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Supportive care needs in patients treated with total laryngectomy and its associated factors

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Submitted

This study was funded by the Michel Keijzer Fund.

ABSTRACT

Background. A group of head and neck cancer (HNC) patients who specifically may have a high need for supportive care are patients treated with total laryngectomy (TL).

Purpose. To investigate (unmet) supportive care needs in TL patients, and its associated factors.

Methods. TL patients (n = 283) completed questions on supportive care needs (SCNS-SF34 and SCNS-HNC). The prevalence of (unmet) supportive care needs, and its associated factors were investigated using logistic regression analyses.

Results. Supportive care needs were highest for HNC-specific functioning (76%), followed by health system, information & patient support (69%), psychological (66%), physical and daily living (62%), sexuality (38%) and lifestyle (19%). Seventy-one percent reported at least one low, moderate or high unmet need, especially regarding HNC-specific functioning (53%). Female gender, living alone, and having a voice prosthesis were significantly positively associated with unmet needs on at least one domain ($p < 0.05$). A worse health-related quality of life was associated with unmet needs on all domains.

Conclusion. The majority of TL patients report at least one low, moderate or high unmet need for supportive care.

INTRODUCTION

Unmet supportive care needs have been reported in 60% to 74% of head and neck cancer (HNC) patients¹⁻⁴. This is higher than the 25% found among Dutch mixed cancer patients⁵, while it fits into the wide range of 1% - 93% reported in a previous systematic review⁶. Often reported supportive care needs among HNC patients are psychological needs (e.g., distress), health system and information needs (e.g., being provided with written information on important aspects of your care), and needs regarding physical and daily living (e.g., pain)^{2-4,7-14}. Also HNC-specific supportive care needs are often reported, for instance, dry mouth, dental health, eating and speech problems^{4,7,9,10,12}. Although highest in the treatment and early follow-up phase^{2,9-11}, SC needs may remain through the long-term follow-up^{3,4,10,12,14}.

A group of HNC patients who specifically may have a high need for supportive care are patients treated with total laryngectomy (TL). These patients encounter several adjustments in normal daily functioning, with which they have to live for the rest of their lives, including adjustments in airway management, smell, swallowing and speech¹⁵⁻¹⁷. In addition, they have often been treated with (chemo)radiation and/or neck dissection, which may induce problems, such as dysphagia and shoulder complaints^{15,18}. In a focus-group study among TL patients (2 to 22 years after TL surgery) several supportive care needs were identified, psychosocial care needs and needs related to treatment-related changes in physical functioning, including eating, swallowing, neck and shoulder pain, speech and tracheostomy and voice prosthesis care¹⁹. No study has, however, quantitatively investigated the prevalence of (unmet) supportive care needs among patients treated with TL in particular.

The aim of this study was to investigate the need for supportive care and unmet needs for supportive care in patients treated with TL. In addition, the association of socio-demographic, clinical and lifestyle factors, and health-related quality of life (HRQOL) with unmet needs was investigated. Based on previous studies among HNC patients, it was hypothesized that a shorter time since diagnosis or treatment^{2,9,11,20} and a lower HRQOL^{2,3} is associated with a higher prevalence of unmet needs. Also, living alone⁴, being unemployed¹¹, and more intensive type of treatment^{2,11,20} were hypothesized to be associated with a higher prevalence of unmet needs. Age^{2,10,20}, gender^{2-4,8,20}, having children³, education level², smoking status^{2,4,11}, and alcohol consumption^{2,4} were not expected to be associated with unmet needs. Insight into unmet supportive care needs of TL patients and its associated factors provides knowledge necessary to tailor care for this specific patient group.

MATERIALS AND METHODS

Design and study population

All 914 members of the Dutch Patient Association for Laryngectomees were asked to participate in this cross-sectional study in November 2014. All members were approached by regular post. The post included an information letter, an informed consent form and a paper-and-pencil questionnaire, which they could complete at home. All approached patients were treated with TL and were older than 18 years. In total, 288 patients (32%) completed the questionnaire. According to the Dutch Medical Research Involving Human Subjects Act, ethical approval was not necessary, because patients were not subjected to procedures or required to follow rules of behavior. All data was collected and analyzed anonymously.

