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Changes in supportive care needs over time from diagnosis up to two years after treatment in head and neck cancer patients: A prospective cohort study

Dominique Molenaar^{a,b}, Irma M. Verdonck-de Leeuw^{a,b,c}, Birgit I. Lissenberg-Witte^d, Robert P. Takes^e, Chris H.J. Terhaard^f, Johannes A. Langendijk^g, C. René Leemans^{a,b}, Femke Jansen^{a,b,*}

^a Cancer Center Amsterdam Research Institute, Amsterdam UMC, Vrije Universiteit Amsterdam, the Netherlands

^b Department of Otolaryngology-Head and Neck Surgery, AmsterdamUMC Location Vrije Universiteit Amsterdam, De Boelelaan 1117, 1081 HV, Amsterdam, the Netherlands

^c Department of Clinical, Neuro- and Developmental Psychology, Faculty of Behavioral and Movement Sciences & Amsterdam Public Health Research Institute, Vrije Universiteit Amsterdam, Van der Boechorststraat 7, 1081 BT, Amsterdam, the Netherlands

^d Amsterdam UMC, Vrije Universiteit Amsterdam, Department of Epidemiology and Data Science, Amsterdam, the Netherlands

^e Department of Otorhinolaryngology and Head and Neck Surgery, Radboud University Medical Center, Nijmegen, the Netherlands

^f Department of Radiotherapy, University Medical Center Utrecht, Utrecht, the Netherlands

^g Department of Radiation Oncology, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands

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ABSTRACT

Objectives: To investigate changes in supportive care needs (SCNs) over time from diagnosis up to 2 years after treatment among head and neck cancer (HNC) patients, in relation to demographic, personal, clinical, psychological, physical, social, lifestyle, and cancer-related quality of life factors.

Materials and methods: Data of the longitudinal NETHERLANDS Quality of Life and Biomedical Cohort study (NET-QUBIC) was used. SCNs were measured using the Supportive Care Needs Survey (SCNS-SF34) and HNC-specific module (SCNS-HNC) before treatment, three, six, 12 and 24 months after treatment. Linear mixed model analyses were used to study SCNs on the physical & daily living (PDL), psychological (PSY), sexuality (SEX), health system, information and patient support (HSIPS), HNC-functioning (HNC-Function), and lifestyle (HNC-Lifestyle) domain, in relation to demographic, personal, clinical, psychological, physical, social, lifestyle, and cancer-related symptoms as measured at baseline.

Results: In total, 563 patients were included. SCNs changed significantly over time. At baseline, 65% had ≥ 1 moderate/high SCN, versus 42.8% at 24 months. Changes in PDL needs were associated with gender, tumor location, smoking, fear of cancer recurrence, oral pain, and appetite loss, changes in PSY with tumor location, fear of recurrence, social support, emotional functioning, physical functioning, coughing, and use of painkillers, changes in SEX with treatment, changes in HSIPS with muscle strength, changes in HNC-Function with tumor stage, location, social support, physical functioning, fatigue, nausea and vomiting, and speech problems, and changes in HNC-Lifestyle with smoking and alcohol use.

Conclusion: SCNs diminish over time, but remain prevalent in HNC patients.

1. Introduction

Treatment of head and neck cancer (HNC) comes at great cost for the patient. Adverse effects are reported not only during treatment, but also long after [1]. HNC patients often report physical and psychological problems, and HNC specific problems such as oral dysfunction,

swallowing problems and malnutrition, and a loss of enjoyment in social eating [2–6]. Patients are also prone to decline in neurocognitive functioning, sleep quality and sexual problems [7–9]. Supportive care is defined by the Multinational Association of Supportive Care in Cancer (MASCC) as “The prevention and management of the adverse effects of cancer and its treatment”. This includes the provision of information and

* Corresponding author. Amsterdam UMC, Location VU University Medical Center, Department of Otolaryngology-Head & Neck Surgery, P.O. Box 7057, 1007 MB, Amsterdam, the Netherlands.

E-mail address: f.jansen1@amsterdamumc.nl (F. Jansen).

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the management of physical and psychological symptoms and side effects from diagnosis to long-term follow-up [10].

Research has shown that over 60% of HNC patients report minor supportive care needs (SCNs) [11–18], and that 30–58% of patients have at least one moderate to high SCN [14,15,17]. Most research was conducted among HNC subgroups, such as oral cavity cancer patients [9, 19–21], patients after total laryngectomy [14], or patients treated with surgery (with and without (chemo)radiotherapy) [22]. Studies investigated SCNs before or shortly after treatment [9,15,21–23], in the first year after treatment [17,18,20,24,25], or in a cross-sectional group of cancer survivors with a wide range of elapsed time since diagnosis or treatment [6,11–14,16,26]. These studies also investigated which factors were associated with SCNs at a particular time point. No study investigated which factors are associated with changes in SCNs over time, which is highly needed to obtain better insight into which groups of HNC patients improve or worsen over time regarding their SCNs. This study aims to investigate changes in SCNs among HNC patients from diagnosis up to two years after treatment in relation to demographic, personal, clinical, physical, psychological, social, and lifestyle factors and cancer-related symptoms as measured at baseline. We hypothesized that, based on previous studies [9,11,15,20,23,26–28], demographic (educational level), clinical (tumor stage, treatment, HPV-status), social (employment), and psychological factors (anxiety, depression, fatigue), and symptoms (eating difficulty, appetite) are associated with changes in SCNs over time. Also, we hypothesized that physical factors and lifestyle factors play a role. Results of this study will provide leads to improve supportive care by better tailoring supportive care to the needs of individual HNC patients.

