Post-Traumatic Distress and Symptom Experience in Patients With Head and Neck Cancer–Related Tracheostomy and Family Caregivers

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OBJECTIVES: To describe post-traumatic distress and identify associated factors in patients with head and neck cancer–related tracheostomy and their family caregivers.

SAMPLE & SETTING: This observational study assessed 22 patients with surgically managed head and neck cancer–related tracheostomy and 17 family caregivers at a comprehensive cancer center.

METHODS & VARIABLES: Instruments included the Impact of Event Scale–Revised, the Memorial Symptom Assessment Scale, and the Patient-Reported Outcomes Measurement Information System Depression 6a Short Form scale.

RESULTS: Post-traumatic distress related to tracheostomy and general depression in patients and family caregivers was highly prevalent. An increased level of physical symptoms was moderately correlated with higher levels of post-traumatic distress.

IMPLICATIONS FOR NURSING: Patients who experienced higher symptom burden may also suffer from post-traumatic distress related to tracheostomy. Oncology nurses can implement post-traumatic distress screening in patients and their family caregivers.

KEYWORDS tracheostomy; post-traumatic distress; caregiver; mental health; depression; PTSD
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Head and neck cancer (HNC), which refers to malignancy in the oral cavity, throat, voice box, paranasal sinuses, nasal cavity, and salivary glands, is the world's sixth most common cancer (Sung et al., 2021). In the United States, HNC comprises 4% of all cancers and has been increasing by 0.8% annually since 2009; there were an estimated 54,000 new cases in 2020 (American Cancer Society, 2020). Treatment options for HNC include radiation therapy, chemotherapy, immunotherapy, and surgery. In a Canadian survivorship study by Giuliani et al. (2016), about 57% of patients with HNC received surgery. A patient will need a tracheostomy as an artificial airway when there is laryngeal deficiency because of malignancy or side effects such as dysphasia and aspiration from multimodal therapies. Tracheostomy creates an altered airway after the excision of a tumor in the trachea and larynx.

Tracheostomy has been used in medicine since 3600 BC, and more than 100,000 tracheostomy surgeries are performed in the United States each year (Cheung & Napolitano, 2014). Tracheostomy is a high-risk procedure. A national analysis of 113,653 adult tracheostomies performed in 2006 found a 19.2% mortality rate in patients with cardiac, respiratory, and neurologic conditions, yet the high mortality rate was mostly associated with primary critical conditions, and HNCs were not identified explicitly as an indication for tracheostomy in the analysis (Shah et al., 2012). A retrospective analysis (N = 171) conducted in a U.S. medical center found that HNC malignancy accounted for 51% of all open tracheostomy procedures (Fattahi et al., 2012). A medical center in Pakistan (N = 130) reported that in 47% of tracheostomies for patients with cancer, the patients had HNC; in addition, more than half of HNC-related tracheostomies could not be decannulated because of the need for permanent tracheostomy (8%) or progressive malignancy (49%) (Bhatti et al., 2015). The postoperative complication rate with tracheostomy ranges from 3.2% to 31%, and complications include hemorrhage, tracheal stenosis, mucus plugs, fistula, infection, and dislodgement (Bhatti et al., 2015; Fattahi et al., 2012; Shah et al., 2012; Straetmans et al., 2010).

The complexity of tracheostomy care and inadequate preparation time put patients and family members at high risk for experiencing psychological distress. Family caregivers play vital roles in providing quality tracheostomy care at home. Each patient must have at least one family caregiver trained in home tracheostomy care before leaving the hospital. Because of the high demand for medical resources for HNC surgery and increasing costs associated with tracheostomy-related hospital stays, patients are discharged before they are entirely ready and comfortable with tracheostomies (Fitzgerald Miller et al., 2008). On average, patients in the United States and their family caregivers are pressured to learn the care for tracheostomy within a short amount of time after surgery (8.8 days) (Hatcher et al., 2016). In contrast, in countries with free public health care, the average length of stay has been reported to be longer (19 days) (McDevitt et al., 2016).

