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Caregiver-Reported Neuropsychiatric Symptoms in Patients Undergoing Treatment for Head and Neck Cancer: A Pilot Study

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Abstract

Background—Patients with cancer experience multiple neuropsychiatric symptoms. While individual symptoms have been studied in patients with head and neck cancer, the broader context of neuropsychiatric symptoms needs to be explored.

Objective—The aims of this pilot study were: 1) to determine the caregiver-reported prevalence and severity of neuropsychiatric symptoms in patients with head and neck cancer, 2) to determine the associated level of caregiver distress, and 3) to describe the effects of neuropsychiatric symptoms on patients and their caregivers.

Methods—Twenty-three family caregivers of patients with head and neck cancer completed the Neuropsychiatric Inventory Questionnaire and participated in a semi-structured interview.

Results—All caregivers reported that patients experienced at least one neuropsychiatric symptom (Mean 7.5; Range 1–12). The most frequently reported symptoms were trouble with appetite and eating (95.7%), altered nighttime behaviors (82.6%), depression/dysphoria (78.3%), decreased alertness (69.6%), inattention (60.9%), apathy/indifference (56.5%), anxiety (56.5%), irritability/lability (52.5%), agitation/aggression (52.2%), and slowed behavior (43.5%). The mean severity rating for nine symptoms was moderate to severe. Most symptoms caused mild to moderate levels of caregiver distress. Qualitative data indicated that neuropsychiatric symptoms negatively affected patients, their caregivers, and other family members. Patients required more caregiver support resulting in increased caregiver burden and distress.

Conclusions—Neuropsychiatric symptoms are common and troubling in patients with head and neck cancer during treatment. Further investigation of their effects on patients and family caregivers is needed.

Implications for Practice—Clinicians should monitor for and treat neuropsychiatric symptoms throughout treatment, and provide caregiver and patient education and support.

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Keywords

neuropsychiatric symptoms; head and neck cancer; caregiving

Introduction

Patients with cancer experience a host of neuropsychiatric symptoms that may form into a neuropsychiatric symptom cluster. Several models[1–5] have been proposed to conceptualize neuropsychiatric symptoms associated with cancer and cancer treatment, their biologic underpinnings, and their clinical manifestations. The models suggest that neuropsychiatric symptoms can be categorized into four domains: 1) mood symptoms (e.g., depression, anxiety, anhedonia); 2) neurocognitive symptoms (e.g., memory loss, inattention, slowed thinking, delirium); 3) neurovegetative symptoms (e.g., anorexia, fatigue), and; 4) somatic symptoms (e.g., pain, fever, gastrointestinal distress). These domains have been explored to a variable extent in the head and neck patient population.

Mood Symptoms: Depression and Anxiety

There is a large body of literature focused on the prevalence of depression and anxiety in patients with head and neck cancer.[6–10] Rates vary dramatically depending on the measurement methods utilized, the assessment time point, the patient population, and treatment variables. In a recent review that included 52 studies,[6] depression in patients with head and neck cancer was reported in 13–40% at diagnosis, 25–52% during treatment, and 11–45% at six-month post-treatment follow-up. Three years after diagnosis, rates of depression declined (9–27%). In a cross-sectional study by Gilbert et al,[7] the prevalence of depression in a mixed sample of patients with head and neck cancer (11% of whom were in active treatment) was 43%. Similarly, anxiety is common in the head and neck population with rates ranging from 12–39%.[8–10] In one study the prevalence of isolated anxiety symptoms was 12.1% and 15.0% for mixed anxiety and depression symptoms.[8] Data suggest that patients with head and neck cancer have higher rates of mixed anxiety and depression symptoms compared to the general population and patients with other cancers.

Neurocognitive Symptoms and Delirium

There is an increased awareness of the effects of cancer and treatment on neurocognitive function.[11–14] A recent editorial in the *Journal of Clinical Oncology* [15] emphasized the growing evidence base to support the effect of chemotherapy on cognition and furthermore implied that “this was the tip of the iceberg.” Unfortunately, most studies have been conducted in patients with breast cancer. Although the literature in other tumor types is growing, it still remains limited.[16–17]

Studies in patients with head and neck cancer have primarily examined neurocognitive impairment as a late effect of incidental radiation therapy to the brain.[18–23] The most commonly affected neurocognitive domains are visual and verbal memory, executive function, attention/concentration, language, and visuospatial ability. Data on neurocognitive deficits associated with concurrent chemoradiation therapy (CCR) is limited.[24] This is an important gap in the knowledge base because today CCR is standard treatment for locally

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advanced head and neck cancer and the addition of chemotherapy to radiation has the potential to substantially increase neurocognitive toxicities.