2. Materials and methods

2.1. Design and study population

Patients who presented with newly diagnosed HNC in seven hospitals in the Netherlands were asked to participate in the NET-QUBIC longitudinal cohort study from April 2014 until July 2018 [29,30]. Inclusion criteria were: age >18 years, tumor in the oral cavity, oropharynx, hypopharynx, or larynx or unknown primary, treatment with curative intent, the ability to write, and read Dutch. Exclusion criteria were: severe psychiatric comorbidities and the inability to understand informed consent, questions or test instructions (29). Patients included in the NET-QUBIC study (n = 739) were asked to fill in patient-reported outcome measures (PROMs) at baseline, before start of treatment (T0), and at three (M3), six (M6), 12 (M12) and 24 months after treatment (M24). Home visits with an interview and objective tests were performed and biobank samples were collected at baseline, M6, M12 and M24. An electronic case report form (eCRF) was completed with clinical data. All patients signed informed consent. The local ethical committee approved the study (Amsterdam UMC, location VUmc, document number: 2013.301[A2018.307]-NL45051.029.13). Below those outcome measures are described that are used in this study. For detailed information, see previous publications [29,31].

2.2. Supportive care needs survey (SCNS-SF34)

The Supportive Care Needs Survey (SCNS-SF34) and the HNC-specific module (SCNS-HNC) were used to assess SCNs among HNC patients [32–34]. The SCNS-SF34 consists of 34 items covering four underlying constructs: physical & daily living needs (PDL), psychological needs (PSY), sexuality needs (SEX) and health system, information and patient support needs (HSIPS) [34]. The SCNS-HNC contains 11 items with two constructs: HNC-specific functioning needs (HNC-function) and lifestyle needs (HNC-lifestyle), and one single item on care of stoma and/or voice prosthesis (results on this single item are not presented in this study). All items are answered on a 5-point scale: “1 = not applicable” for issues that are no problem to the patient; “2 = satisfied” for issues on which a patient

needs support but the support is already satisfactorily fulfilled; and “3 = low unmet need”, “4 = moderate unmet need”, and “5 = high unmet need”. All questions are answered with regard to the last month and converted to a score ranging from 0 to 100, with 100 representing the highest SCNs [34]. At least half of the items of a particular domain needed to be completed in order to calculate a total domain score. In addition, all patients were dichotomized into having SCNs (yes/no), defined as having at least one moderate or high unmet SCN per domain (score 4 or 5).

Patients were asked to complete the SCNS-SF34 and SCNS-HNC for scientific research, the answers they provided to the questionnaire were not evaluated by their healthcare professionals, and therefore did not influence the received supportive care. All patients received supportive care as usual.

2.3. Factors studied in relation to supportive care needs

Demographic factors were age, gender, living situation (living alone or living together), educational level and employment status. Personal factors were personality (NEO Five factor Inventory) [35], coping (Utrecht Coping List) [36] and self-efficacy (Generalized Self-efficacy scale). Clinical factors were treatment (single or multimodality treatment), tumor stage (I, II, III or IV), tumor location (oral cavity, oropharynx HPV positive, oropharynx HPV negative, oropharynx HPV unknown, hypopharynx, larynx and unknown primary), comorbidity (none, mild, moderate or severe using the Adult Comorbidity Evaluation 27 (ACE-27) [37]) and WHO performance score (WHO 0 or WHO I/II/III). Physical factors included muscle strength, measured using a JAMAR handgrip dynamometer for the upper extremities [38]. Muscle strength was dichotomized into <10th percentile and ≥10th percentile based on values set by the Nutritional Assessment Platform, taking the highest grip strength value [39]. Psychological factors investigated were symptoms of anxiety and depression (HADS) [40], and fear of cancer recurrence (CWS) [41]. Social factor included social support (Social Support List – Interactions) [42]. Lifestyle factors were smoking and alcohol usage, and body mass index (BMI). Smoking and alcohol usage were measured using study specific questionnaires. Patients were categorized into the smoking group in case they currently smoked every day. Alcohol usage was scored as excessive when consumption exceeded 14 glasses per week for women and 21 for men [43]. The EORTC QLQ-C30 and HN35 were used to measure quality of life and cancer-related symptoms. The EORTC QLQ-C30 consists of five functional scales: physical, role, emotional, neurocognitive and social functioning, three symptom scales: nausea and vomiting, fatigue and pain, and 6 single items: dyspnea, insomnia, loss of appetite, constipation, diarrhea and financial difficulties [44,45]. The EORTC QLQ-H&N35 comprises seven symptom scales: pain, swallowing, senses, speech, social eating, social contact and sexuality and 11 symptom items: problems with teeth, dry mouth, sticky saliva, cough, feeling ill, opening the mouth wide, weight loss, weight gain, use of nutritional supplements, feeding tubes, and painkillers [46]. All EORTC scores are converted to a score ranging from 0 to 100. Higher scores on the functioning domains indicate better functioning and higher scores on the symptom domains indicate higher symptom burden. All factors were assessed before start of treatment.