Side effects of HNC-related tracheostomy make patients physically and emotionally vulnerable. Patients experience not only various site-specific symptoms such as dysphagia, dysphonia, xerostomia, mucositis, dysgeusia, trismus, neck stiffness, and dental issues (e.g., dental caries, missing teeth) but also endure other general side effects, including chronic fatigue and loss of appetite (Epstein et al., 2012). Disruption to daily activities is common in patients living with HNC (Ganzer et al., 2015), and many patients feel that they are held captive (Björklund et al., 2010). In Sweden, a qualitative study (N = 56) found that 27% of patients were able to resume their normal activities two and a half years after completing their treatments (Isaksson et al., 2016). Significant themes have been reported in several qualitative studies, including loss of taste as the worst feature of HNC (Molassiotis & Rogers, 2012), social withdrawal associated with swallowing difficulty (Björklund et al., 2010), and loss of job because of impaired communication (Grattan et al., 2018). Patients were also frequently disappointed and frustrated about losing control of their normal lives and depending on others for help (Nakarada-Kordic et al., 2018).

In the literature, there is no documentation about the level of post-traumatic distress in patients with tracheostomies or their family caregivers six months or more after the surgery. Although there is a lack of post-traumatic distress reporting, other negative psychological symptoms have been reported in patients with HNC. Evidence has shown that the prevalence of post-traumatic stress disorder (PTSD) in patients at 12 months after an intensive care unit (ICU) stay was between 17% and 34% (Hatch et al., 2018). Anxiety and depression are major psychological conditions reported by patients with HNC and their family caregivers. A German study (N = 817) found 48.3% of patients with HNC had depression as measured by the Patient Health Questionnaire–9 (Hammermüller et al., 2021). Another study from Taiwan found that 12.9% of family caregivers of patients with HNC had a diagnosis of depressive disorder six months after treatment completion (Lee et al., 2017).

Patients with HNC experience many transitions as they progress through the treatment course, including physical, psychological, social, and spiritual changes (Wang et al., 2021). Therefore, the current study was grounded in Meleis's (1991) transition theory. The transition participants experienced from normal breathing to tracheostomy-dependent breathing was a change in health status that led to a change in physical and mental needs. The objectives of this observational study were (a) to describe the prevalence of post-traumatic distress in patients with HNC-associated tracheostomy and their family caregivers and (b) to identify factors associated with higher tracheostomy-related distress.

