and caregivers is too limited to generalize results to the entire population. However, the gained insight has resulted in a number of discrepancies between patients with head and neck cancer and their caregivers, and patients suffering from other malignant dysfunctions.

CONCLUSION

Implications for clinical practice

This is the first study investigating the prevalence of symptoms in patients with head and neck cancer and their impact on daily functioning during the palliative phase reported by patients themselves and their family caregivers. These patients experience a large number of different symptoms. We found that most frequently reported somatic symptoms were: fatigue, pain, weakness, trouble with short walks outside, and dysphagia, which is consistent with research involving a wide palliative cancer population. In the psychosocial area, these are worrying, sadness, tenseness, depressed mood, and powerlessness. For these symptoms, there are no comparative prevalence figures yet available. The symptom with the greatest impact on daily functioning, according to patients, is dyspnoea. According to the caregivers, this is the symptom “trouble with short walks outside”. For a number of symptoms, the mutual discrepancies between patients and their caregivers are significant.

These results were limited due to several aspects such as a relatively low accrual rate, mainly because of the condition of patients and the use of a non-validated questionnaire. Future research should, therefore, be focused on replication of our results with further validation of the used questionnaire. We do, however, believe that the results give valuable insight into symptoms experienced by patients with head and neck cancer in the palliative phase and their impact on daily functioning of those patients, a subject that is clearly underexposed in research.

Furthermore, we suggest that care for patients with head and neck cancer in the palliative phase should include targeted screening. This screening should focus on highly prevalent symptoms as fatigue and psychosocial symptoms which, because they are less visible, may now receive less attention. We also suggest that in the relationship between healthcare workers and patients and their caregivers, attention should be paid to the discrepancies between patients and caregivers found in this study. By making this difference in perception open for discussion, patients and caregivers can become more aware of this within their relationship. Insight regarding possible discrepancies may contribute to better and targeted healthcare and hence improve the quality of life of patients with head and neck cancer and their caregivers.

REFERENCELIST

1. De Boer MF, McCormick LK, Pruyt JF, et al. Physical and psychosocial correlates of head and neck cancer: a review of the literature. *Otolaryngol Head Neck Surg* 1999;120(3):427-36.
2. Parkin DM, Pisani P, Ferlay J. Global cancer statistics. *CA Cancer J Clin* 1999;49(1):33-64, 1.
3. Siegel R, Ward E, Brawley O, et al. Cancer statistics, 2011: the impact of eliminating socioeconomic and racial disparities on premature cancer deaths. *CA Cancer J Clin* 2011;61(4):212-36.
4. Visser O, Siesling S, Van Dijk JAAM. Incidence of cancer in the Netherlands 1999/2000. Eleventh Report of the Netherlands Cancer Registry. Utrecht: Vereniging Integrale Kankercentra 2003.
5. Traue D, Booth S. Introduction. In: Booth S, Davies A, eds. Palliative care consultations in head and neck cancer. New York: Oxford University Press 2006:1-8.
6. Ledebor QC, Offerman MP, van der Velden LA, et al. Experience of palliative care for patients with head and neck cancer through the eyes of next of kin. *Head & neck* 2008;30(4):479-84.
7. Ledebor QC, van der Schroeff MP, Pruyt JF, et al. Survival of patients with palliative head and neck cancer. *Head & neck* 2011;33(7):1021-6.
8. Zylitz Z, Teunissen SCCM, De Graeff A. Inleiding. In: De Graeff A, Hesselmann GM, Krol R, et al., eds. Palliatieve zorg: Richtlijnen voor de praktijk Utrecht: Vereniging voor Integrale kankercentra 2006.
9. De Graeff A, Hesselmann GM, Krol R, et al. Palliatieve zorg : Richtlijnen voor de praktijk. Utrecht: Vereniging van Integrale Kankercentra 2006.
10. Chang VT, Hwang SS, Feuerman M, et al. Symptom and quality of life survey of medical oncology patients at a veterans affairs medical center: a role for symptom assessment. *Cancer* 2000;88(5):1175-83.
11. Cleeland CS, Reyes-Gibby CC. When is it justified to treat symptoms? Measuring symptom burden. *Oncology (Williston Park, NY)* 2002;16(9 Suppl 10):64-70.
12. Cowan JD, Walsh D, Homsy J. Palliative medicine in a United States cancer center: a prospective study. *The American journal of hospice & palliative care* 2002;19(4):240-50.
13. Forbes K. Palliative care in patients with cancer of the head and neck. *Clinical otolaryngology and allied sciences* 1997;22(2):117-22.
14. Lidstone V, Butters E, Seed PT, et al. Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliat Med* 2003;17(7):588-95.
15. Teunissen SC, de Graeff A, de Haes HC, et al. Prognostic significance of symptoms of hospitalised advanced cancer patients. *Eur J Cancer* 2006;42(15):2510-6.
16. Teunissen SC, Wesker W, Kruitwagen C, et al. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 2007;34(1):94-104.
17. Zabora J, BrintzenhofeSzoc K, Curbow B, et al. The prevalence of psychological distress by cancer site. *Psycho-oncology* 2001;10(1):19-28.
18. Broberger E, Tishelman C, von Essen L. Discrepancies and similarities in how patients with lung cancer and their professional and family caregivers assess symptom occurrence and symptom distress. *Journal of pain and symptom management* 2005;29(6):572-83.
19. Lobchuk MM, Degner LF. Symptom experiences: perceptual accuracy between advanced-stage cancer patients and family caregivers in the home care setting. *J Clin Oncol* 2002;20(16):3495-507.
20. McPherson CJ, Wilson KG, Lobchuk MM, et al. Family caregivers' assessment of symptoms in patients with advanced cancer: concordance with patients and factors affecting accuracy. *Journal of pain and symptom management* 2008;35(1):70-82.

