



Post-traumatic stress in head and neck cancer survivors and their partners

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Abstract

Purpose Head and neck cancer (HNC) diagnosis and treatment are distressing and have immediate detrimental impacts on functioning and quality of life (QoL). Nevertheless, little is known about long-term psychosocial effects. The aim of this study was to determine the prevalence and correlates of clinical post-traumatic stress disorder (PTSD) and subclinical post-traumatic stress symptoms (PTSS) in HNC patients surviving more than 2 years since treatment and in their partners.

Methods HNC survivors identified from the cancer registry of a London hospital and their partners completed measures of PTSS, depression and anxiety, fear of cancer recurrence, social support, appearance concerns and health-related QoL. Data regarding their clinical and demographic characteristics were also collected. Correlations, as well as linear and logistic regression coefficients, were calculated to estimate associations with PTSS scores.

Results In this analysis of 93 HNC survivors, at a mean of 6 years (SD = 4) after treatment, 33.4% reported PTSS and 11.8% met the criteria for post-traumatic stress disorder (PTSD). Fear of cancer recurrence was independently associated with PTSS ($p < .01$). In subgroup analyses of patient-partner dyads, 15.4% of patients and 12.8% of partners reported PTSD, with a further 33.3% of patients and 25.7% of partners demonstrating PTSS. Patients' and partners' scores did not differ significantly ($p > .05$).

Conclusions This is the first examination of post-traumatic stress in survivors of HNC and shows that high levels of cancer-related PTSS exist for many years after diagnosis in both patients and their partners.

Keywords Cancer · Head and neck neoplasms · Survivors · Caregivers · Post-traumatic stress disorder

Background

Head and neck cancer (HNC) is currently the sixth most common cancer worldwide [1, 2] with a steadily increasing incidence [3]. Five-year survival rates have risen to around 50% with an increase of cases related to human papillomavirus (HPV) infection. HPV-positive HNC patients are much younger and have a better prognosis [4, 5]. Thus, there are more HNC survivors facing long-term sequelae of HNC treatment. HNC is now better viewed as a chronic disease making quality of life (QoL) and overall wellbeing as treatment outcomes

highly relevant. Depending on the site, HNC can significantly impact eating, drinking, swallowing, appearance and social interaction, with marked adverse effects on QoL and psychosocial function [3, 6, 7].

The focus of HNC studies has been more on the potential demographic, functional and clinical characteristics associated with survivorship and QoL [8], whereas psychosocial factors, particularly depression and anxiety, are the factors most strongly associated with poorer QoL [9]. In survivors (i.e. those who have completed their primary treatment for HNC), prevalence rates for clinically significant symptoms of depression and anxiety are reported as 19–31 and 16%, respectively [10, 9]. Caregivers of HNC patients are also at risk for psychological distress and previous studies have suggested that caregivers may suffer equal or even higher levels of distress than patients [11, 12]. A diagnosis of HNC places a significant burden on the patients' carers [11], but less is known about the specific issues they face.

HNC treatment can be intrusive resulting in permanent functional and disfiguring changes, thereby increasing the

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likelihood of a post-traumatic stress reaction. Despite the potentially highly traumatic nature of HNC [13], the prevalence of post-traumatic stress symptoms (PTSS) and post-traumatic stress disorder (PTSD) in long-term HNC survivors has not been investigated. PTSD is a psychiatric condition that affects some people when they have witnessed or experienced a traumatic event involving the risk of serious injury or death [14]. Symptoms such as flashbacks, avoiding cancer-related experiences and increased anxiety have been reported in other cancer survivor groups with PTSD prevalence rates of 5–17% [15–18]. In newly diagnosed HNC patients, 12% of patients and 29% of partners met the criteria for PTSD caseness [19]. Richardson and colleagues (2016) found that 19% of HNC patients [20] and their caregivers [21] met the criteria for PTSD 6 months after treatment. To the best of the authors' knowledge, there have been no studies investigating whether cancer-related PTSS exist in long-term HNC survivors and in their partners. Therefore, the purpose of this study was to (i) estimate the prevalence of PTSS in a cohort of British HNC survivors, (ii) identify potential demographic and clinical and psychosocial correlates of PTSS and (iii) compare PTSS levels in a subgroup of HNC survivors and their partners.