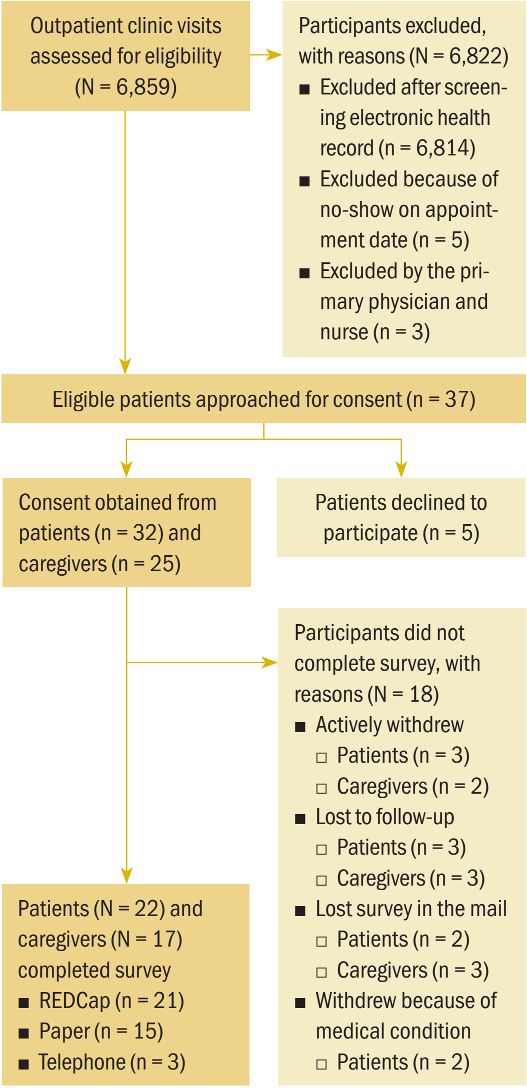
Sample and Setting

Between October 2020 and March 2021, the authors recruited adult patients living with tracheostomy and their family caregivers who had provided tracheostomy care at home independently within the past six months preceding study enrollment. Patients and family caregivers were excluded who did not speak English, had difficulties reading or writing, or had cognitive impairment. According to the local hospital protocol, adult patients receiving tracheostomy surgery identified designated family caregivers to assist with tracheostomy care at home. These family caregivers received training in tracheostomy care from the clinical nurses before discharge. In addition, in contrast to hospitals that have postoperative patients with tracheostomies stay in the ICU, the patients in this study were transferred to an acute step-down unit after their stay on the postanesthesia care unit.

Study participants were recruited from the Ear, Nose, and Throat Institute of the University Hospitals Seidman Cancer Center, which is a clinical partner of the Case Comprehensive Cancer Center, a National Cancer Institute–designated comprehensive cancer center at Case Western Reserve University in Cleveland, Ohio.

The sampling process for this study is illustrated in Figure 1. A total of 37 patients and 25 caregivers were invited to participate in the study, including 58 face-to-face invitations (35 patients and 23 caregivers) and 4 telephone invitations (2 patients and 2 family caregivers). The refusal rate for the study was 5 out of 37 for patients and 0 out of 25 for caregivers. Reasons for refusing to participate included that they did not want to participate over the telephone (n = 2), "the patient refused to learn the tracheostomy care" (n = 1), they "felt overwhelmed with the treatment" (n = 1), and "the survey questions were 'a bit touchy' as they tried to return to normalcy" (n = 1). The withdrawal rate was 10 out of 32 for patients and 8 out of 25 for caregivers.

FIGURE 1. CONSORT Flow Diagram for Sampling Process



CONSORT—Consolidated Standards of Reporting Trials

Methods and Variables

A cross-sectional observational design was used to describe the prevalence of post-traumatic distress. Data collection was executed through REDCap survey links and mailed paper questionnaires, and by telephone (with the principal investigator reading the survey questions). All participants were asked to report their distress related to their tracheostomy using the Impact of Event Scale—Revised (IES-R) (Weiss & Marmar, 1997). Participants self-reported their depression in the past seven days using the Patient-Reported Outcomes Measurement Information System (PROMIS) Depression 6a Short Form scale (Pilkonis et al., 2011). Participants also used the Memorial Symptom Assessment Scale (MSAS) to report symptom experiences (Portenoy et al., 1994). Finally, participants' clinical backgrounds, including diagnosis, treatment plan, and healthcare use, were collected by the principal investigator through a review of electronic health records.

IES-R

The IES-R measures an individual's distress level related to a specific event by recording the extent to which the individual has been affected in the past seven days by difficulties related to that event (Horowitz et al., 1979). The event in this study was set as the tracheostomy surgery. The first version of the IES was originally created in 1979 and had 15 items. The current version, the IES-R, was developed in 1997 and has 22 items. The IES-R assesses the following three primary PTSD constructs: intrusion, avoidance, and hyperarousal symptoms (Horowitz et al., 1979). The term "intrusion" refers to repeated thoughts of an event. "Avoidance" refers to an individual's use of effort to avoid event-related behavior or thoughts. "Hyperarousal symptoms" refers to physiologic symptoms related to the event, including difficulty sleeping and feelings of irritability and anger. Each item on the IES-R is rated on a five-point scale, with possible scores ranging from 0 (not at all) to 4 (extremely). The IES-R yields a total score ranging from 0 to 88. A score between 24 and 32 indicates that PTSD is a clinical concern, and individuals with scores within this range have some symptoms of PTSD. A score of 33–38 represents a likely diagnosis of PTSD. The IES-R is a valid instrument, with high internal consistency and reliability (Creamer et al., 2003).