Patient-reported outcome measures

Supportive care needs were measured using the 34-item Short-Form Supportive Care Needs Survey (SCNS-SF34)²⁰⁻²², the HNC-specific module (SCNS-HNC)²⁰, and six additional single items (Table 1). The SCNS-SF34 consists of 34 items which were originally reported to have five underlying domains; physical & daily living, psychological, sexuality, patient care & support, and health system & information needs^{21,22}. Recently, we translated this measure into Dutch and assessed its psychometric characteristics among Dutch mixed HNC patients (between 3 months and five years after treatment)²⁰. In this previous study, we found four underlying domains using 33 items: physical & daily living needs (5 items), psychological needs (10 items), sexuality needs (3 items), and health system, information & patient support needs (15 items)²⁰. This four-factor structure also showed good internal consistency in the present study (Cronbach's alpha ranged from 0.83 to 0.95), and was used in this study. The one item not included in one of the four domains (i.e., more choice about which hospital you attend) was measured as a single item. Besides assessing its factor structure and internal consistency, the previous study among mixed HNC patients also reported that the SCNS-SF34 was construct valid and had good test-retest reliability²⁰.

The SCNS-HNC contains 11 items on two underlying domains, namely HNC-specific functioning (8 items) and lifestyle needs (2 items), and one single item on stoma care and/or voice prosthesis care. The SCNS-HNC has also previously been validated among Dutch mixed HNC patients²⁰. Internal consistency using Cronbach's alpha in this TL population was 0.84 (HNC-specific functioning needs) and 0.54 (lifestyle needs). In addition, the previous study showed evidence for its construct validity and test-retest reliability²⁰.

Content validity, however, showed that some additional items may need to be added which may be relevant in a general HNC population²⁰, but especially in a TL population. This is the reason why we added six additional single items (last six items of Table 1).

Table 1. Supportive care needs and unmet needs among patients treated with total laryngectomy

SCNS-SF34 and SCNS-HNC domains and items	% with a need	% with an unmet need	Median total score [IQR]
<u>Physical & daily living</u>	62.1%	37.1%	10 [0 - 25]
Pain	20.9%	8.8%	
Lack of energy/tiredness	41.6%	27.1%	
Feelings unwell a lot of the time	16.9%	8.5%	
Work around the home	44.0%	20.2%	
Not being able to do the things you used to do	45.4%	22.9%	
<u>Psychological</u>	66.3%	39.2%	8 [0 - 25]
Anxiety	20.6%	14.0%	
Feeling down or depressed	28.8%	18.5%	
Feelings of sadness	29.4%	18.3%	
Fears about the cancer spreading	35.3%	24.2%	
Worry that the results of treatment are beyond your control	29.4%	14.5%	
Uncertainty about the future	37.9%	21.0%	
Learning to feel in control of your situation	36.2%	12.5%	
Keeping a positive outlook	47.6%	12.2%	
Feelings about death and dying	27.2%	16.2%	
Concerns about the worries of those close to you	41.2%	18.7%	
<u>Sexuality</u>	38.0%	23.0%	0 [0 - 17]
Changes in sexual feelings	31.9%	19.0%	
Changes in your sexual relationships	31.0%	18.6%	
To be given information about sexual relationships	19.3%	9.1%	

Table 1. Continued.

SCNS-SF34 and SCNS-HNC domains and items	% with a need	% with an unmet need	Median total score [IQR]
<u>Health system, information & patient support</u>	69.1%	34.9%	13 [0 - 25]
More choice about which cancer specialists you see	30.9%	6.9%	
Reassurance by medical staff that the way you feel is normal	44.4%	12.4%	
Hospital staff attending promptly to your physical needs	46.5%	10.6%	
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	43.8%	9.4%	
Being given written information about the important aspects of your care	47.8%	14.2%	
Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	38.0%	10.6%	
Being given explanations of those tests for which you would like explanations	42.9%	13.9%	
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	47.8%	16.1%	
Being informed about your test results as soon as feasible	40.6%	15.2%	
Being informed about cancer which is under control or diminishing (that is, remission)	39.4%	15.0%	
Being informed about things you can do to help yourself to get well	39.4%	15.0%	
Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	34.8%	14.3%	
Being treated like a person not just another case	50.2%	17.5%	
Being treated in a hospital or clinic that is as physically pleasant as possible	52.0%	17.2%	
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	50.5%	17.8%	

Table 1. Continued.