Methods

Participants

Prospective participants were identified through the cancer registry at Barts Health NHS Trust. Eligible patients were those who had received a diagnosis of HNC, had completed active treatment (i.e. were in the follow-up phase) and were \geq 2 years after diagnosis. Potential participants were sent an invitation letter asking whether they would be willing for the research team to invite their spouse to the study.

The study questionnaires along with the information sheet and consent forms were mailed to those interested in participating. Patients and their partners were provided with separate postage-paid return envelopes. No financial incentives or any other forms of compensation were used. Ethics approval was obtained from the Office for Research Ethics Committees Northern Ireland (ORECNI) (Reference: 15/NI/0009).

Measures

Demographic and clinical variables

Sociodemographic information sought included gender, ethnicity, education, marital status and work status. Clinical variables included cancer site and stage, treatment type, time since treatment and whether there had been a recurrence. Medical comorbidity was measured using the Self-Administered Comorbidity Questionnaire (SCQ) [22]. Participants' self-reported history of

anxiety or depression preceding their HNC diagnosis was also evaluated.

Psychosocial variables and QoL

The Hospital Anxiety and Depression Scale (HADS) [23], which has been validated for use in cancer patients [24], was selected to assess participants' levels of psychological distress. This instrument consists of two subscales: seven items assessing levels of depressive symptoms and seven items for levels of anxiety. Higher scores (range = 0–21) indicate increased distress. Social support (SS) was measured using the ENRICH Social Support Inventory (ESSI) [25], a reliable seven-item scale previously used in cancer patients [26]. A total score can be produced by summation, with greater scores representing greater social support. Fear of cancer recurrence (FoR) was assessed using a seven-item questionnaire measuring worries associated with the risk of cancer coming back and their impact on daily life [27]. This instrument has been previously used in HNC patients [28]. Scores range from 6 to 40 with higher scores representing greater FoR. The Assessment of Life Threat and Treatment Intensity (ALTTIQ) [29] is a seven-item questionnaire used to examine how threatening and intense patients perceive cancer and its treatment to be [17, 30]. Responses are summed and scores range from 7 to 35. The global QoL scale of the EORTC QLQ-C30 Version 3 [31] was used as the main QoL outcome. Responses are transformed to fit a 0–100 distribution. The QLQ-C30 has been extensively used in studies of HNC patients [32]. Finally, the Derriford Appearance Scale (DAS24) [33] was used to measure levels of appearance concerns. The total score ranges from 11 to 96, with lower scores reflecting low levels of social anxiety and avoidant behaviour.

Post-traumatic stress

The PTSD Checklist-Civilian Version (PCL-C) [34] is a validated 17-item self-report scale assessing the severity of traumatic stress symptoms [35]. Responses range from 1 'Not at all' to 5 'Extremely' and a total score (range = 17–85) can be obtained by summation. Scores \geq 44 are classified as indicative of PTSD for adults who have experienced acute trauma [36]. The PCL reflects the *Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition* (DSM-IV) symptoms of PTSD. Using the cluster scoring method, a predefined level of symptoms in each symptom cluster (i.e. intrusive thoughts, avoidant behaviour, hyperarousal) needs to be endorsed in order for the scores to indicate PTSD [19]. Meeting the threshold in two symptom clusters indicates partial PTSD (i.e. PTSS) [17]. Questions were modified to reflect cancer and its treatment as the traumatic stressor of interest.

Statistical methods

In bivariate analyses, *t* tests and analysis of variance (ANOVA) were used in order to compare mean levels of PCL-C scores. Pearson's correlation coefficient was used to examine the associations between continuous variables and the PCL-C. Potential correlates of PTSS were then assessed using multiple linear regression analysis with patients' PCL-C score as the outcome variable. The association of the same variables with full or partial PTSD was assessed using binary logistic regression. A stepwise modelling approach was followed whereby only variables that were significantly associated ($p < .05$) with PCL-C in bivariate analyses were included in multiple regression models.