Delirium is a common neuropsychiatric complication in patients with cancer.[25] Delirium is characterized by an acute change in level of consciousness, inattentiveness, and altered cognition. In patients with head and neck cancer, the vast majority of studies have been conducted in the perioperative setting in patients undergoing surgical treatment.[26–29] In a previous study, we examined the development of delirium in patients with head and neck cancer during outpatient treatment.[30] Nine percent of these patients had documented delirium and 45.3% had subsyndromal delirium (the presence of one or more delirium symptoms without meeting diagnostic criteria) during at least one assessment during treatment. Following treatment, 31% of patients (N = 59) and 43% of caregivers (N = 23) reported that patients may have experienced delirium during treatment.

Neurovegetative Symptoms

Fatigue is one of the most commonly reported symptoms in patients with cancer. Descriptive studies in patients with head and neck cancer suggest that fatigue is common, that it increases during radiation therapy, and that it persists after treatment.[31,32] Hickok et al[31] described the course of fatigue in 372 cancer patients undergoing radiation therapy: of the 23 patients with HNC, 56% reported baseline fatigue with a mean intensity of less than 2 (scale 0–10). By week 5 of radiation therapy, 93% of patients reported fatigue with a mean intensity of greater than 4. Similarly, in a cohort of 117 patients with head and neck cancer undergoing radiation therapy, investigators[32] using the Multidimensional Fatigue Inventory (scale 0–80) noted that the mean level of fatigue increased from a baseline level of 26 to 36 during radiation therapy ($p < .0001$) and remained elevated six weeks post treatment ($p < .0001$). Post-treatment fatigue has been shown to correlate with younger age, history of radiation therapy, time since completion of therapy, and depressive symptoms.[33]

An overwhelming nutritional issue facing patients with head and neck cancer is the inability to aliment due to obstructive tumor, the effects of extirpative surgery, or the acute and late effects of radiation therapy. In a sample of 68 patients who completed radiation for head and neck cancer, Cooperstein et al[34] found that 68.2% of patients within 6 months of therapy complained of some degree of anorexia and 31.8% indicated that the anorexia was moderate to severe. In patients who completed therapy ≥ 6 months prior to study entry, 30.4% of patients complained of anorexia of any degree and 13% indicated that symptoms were moderate to severe.

Somatic Symptoms

Somatic symptoms are an anticipated complication of head and neck cancer and its therapy with pain being the cardinal problem. Pain is a presenting symptom for a significant cohort of patients.[35] Furthermore, primary treatment with either surgery or a radiation-based approach is associated with clinically significant pain which requires pharmacological intervention in the vast majority of patients.[36] Pain may adversely affect critical functions such as eating, drinking, talking, and maintaining oral care.[37]

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Neuropsychiatric Symptom Domains: Knowledge Deficits

Studies addressing isolated neuropsychiatric symptoms and symptom domains have been reported in the head and neck cancer population as described above; however, there are limitations in the current body of knowledge. Our review of the literature suggests that the broad range of neuropsychiatric symptoms in patients with head and neck cancer has not been systematically described. Specifically, symptoms such as irritability, agitation, and aggression have not been reported; yet in our clinical experience these symptoms are problematic. The impact of neuropsychiatric symptoms on patients and their family caregivers is also unknown. Finally, studies exploring the clustering and interrelationship between these symptoms and symptom domains are scant. To begin to address these gaps in our understanding of the neuropsychiatric symptoms associated with head and neck cancer therapy, we conducted a pilot study with the following aims: 1) to determine the caregiver-reported prevalence and severity of neuropsychiatric symptoms in patients with head and neck cancer during treatment, 2) to determine the associated level of caregiver distress, and 3) to describe the negative effects of neuropsychiatric symptoms on patients and caregivers from the caregiver perspective.

Methods

This pilot study used a retrospective mixed-methods design. The sample was comprised of family caregivers of patients with head and neck cancer who participated in a prospective study of neurocognitive function associated with radiation-based therapy.[38] Eligible caregivers were ≥ 21 years of age and spoke English. Caregivers of patients who were known to be deceased were excluded. Patients and caregivers were given information about the study during a follow-up clinic visit. Both patients and caregivers provided written informed consent for the caregivers to participate in the study. This study was approved by the Vanderbilt University Institutional Review Board and the Vanderbilt-Ingram Cancer Center Scientific Review Committee.