PROMIS Depression 6a

The PROMIS Depression 6a measures an individual's level of depression in the past seven days by having participants rate the frequency of feeling worthless, helpless, depressed, hopeless, like a failure, and unhappy on a five-point Likert-type scale (Pilkonis et al., 2011). The items examine feelings related to low levels of positive affect and individuals' personal experiences with negative affect, including self-image and negative mood. The instrument also has shown high reliability (with a Cronbach's alpha greater than 0.9 for each item) and good structural, convergent, and discriminant validity in patients with prostate cancer (Quach et al., 2016). The T score for each participant was used for the interpretation of results ($\bar{X}$ = 50, SD = 10). A T score of 50 is consistent with the average performance of the U.S. general population. A T score between 55 and 60 is considered to indicate mild symptoms of depression. A T score between 60 and 70 indicates moderate depression, and a score between 70 and 80 indicates severe depression.

MSAS

The 32-item MSAS assesses common physical and psychological symptoms experienced by individuals with cancer (Portenoy et al., 1994). Patients report whether a symptom occurred during the previous week or the preceding seven days and any distress that symptom may have caused. The scale provides a measure of an individual's perception of their symptom frequency, severity, and symptom-related distress. The frequency dimension is measured with a four-point Likert-type scale, with 1 being "rarely" and 4 being "almost constantly." The severity dimension is also measured with a five-point Likert-type scale, with 1 being "slightly" and 4 being "very severe." The third dimension of symptom-related distress is measured on a five-point Likert-type scale, with 0 being "not at all" and 4 being "very much." The Cronbach's alpha for this instrument has been found to range from 0.76 to 0.87 (Portenoy et al., 1994).

Statistical Analysis

Participants were recontacted by the principal investigator to complete missed survey questions (n = 3), resulting in no missing data in the sample. All paper and telephone surveys were transferred to REDCap surveys, which were then exported into IBM SPSS Statistics, version 25.0. A p value of 0.05 was set for all analyses. Patient and family caregiver results were initially compared using bivariate statistics (chi-square test for categorical variables and analysis of variance for continuous variables). Descriptive statistics were conducted, and the authors explored associations between post-traumatic distress and symptom burden with nonparametric (Spearman rank order) correlational analysis. Sample sizes of 39 and 22 were powered to detect a nonzero correlation coefficient greater than 0.44 and 0.57, respectively (Hulley, 2013).

Ethical Approval

Ethical approval was obtained from the institutional review board of University Hospitals Cleveland Medical Center (#20201114). Privacy and confidentiality of the participants were protected by using digital encoding of the questionnaires and encrypted data storage on a password-protected research computer.

Results

Description of Demographic and Clinical Characteristics

A total of 39 participants were included in the final analysis, consisting of 22 patients and 17 family caregivers (see Table 1). The authors recruited 17 dyads, and 1 caregiver continued to participate in the study even after the care recipient died during the study. There were no significant differences between the patient group and the family caregiver group in the demographic data. Participants in the study were predominantly White and highly educated. The mean age was 64 years, with a range of 40–83 years. Half of the patients were unemployed, and five were on disability. Family caregivers were mostly female spouses who were working (n = 7) or retired (n = 8). Most family caregivers (n = 11) received extra help from homecare nurses, therapists, or other family members.

Of the 22 patients, 7 were treated for stage I cancer, 3 for stage II, 9 for stage III, and 3 for stage IV. More than half (n = 12) were living with their tracheostomies while completing the surveys, and five had disposable inner cannulas for their tracheostomies. In addition to surgical treatment, most patients received multiple treatment modalities, including radiation or proton therapy (n = 18), chemotherapy (n = 12), and immunotherapy (n = 4). Of note, eight patients received treatment for an HNC recurrence. In terms of discharge plans, of the 22 patients, 19 were discharged home with home care and 3 were transferred to a skilled nursing rehabilitation facility. Nine patients used hospital services within 30 days of discharge, including seven emergency department visits and six readmissions.