Regarding the dyadic data analyses, differences between patients' and partners' scores on the PCL-C, as well as on their depression and anxiety scores, were examined using paired *t* tests and McNemar's χ^2 test, as appropriate. The Mann-Whitney *U* and Kruskal-Wallis *H* tests were used for comparisons within subgroups due to their small sample size. Correlation coefficients were calculated to examine the association between all continuous variables and participants' PCL-C scores. Agreement between patients' and partners' levels of post-traumatic stress was assessed using weighted Cohen's kappa. In addition, overall PCL-C scores in dyads were examined for absolute agreement using the two-way mixed-effects intraclass correlation coefficient (ICC). All data were coded and analysed using IBM SPSS Statistics Version 23.

Results

As shown in the consort diagram (Fig. 1), the final study sample consisted of 93 HNC survivors while the dyadic analysis was conducted on data from a subsample of 39 patient-partner dyads.¹ There was no time lag between patients' and partners' return of the completed questionnaire. Table 1 presents the sample characteristics. Patients' mean (\pm SD) age at enrolment was 66 years (11) and the overall male to female ratio was 1:0.72. The majority of patients were White British (84.8%) and their education was at least of high school level. Sixty eight percent were partnered and 66% were not in paid employment. Patients were at a mean (\pm SD) of 6.3 years (4) after treatment and 56% of them had an oral cavity tumour. The majority had early-stage cancer (i.e. stage one or two) (66%) and did not have a recurrence (83%). Eighty seven percent were treated with surgery either alone or with adjuvant chemo-radiation. Fifteen percent reported a history of anxiety while 25.8% reported a history of depression.

¹ 4/39 caregivers were family members other than partners.

Prevalence of post-traumatic stress in HNC survivors and their partners

In this sample of HNC survivors ($N = 93$), the mean (\pm SD) PCL-C score was 28.2 (11.5). As shown in Table 2, 11.8% of patients scored ≥ 44 indicating the presence of PTSD. Based on the cluster scoring method, 12.9% of patients met the criteria for estimated PTSD caseness. A further 10.8% rated two out of three PTSD symptom clusters as moderately to extremely reoccurring (i.e. 'partial PTSD'). Overall, 46.3% met the criteria for at least one PTSD symptom cluster. Across the symptom clusters, 33.3% met the criteria for intrusion, 29% for hyperarousal and 20.4% for avoidance.

With regard to the prevalence of post-traumatic stress in the subsample of 39 patient-partner dyads, the mean (\pm SD) PCL-C score was 28.6 (10.4) for patients and 27.8 (12.5) for partners. Patients' and partners' PTSS scores were not significantly different ($t(38) = 0.35$, $p = .731$) and did not correlate with each other ($r = 0.23$, $p = .15$). Thirteen percent of patients and 15.4% of partners scored ≥ 44 indicating PTSD caseness.

Using the cluster scoring method, 6/39 (15.4%) of patients and 5/39 (12.8%) of partners endorsed the threshold symptom level reflecting PTSD caseness. A further 15.4% of patients and 10.3% of partners rated two out of three PTSD symptom clusters as moderately to extremely reoccurring (partial PTSD). Overall, 48.7% of patients and 38.5% of partners met the criteria for at least one PTSD symptom cluster. Both patients and carers rated more highly symptoms of intrusion, with 35.9 and 33.3%, respectively, meeting the threshold. Patients endorsed more symptoms of avoidance (25.6%) and hyperarousal (33.3%) in comparison to their partners (12.8 and 28.2%, respectively); however, the difference was not statistically significant (Table 3).