2.4. Statistical analysis

Statistical analysis was performed using IBM SPSS, version 26. Outcomes were described using frequencies and percentages, or mean and standard deviation (SD). To investigate possible differences between included and excluded patients, independent sample *t*-test and chi-square tests were performed. To describe changes in SCNs over time, linear mixed models were created per SCN domain, with fixed effects for time (categorical variable), and random intercepts at patient level. Estimated differences were extracted from the models. A Bonferroni correction was applied to correct for multiple testing; changes over time were significant

when $p < 0.01$. To investigate which factors are associated with changes in SCNs, a multivariate mixed model was built (compound symmetry matrix) per SCN domain, adding the potential factor and time*factor to the model. Time*factor variables that were significant ($p < 0.05$), were added to the multivariate mixed model, using forward selection.

3. Results

Among the 739 patients participating in NET-QUBIC, 563 completed the SCNS-SF34 or SCNS-HNC at baseline and were included in this study. Included patients had a better comorbidity score and WHO classification in comparison to the excluded patients (Table 1).

In the study population ($n = 563$), 417 (74.1%) patients were male and the average age was 63 years (SD 9.4). The most prevalent tumor

Table 1

Socio-demographic and clinical characteristics of included and excluded head and neck cancer patients.

Characteristics	Included patients N = 563	Excluded N = 176	p-value
Age (SD)	63.0 (9.4)	62.5 (10.7)	0.231
Gender			0.805
Male(%)	417 (74.1)	132 (75)	
Female(%)	146 (25.9)	44 (25)	
Educational level ^a			0.191
Low(%)	215 (41.6)	64 (48.9)	
Middle(%)	136 (26.3)	35 (26.7)	
High(%)	166 (32.1)	32 (24.4)	
Tumor location			0.320
Oral cavity(%)	155 (27.5)	44 (25.0)	
Oropharynx HPV positive(%)	104 (18.5)	26 (14.8)	
Oropharynx HPV negative(%)	70 (12.4)	29 (16.5)	
Oropharynx HPV unknown(%)	27 (4.8)	6 (3.4)	
Hypopharynx(%)	35 (6.2)	17 (9.7)	
Larynx(%)	154 (27.4)	51 (29.0)	
Unknown primary(%)	18 (3.2)	3 (1.7)	
Tumor stage			0.104
I(%)	134 (23.8)	29 (16.5)	
II(%)	104 (18.5)	28 (15.9)	
III(%)	91 (16.2)	36 (20.5)	
IV(%)	234 (41.6)	83 (47.2)	
Treatment ^b			0.521
Single(%) ^c	305 (54.2)	88 (50)	
Surgery(%)	115 (20.4)	37 (21.0)	
Radiotherapy(%)	190 (33.7)	51 (29.0)	
Multiple(%) ^d	258 (45.8)	87 (49.4)	
Chemoradiotherapy(%)	156 (27.7)	59 (33.5)	
Surgery and radiotherapy(%)	82 (14.6)	24 (13.6)	
Surgery and chemoradiotherapy(%)	19 (3.4)	4 (2.3)	
Radiotherapy and hyperthermia(%)	1 (0.2)	0 (0.0)	
Comorbidities			0.002
Unknown(%)	27 (4.8)	13 (7.4)	
None(%)	172 (30.6)	32 (18.2)	
Mild(%)	205 (36.4)	59 (33.5)	
Moderate(%)	108 (19.2)	47 (26.7)	
Severe(%)	51 (9.1)	25 (14.2)	
WHO status ^e			0.029
Having no restrictions (%)	398 (70.7)	109 (61.9)	
Having any type of restrictions (%)	165 (29.3)	67 (38.1)	

^a Low education level includes primary education, lower or preparatory vocational education, and intermediary general secondary education. Middle education level includes senior general secondary education and higher general secondary education. High education level includes higher professional education and university.

^b 1 patient died before surgery.

^c Single treatment = surgery or CO2 laser or radiotherapy.

^d Multiple treatment = e.g. chemoradiotherapy or surgery and radiotherapy or surgery and chemoradiotherapy.

^e Having no restriction = WHO 0, having any type of restrictions = WHO I, II and III. No patient had a WHO IV score.

locations were oropharynx (35.7%), oral cavity (27.5%) and larynx (27.4%). Most patients presented with an advanced tumor stage (16.2% stage III and 41.6% stage IV). The majority (54.2%) of the patients received single treatment which consisted of either surgery or radiotherapy (Table 1). Over time, 149 patients dropped out of the study, mostly due to mortality ($n = 71$, 47.7%), physical ($n = 26$, 17.4%), psychological or logistic reasons (both $n = 15$, 10.1%) (Fig. 1).

3.1. Changes in supportive care needs from time of diagnosis to 2 years after treatment

At baseline, 65.0% of patients (353 of 543 patients) had SCNs in at least one domain versus 42.8% (68 of 159 patients) at M24. SCNs changed significantly over time for all domains (Fig. 2 and Tables 2 and 3). The need for support on PDL increased significantly from baseline (mean 15.7; SD 20.8) to 3 months after treatment (mean 20.2; SD 22.7) after which it gradually returned to baseline level. The need for support on all other domains significantly decreased over time (Fig. 2 and Table 2). The need for support on HNC-function and HNC-lifestyle was significantly lower at M24 compared to baseline (estimated difference = -2.9 (99%CI -5.5 to -0.4) and -5.0 (99%CI -8.1 to -1.8) respectively) (Fig. 2 and Table 3).