21. Milne DJ, Mulder LL, Beelen HC, et al. Patients' self-report and family caregivers' perception of quality of life in patients with advanced cancer: how do they compare? *European journal of cancer care* 2006;15(2):125-32.
22. Groenvold M, Petersen MA, Aaronson NK, et al. The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006;42(1):55-64.
23. Petersen MA, Groenvold M, Aaronson N, et al. Item response theory was used to shorten EORTC QLQ-C30 scales for use in palliative care. *Journal of clinical epidemiology* 2006;59(1):36-44.
24. Pruyt JF, Heule-Dieleman HA, Knegt PP, et al. On the enhancement of efficiency in care for cancer patients in outpatient clinics: an instrument to accelerate psychosocial screening and referral. *Patient education and counseling* 2004;53(2):135-40.
25. Chaukar DA, Walvekar RR, Das AK, et al. Quality of life in head and neck cancer survivors: a cross-sectional survey. *American journal of otolaryngology* 2009;30(3):176-80.
26. Harrison LB, Zelefsky MJ, Pfister DG, et al. Detailed quality of life assessment in patients treated with primary radiotherapy for squamous cell cancer of the base of the tongue. *Head & neck* 1997;19(3):169-75.
27. List MA, Bilir SP. Functional outcomes in head and neck cancer. *Seminars in radiation oncology* 2004;14(2):178-89.
28. List MA, Mumby P, Haraf D, et al. Performance and quality of life outcome in patients completing concomitant chemoradiotherapy protocols for head and neck cancer. *Qual Life Res* 1997;6(3):274-84.
29. De Graeff A, De Leeuw JR, Ros WJ, et al. Pretreatment factors predicting quality of life after treatment for head and neck cancer. *Head & neck* 2000;22(4):398-407.
30. Hammerlid E, Silander E, Hornestam L, et al. Health-related quality of life three years after diagnosis of head and neck cancer--a longitudinal study. *Head & neck* 2001;23(2):113-25.
31. Hassanein KA, Musgrove BT, Bradbury E. Functional status of patients with oral cancer and its relation to style of coping, social support and psychological status. *The British journal of oral & maxillofacial surgery* 2001;39(5):340-5.
32. Holloway RL, Hellewell JL, Marbella AM, et al. Psychosocial effects in long-term head and neck cancer survivors. *Head & neck* 2005;27(4):281-8.
33. Scharloo M, Baatenburg de Jong RJ, Langeveld TP, et al. Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head & neck* 2005;27(10):857-63.
34. Van den Beuken MHJ. Symptoms in patients with cancer. Universiteit Maastricht, 2009.
35. Nalbadian M, Nikolaou A, Nikolaidis V, et al. Factors influencing quality of life in laryngectomized patients. *Eur Arch Otorhinolaryngol* 2001;258(7):336-40.
36. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *Journal of clinical epidemiology* 2002;55(11):1130-43.
37. Mesters I, van den Borne H, McCormick L, et al. Openness to discuss cancer in the nuclear family: scale, development, and validation. *Psychosomatic medicine* 1997;59(3):269-79.
38. Jubb AM. Palliative care research: trading ethics for an evidence base. *Journal of medical ethics* 2002;28(6):342-6.
39. Stromgren AS, Sjogren P, Goldschmidt D, et al. A longitudinal study of palliative care: patient-evaluated outcome and impact of attrition. *Cancer* 2005;103(8):1747-55.