

ORIGINAL ARTICLE

Identifying unmet needs and limitations in physical health in survivors of Head and Neck Cancer

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ABSTRACT

Objective: To gain insight into the level of unmet needs and limitations in physical health experienced by survivors of head and neck cancer, and to evaluate whether unmet needs in physical health and limitations in physical performance are associated.

Materials and methods: In this cross-sectional study, unmet needs were measured with Supportive Care Needs Surveys (SCNS-SF34, SCNS-HNC). Limitations in physical health were measured for maximal mouth opening, neck and shoulder function, hand grip strength and lower body strength, level of mobility and walking ability.

Results: The SCNSs showed that 48% had a cancer generic unmet need and 46% had at least one HNC-specific unmet need. In total, 76% of sHNC had a cancer generic limitation in physical health and that 58% had an HNC-specific limitation in the mobility of neck and shoulders or maximum mouth opening. The domain of physical and daily living needs showed a weak association with lateral flexion of the neck to the left ($R = -0.319$; $p = 0.024$).

Conclusion: Survivors of HNC might benefit from the use of both SCNSs and physical performance measurements during usual care follow-up for early and optimal identification of unmet needs and limitations in physical health.

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1 | INTRODUCTION

Head and neck cancer (HNC) is a major healthcare issue, reflected by a worldwide incidence of more than 650.000 and mortality of over 330.000 persons per year. (Bray et al., 2018) Advancements in medical treatment and diagnosis have led to an increase in the number of survivors of Head and Neck Cancer (sHNC). In contrast, a high number of sHNC experience treatment-related morbidity causing deficits in physical, social, emotional and psychological health. These deficits influence the health-related quality of life (HRQoL) negatively. (Eickmeyer et al., 2014; Oskam et al., 2013; Wells et al., 2016) Physiotherapy, as part of the interdisciplinary treatment team, focuses on the treatment of limitations in physical health. Treatment indications are limitations in maximum mouth opening (MMO), neck and shoulders function, hand grip strength (HGS) and lower body strength, level of mobility and/or walking ability. (Dijkstra et al., 2006; Gane et al., 2019; Hinte et al., 2019; Lonbro et al., 2013; Nieuwenhuizen et al., 2018; Pauli et al., 2013; Rogers et al., 2006) The reported incidence of these physical limitations is high but varies considerably due to heterogeneous study populations, treatment modalities, and different methods of measurement. (Dijkstra et al., 2006; Gane et al., 2019; Hinte et al., 2019; Lonbro et al., 2013; Nieuwenhuizen et al., 2018; Pauli et al., 2013; Rogers et al., 2006) However, an important prerequisite for initiating physiotherapy intervention is adequate identification of sHNC with unmet needs or limitations in physical health. The identification of sHNC with unmet needs or limitations in physical health can be based on Patient Identified Problems (PIPs), and Non-Patient Identified Problems (NPIPs), as described by Rothstein et al. (Rothstein et al., 2003) The PIPs are defined as unmet needs or limitations expressed by sHNC during for example follow-up consultations. Identification of possible unmet needs or limitations requiring physiotherapy is thereby dependent on the ability of sHNC to express and recognise their limitations in physical health. This can result in an inconsistent referral and fragmented care. (Rodriguez et al., 2019) The identification of NPIPs concerns the unmet needs and limitations that remain unrecognised or unexpressed by sHNC. The NPIPs can be identified by the treatment team during follow-up based on clinical reasoning, physical performance measurements and patient-reported outcome measurements (PROMs). For example, a sHNC who is satisfied with being on a liquid diet and does not express any limitations during follow-up could still be identified with trismus through a simple measurement of MMO. This patient can consequently be made aware of the problem and its consequences, and possibly start treatment. The identification of NPIPs is important because when left untreated, limitations in physical health can negatively influence treatment-related morbidity and HRQoL. (Capozzi et al., 2016; Oskam et al., 2013; Wells et al., 2016).

The identification of unmet needs and limitations in physical health can therefore possibly be optimised by routinely using supportive care needs surveys (SCNSs) and physical performance measurements during follow-ups. (Berezowska et al., 2019; Shunmuga Sundaram et al., 2019) SCNSs offer valid and reliable PROMs that give insight into the level and area of the experienced unmet needs in physical health but the use of SCNSs shows great variation across

HNC treatment centres. (Jansen, Witte, et al., 2016) Physical performance measurements alternatively offer objective outcomes on limitations in physical health. Limitations in physical health can be objectified for each sHNC with the use of age- and sex-stratified reference values. Physical performance measurements are currently no routine part of clinical follow-up and are mainly performed for research purposes. (Douma et al., 2019).

This study, therefore, aims to get insight into the level of unmet needs and limitations in physical health as measured with SCNSs and physical performance measurements for sHNC. The secondary aim of this study was to assess whether unmet needs in physical health as identified by SCNSs, and limitations in physical health as identified with physical performance measurements measure the same construct within physical health. If they measure the same construct, there would be no need for implementing both methods during clinical follow-up consultations. It was hypothesised that worse performance on physical performance measurements would be associated with more unmet needs measuring the most similar construct in physical health. The findings of this study could help to optimise the identification of sHNC with limitations in physical health.