3.2. Factors associated with changes in supportive care needs

Changes in SCNs over time were investigated in relation to different factors as assessed at baseline (see supplementary material 1 for the univariate results and Table 4 for the multivariate results). Changes in SCNs among subgroups of HNC patients were defined as ‘worse’, when they showed a smaller reduction in SCNs or a larger increase in SCNs over time, in comparison to the reference/comparison group.

Changes in PDL needs over time were significantly associated with gender, tumor location, smoking, fear of cancer recurrence (FCR), oral pain, and appetite loss at baseline (Table 4). Graphical visualizations of the results are provided in supplementary material 2. Inspection of these graphs show that PDL needs at baseline were comparable among men and women, patients with different tumor localizations and smokers and non-smokers, however, changes in PDL needs was significantly worse among women, patients with a hypopharyngeal tumor and those who smoked. Patients who had more FCR, oral pain and appetite loss had poorer PDL needs at baseline, however, changes in PDL needs was worse for those with low FCR, oral pain and appetite loss at baseline (i.e., those with low symptoms had a larger increase in PDL needs over time) (Table 3). Differences in changes in PDL needs were especially observed from T0-M3 (gender, oral pain, appetite loss), M6-M12 (tumor location) and M12-M24 (smoking, FCR).

Changes in PSY needs over time were significantly associated with social support, tumor location, FCR, physical functioning, emotional functioning, coughing and use of painkillers. PSY needs at baseline were comparable among patients with different tumor localizations and among those who did and did not use painkillers, however, changes in PSY needs were significantly worse among patients with a hypopharyngeal tumor and those who used painkillers. Patients who scored high on seeking social support, with more FCR and worse physical functioning, emotional functioning and coughing had higher PSY needs at baseline, however, changes in PSY were significantly worse for patients scoring low on seeking social support, those with low FCR, high emotional functioning and low levels of coughing. Patients with poorer physical functioning showed a worse change in PSY needs. Differences in changes in PSY needs were especially shown from T0-M3 (social support, FCR, physical functioning, emotional functioning), T0-M6 (tumor location) and M3-M12 (painkillers).

Changes in SEX needs over time were significantly associated with treatment. At baseline patient who were about to receive single or multimodality treatment had comparable SEX needs. Over time, patients treated with multimodality treatment showed fluctuation changes in SEX