TABLE 1. Sample Characteristics (N = 39)

Characteristic	n
Sex	
Male	20
Female	19
Race	
Black	5
White	33
Other	1
Ethnicity	
Hispanic	36
Non-Hispanic	3
Marital status	
Married or in a relationship	28
Not married or in a relationship	8
Divorced	2
Widowed	1
Employment status	
Retired	19
Employed	13
Receiving disability	5
Unemployed	2
Education	
High school diploma	10
College degree	19
Postgraduate degree	10
Annual income ($)	
Less than 20,000	5
20,000–49,000	15
50,000 or greater	19

Post-Traumatic Distress With Tracheostomy

The prevalence of clinically concerning post-traumatic distress related to tracheostomy was 12 out of 39 in the current study, representing 7 out of 22 in the patient group and 5 out of 17 in the caregiver group, with a score of 33–38 indicating a probable diagnosis of PTSD (Weiss & Marmar, 1997) (see Table 2). Five patients and two caregivers reported scores indicating that they had suppressed immune functions resulting from experiencing high post-traumatic distress. Patients reported a statistically nonsignificant higher level of post-traumatic distress than their family caregivers on the IES-R and its subscales of intrusion, avoidance, and hyperarousal symptoms. Of note, the dominant type of distress was different for patients and family caregivers. The mean score in the patient group for avoidance ($\bar{X}$ = 9.55, SD = 9.25) was higher than scores for intrusion ($\bar{X}$ = 8, SD = 8.7) and hyperarousal symptoms ($\bar{X}$ = 5.14, SD = 6.83). In contrast, the average intrusion score ($\bar{X}$ = 7.18, SD = 9.36) in the family caregiver group was higher than the scores for avoidance ($\bar{X}$ = 5.76, SD = 7.61) and hyperarousal symptoms ($\bar{X}$ = 4.82, SD = 6.54). In addition, the authors did not find a statistically significant difference between the depression scores (p = 0.875) of patients and caregivers. Of the 39 participants, 22 reported no depressive symptoms. The prevalence of mild depression and moderate depression was 10 and 5, respectively, out of 39 in this study.

MSAS and Symptom Experience

Of the 32 symptoms assessed, patients reported an average of 13 symptoms. The mean physical symptom score was low ($\bar{X}$ = 0.73, SD = 0.52 out of 4). The mean global distress score ($\bar{X}$ = 0.87, SD = 0.86) and psychological symptom score ($\bar{X}$ = 0.9, SD = 1.05 out of 4) were low as well. The top six most distressing symptoms reported by patients were pain, difficulty swallowing, lack of energy, feeling drowsy, cough, and difficulty sleeping. These were different from the most frequently reported symptoms, which included numbness and tingling in hands/feet, worrying, problems with self-image ("I do not look like myself"), weight loss, and feeling sad. Frequency, intensity, and distress for each symptom were recorded (see Table 3).

Associations With Post-Traumatic Distress

This study found no significant correlations between an individual's tracheostomy-related post-traumatic distress and their age, sex, ethnicity, education, or annual income (see Table 4). No demographic group was associated with increased distress. In contrast, there were moderate positive correlations between post-traumatic distress and patients' physical symptoms ($r[21]$ = 0.544, p = 0.009), psychological

TABLE 2. Study Instrument Scores and Outcomes (N = 39)

		Patients (N = 22)		Family Caregivers (N = 17)			
Instrument	**Possible Range**	$\bar{X}$	**SD**	$\bar{X}$	**SD**	**p**	**α**
IES-R							
Total mean score	0–88	22.68	23	17.76	22.79	0.51	0.973
Avoidance subscale	0–32	8	8.7	7.18	9.36	0.778	0.949
Hyperarousal subscale	0–32	9.55	9.25	5.76	7.61	0.181	0.934
Intrusion subscale	0–24	5.14	6.83	4.82	6.45	0.885	0.935
PROMIS Depression 6a							
Depression	38.4–80.3	51.92	11.33	52.49	10.9	0.875	0.954
MSAS							
Total score	0–4	0.72	0.53	–	–	–	0.902
Global distress	0–4	0.87	0.86	–	–	–	0.895
Psychological subscale	0–4	0.9	1.05	–	–	–	0.969
Physical subscale	0–4	0.73	0.52	–	–	–	0.909
Number of symptoms	0–4	12.64	8.45	–	–	–	–
Interpretation	**Range**		**n**		**n**		
IES-R							
Of clinical concern	24–32		2		2		
Possible PTSD	33–38		–		1		
Suppressed immunity	39–88		5		2		
PROMIS Depression 6a							
Within normal limits	20–55		13		9		
Mild	55–60		5		5		
Moderate	60–70		3		2		
Severe	70–80		1		1		