2 | METHODS

2.1 | Study setting and participants

Participants for this cross-sectional study were recruited between January 2018 and June 2019. Two convenient samples were used. The first group was approached during patient support group meetings of the Dutch Head and Neck Oncology patient federation. The second group consisted of sHNCs scheduled for usual care follow-up appointments at Radboud university medical center (Radboudumc, Nijmegen, the Netherlands). Measurements took place at the physiotherapy department of the Radboudumc in Nijmegen, the Netherlands. sHNC were included in this study when they completed medical treatment and were 18 years or older. sHNC were excluded from this study when they were not able to speak or understand Dutch, were receiving palliative care or were at risk when performing physical measurements. Safety and possible risks during physical measurements were assessed before inclusion, using the modified Physical Activity Readiness Questionnaire (PARQ). Participants were also excluded if they answered both yes to one or more out of seven questions of the PARQ and were judged to be unsafe to participate in exercise after patients contacted their general practitioner. (Shephard, 1988; Thomas et al., 1992) Prior to the physical measurements written consent was obtained. This study was conducted according to the principles of the Declaration of Helsinki (64th version, October 19th, 2013). The protocol (NL2017-3508) was approved by the Ethics Committee of the Radboudumc. The electronic data capture (EDC) program of Castor (Ciwit BV, Amsterdam, the Netherlands; <http://www.castoredc.com>) was used for filling out the questionnaires by the participating sHNC in this study and for storing all physical performance measurement data.

2.2 | Measurements

Cancer generic unmet needs were measured with the Supportive Care Needs Survey Short-Form 34 (SCNS-SF34). Head and neck cancer-specific unmet needs were identified with the Supportive Care Needs Survey Head and Neck Cancer (SCNS-HNC). (Boyes et al., 2009).

Cancer generic limitations in physical health were identified with physical performance measurements on HGS and lower body strength, the level of mobility and walking ability. sHNC-specific limitations in physical health were measured for MMO, and neck and shoulder function. (Douma et al., 2019) Limitations in physical health were defined as participants scoring 80% or lower on the physical performance measurement in relation to validated age and sex reference values. The cut-off value of 80% was based on the author's expert opinion and considers the previously published measurement errors. (Hinte et al., 2020).

2.2.1 | Supportive care needs surveys

The SCNS-SF34 was used to measure generic cancer-related unmet needs as experienced in the last month. It consists of 4 underlying domains using 34 items: physical and daily living needs (5 items), psychological needs (10 items), sexuality needs (3 items), health system need (1 item), and information and patient support needs (15 items). (Boyes et al., 2009; Jansen, Witte, et al., 2016) Each item can be scored on a 5-point scale. Each scale can be divided into a 'no need' category (1 = not applicable, for issues that were no problem to the patient; 2 = satisfied, for issues on which a patient needed support but the support was satisfactory) and a 'need' category that has three subcategories (3 = low need, 4 = moderate need, and 5 = high need) indicating the level of need for additional care. To interpret this, scores of 2 or lower indicate no unmet need, and scores higher than 2 indicate some level of unmet need. A standardised Likert summated for unmet needs per domain can be calculated and converted to a standardised 0 to 100 score, with a higher score indicating a higher level of need. For this study only, the physical and daily living needs domain was used.

The SCNS-HNC measured HNC-specific unmet needs for supportive care in the last month. It measures the need for supportive care for 11 HNC-specific issues using the same scaling (1 to 5 Likert scale) as the SCNS-SF34 added by one single free-text item in which patients could report any additional needs. (Jansen, Witte, et al., 2016) For this study, next to the total score, we selected the questions with relevant outcomes in physical health. These were question 1: 'Do you have an unmet need for help with problems with chewing and/or swallowing?' and question 9: 'Do you have an unmet need or problem in the mobility of neck and shoulders?'

Both the SCNS-SF34 and SCNS-HNC were found to be reliable and valid in Dutch. (Jansen, Witte, et al., 2016) The test-retest reliability of SCNS-SF34 and SCNS-HNC domains shows Intraclass

Correlation Coefficients (ICC's) of 0.74 to 0.83. (Jansen, Witte, et al., 2016).

2.2.2 | Physical performance measurements

Maximum mouth opening

The MMO was measured intra-orally with a cardboard ruler (TheraBite® Range of Motion Scale, Atos Medical Inc., New Berlin, Wisconsin, United States). The measurement of MMO with a cardboard ruler is found test-retest reliable (ICC of 0.95), with a Smallest Detectable Change (SDC) of 6.6 mm. (Hinte et al., 2020) To determine whether limitations were present reference values corrected for age and sex were used as published by Gallagher et al. (Gallagher et al., 2004).

Neck function

The CROM® (Cervical Range of Motion Instrument; Performance Attainment Associates, Lindstrom, Minnesota, USA) was used to measure the lateral flexion and rotation of the neck. (Audette et al., 2010) These measurements have been demonstrated to be reliable with an ICC between 0.79 and 0.87 and SDCs between 10.64 and 15.44 degrees. (Hinte et al., 2020) Reference values corrected for age and sex as described by Youdas et al. for the cervical range of movement were used. (Youdas et al., 1992).