SCNS-SF34 and SCNS-HNC domains and items	% with a need	% with an unmet need	Median total score [IQR]
<u>HNC-specific functioning</u>	75.9%	53.2%	16 [3 - 31]
Problems with chewing and/or swallowing	45.8%	26.0%	
Problems with dry mouth and/or sticky saliva	46.8%	27.3%	
Problems with weight (underweight or overweight)	46.6%	19.1%	
To be informed on nutrition	33.3%	13.4%	
Difficulty speaking	52.5%	27.9%	
Problems with hearing	37.5%	16.6%	
Oral hygiene	36.1%	7.8%	
Problems with mobility of neck or shoulders	51.8%	27.7%	
<u>Lifestyle</u>	18.8%	5.4%	0 [0 - 0]
Quit smoking	4.7%	1.8%	
Quit drinking	18.4%	5.1%	
<u>Single items</u>			
More choice about which hospital you attend	33.9%	8.8%	
Care of your stoma and/or voice prosthesis	49.6%	16.4%	
Problems with taste and olfaction	60.9%	35.0%	
Problems with coughing	44.3%	23.2%	
Difficulty eating	48.9%	26.4%	
Shortness of breath	44.0%	23.8%	
Problems with social eating	50.5%	30.2%	
Loss of appetite	27.6%	12.0%	

Abbreviations: SCNS-SF34, 34-item Short-Form Supportive Care Needs Survey; SCNS-HNC, the SCNS head and neck cancer-specific module; IQR, interquartile range

All SCNS-SF34, SCNS-HNC and single items are answered on a 5-point scale²², namely: '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 satisfactory fulfilled; and '3 = low unmet need', '4 = moderate unmet need' and '5 = high unmet need' for issues on which a patient reports respectively a low, moderate or high need for additional supportive care. Patients are asked to take the last month into account when answering the questions. In this study an item score ≥ 2 was used to identify patients with a need, while an item score ≥ 3 was used to identify patients with unmet needs. In addition, a total score per domain was calculated and converted to a 0 - 100 score, with a higher score indicating a higher level of supportive care needs.

Besides questions on (unmet) supportive care needs, several factors potentially associated with unmet needs were measured via patient self-report using study-specific questions. Socio-demographic factors included age, gender, having children, living arrangements, education level, and employment status. Clinical factors included time since TL, treatment (TL with or without (chemo)radiation) and current speech method (voice prosthesis, injection method, electrolarynx or other (multiple answers were possible)). Lifestyle factors included smoking (is not a smoker, is a smoker or quitted smoking) and drinking behavior (does not drink, does drink or quitted drinking). HRQOL was measured using the EuroQoL-5 dimensions (EQ-5D) questionnaire. The EQ-5D measures current problems on five dimensions of HRQOL, namely mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Participants can answer they have no problems, some problems or extreme problems. Based on these five dimensions, an EQ-5D total score was generated using the Dutch Index Tariff²³. A higher score indicated a better HRQOL. Pickard et al.²⁴ previously presented evidence on the validity and reliability of this measure in different groups of cancer patients.

Statistical analyses

Statistical analyses were performed using the IBM Statistical Package for the Social Science (SPSS) version 22 (IBM Corp., Armonk, NY USA). Socio-demographic, clinical and lifestyle factors and HRQOL were described using frequencies, percentages, means and standard deviations (SD) or medians and (interquartile) ranges. The need for supportive care among TL patients was assessed by calculating the total score per domain converted to a 0 - 100 score. Missing data on the SCNS-SF34 and SCNS-HNC was imputed by the mean score of the other items of the particular domain in case less than half of the items within the domain were missing²². In addition, the prevalence of supportive care needs (one or more items with a score ≥ 2) and unmet needs (one or more items with a score ≥ 3) was assessed in total and per supportive care domain. To assess factors associated with at least one overall low, moderate or high unmet need and at least one low, moderate or high unmet need per domain, forward multivariate logistic regression analyses were used. The p-value for entry in the model was < 0.10 . In case the p-value in the final model was < 0.05 the factor was also considered to be statistically significantly associated with the outcome. Included factors were age, gender, having children, living arrangements, education level, employment status, time since TL, treatment, having a voice prosthesis, smoking, drinking and HRQOL. Factors associated with unmet lifestyle needs were not assessed, since the percentage of unmet needs and Cronbach's alpha were too low. Also, factors associated with the total 0 - 100 score were not assessed, since data were heavily skewed to the right.

RESULTS

Of the 288 TL patients who participated in the study, 5 patients did not complete any of the supportive care needs questions and were excluded. Most of the 283 TL patients were men (84%) and the mean age was 70 (SD = 9) (Table 2). Most TL patients had a lower education level (49%), followed by a secondary (25%), higher (18%) or elementary education level (9%). Time since TL ranged from 0 to 37 years (median = 7). Most TL patients also received radiation (72%) or chemoradiation (9%) prior to or after TL.