IES-R—Impact of Event Scale–Revised; MSAS—Memorial Symptom Assessment Scale; PROMIS—Patient-Reported Outcomes Measurement Information System; PTSD—post-traumatic stress disorder

Note. A T score of 54.7 in the PROMIS Depression 6a Short Form scale is a screening cut point for depression. An IES-R score between 33 and 38 is indicative of a PTSD diagnosis.

symptoms (r[21] = 0.584, p = 0.004), and global distress (r[21] = 0.749, p < 0.001). Increases in physical and psychological symptom experiences were correlated with increases in tracheostomy-related distress. In addition, the number of treatment modalities (chemotherapy, radiation therapy, immunotherapy) that patients received had a weak positive correlation with overall physical symptoms (r[21] = 0.475, p = 0.026) and psychological symptoms (r[21] = 0.438, p = 0.041).

Discussion

This observational study described the prevalence of post-traumatic distress in 22 patients with HNC and 17 family caregivers within six months after tracheostomy surgery. The main finding was that the occurrence of post-traumatic distress, defined as an IES-R score greater than 32, was high (12 out of 39) in patients and their family caregivers (Horowitz et al., 1979). Secondary findings were that post-traumatic distress was related to physical burden but was not related to age, sex, ethnicity, marital status, annual income, and education level.

This is the first study to identify a high prevalence of post-traumatic distress related to tracheostomy. Of note, family caregivers experienced post-traumatic distress to the same extent as patients. These findings are consistent with those from previous research on other causes of post-traumatic distress in patients and caregivers. The prevalence of post-traumatic distress is not specific to tracheostomy but has been observed in 22% of patients and

33.1% in family caregivers three months after being discharged from the ICU (Azoulay et al., 2005; Hatch et al., 2018). This result may explain why patients and their family caregivers have reported overall negative experiences with tracheostomy care, support, management, and coping with altered communication, body image, and stigma (Nakarada-Kordic et al., 2018). Avoidance of anything that would remind patients of tracheostomy was indicated by high scores on the avoidance subscale. This was consistent with evidence indicating that patients become less confident and more self-conscious in public after a tracheostomy, particularly in relation to their perception of their self-image and voice changes. In a study by Foster (2010), a patient commented, "You walk around with this plaster on your throat and perhaps you would rather people didn't ask you questions about it" (p. 40). Patients with a tracheostomy have described their experience as "awful" when they could not make a sound and reported that communication became "tiresome" and that they felt "powerless" (Al Humaid & Wiechula, 2017).

Family caregivers' distress related to patients' tracheostomies could also be related to their difficulties in accepting and adjusting to their loved ones' altered appearance and their caregiving burden. Björklund et al. (2010) reported that one patient explained, "My husband is really thoughtful, but he finds it difficult to touch me, and I feel it's a big minus" (p. 28). In addition, Ross et al. (2010) found that family members who spent more time caregiving had worse psychological health ($r = -0.31$, $p < 0.01$). Family caregivers in that study spent an average of 12.67 hours on tracheostomy care each week, not including other caregiving tasks. These findings indicate the importance of acknowledging and supporting the psychological distress faced by family caregivers of patients with HNC.

In addition, the authors found that higher levels of post-traumatic distress related to tracheostomy were moderately associated with more severe physical symptoms and psychological symptoms but were not related to age, sex, ethnicity, marital status, annual income, and education level. These results are consistent with those of Starr et al. (2004), who found that post-traumatic distress was higher in those with higher symptom severity but was not significantly associated with age, sex, marital status, or length of ICU stay in patients after orthopedic trauma.