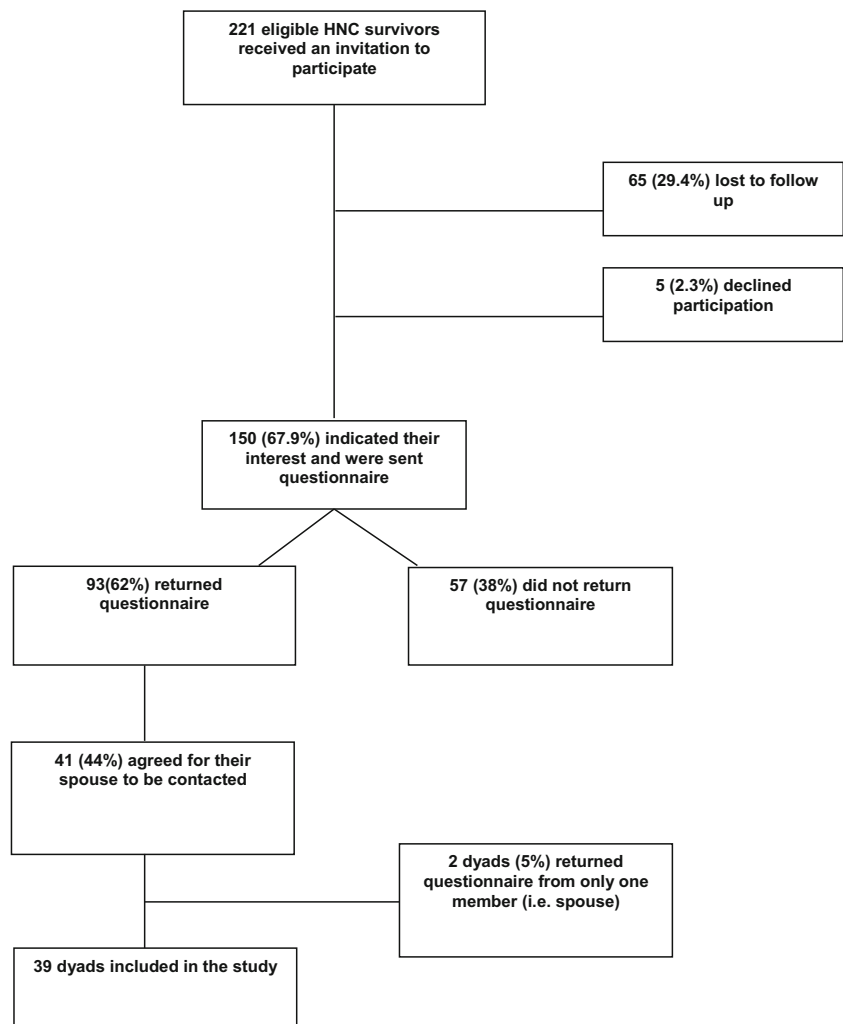
Concordance analysis for levels of post-traumatic stress (i.e. symptomatic in three symptom clusters, symptomatic in two symptom clusters, symptomatic in one symptom cluster and asymptomatic) between patients and their partners showed that the strength of agreement was poor ($\kappa_w = 0.187$, $p = .127$). Similarly, the ICC test showed little agreement between patients' and partners' overall PCL-C scores (ICC = 0.378, 95% CI (-0.202 to 0.676), $F(38.38) = 1.59$, $p = .078$). Dyads with male caregivers ($n = 13$) appeared more congruent than dyads with female caregivers ($n = 26$); however, this did not reach statistical significance.

Bivariate associations with PTSS

Table 1 presents the bivariate associations between patients' total PCL-C scores and the variable categories of interest. There were no significant associations between clinical variables and levels of post-traumatic stress.

Among demographic variables, a negative PCL-C association was found for age at the time of completing the

Fig. 1 Consort diagram for study participants



questionnaire. There were no other significant associations between demographic variables and PCL-C scores.

Among psychosocial variables, there were significant PCL-C associations for FoR, symptoms of anxiety and depression, as well as for appearance concerns. Levels of perceived threat were also highly positively correlated with patients' PCL-C scores. SS levels were not significantly associated with PCL-C scores. Finally, there was a large negative correlation between PCL-C scores and QoL.