Shoulder function

Shoulder abduction of the left and right side was measured with a digital inclinometer (Baseline® Digital Inclinometer, Fabrication Enterprises Inc., White Plains, New York, USA), which has an ICC of 0.77 and 0.81 for test-retest reliability and an SDC of 36.68 and 31.27 degrees respectively. Reference values corrected for age and sex for the abduction of the shoulder as reported by Stathokostas et al. were used. (Stathokostas et al., 2013) For participants younger than 55 years of age, reference values were not reported and a reference for 55-year-old persons (142°) was used. (Stathokostas et al., 2013).

2.2.3 | Hand grip strength

Hand grip strength was measured for the left and right hand by the JAMAR® hand-held dynamometer (Sammons Preston Rolyan, Warrenville, Illinois, USA) with an ICC of 0.88 and 0.96 for test-retest reliability, and SDC of 12.96 and 8.26 kilograms, respectively. (Hinte et al., 2020) Reference values corrected for age and sex were used as described by Dodds et al. (Dodds et al., 2016).

Lower body strength

Lower body strength was measured with the Thirty Seconds Chair To Stand test (30-SCTS). (Jones et al., 1999) The 30-SCST has been found test-retest reliable with an ICC of 0.92 and SDC of 2.96 repetitions. (Hinte et al., 2020) Reference values corrected for age and sex

for community-dwelling elderly as described by Jones and Rikli were used. (Jones et al., 1999).

Timed up and go test

The level of mobility was measured with the Timed Up and Go test (TUG). The measurement of the level of mobility measured with TUG has been found test-retest reliable with an ICC 0.98 and an SDC of 1.54 seconds. (Hinte et al., 2020) Reference values for designated age groups were used (60 to 69, 8.1 seconds; 70 to 79, 9.2 seconds; 80 to 99, 11.3 seconds. (Steffen et al., 2002) In the case of age below 60, the lowest value was used (8.1 seconds). (Steffen et al., 2002).

Six minute walking test

Walking ability was evaluated using a self-paced six minute walking test (6 MWT) on a 20-meter circuit. (Steffen et al., 2002) The measurement of walking ability with the 6 MWT has been found test-retest reliable with an ICC of 0.97 and an SDC of 56.67 metres. (Hinte et al., 2020) For reference values, we used the age- and sex-stratified regression formula as described by Gibbons et al. (Gibbons et al., 2001).

Statistical analysis

The demographic, personal and clinical characteristics of sHNC were described. Categorical data were presented as exact numbers and percentages. For normal distributed continuous data, means and standard deviations (SD) were calculated. For ordinal and non-normal distributed continuous data, medians and interquartile

ranges (IQR; the difference between the 25th and 75th percentile) were calculated. Differences between the two included groups of sHNC (patient federation group versus the Radboudumc routine follow up group) were analysed with independent samples T tests for normally distributed data and the Mann-Whitney U test for not normally distributed data. Chi-square tests were used for nominal and ordinal data. Unmet needs as identified with SCNS-SF34 and SCNS-HNC were presented for the physical and daily living needs domain score and single-item scores. Limitations in physical health as identified with physical performance measurements were presented as a percentage of the age- and sex-corrected reference values. In all analyses, two-sided p-values <0.05 were considered to be statistically significant. All analyses were performed using SPSS version 25 (SPSS Inc, Chicago, Illinois, USA).

Bivariable analyses

To determine the strength of the association between unmet needs as measured with SCNSs and limitations in physical health, we formulated hypotheses (see also Table 1). Cancer generic unmet needs as measured by the SCNS-SF34 physical and daily living needs domain score were hypothesised to be associated with limitations in physical health as measured with cancer generic physical performance measurements. HNC-specific unmet physical needs (SCNS-HNC) were hypothesised to be associated with physical performance measurement which measured a similar HNC-specific construct (questions 1 and 9). For example, question 9 of the SCNS-HNC: 'Do you have an

TABLE 1 Associations between unmet needs identified with Supportive Care needs Surveys and limitations in physical health as measured with physical performance tests

Unmet needs identified with SCNS domain/item	Limitations in physical health identified with physical performance measurements	Association R	p-value	OR	95% CI
Hypothesised strong relationship					
SCNS-SF34 Physical & Daily Living Needs Domain	Upper body strength	0.251	0.079		
	Lower body strength	0.160	0.268		
	Level of mobility	-0.153	0.287		
	Walking ability	-0.023	0.876		
SCNS-HNC, Question 1: problems with chewing and/or swallowing	Maximum Mouth Opening			0.286	0.031-2.556
SCNS-HNC, Question 9: problems with mobility of neck and shoulders	Shoulder abduction left			n/a	n/a
	Shoulder abduction right			n/a	n/a
	Lateral flexion neck left			2.488	0.741-8.350
	Lateral flexion neck right			1.200	0.250-5.760
Hypothesised moderate relationship					
SCNS-SF34 Physical & Daily Living Needs Domain	Shoulder abduction left	-0.195	0.175		
	Shoulder abduction right	-0.121	0.402		
	Lateral flexion neck left	-0.319	0.024*		
	Lateral flexion neck right	-0.021	0.885		