Need for supportive care

The highest need concerned the HNC-specific functioning domain (76%), followed by health system, information & patient support (69%), psychological (66%), physical and daily living (62%), sexuality (38%) and lifestyle needs (19%) (Table 1). Most reported HNC-specific functioning needs were needs regarding difficulty speaking (53%), problems with mobility of neck and shoulders (52%), and problems with dry mouth and/or sticky saliva (47%). Being treated in a hospital or clinic that is as physically pleasant as possible (52%), having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up (51%), and being treated like a person not just another case (50%) were the most important health system, information & patient support needs. Most reported psychological needs were keeping a positive outlook (48%) and concerns about the worries of those close to you (41%). Regarding physical and daily living, not being able to do the things you used to do (45%), work around the home (44%) and lack of energy/tiredness (42%) were the most important needs. For sexuality, changes in sexual feelings (32%), and for lifestyle, quit drinking were most important (18%). Furthermore, high needs were reported on several (HNC and TL-specific) single items, such as problems with taste and olfaction (61%), problems with social eating (51%) and care of your stoma and/or voice prosthesis (50%).

Unmet needs for supportive care

Over all questions on supportive care needs, 71% of TL patients reported at least one low, moderate or high unmet need. The highest percentage of unmet need concerned the HNC-specific functioning domain (53%), followed by the psychological (39%), physical & daily living (37%), health system, information & patient support (35%), sexuality (23%) and lifestyle domain (5%) (Table 1). For all domains and items, the percentage of patients that reported an unmet need was much lower than the percentage of patients that reported a need. The top 10 unmet needs were: problems with taste and olfaction (35%), problems

with social eating (30%), difficulty speaking (28%), problems with mobility of neck or shoulders (28%), problems with dry mouth and/or sticky saliva (27%), lack of energy or tiredness (27%), difficulty eating (26%), problems with chewing and/or swallowing (26%), fears about the cancer spreading (24%), and shortness of breath (24%).

Table 2: Patient characteristics

	Patients treated with total laryngectomy n = 283
Mean [SD] age ¹	70 (9)
Sex ²	
- men	84%
- women	16%
Having children ³	
- no	15%
- yes	85%
Living arrangements ³	
- living alone	21%
- living with partner	68%
- living with partner and children	7%
- other (e.g., with children or in an institution)	3%
Education level ⁴	
- elementary	9%
- lower	49%
- secondary	25%
- higher	18%
Employment status	
- employed in paid work	11%
- not employed/not able to work	15%
- retired	74%
Smoking status ⁴	
- is not a smoker	67%
- is a smoker or quitted smoking	33%
Drinking status ⁴	
- does not drink	31%
- drinks	60%
- quitted drinking	9%

Table 2: Continued.

	Patients treated with total laryngectomy n = 283
Median [IQR] years since total laryngectomy ²	7 [2 - 14]
Received other treatments ⁵	
- no	19%
- yes, radiation	72%
- yes, chemoradiation	9%
Current speech method*	
- voice prosthesis	83%
- injection method	18%
- electrolarynx	5%
- other (e.g., cannot speak)	3%
Median [IQR] health-related quality of life (EQ-5D utility score)	0.89 [0.81 - 1.00]

Abbreviations: SD, standard deviation; IQR, interquartile range; EQ-5D, EuroQol-5 dimensions

¹ Age is missing in two patients.

² Gender and time since total laryngectomy are missing in four patients.

³ Having children, living situation and health-related quality of life are missing in seven patients.

⁴ Education level, smoking status, drinking status are missing in three patients.

⁵ Received other treatment and current speech method are missing in six patients.

* Multiple answers possible

Factors associated with unmet needs

Several factors were, based on a p-value for entry < 0.10, included in the final model (Table 3). The explained variance (via Nagelkerke's R²) ranged from 0.10 (total supportive care needs and sexuality needs) to 0.29 (physical & daily living needs). Patients with a lower (worse) HRQOL reported significantly more often unmet needs on all supportive care needs domains and the overall domain, compared to patients with a higher (better) HRQOL (all p-values ≤ 0.002). In addition, psychological unmet needs were significantly more often reported in women (p = 0.029), and in patients with a voice prosthesis (compared to patients without a voice prosthesis, p = 0.022). Health, system, information & patient support unmet needs were found to be significantly more prevalent in patients living alone (compared to patients living together, p = 0.017).