Multivariable analyses

Table 4 presents the results of the multiple linear regression analysis for patients' PCL-C scores and the variables that were statistically significant in bivariate analyses ($p < .05$). Results of a binary logistic regression for full or partial PTSD and the same explanatory factors are also presented in Table 4. Although the full linear regression model accounted for 73.4% of the variance in PCL-C scores ($p < .001$), FoR was the only independent correlate of PTSS. There was a favourable statistical trend ($p < .1$) for symptoms of anxiety,

QoL and appearance concerns; however, these were not statistically significant ($p > .05$). In the logistic regression model, FoR was the only significant correlate of PTSS.

Dyads subsample: bivariate analyses

Although we were underpowered to detect differences in PTSS levels between patients and their partners or to investigate interactions within subgroups of partners, we carried out bivariate analyses to identify any trends in the data.

With regard to their background characteristics, patients' and partners' symptoms of depression and anxiety, as well as their SS levels, did not differ significantly (anxiety, $t(38) = 1.17$, $p = .25$; depression, $t(38) = 0.04$, $p = .97$; SS $t(38) = 1.79$, $p = .082$) and were not significantly associated with each other (anxiety, $r = -0.006$, $p = .97$; depression, $r = 0.23$, $p = .17$; SS, $r = 0.29$, $p = .07$). Furthermore, 10% of patients and 12.8% of partners reported previous anxiety while 23% of patients and 23% of partners reported previous depression.

Regarding potential correlates of PTSS levels in partners, between the clinical variables, prior history of depression was

Table 1 Characteristics of the patient sample and bivariate associations with PTSS (PCL-C scores)

Variable	Mean (SD), range	Frequency (valid %)	PCL-C mean (SD)	Correlation (<i>r</i>) †	<i>p</i> value‡
Age at enrolment, years (<i>n</i> = 93)	66 (11), 30–92			−0.249	.016
Gender (<i>n</i> = 93)					.205
Male		54 (58.1)	29.5 (12.1)		
Female		39 (41.9)	26.4 (10.4)		
Ethnicity (<i>n</i> = 92, missing = 1)					.694
White British		78 (84.8)	28.2 (11.3)		
White other		7 (7.6)	25.7 (9.1)		
Asian		5 (5.4)	32.6 (15.5)		
Black		2 (2.2)	33.5 (23.3)		
Education (<i>n</i> = 77, missing = 16)					.527
> High school		40 (51.9)	29.4 (11.3)		
≤ High school		37 (48.1)	27.6 (12.5)		
Relationship status (<i>n</i> = 92, missing = 1)					.186
Partnered		63 (67.7)	29.3 (12.3)		
Non-partnered		29 (31.2)	26.2 (9.3)		
Work status (<i>n</i> = 91, missing = 2)					.359
Employed		31 (34.1)	29.9 (12.2)		
Unemployed		60 (65.9)	27.6 (11.2)		
Site (<i>n</i> = 93)					.158
Oral Cavity		52 (55.9)	28.4 (12)		
Oropharynx		22 (23.7)	26.8 (8.2)		
Nasopharynx		4 (4.3)	34 (15.6)		
Nasal Cavity		5 (5.4)	21.8 (4.6)		
Salivary gland		2 (2.2)	27 (11.3)		
Hypopharynx		2 (2.2)	29 (2.8)		
Larynx		2 (2.2)	17.5 (.1)		
Unknown primary		4 (4.3)	42 (17.9)		
Stage (<i>n</i> = 87, missing = 6)					.640
Tx (tumour cannot be evaluated)		7 (8)	34.3 (17.9)		
T1		23 (26.4)	28.6 (11)		
T2		34 (39.1)	26.7 (10)		
T3		10 (11.5)	28.1 (9.2)		
T4		13 (14.9)	28.4 (14)		
Treatment (<i>n</i> = 93)					.957
Surgery		32 (34.4)	28.9 (13.9)		
Surgery and radiotherapy		23 (24.7)	27 (10)		
Chemotherapy and radiotherapy		9 (9.7)	26.7 (3.4)		
Chemotherapy and radiotherapy and surgery		26 (28)	28.4 (11.6)		
Radiotherapy		2 (2.2)	31 (18.4)		
Other		1 (1.1)	36 (−)		
Time since treatment, months (<i>n</i> = 84, missing = 9)	75 (48), 24–165			−0.039	.727
Recurrence (<i>n</i> = 90, missing = 3)					.961
No		75 (83.3)	28.5 (11.7)		
Yes		15 (16.7)	28.7 (11)		
Self-administered comorbidity (possible range = 0–45) (<i>n</i> = 82, missing = 11)	5 (3.6), 0–18			0.193	.083
History of depression (<i>n</i> = 93)					.083
Yes		24 (25.8)	31.7 (10.9)		
No		69 (74.2)	27 (11.5)		
History of anxiety (<i>n</i> = 92, missing = 1)					.140
Yes		14 (15.2)	31 (14)		
No		78 (84.8)	27.7 (11.1)		
HADS Depression Score (<i>n</i> = 92, missing = 1)	3.6 (3.3), 0–14			0.625	.000
HADS Anxiety Score (<i>n</i> = 92, missing = 1)	5.4 (3.9), 0–18			0.676	.000
Social Support Score (<i>n</i> = 92, missing = 1)	28.1 (6.2), 9–34			−0.144	.172
Appearance Concerns Score (<i>n</i> = 88, missing = 5)	26.4 (11.1), 11–66			584	.000
Quality of Life Score (<i>n</i> = 91, missing = 2)	72.2 (22.5), 17–100			−0.516	.000
Fear of Recurrence Score (<i>n</i> = 91, missing = 2)	17.3 (8.1), 6–39			0.743	.000
Appraisal of Life Threat and Treatment Intensity Score (<i>n</i> = 85, missing = 8)	20.7 (7.5), 7–35			0.555	.000