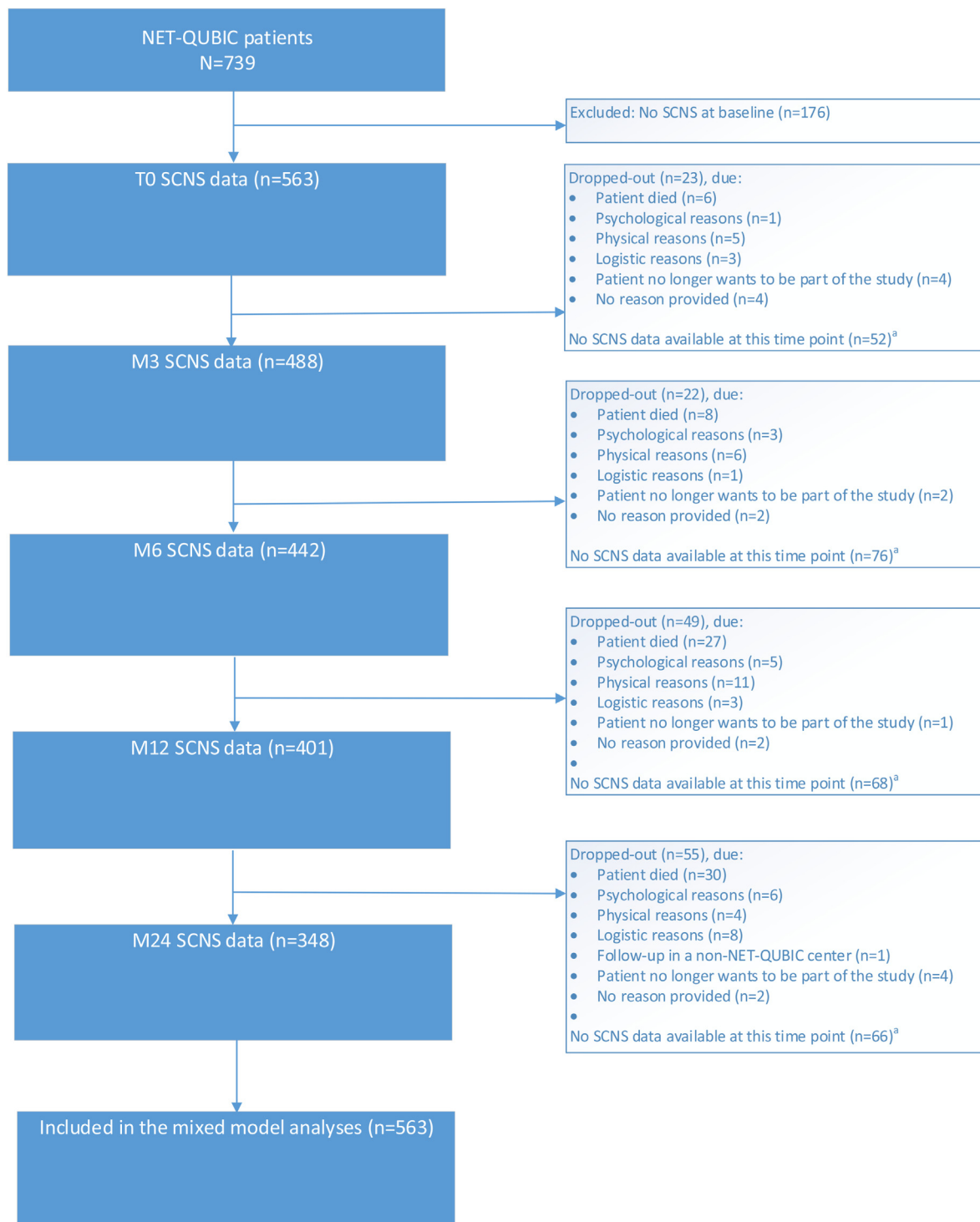


Fig. 1. Flow diagram

^a Patients coded as 'no SCNS data available at this time point' were not coded as drop-out, as they still participated in one of the other NET-QUBIC components (i.e., home visit or biobank). Also, they may have completed the SCNS at a later time point.

needs, compared to more constant SEX needs among patients treated with single treatment.

Changes in HSIPS needs over time was associated with handgrip strength. At baseline HSIPS needs were comparable between patients with normal/high and low handgrip strength. Changes in HSIPS among patients with low grip strength showed an increase from T0 to M3, and a reduction in needs from M12 to M24, whereas patients with normal/high grip strength showed a reduction from baseline onwards.

Changes in HNC-function needs (measured at T0 and M24) were significantly associated with tumor stage, tumor location, social support, physical functioning, fatigue, nausea and vomiting and speech problems. HNC-function needs at baseline were comparable among patients with different tumor locations, different levels of social support, physical functioning, fatigue and nausea and vomiting, however, changes in HNC-function needs were significantly worse among patients with a laryngeal tumor, those who receive more social support, and those with low

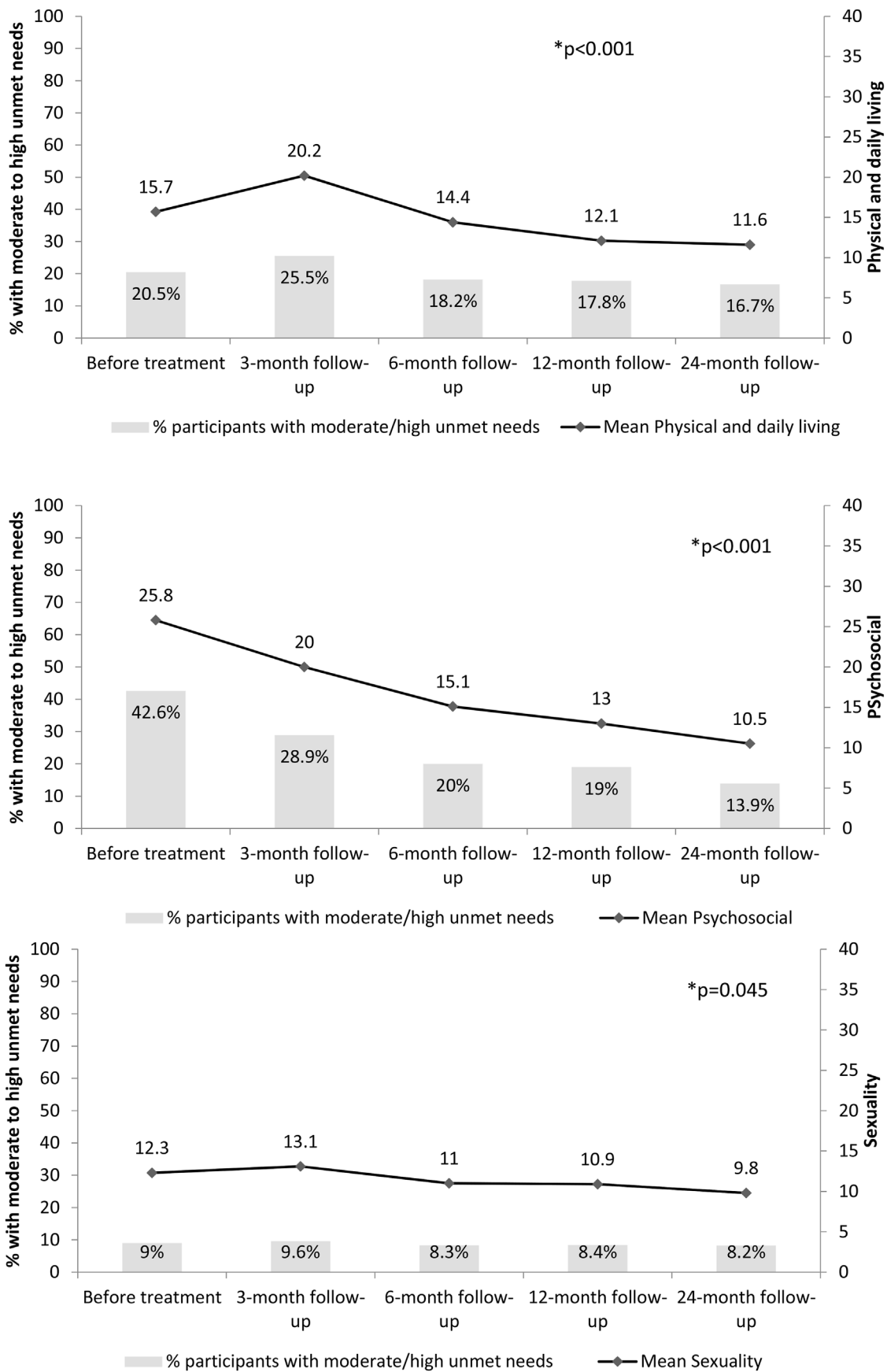


Fig. 2. Visual representation of changes in supportive care need over time for all six supportive care need domains. Line graphs represent the average 0–100 score per domain. The bar charts represent the percentage of patients with moderate to high unmet needs.