Table 3. Factors associated with unmet needs among patients treated with total laryngectomy¹

	Total n = 276	SCNS-SF34 Physical & daily living n = 267	Psychological n = 252	Sexuality n = 266	Health, system, information & patient support n = 260	SCNS-HNC ² HNC-specific functioning n = 265
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age					P = 0.068	
- < 63 years					1.44 [0.61 – 3.40]	
- 64 – 69 years					1.93 [0.85 – 4.37]	
- 70 – 76 years					2.91 [1.29 – 6.60]	
- ≥ 77 years					Reference	
Sex			P = 0.029			
- men			Reference			
- women			2.36 [1.10 – 5.10]			
Living arrangements				P = 0.017		
- living alone				Reference		
- living together				0.44 [0.22 – 0.86]		
Education level					P = 0.065	
- elementary					1.79 [0.59 – 5.40]	
- lower					2.34 [1.10 – 4.95]	
- secondary					3.01 [1.30 – 7.01]	
- higher					Reference	

DISCUSSION

This study aimed to provide insight into (unmet) needs for supportive care in TL patients. In addition, the association of socio-demographic, clinical and lifestyle factors, and HRQOL with unmet needs was investigated. We found that many TL patients have supportive care needs, especially regarding HNC-specific functioning (76%), health system, information & patient support (69%), psychological (66%) and physical and daily living needs (62%). For many of these patients their need for supportive care was satisfactorily fulfilled, since reported unmet needs on the abovementioned domains were much lower, with respectively 53%, 35%, 39% and 37%. Nevertheless, 71% of all TL patients reported at least one low, moderate or high unmet need. Patients with a worse HRQOL reported significantly more often unmet needs on all supportive care domains compared to patients with a better HRQOL. Also socio-demographic and clinical factors were found to be associated with unmet needs.

Our finding that more than seven out of ten TL patients have at least one low, moderate or high unmet need for supportive care is supported by previous studies in mixed HNC patients in which unmet needs of 60% - 74% were reported¹⁻⁴. Clear comparison of our findings to previous studies on (unmet) supportive care needs in HNC patients is, however, limited. Only four of the previous studies also used the SCNS-SF34^{1,3,13,14}, while the other studies used the Cancer Needs Questionnaire Short Form (CNQ-SF)^{7,9,10}, the Cancer Survivors' Unmet Needs Measure (CaSUN)², the Survivors Unmet Needs Survey (SUNS)¹¹, the Patient Concerns Inventory (PCI)⁴ or a study-specific questionnaire¹². We favored the SCNS-SF34 over the other patient-reported outcome measures as this measurement instrument is most frequently used, and has previously been validated in Dutch among HNC patients specifically²⁰.

Another reason why the comparison of findings is limited is the multiple ways used to calculate domain scores on the SCNS-SF34, as shown in the different SCNS-SF34 studies^{1,3,13,14}. Previous studies investigated factors associated with moderate or high unmet needs¹, factors associated with number of low, moderate or high unmet needs¹⁴, or factors associated with continuous outcomes of the SCNS-SF34^{3,13}. In our study the continuous outcomes of the SCNS-SF34 were heavily skewed to the right, which is why we decided to dichotomize between patients with at least one low, moderate or high unmet need and patients without such a need. In contrast to Boyes et al.¹ we thus also categorized low unmet needs as unmet needs. We hypothesize that besides focusing on patients with

moderate or high unmet needs, it is of importance to focus on patients with low unmet needs as well, as the provision of low-intensive supportive care (e.g. the provision of information or self-management interventions) may prevent the development to more serious needs, for which more-intensive (and more costly) supportive care interventions may be necessary. More research on this matter is, however, warranted.

We found that HNC-specific and TL-specific unmet needs were highly prevalent among TL patients, as 53% reported low, moderate or high unmet needs on the HNC-specific functioning domain and 12% to 35% reported unmet needs on HNC-specific or TL-specific single items. Eight of the 10 most prevalent unmet needs were HNC or TL-specific. These results are in contrast to two previous studies in respectively newly diagnosed oral cancer patients⁹ and mixed HNC patients up to 5 years after diagnosis³, which found no HNC-specific unmet needs among its top 10. This may, however, be explained by their use of a more limited HNC measurement instrument. In the study of Wells et al.⁴ in mixed HNC patients 3 months to 5 years after treatment, comparable to our findings, multiple HNC-specific unmet needs were reported among its top 10, including needs regarding dry mouth, dental health, swallowing, speech, chewing and eating, and taste loss. Based on these results it seems that regular care may not always fit the needs of individual patients, and that it is important to provide TL patients with tailored supportive care. To facilitate TL patients to have an active role themselves to manage these HNC-specific and TL-specific problems, we recently developed and tested a self-help application consisting of information and self-care advice on stoma care, voice prosthesis care, speech, smelling, nutrition and mobility of neck or shoulders, and of a guided self-help exercise program targeting speech, swallowing and neck and shoulder problems. Previous research showed that this application is feasible and valued by both TL patients and their care providers^{19,25}. Currently, the (cost)effectiveness of the exercise program is being investigated among TL patients²⁶.