PTSS post-traumatic stress symptoms, PCL-C Post-Traumatic Stress Disorder Checklist—Civilian Version, *N* number of patients, *SD* standard deviation

†Pearson's product-moment correlation coefficient

‡Independent sample *t* test or analysis of variance

Table 2 Prevalence of cancer-related post-traumatic stress in head and neck cancer survivors ($N = 93$)

PTSD measure†	Frequency (%)	95% confidence intervals
PCL-C Score ≥ 44	11 (11.8)	6.7 to 20
Symptomatic in 3 symptom clusters	12 (12.9)	7.5 to 21.2
Symptomatic in 2 symptom clusters	10 (10.8)	6 to 18.7
Symptomatic in 1 symptom cluster	21 (22.6)	15.3 to 32.1
Non-symptomatic	50 (53.8)	43.7 to 63.6
Met the cluster B (intrusion) criteria	31 (33.3)	24.6 to 43.4
Met the cluster C (avoidance) criteria	19 (20.4)	13.5 to 29.7
Met the cluster D (hyperarousal) criteria	27 (29)	20.8 to 38.9

HNC head and neck cancer, PTSD post-traumatic stress disorder

†As measured with the PTSD Checklist—Civilian Version (PCL-C). Symptom clusters include at least one intrusion symptom, three avoidance symptoms and two hyperarousal symptoms. Symptomatic in all three clusters constitutes full PTSD

associated with higher PCL-C scores ($U = 64$, $p < .05$). Among the demographics, the only significant relationship was for gender ($U = 52$, $p < .01$) indicating that female partners ($n = 26$) experienced more severe PTSS than their male counterparts ($n = 13$).

Among the psychosocial variables, significant PCL-C relationships were found for symptoms of depression ($r = 0.570$, $p < .01$), anxiety ($r = 0.766$, $p < .01$) and levels of social support ($r = -0.560$, $p < .01$).