Abbreviations: AUC: Area Under the Curve; SCNS-SF34: Supportive Care Needs Survey Short-Form 34; SCNS-HNC: Supportive Care Needs Survey Head and Neck Cancer module; OR: Odds Ratio; N/A: not applicable (to small number of sHNC with limitations); * ($p < 0.05$)

*: $p < 0.05$

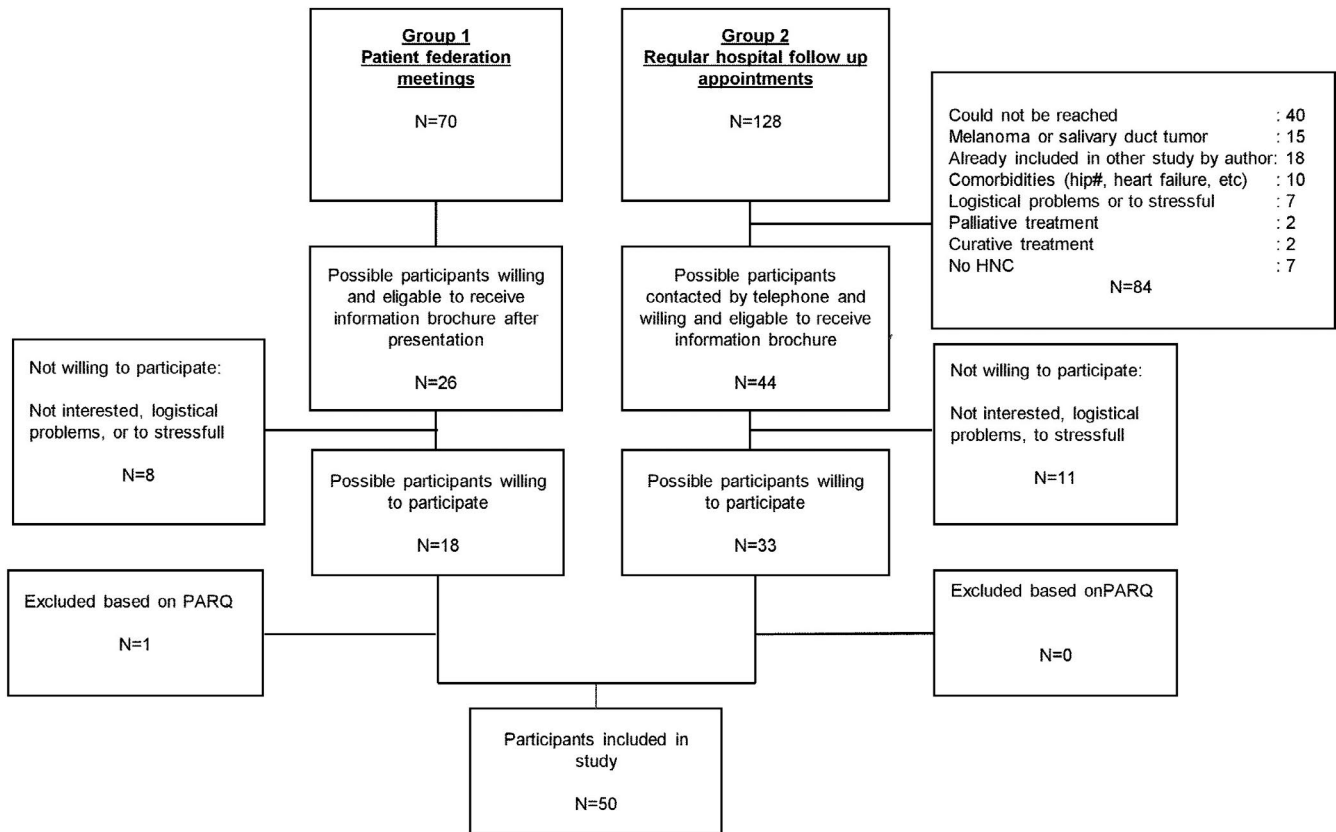


FIGURE 1 Recruitment and enrollment participants HNC, head and neck cancer; PARQ, Physical Activity Readiness Questionnaire

unmet need in the mobility of neck and shoulders?' was expected to show association with limitations in shoulder abduction. An association smaller than 0.50 was defined as weak, 0.50 to 0.75 as moderate and greater than 0.75 as strong. (Portney, 2014).

Association analyses were performed using Pearson correlation coefficients for normally distributed data and Spearman's Rho for non-normally distributed data. A chi-square analysis was performed to test the association between unmet needs (yes/no) for questions 1 and 9 of the SCNS-HNC, and limitations in physical performance dichotomised (yes/no). An OR below or above 1 was regarded as an indication of association, while a proxy for statistical significance was considered if the Confidence interval of the OR did not include a value of 1. (Szumilas, 2010).

Multivariable analysis

The hypothesised associations were checked for the influence of confounding variables as known in literature (age, sex, years of HNC survivorship, number of physiotherapy treatments) (Douma et al., 2019) and the included group (patient federation or usual care follow-up). The magnitude of associations was verified through binary logistic and linear regression model analysis. To determine the maximum number of variables to be included in the regression model, we used the rule of thumb of 10 patients per determinant. Consequently, our sample of 50 patient allowed to include a maximum of 5 variables into the regression model. No multicollinearity ($rp > 0.60$) was found.