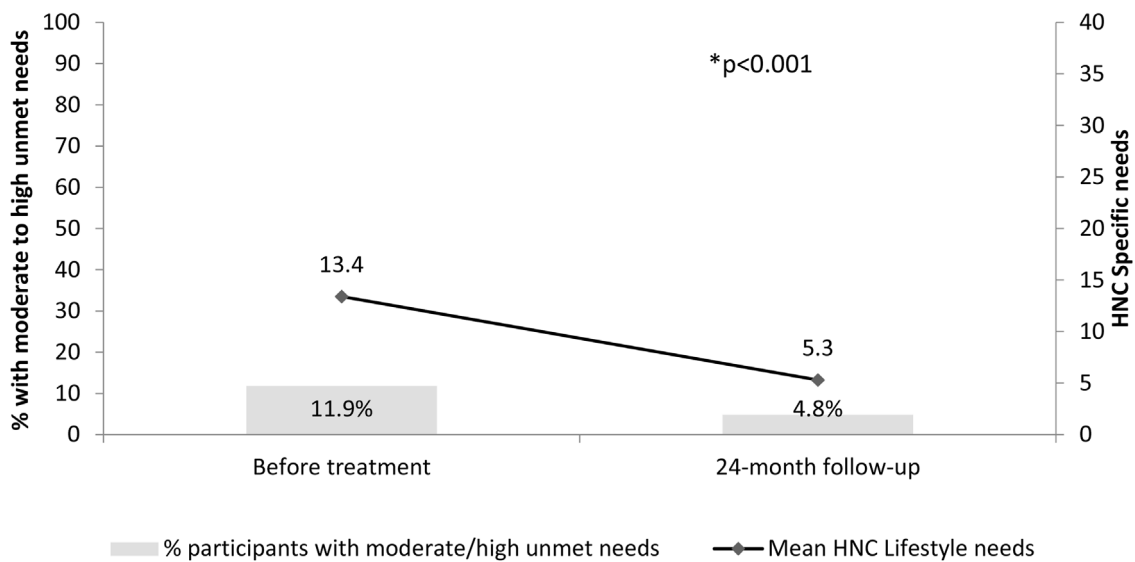
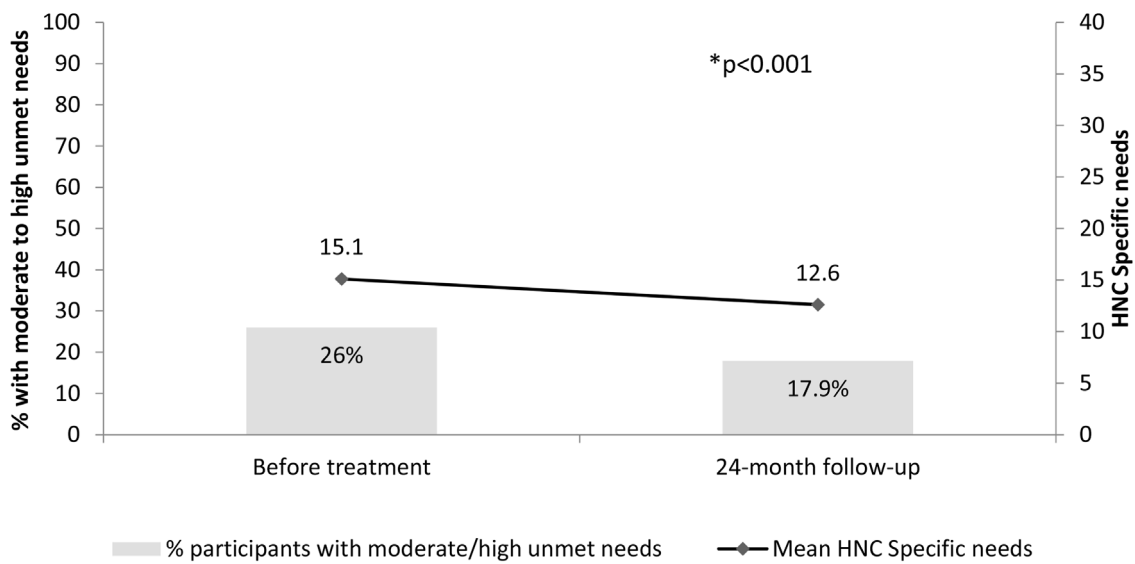
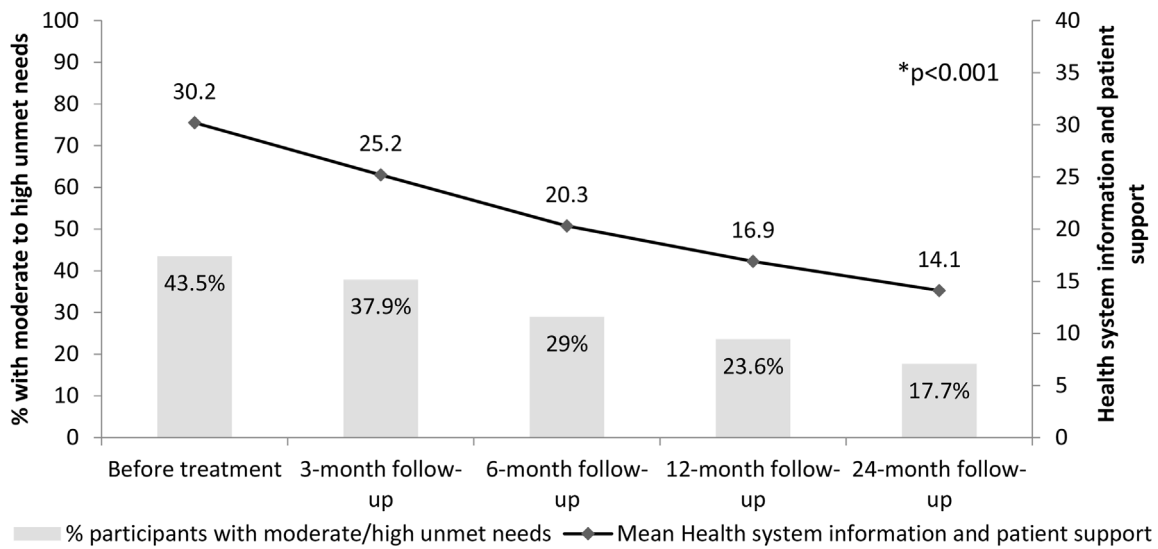