Regarding possible interactions between partners' PCL-C scores and patients' characteristics or vice versa, there was a statistically significant relationship between partners' PCL-C scores and patients' QoL ($r = -0.329$, $p < .05$). Patients' PCL-C score was associated only with partners' SS levels ($r = -0.445$, $p < .01$).

Conclusions

This is the first study to examine post-traumatic stress in long-term HNC survivors and their partners. In this sample of HNC survivors, 13% of patients met the diagnostic criteria for

PTSD, with an additional 33% experiencing some PTSS. This is a much higher prevalence in comparison to that of the general adult population in the UK (4.4%) [37] but similar to other cancer survivor populations such as haematological (8%) or breast (12%) cancer [17, 16]. Our findings are also comparable to those of Posluszny et al. (2015) [19] who reported a 12% prevalence of PTSD in HNC patients approximately 2 months after diagnosis, though Richardson et al. (2016) [20] in their study of HNC patients 6 months after treatment reported a higher rate of 19%. In our sample, mean time since treatment was 6 years suggesting that PTSS may persist for many years after diagnosis. In the context of the growing literature on PTSD/PTSS among HNC patients, longitudinal research is needed in order to understand better the duration and course of these symptoms.

Results from our subgroup analyses showed that 15.4% of patients and 12.8% of partners reported PTSD. Scores from a further 33.3% of patients and 25.7% of partners were indicative of PTSS. These results are not in line with the findings of Posluszny et al. (2015) who reported significantly higher levels of PTSD in partners than in patients. Nevertheless, Richardson's findings suggested a similar prevalence rate

Table 3 Prevalence of cancer-related post-traumatic stress in dyads of HNC survivors and their partners ($N = 39$)

Measure	Patient frequency (%)	Partner frequency (%)	Test statistic	p value
PCL mean score (SD)	28.6 (10.4)	27.8 (12.5)	$t(38) = 0.35$.731
Symptomatic in 3 symptom clusters	6 (15.4)	5 (12.8)	—*	1
Symptomatic in 2 symptom clusters	6 (15.4)	4 (10.3)	—*	.754
Symptomatic in 1 symptom cluster	7 (17.9)	6 (15.4)	—*	1
Non-symptomatic	20 (51.3)	24 (61.5)		
Met the cluster B (intrusion) criteria	14 (35.9)	13 (33.3)	—*	1
Met the cluster C (avoidance) criteria	10 (25.6)	5 (12.8)	—*	.180
Met the cluster D (hyperarousal) criteria	13 (33.3)	11 (28.2)	—*	.791

*McNemar's test

Table 4 Multiple linear regression for survivors' PCL-C score and logistic regression for meeting symptom criteria for full or partial PTSD ($N = 78$)

Variable	PCL-C score			Full or partial PTSD†		
	B	95% CI	<i>p</i>	Odds ratio	95% CI	<i>p</i>
Age at questionnaire completion	−0.05	−0.18 to .08	.467	0.98	0.91 to 1.05	.533
HADS Anxiety Score	0.53	−0.04 to 1.10	.068	1.14	0.83 to 1.56	.427
HADS Depression Score	0.36	−0.33 to 1.05	.304	1.12	0.83 to 1.51	.468
Appraisal of life threat and treatment intensity	0.15	−0.13 to .43	.300	1.02	0.87 to 1.21	.790
Fear of recurrence	0.60	0.31 to 0.88	.000	1.18	1.01 to 1.37	.038
Appearance concerns	0.16	−0.02 to 0.34	.074	1.04	0.95 to 1.14	.403
Quality of life	−0.08	−0.16 to 0.01	.086	0.97	0.93 to 1.01	.128

B beta coefficient, *PCL-C* Post-Traumatic Stress Disorder Checklist—Civilian Version, *PTSD* post-traumatic stress disorder, *CI* confidence intervals

†No. of events/no. of patients = 20/78

between HNC patients and their caregivers [21, 20]. Further research employing greater sample sizes is needed.