In addition to HNC and TL-specific unmet needs, psychological and physical and daily living unmet needs were often reported in our study (respectively 39% and 37% of all patients reported at least one low, moderate or high unmet need). A psychological unmet need reported by almost one out of five TL patients was concerns about the worries of those close to them. Caregivers of TL patients often help TL patients with daily care, which may place a burden on the caregiver's daily life²⁷. Although recently published research among caregivers of HNC patients indicated that the perceived burden from the caregivers' perspective was relatively low²⁸, about half of all caregivers report at least one moderate

to high unmet need²⁸⁻²⁹. Whether these needs among HNC caregivers are comparable to those of caregivers of a more homogeneous group of TL-patients need, however, to be further investigated. A currently ongoing Dutch longitudinal cohort study measures supportive care needs among caregivers of HNC patients using the caregivers version of the SCNS (i.e., the SCNS-P&C)³⁰, enabling the opportunity to investigate supportive care needs of both HNC and TL caregivers in more detail (over time)^{31,32}.

To investigate which TL patients have a particular need for additional supportive care, we investigated factors associated with unmet needs. As hypothesized^{2,4,9,11,20}, time since diagnosis or treatment, living alone, and a more intensive type of treatment were based on a p-value for entry of < 0.10 included in the final model of at least one supportive care domain, of which living alone was also found to be significantly associated. Also, comparable to previous research in HNC patients^{2,3}, a worse HRQOL was consistently found to be significantly associated with unmet needs. In addition, although not hypothesized, female gender, and patients with a voice prosthesis (compared to patients without a voice prosthesis) were significantly positively associated with unmet needs. These results indicate that some TL patients are in higher need for additional supportive care than others, which should be taken into account when tailoring care to the individual needs of patients. However, it should also be noted that the explained variance of our results were with 10% - 29% relatively low, further research is, therefore, recommended to investigate explanatory factors (e.g. other clinical factors, personal factors or social support) in more detail (over time).

A strength of the current study is that this is the first study that specifically focused on (unmet) supportive care needs in TL patients. Also, HNC and TL-specific needs were measured using the recently validated SCNS-HNC²⁰ and some single items targeting TL patients specifically. Only half of the previous studies measured HNC-specific needs^{3,4,7,9,10}, mostly limited to a few questions on HNC-specific coping needs^{7,9,10} or needs regarding smoking cessation, alcohol cessation, feeling better about appearance, or finding meaning and purpose in life³. Another strength is the sample size of 283 TL patients, which is quite high when taking into account that on average only 150 patients are treated by TL each year in the Netherlands³³. However, it should be taken into account that the patients were selected via the Dutch Patient Association for Laryngectomees, and that the response rate was rather low (32%), which may have resulted in selection bias and reduced generalizability to all TL patients. The low response rate may be due to the fact that study procedures were anonymized, and we were, therefore, not able to send reminders to non-

responders. Because of these study procedures, we were also not able to collect data from the medical file. We had to rely on patient self-report for clinical information, which is also why some potential relevant clinical information was not collected. Another limitation is the cross-sectional design, hampering the ability to draw conclusions on causality of findings and to distinguish (unmet) supportive care needs at different moments in the cancer trajectory. Also, although this study sample was homogeneous regarding the study sample (i.e. TL patients only), time since TL was quit heterogeneous.

In conclusion, the majority of TL patients have supportive care needs, especially regarding HNC-specific functioning, health system, information & patient support, psychological, and physical and daily living needs. In total, 71% of all TL patients reported at least one low, moderate or high unmet need. Several socio-demographic and clinical factors were found to be associated with unmet needs on at least one supportive care domain. Also, patients with a worse HRQOL reported significantly more often unmet needs on all domains compared to patients with a better HRQOL. More research is needed on the course of (unmet) supportive care needs over time.

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