Fig. 2. (continued).

Table 2

Changes in supportive care needs over time
SCNS-SF34 scores range from 0 to 100, with 100 representing the highest need for supportive care.

	Descriptive analysis	Linear mixed model analysis	
	Mean (SD)	Estimated mean change from pre-treatment	99% CI
Pretreatment			
Physical and daily living (n = 557)	15.7 (20.8)	Ref.	Ref.
Psychological (n = 559)	25.8 (24.1)		
Sexuality (n = 556)	12.3 (19.8)		
Health system, information and patient support (n = 556)	30.2 (23.0)		
3-month follow-up			
Physical and daily living (n = 487)	20.2 (22.7)	5.0	2.8 to 7.3
Psychological (n = 488)	20.0 (22.5)	-5.7	-8.0 to -3.4
Sexuality (n = 480)	13.1 (20.9)	0.7	-1.7 to 3.1
Health system, information and patient support (n = 485)	25.2 (20.0)	-4.8	-7.2 to -2.3
6-month follow-up			
Physical and daily living (n = 440)	14.4 (19.0)	-0.5	-2.8 to 1.9
Psychological (n = 441)	15.1 (20.3)	-10.4	-12.8 to -8.0
Sexuality (n = 433)	11.0 (20.3)	-1.4	-4.0 to 1.1
Health system, information and patient support (n = 441)	20.3 (19.8)	-9.9	-12.5 to -7.4
12-month follow-up			
Physical and daily living (n = 400)	12.1 (17.6)	-2.1	-4.5 to 0.3
Psychological (n = 399)	13.0 (19.0)	-12.0	-14.5 to -9.5
Sexuality (n = 392)	10.9 (20.1)	-1.2	-3.8 to 1.4
Health system, information and patient support (n = 398)	16.9 (19.4)	-13.2	-15.9 to -10.5
24-month follow-up			
Physical and daily living (n = 347)	11.6 (17.5)	-2.2	-4.7 to 0.4
Psychological (n = 346)	10.5 (16.5)	-13.9	-16.5 to -11.2
Sexuality (n = 341)	9.8 (19.2)	-2.2	-4.9 to 0.5
Health system, information and patient support (n = 344)	14.1 (17.8)	-15.4	-18.2 to -12.6

physical functioning, and better scores on fatigue and nausea and vomiting. Patients with a stage III tumor and patients with a higher level of speech problems had higher HNC-function needs at baseline, however, changes in HNC-function needs were significantly worse among those with a stage IV tumor and those with low speech problems.

Changes in HNC-lifestyle needs over time were associated with daily smoking and excessive alcohol consumption. At baseline patient who drink excessively and those who smoke daily had somewhat higher HNC-lifestyle needs. Changes in HNC-lifestyle over time were significantly worse among patients who did not smoke and did not drink alcohol excessively.

4. Discussion

Among HNC survivors, 65.0% of patients had SCNs at baseline in at

Table 3

Changes in head and neck cancer specific supportive care needs over time
SCNS-HNC scores range from 0 to 100, with 100 representing the highest need for supportive care.

	Linear mixed model analysis			p-value
	Mean	Mean change from pretreatment	99% CI	
HNC Specific Functioning				
Pre-treatment (n = 557)	15.1 (17.5)			
24 months (n = 188)		-2.9	-5.5 to -0.4	0.003
HNC Specific Lifestyle				
Pre-treatment (n = 553)	13.4 (24.0)			
24 months (n = 187)		-5.0	-8.1 to -1.8	<0.001

least one domain. At M24 still 42.8% of all patients had SCNs, especially regarding HNC-function, HSIPS and PDL needs. SCNs on all domains significantly changed over time. SCNs on the PDL domain increased up to 3 months follow-up after which it decreased over time. The SCNs on all other domains decreased from baseline onwards.