Clinical correlates of PTSS and PTSD

In bivariate analysis, younger age was significantly associated with higher PTSS, consistent with the findings from the PTSD literature [35]. Younger survivors may face more financial and social challenges [17] and the emotional response of older HNC patients is more positive [38]. It is striking that there was no significant effect of cancer stage, site or treatment. This is in agreement with previous findings [35, 21] and emphasises that PTSS experienced by cancer survivors may not consequently be connected to the severity of cancer or to sociodemographic factors. Contrary to previous findings, the time since treatment was not associated with reduced PTSS [17, 39]. Although patients with previous depression and anxiety were at higher risk for psychological distress and PTSD, this did not have a significant impact on PTSS scores. Reports of PTSS are more likely to reflect difficulties in adjustment to cancer [40]. Medical comorbidity has been shown to be a risk factor for PTSS [17]; however, this was not replicated in our sample.

FoR was the strongest correlate of post-traumatic stress. FoR is a common emotional response to cancer but differs from a psychopathological response that is characterised by features of avoidance and hyperarousal such as PTSD. Nevertheless, FoR, depending on its intensity, can be difficult to distinguish from anxiety and PTSS.

QoL, anxiety and appearance concerns showed significant but weak trends consistent with previous research [40]. In our sample, mean patient QoL was very close to the 2014 European general population mean (\pm SD) of 75.7 (21.2) [41]. Other studies have reported a negative correlation between appearance concerns and depression [42]; however, our study is the first to present findings on the association with

PTSS. As the face is difficult to avoid, facial disfigurement may be acting as a constant reminder and trigger of trauma.

Survivors and their partners experienced similar levels of PTSS but they showed little agreement in their appraisals of post-traumatic stress symptoms. Trends in the data indicated that female partners, those with a history of depression and those with less SS showed higher PTSS. Higher PTSS in partners was also related to more depressive symptoms, anxiety and lower patient QoL. Although further investigation is needed in order to confirm these patterns, our findings are in line with the previous research that suggests a proportion of HNC partners experience poorer psychological health in comparison to population norms and that caregivers are affected by patients' wellbeing (and vice versa) [11, 12]. Further study of the factors affecting patient-caregiver PTSS congruence is warranted as this may influence coping with cancer overall.

Study limitations

This study has some limitations, including the cross-sectional design, the small sample size and the inclusion of patients from one cancer centre. The cross-sectional design limits our ability to infer causal relationships or to draw conclusions about the duration of PTSS since diagnosis. Although the inclusion of partners is a strength, given how little we know about partners' emotional response to HNC, our sample size was too small for subgroup analyses among patients or dyads. Our participants were recruited from a single centre, limiting the generalisability of our results. Furthermore, our sample consisted of predominantly White patients and the recurrence rate was low which may further affect the generalisability of our findings. Nevertheless, our results show levels slightly higher than those reported in other cancer survivor groups [17, 35]. Finally, the assessment of PTSS/PTSD in this study was based on the diagnostic criteria of DSM-IV. This is a limitation as there are notable changes to the PTSD criteria

in DSM-V. Therefore, relevancy of these finding to DSM-V is not known. However, our results add to the existing literature on the prevalence of cancer-related PTSD and allow a reliable comparison of PTSS/PTSD rates between HNC survivors and different patient groups, as well as between HNC survivors and newly diagnosed patients.

In conclusion, we found that in some HNC patients, symptoms of cancer-related PTSD exist for many years and also affect caregivers. Clinicians and researchers need to be aware of this type of psychological response to HNC in survivors and to take this into account when addressing the needs of patients and their partners. PTSD is a treatable condition and referral to psychological services should be considered. Psychological interventions to reduce PTSD symptoms in HNC patients have shown some effectiveness [43, 44] but further research is required for the development of targeted interventions that can also be used at an earlier stage to prevent PTSS in cancer survivors. Our study has identified potentially modifiable factors that may play a role in the development of cancer-related PTSD—namely, fear of recurrence. Understanding the issues HNC survivors and their caregivers face will enable the identification of those at highest risk of suffering from post-traumatic stress.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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