The co-occurrence of physical and psychological symptoms was common in patients with HNC during post-treatment survivorship, with disruption to daily activities being a characteristic of HNC-specific physical symptoms. The authors' results also indicated that swallowing, speech, and pain were the most distressing symptoms for patients, and the total number of physical symptoms ($\bar{X} = 12.64$) and psychological distress ($\bar{X} = 0.92$) observed in this study was greater than that observed by Chang et al. (2000) ($\bar{X} = 9.8$ and $\bar{X} = 0.76$, respectively) in patients with HNC. The high symptom distress scores observed in this study corroborate with Pfeifer et al. (2015), who found high physical ($\bar{X} = 0.79$), psychological ($\bar{X} = 0.95$), and global distress ($\bar{X} = 1.1$) in patients undergoing HNC treatment. HNC-specific symptom management interventions for patients and caregivers are urgently needed to reduce anxiety and post-traumatic distress.

The high rate of post-traumatic distress in this study suggests a need for early screening strategies and preventive interventions. First, a useful step would be the implementation of simple post-traumatic distress screening tools into the routine practice of follow-up care. Early detection of post-traumatic distress warrants the delivery of prompt support by the interprofessional team. One implementation study of a standardized PTSD screening tool in the electronic health record for hospitalized youth ($N = 562$) found significantly higher use of psychological consultation services (Price et al., 2019). An algorithm-based PTSD screening tool based on patients' electronic health records developed by Russo et al. (2013) was also a feasible approach for PTSD screening. Second, psychological support programs should be made available to patients receiving HNC treatment. Previous studies have found nurse-led psychoeducation sessions effective at improving the physical and emotional functioning of patients with HNC (Duffy et al., 2006; van der Meulen et al., 2014). Other preliminary studies examining meditation therapy and cognitive behavioral therapy have had promising implications for clinical practice (Richardson et al., 2019).

This study's results indicate that a lower symptom burden was associated with a lower level of

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KNOWLEDGE TRANSLATION

- Patients and family members are at risk of experiencing post-traumatic distress after tracheostomy surgery.
- Post-traumatic distress is associated with high physical symptom burden.
- Symptom management is critical to the physical and psychological well-being of patients and family caregivers.

TABLE 3. Symptom Experience: Memorial Symptom Assessment Scale (N = 22)

		Degree of Symptom		
Symptom	Overall Prevalence (n)	Frequency Freq–Con (%)	Intensity Mod–VSev (%)	Distress QB–VM (%)
Pain	17	8	11	5
Difficulty swallowing	15	11	13	9
Feeling drowsy	15	8	9	2
Lack of energy	15	8	9	4
Cough	14	6	6	4
Difficulty sleeping	14	8	9	5
Dry mouth	13	6	9	3
Numbness/tingling in hands or feet	11	4	3	3
Worrying	11	5	7	4
Diarrhea	9	5	6	1
Feeling irritable	9	4	6	3
Feeling nervous	9	3	5	3
Feeling sad	9	2	5	3
Problems with self-image ("I do not look like myself.")	9	–	6	2
Weight loss	9	–	2	2
Constipation	7	–	3	–
Difficulty concentrating	7	3	4	3
Dizziness	7	–	2	1
Lack of appetite	7	2	3	–
Mouth sores	7	–	4	2
Shortness of breath	7	1	4	3
Swelling of arms or legs	7	–	4	1
Sweats	6	–	3	–
Change in the way food tastes	5	–	2	2
Feeling bloated	5	1	2	1
Hair loss	5	–	1	–
Itching	5	1	1	–
Nausea	5	1	2	1
Changes in skin	4	–	1	–
Problems with sexual interest or activity	4	1	1	–
Problems with urination	4	1	1	1
Vomiting	4	–	1	1