The finding that 42.8–65.0% of patients have SCNs is somewhat higher compared to SCNs of 30%–58% found in previous studies [14,15,17], which might be due to previous studies not including HNC specific modules. Unfortunately it is difficult to make clear comparisons among studies due to heterogeneity in used measurement instrument and timing of assessment [9,11,15,17,26]. Consistent with our study, however, previous studies showed lower SCNs among HNC patients who were longer after treatment [13,21,47]. Nevertheless, a subgroup of HNC patients still had SCNs 2 years after treatment, warranting tailored supportive care also in the long-term.

In order to better tailor supportive care to the individual patient, better insight into groups of HNC patients that improve or worsen over time is important. We found that demographic (gender), personal (seeking social support), clinical (tumor location, stage and treatment), physical (muscle strength), psychological (FCR), social (social support), lifestyle (smoking and alcohol consumption) and several symptom-specific factors at baseline were associated with changes in SCNs over time. Patients with a tumor of the hypopharynx or larynx showed worse changes in PDL (hypopharynx), PSY (hypopharynx) and HNC specific functioning needs (larynx) over time, compared to the other tumor localizations. This was an unexpected finding since earlier research showed no association between tumor location and SCNs [11–13,47], except for one study by Henry et al. (2020) who found higher SCNs among patients with an unknown primary compared to those with a known HNC primary [15]. Our finding that changes in SCNs differ over time among tumor locations might be due to the fact that we had sufficient power to categorize patients with hypopharynx cancer in a separate group, whereas almost all previous studies combined patients with hypopharyngeal and laryngeal cancer into one treatment group. The finding may also be explained by treatment, as both type of treatment and extend of treatment (e.g., major or minor surgery) differs per tumor location.

Interestingly we found that patients who perform better at baseline (i.e. non-smokers, non-drinkers and those with lower levels of FCR and symptoms) showed worse changes in SCNs over time. SCNs among those patients were relatively low at baseline, and increased after treatment. SCNs remained lower or increased to similar SCNs as patients who are less well-performing at baseline. To identify HNC patients in need for supportive care we should thus not only focus on patients who perform poorly at baseline, but also on patients who are well-performing. Further research is needed to investigate presenting symptoms after treatment in relation to changes in SCNs from that time point onwards.

The greatest strength of the current study is that it is the first longitudinal cohort study investigating changes in SCNs from before start of

Table 4
Multivariate linear mixed model results on baseline factor*time per SCNS domain.

	Physical and daily living	Psychological	Sexuality	Health system, information and patient support	HNC specific functioning	HNC specific Lifestyle
Demographic						
Gender	p < 0.001					
Personal						
UCL Seeking social support		p = 0.001				
Clinical						
Type of treatment			p = 0.042			
Tumor stage					p < 0.001	
Tumor location	p = 0.013	p < 0.001			p < 0.001	
Physical						
Muscle strength				p = 0.002		
Psychological						
Fear of recurrence	p = 0.007	p < 0.001				
Social						
Social support					p < 0.001	
Lifestyle						
Daily smoking	p = 0.018					p < 0.001
Excessive alcohol						p = 0.014
Symptom specific						
Physical functioning		p = 0.021			p < 0.001	
Emotional functioning		p = 0.001				
Fatigue					p = 0.075	
Nausea and vomiting					p < 0.001	
Appetite loss	p = 0.004					
Oral pain	p < 0.001					
Speech problems					p = 0.008	
Coughing		p = 0.030				
Painkiller usage		p = 0.006				

treatment up to 2 years after treatment among patients with various HNC tumor locations, stages and treatment modalities. We used data of a large cohort of 563 patients, which enabled us to investigate a broad spectrum of factors in association to changes in SCNs. However, of the initial 739 patients participating in the NET-QUBIC study, 176 did not fill in the baseline SCNS questionnaire and were excluded. Included patients had a better physical performance and less comorbidity compared to the excluded patients, limiting the generalizability of our findings to all HNC patients. Over the course of 2 years, 215 patient dropped out, mainly due to patient death or because they were no longer willing to participate in the NET-QUBIC project. This combination of drop-out might have led to a selection of more healthy participants over the course of years. Another limitation is that SCNs were measured at baseline and beyond 3 months after treatment, so we do not have insight in SCNs during or shortly after treatment. Also, the SCNS–HNC was completed at baseline only and, in a subsample, at 24 months follow-up, limiting the interpretation of findings related to HNC-specific needs. Finally, we focused on changes in SCNs over time. Not all changes may, however, be clinically relevant. So far, however, no information is available on minimal clinically important differences on the SCNS-SF34 and SCNS–HNC.

5. Conclusion

A majority of HNC patients have SCNs at baseline. Although SCNs reduced over time, still almost half of HNC patients had SCNs 2 years after treatment. Changes in SCNs over time were associated with demographic (gender), personal (seeking social support), clinical (tumor location, stage and treatment), physical (muscle strength), psychological (FCR), social (social support), lifestyle (smoking and alcohol consumption) and several HNC-specific cancer related quality of life factors.

Author contributions

Dominique Molenaar and Femke Jansen had full access to all the data in the study and take responsibility for the integrity of the data and the

accuracy of the data analysis. *Concept and design:* All authors. *Acquisition of data:* All authors. *Analysis and interpretation of data:* Molenaar, Verdonck-de Leeuw, Lissenberg-Witte and Jansen. *Drafting of the manuscript:* Molenaar, Verdonck-de Leeuw and Jansen. *Critical revision of the manuscript for important intellectual content:* All authors. *Statistical analysis:* Molenaar, Lissenberg-Witte and Jansen.

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Declaration of competing interest

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Appendix A. Supplementary data

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