3 | RESULTS

In total, 50 sHNC participated in this study, of which 29 were male and 21 were female. The mean age of all participants was 69 years (SD 9.9). The median time of cancer survivorship was 3 years (IQR 1.0 – 5.25). In the patient federation, 18 out of 70 asked patients agreed to participate. In the usual care follow-up group, 33 out of 128 patients agreed to participate. The flow chart of the recruitment and enrolment of participants is depicted in Fig. 1 Demographic, participant and treatment characteristics for the two included groups of participants are depicted in Table 2. The usual care follow-up group consisted of more females ($p = 0.04$), showed fewer years of cancer survivorship ($p = 0.02$) and the tumour location was different compared to the patient federation group ($p = 0.00$).

In the SCNS-SF34 physical and daily living needs domain, 48% of the sHNC reported one or more cancer generic unmet needs. In total, 46% of sHNC reported at least one HNC-specific unmet need (SCNS-HNC) as measured with question 1 and 9. An oversight of unmet needs identified with SCNSs is depicted in Table 3.

Identifying limitations in physical health with the use of physical performance measurements demonstrated that 76% of the sHNC had at least 1 cancer generic limitation. Cancer generic limitations in physical health in sHNC were measured for HGS and lower body strength (both 30%) and walking ability (70%). HNC-specific limitations in physical health were measured in 16% of the sHNC for MMO

TABLE 2 Demographic, participant and treatment characteristics

Characteristic	Patient federation Group N = 17	SD IQR Percentage	Usual care follow-up Group N = 33	SD IQR Percentage	P
Sex					
Male (%)	13	76.5%	15	45.5%	0.04*
Female (%)	4	23.5%	18	54.5%	
Age (years) (mean, SD)	68.3	8.0	68.7	10.9	0.46
Body Mass index (median, IQR)	25.3	23.3 – 27.5	25.4	23.9 – 26.2	0.90
Smoking Yes (%)	0	-	4	12.1%	
No, but used to (%)	16	94.1%	23	69.7%	0.13
No (%)	1	5.9%	6	18.2%	
Pack-years in history (median, IQR)	26.3	12.5 – 45	15	1.9 – 23.0	0.15
Alcohol usage (>1 daily)					
Yes (%)	9	52.9%	13	39.4%	0.32
No (%)	8	47.1%	20	60.6%	
Glasses per day (median, IQR)	1	0.0 – 3.0	0	0.0 – 1.5	0.28
Level of education					
Lower (%)	7	41.2%	14	42.4%	
Middle (%)	8	47.1%	9	27.3%	0.33
Higher (%)	2	11.8%	10	30.3%	
Social status					
Living alone (%)	5	29.4%	11	33.3%	0.78
Living with a partner (%)	12	70.6%	22	66.7%	
Years since cancer treatment (median, IQR)	4.0	2.0 – 10.5	2	1.0 – 4.5	0.02*
Tumour location					
Oral cavity (%)	1	5.9%	27	81.8%	
Nasopharynx (%)	0	0.0%	1	3.0%	
Oropharynx (%)	1	5.9%	1	3.0%	0.00*
Larynx (%)	12	70.6%	0	-	
Other (%)	3	17.6%	4	12.1%	
Oncology treatment					
Surgery (%)	3	17.6%	16	48.5%	
Surgery and radiotherapy (%)	9	52.9%	9	27.3%	
Radiotherapy (%)	1	5.9%	3	9.1%	0.24
Surgery, radiotherapy and chemotherapy (%)	3	17.6%	4	12.1%	
Radiotherapy +chemotherapy (%)	1	5.9%	1	3.0%	
Neck dissection					
Unilateral (%)	3	17.6%	19	57.6%	
Bilateral (%)	2	11.8%	4	12.1%	0.17
No (%)	12	70.6%	10	30.3%	

Abbreviations: IQR: Interquartile range; SD: Standard deviation;

* $p < 0.05$

and 6% and 8% shoulder abduction for the left and right shoulder respectively. In total, 58% of sHNC demonstrated at least one HNC-specific limitation in physical health. Specified information on limitations in physical health as identified with physical performance tests is presented in Table 4.

3.1.1 | Bivariable association analyses

Unmet needs identified in the physical and daily living needs domain score (SCNS-SF34) showed no association with limitations in physical health as identified with the measurements on physical

TABLE 3 Generic and head and neck cancer-specific unmet physical needs for supportive care.