Freq–Con—frequently to constantly; Mod–VSev—moderate to very severe; QB–VM—quite a bit to very much

psychological distress. Therefore, future studies on symptom reduction may be of benefit in preventing post-traumatic distress in patients with tracheostomy and their caregivers. Prospective symptom management programs that equip patients and family caregivers with health management information and skills to prevent symptom deterioration associated with treatment toxicities could be beneficial. Digital technologies have the advantage of involving patients and caregivers in health management remotely. Mobile or web-based applications such as Springboard Beyond Cancer from the American Cancer Society (Leach et al., 2019) and Help to Overcome Problems Effectively from the UK National Health Service (Martin et al., 2020) are useful survivorship support tools. Peterson et al. (2018) tested an HNC-specific mobile application that included symptom monitoring and informational support functions in a randomized controlled study and found that patients undergoing chemotherapy and radiation therapy

TABLE 4. Correlations of Participant Characteristics With the IES-R and PROMIS Depression 6a

Variable	Post-Traumatic Distress (IES-R) Total Score	Post-Traumatic Distress (IES-R) Hyperarousal	Post-Traumatic Distress (IES-R) Intrusion	Post-Traumatic Distress (IES-R) Avoidance	PROMIS Depression 6a
Demographic characteristics (N = 39)					
Age	–0.178	–0.199	–0.167	–0.2	–0.041
Annual income	–0.262	0.273	0.269	–0.198	–0.075
Education	–0.146	0.061	–0.126	–0.13	0.021
Ethnicity	0.21	0.289	0.219	0.12	0.298
Marital status	0.289	0.187	0.322	0.218	0.097
Sex	0.087	0.03	0.025	0.133	–0.03
Symptom characteristics (MSAS) (N = 22)					
Global distress	0.749**	0.691**	0.717**	0.645**	0.086**
Psychological symptoms	0.584**	0.581**	0.606**	0.441*	0.793**
Physical symptoms	0.544**	0.588**	0.506*	0.425*	0.636**

* $p < 0.05$ level (2-tailed); ** $p < 0.01$ (2-tailed)
IES-R—Impact of Event Scale–Revised; MSAS—Memorial Symptom Assessment Scale; PROMIS—Patient-Reported Outcomes Measurement Information System
Note. Nonparametric correlation analysis (Spearman rank order) was conducted among demographic characteristics, symptom characteristics, and post-traumatic distress and depression variables. The symptom characteristics (global, psychological, physical) were scores from the MSAS subscales. The post-traumatic distress variables (hyperarousal symptoms, intrusion, avoidance) were scores from the IES-R subscales. The depression variable was calculated using scores from the PROMIS Depression 6a.

who used the application had a high adherence rate (80%) and reported significantly fewer symptoms than those receiving standard care. Family caregivers' needs should also be acknowledged and supported. An ongoing clinical trial is testing an innovative face-to-face nurse-led intervention using simulation techniques to support family caregivers (Mazanec et al., 2021), which could be used to meet family caregivers in a timely and effective manner during radiation treatment. Additional studies that take all these variables into account will need to be undertaken.

Limitations

Although this study contributes valuable knowledge, the generalizability of its results is subject to certain limitations. This study was limited to survey questions and lacked the qualitative analysis of factors that may inhibit or exacerbate the development of post-traumatic distress associated with tracheostomy. Another weakness is the small sample size, which was limited by the duration of data collection. Although the sample size in this study was small, the descriptive data for the patient group was comparable to the characteristics of patients reported in previous HNC studies (Qualizza et al., 2019; Wu et al., 2016). Future studies should use a longitudinal approach to assess symptoms and post-traumatic distress in this population.

Conclusion

This observational study of patients living with an HNC-related tracheostomy and their family caregivers is the first study to use a quantitative approach to examine the psychological experience of receiving tracheostomies. It contributes to the existing knowledge on the prevalence of tracheostomy-related post-traumatic distress and its associations with demographic characteristics and symptom burden. Subsequent studies could assess the long-term influence of tracheostomy with longitudinal data that include patients and family caregivers from heterogeneous demographic backgrounds. Greater efforts are needed to ensure the recognition and support of psychological needs in patients and their family caregivers.

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