	Number of items	Number of patients with a need	Percentage of patients with at least 1 unmet need	Mean total domain score (SD)	Median total domain score (IQR)
SCNS-SF34	34	35	70%	-	-
Physical & daily living domain	5	24	48%	18.5 (20.1)	15 (0 - 25)
Question 1: Pain	1	13	26%	-	-
Question 2: Lack of energy/ tiredness	1	18	36%	-	-
Question 3: Feeling unwell a lot of the time	1	5	10%	-	-
Question 4: Work around the home	1	11	22%	-	-
Question 5: Not being able to do things you used to do	1	10	20%	-	-
SCNS-HNC	11	42	84%	-	-
Head and neck cancer-specific functioning total domain score	9	37	74%	26.5 (20.1)	23.3 (12.5 - 40.6)
Question 1: Problems with chewing and/or swallowing	1	15	30%		
Question 9: Problems with mobility of neck and/or shoulders	1	17	34%		
Question 1 & 9: total number of participants reporting HNC-specific unmet needs.	2	23	46%		

Abbreviations: SCNS-SF34: Supportive Care Needs Survey 34-item short-form survey; SCNS-HNC: Supportive Care Needs Survey Head and Neck Cancer Module; SD: standard deviation; IQR: interquartile range.

TABLE 4 Cancer generic and head and neck cancer-specific physical limitations

Physical outcome	Test	Mean (SD)	Median (IQR)	Number of patients $\geq 20\%$ under reference value of 100%	Number of patients $\geq 40\%$ under reference value of 100%
Maximum opening of the mouth	Therabite cardboard ruler	106% (25%)	108% (78%–138%)	8* (16%)	3 (6%)
Shoulder abduction left	Digital inclinometer	114% (18%)	119% (106%–132%)	3 (6%)	1 (2%)
Shoulder abduction right	Digital inclinometer	115% (18%)	115% (98%–132%)	4 (8%)	0 (0%)
Lateral flexion neck left	CROM	108% (34%)	105% (54%–156%)	13 (26%)	1 (2%)
Lateral flexion neck right	CROM	112% (35%)	107% (70%–144%)	7 (14%)	2 (4%)
Rotation neck left	CROM	118% (25%)	118% (84%–152%)	1 (2%)	0 (0%)
Rotation neck right	CROM	116% (24%)	114% (83%–145%)	3 (6%)	1 (2%)
Lower body strength	30SCST	92% (31%)	93% (59%–127%)	15 (30%)	8 (16%)
Upper body strength	Grip Strength	99% (36%)	97% (43%–151%)	15 (30%)	7 (14%)
Level of mobility	TUG	127% (35%)	130% (80%–180%)	6 (12%)	2 (4%)
Walking ability	6 MWT	71% (19%)	73% (59%–97%)	35 (70%)	11 (22%)
HNC-specific limitations	Therabite cardboard ruler, digital inclinometer, CROM	n/a	n/a	29 (58%)	4 (8%)
Cancer generic limitations	30SCST, Grip Strength, TUG, 6 MWT	n/a	n/a	38 (76%)	17 (34%)

Abbreviations: CROM=Cervical Range Of Motion, IQR Interquartile Range, N/a: Not Applicable, SD =Standard Deviation, TUG =Timed up and Go Test, 6 MWT =Six Minute Walk Test, 30SCST =30 seconds Chair to Stand Test

performance except for a weak association between the domain score of physical health and lateral flexion of the neck to the left ($R = -0.319$; $p = 0.024$). Unmet needs identified with the SCNS-HNC question 1: 'Do you experience problems with chewing and/or swallowing?' showed no significant association with the measurements on MMO (OR 0.286; CI 0.031 – 2.556). Unmet needs identified with the SCNS-HNC for question 9: 'Do you experience problems with mobility of neck and shoulders?' showed no significant association with the left lateral flexion of the neck (OR 2.488; CI 0.741 – 8.350). All bivariable association outcomes are presented in Table 1.

3.1.2 | Multivariable analysis

The corrected models revealed no significant effect of the possible confounders on the associations as hypothesised in this study or demonstrated in the bivariable analysis.

4 | DISCUSSION

The primary aim of this study was to gain insight into the level of unmet needs and limitations in physical health experienced by sHNC, and to research if unmet needs in physical health and limitations in physical health showed an association. This insight could improve the referral to physiotherapists and thereby optimise patient care and HRQoL. It was shown that a high number of sHNC experience cancer generic, and HNC-specific unmet needs and limitations in physical health as measured with SCNSs and physical performance measurements. More specifically, a higher percentage of sHNC showed generic limitations (76%) compared to generic unmet needs (48%). For HNC-specific limitations (58%) and unmet needs (46%), this difference was in the same direction, but smaller. This could indicate that generic and HNC-specific measurements in part overlap but also measure different constructs. This was confirmed when we only found two limited associations based on our predefined hypotheses. The association found between the domain of physical health and lateral flexion of the neck was weak. This could be explained by the limited rationale for an association between a generic domain score and a specific range of motion measurement. The association found between the HNC-specific question about neck and shoulder mobility and lateral flexion of the neck to the left does have a clear rationale but is not significant. The confidence interval of the Odds Ratio (OR 2.488; CI 0.741 – 8.350) is wide and contains the value of 1 which limits the strength of the association. No other associations between unmet needs in physical health and limitations in physical performance measurements were found. This indicates that unmet needs as identified by SCNSs and physical measurements focus on different constructs, which is in line with the findings of other authors. (Boyes et al., 2012; Hamilton et al., 2017; Kotronoulas et al., 2014) The high level of cancer generic limitations found with physical performance measurements that did not associate with unmet

needs could indicate that sHNC do not report problems concerning strength or walking distance. These NPIPs can severely impact HRQoL and are therefore important to identify. (Nieuwenhuizen et al., 2018) The measurement of unmet needs based on these SCNSs is therefore unlikely to provide complete and optimal identification of PIPs and NPIPs in physical health for sHNC. Therefore, these SCNSs could be combined with objective measured physical performance measurements. (Boyes et al., 2012; Kotronoulas et al., 2014).

4.1.1 | Unmet needs identified with Supportive Care Needs Surveys

In our study, the number of sHNC reporting generic unmet needs measured with the SCNS-SF34 (48%) is in line with previous research on sHNC with a total laryngectomy (37%). (Jansen et al., 2018) Wells et al. describe that most unmet needs are in the physical and daily living needs domain; however, there is a lack of specified data to compare our findings. (Wells et al., 2015) The study of Giuliani et al. only reports single items in the domain of physical health (e.g. 'unmet needs in comprehensive personal recovery and rehabilitation assessment/clinic' (23.2%)), and these numbers are comparable to SCNS-SF34 single items in our study regarding 'not being able to do the things you used to do' and 'work around the house'. (Giuliani et al., 2016) The number of generic unmet needs in our study is slightly lower in comparison with the general cancer survivor population of which 66% reported unmet needs in physical health. (Jansen et al., 2015) This could be due to the specific socio-economic distribution of sHNC which can lead to avoidance of care and an underreport of unmet needs. (O'Brien et al., 2017).

We used the SCNS-SF34 and SCNS-HNC to identify unmet needs because they are used most frequently in HNC research and have both been validated in Dutch for HNC patients. (Jansen, Witte, et al., 2016) We dichotomised the 5-point SCNS scales into yes/no unmet needs which limits the ability to differentiate between patients. Patients that reported no needs or have unmet needs that were met were both scored as no need. The level of unmet needs (low, moderate and high) was also lost in the dichotomisation. It would be of interest to look into specific subgroups of patients and for example the patients who report that their needs were met and explore possible association with limitations in physical health or reported use of physiotherapy. Other PROMs that can be used as the distress thermometer have limitations. The distress thermometer is not a cancer-specific instrument, and it measures the presence of problems, not unmet needs or physical limitations. Taking into account the widespread use of the distress thermometer, it would be of interest to include the distress thermometer in future studies to evaluate its association with the other two methods of identifying unmet needs. Unmet needs can also be identified through the widely used EORTC-QLQ-C30 and EORTC-QLQ-HN35. However, the studies that provided the cut-off values used the SCNS-SF34 as a

criterion. This indicates that SCNS-SF34 can be regarded as the primary and most optimal measurement for the identification of unmet needs. But we acknowledge that the widespread use of the EORTC questionnaires would advocate future research into association between unmet needs as identified by the EORTC questionnaires and limitations in physical health as identified by physical performance tests. (Jansen et al., 2016; Snyder et al., 2010, 2013).

The use of PROMs, like SCNSs, to identify problems and/or unmet needs during follow-up consultations in cancer care is a point of debate. PROMs offer a time-efficient and practical method of gaining insight into for example distress, unmet needs, health problems and HRQoL. (Kotronoulas et al., 2014) However, efficacy can be limited by patient adherence, interpretation and response handling by treating physicians. (Duman-Lubberding et al., 2015; Kotronoulas et al., 2014) In HNC care, an eHealth application like Oncokompas that uses PROMs to support self-management of symptoms/needs and HRQoL provides tailored advice to sHNC on allied health care. Research has shown it to be feasible, equally effective on utilities, and not more expensive than usual care. (Duman-Lubberding et al., 2016; Hout et al., 2020; Van Der Hout et al., 2017).

However, our study has shown that a large part of the limitations in physical health is likely to remain unreported or unidentified with the use of PROMs as a single method of identification. Survivors of HNC could therefore benefit from the identification and objectification of limitations in physical health with the use of a core set of physical performance measurements. The challenge thereby lies in providing patient-tailored, effective, and practical methods of identifying limitations in physical performance for supportive care without overdemanding sHNC. This is confirmed by research that states that sHNC feel that allied health professional care is not needed or beneficial due to a blanket approach, and more targeted allied health professional care would be beneficial. (Rocke et al., 2020).

4.1.2 | Unmet needs identified with physical performance measurements

Physical measurements are currently no routine part of sHNC follow-up consultations and are mainly used for research purposes or during physiotherapy care. (Douma et al., 2019).

Our study is unique in the fact that it relates sHNC physical performance measurement outcomes to sHNC to age and sex-stratified reference values. To determine whether a survivor has limitations in physical health, the age and sex-stratified reference values were chosen based on expert opinion and guideline recommendations but are known to vary among populations and measurement protocol used. (Dodds et al., 2016; Salbach et al., 2015) The reference values used have not been validated for use with sHNC, which may have led to over- or underestimation of performance. The use of the 80% cut-off value to identify problems in physical health with the use of physical performance measurements is arbitrary. A possible benefit of the use of physical performance measurements is the ability to objectify both patient-reported problems in physical health as

non-patient identified problems. (Rothstein et al., 2003) The 80% percent was chosen to take into account measurement error as we previously published for the physical performance measurements used. (Hinte et al., 2020) The reference values give insight into sHNC performance in comparison with age and gender stratified healthy peers, but it is unclear whether recovery up to the level of healthy peers can be expected in the sHNC population.

4.1.3 | Physical performance related to age and sex-stratified reference values

The number of sHNC that showed limitations in MMO is nearly the same compared to when the criteria for trismus (MMO ≤ 35 mm) would have been used (16% versus 18%). These numbers are lower than trismus incidence for sHNC reported in the literature. (Kamstra et al., 2017) However, this could be explained by the shorter moment of survivorship during measurement in these studies (<1 year). (Wetzels et al., 2014).

A remarkable finding was that measured AROM for shoulder in sHNC was predominantly as good or better than the reference values. Research confirms that shoulder function significantly deteriorates after the medical intervention to restore up to normal after 1 year of follow-up with except for sHNC with a high-risk profile. (Gane et al., 2019; Hinte et al., 2019; Speksnijder et al., 2013; Wilgen et al., 2004) This study also showed that a high percentage of sHNC had reduced HGS (30%) and lower body strength (30%) and walking ability (70%). This indicates that sHNC are weaker and less mobile compared with healthy peers. This is in line with research that indicates that sHNC are more sedentary and less physical active, which results in less strength and endurance which is related to a lower HRQoL. (Nieuwenhuizen et al., 2018; Rogers et al., 2006; Sammut et al., 2014).

4.1.4 | Strengths and limitations

The cross-sectional design, patient-reported treatment-related variables, and a relatively long median survivorship time of 3 years gives insight into the physical health status of the population of sHNC. The cross-sectional design prevents insight into causal relationships or different phases during the course of reported unmet needs and limitations in physical performance during cancer survivorship. The participation rate for the two groups in this study was low; patient federation group (24%), hospital follow-up group (26%). (Hinte et al., 2020) The participants possibly represented a 'relatively active' selection of sHNC because they all were living independently, were mobile without walking aid and did not have comorbidities that prevented them from safely performing the physical measurements. These two factors could indicate a possible participation bias, with only the actively persons engaged. The relatively high percentage of females in this study is not in line with other studies researching sHNC possibly caused by

volunteer bias. The study included 50 sHNC where other publications on unmet needs in sHNC included larger populations. (Boyes et al., 2012; Jansen et al., 2018; Wells et al., 2015) We transformed the outcomes of the SCNSs into a binary outcome (yes/no needs) which removed the level need (low, moderate, high) from the analysis.

The primary strength is that this study combines PROMs and objective physical measurements to identify sHNC with unmet needs in physical health. Another strength of this study is the two groups of participants that more accurately reflect all types of sHNC and the use of an electronic data capture system that ensured completion of all questionnaires without missing data. The physical performance measurements also had no missing data.

4.1.5 | Future research

Future research could be focussed on the longitudinal course of unmet needs and limitations in physical performance in physical health for sHNC. Secondary, research into the most optimal SCNSs and physical performance measurements could optimise the identification of sHNC with reported and unreported limitations in physical health. The SCNSs used in this study are not physiotherapy specific, and an interdisciplinary diagnostic analysis with the use of shared decision-making should take place to find an optimal and adequate healthcare plan. This future research could improve the referral of sHNC with unmet needs or limitations in physical health to allied healthcare professionals as physiotherapists and improve research into patient-tailored interventions in physical health.

4.1.6 | Conclusion

This study showed that sHNC experience both a high level of unmet needs and limitations in physical health. The domain of physical and daily living needs showed a weak and less clinically relevant association with lateral flexion of the neck to the left ($R = -0.319$; $p = 0.024$). Unmet needs in physical health as identified with SCNS-SF-34 and SCNS-HNC do not associate with limitations in physical health as identified with physical performance measurements, indicating that they measure a different construct. Identification of sHNC with unmet needs or limitations in physical health might benefit from the addition of physical performance measurements during follow-up. This could lead to better patient awareness regarding physical health and optimisation of referral of sHNC to specialized physiotherapy.

5 | MEETINGS AT WHICH THE MANUSCRIPT WAS PRESENTED, IF APPROPRIATE

None.

6 | CONFLICT-OF-INTEREST STATEMENT

The authors have no conflicts of interest to declare. All co-authors have seen and agree with the contents of the manuscript, and there is no financial interest to report. We certify that the submission is original work and is not under review at any other publication.

7 | STATEMENT OF CONTRIBUTION

Gerben van Hinte: Conceptualisation; Methodology; Formal analysis; Investigation; Data Curation; Writing—Original Draft; Writing—Review and Editing; Visualisation; Project administration; Funding acquisition. **Ruud A. Leijendekkers:** Formal analysis; Investigation; Writing—Review and Editing; Visualisation; Project administration. **Matthias A.W. Merckx:** Conceptualisation; Methodology; Writing—Review and Editing. **Robert P. Takes:** Conceptualisation; Methodology; Writing—Review and Editing. **Maria W.G. Nijhuis-van der Sanden:** Conceptualisation; Methodology; Writing—Review and Editing; Supervision. **Caroline M. Speksnijder:** Conceptualisation; Methodology; Writing—Review and Editing; Supervision.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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