Variables and Measures

The caregivers completed two self-report instruments: a sociodemographic questionnaire and the modified Neuropsychiatric Inventory Questionnaire (NPI-Q).[39] The sociodemographic questionnaire assessed information on age, sex, race/ethnicity, marital status, education, employment status, annual household income, and relationship to patient. The NPI-Q is a 12-item instrument that allows caregivers to indicate the presence, severity, and distress associated with abnormal neuropsychiatric symptoms. The neuropsychiatric symptoms include delusions, hallucinations, agitation or aggression, depression or dysphoria, anxiety, elation or euphoria, apathy or indifference, disinhibition, irritability or lability, motor disturbance, altered nighttime behaviors, and appetite and eating. Validity of the NPI-Q has been established in people with dementia and in acutely ill older hospitalized patients.[39,40] In the initial NPI-Q validation study, test-retest correlations were 0.80 and 0.94 for the total symptom and distress scores, respectively. Interscale correlation between the NPI-Q and the Neuropsychiatric Inventory was 0.91, demonstrating convergent validity. Interscale item correlations for caregiver distress ratings ranged from 0.71 – 0.97.[39] In a study of patients with malignant brain tumors,[41] the NPI-Q had a Chronbach’s alpha of 0.78.

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In the current pilot study, the researchers modified the NPI-Q by adding eight additional neuropsychiatric symptoms more specifically associated with delirium including: inattention; disorientation; decreased alertness; disorganized thinking; hyperactive behavior; slowed behavior; inappropriate communication; and illusions. Questions on the modified NPI-Q were answered "yes" or "no" to indicate whether patients were observed to experience or exhibit the symptom at any point during treatment. If the answer was "yes," caregivers then rated the symptom severity on a scale of 1 (mild) to 3 (severe). They also rated their level of distress associated with the symptom on a scale of 0 (not at all) to 5 (extreme or very severe).

After the questionnaires were completed, the caregivers participated in a semi-structured interview conducted by a trained research team member. Caregiver responses on the NPI-Q were used to guide the interview and to explore the neuropsychiatric symptoms experienced by patients during treatment and their impact on patients and caregivers. For example, if caregivers indicated on the NPI-Q that patients experienced anxiety, then the caregivers were asked to describe the patients' anxiety symptoms and how the anxiety affected the patients and themselves as caregivers.

Analysis

Quantitative data were analyzed using SPSS version 17. Descriptive statistics and frequency distributions were generated for the sample characteristics, symptom prevalence, and symptom severity and caregiver distress scores.

Qualitative description[42] was used to analyze and present the interview data. The digitally recorded interviews were transcribed verbatim. The transcribed interviews were compared to the audio files for accuracy. The transcriptions were read through in their entirety. Two investigators (S.B., D.H.) independently coded the transcripts using the neuropsychiatric symptoms as codes. Symptom descriptions and the impact of the symptoms on the patients and caregivers were ascertained from the qualitative data.

Results

Caregiver and Patient Characteristics

The caregiver and patient characteristics are summarized in Table 1 and Table 2, respectively. All were Caucasian and the majority were married. All but one of the caregivers were female. Most of the caregivers were identified as the patients' spouses/ partners. A majority of patients had oropharyngeal cancer (56.5%), stage IV disease (78.3%), and received induction chemotherapy followed by concurrent chemoradiation therapy (69.1%).

Prevalence of Caregiver-Reported Neuropsychiatric Symptoms

The caregiver-reported prevalence, severity, and distress associated with neuropsychiatric symptoms are summarized in Table 3. All patients were reported to have had at least one neuropsychiatric symptom. The average number of symptoms per patient was 7.5 (median = 8.0; range 1 – 12). Nine of the 20 symptoms assessed on the modified NPI-Q, were observed

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by > 50% of caregivers. These data demonstrate a high prevalence of neuropsychiatric symptoms in patients with head and neck cancer during treatment.

As might be expected in a sample of patients with head and neck cancer undergoing treatment, trouble with appetite and eating was the most frequently reported symptom (95.7% of patients). Other frequently reported symptoms included altered nighttime behaviors (82.6%), depression/dysphoria (78.3%), decreased alertness (69.6%), inattention (60.9%), apathy/indifference (56.5%), anxiety (56.5%), irritability/lability (52.2%), agitation/aggression (52.2%), and slowed behavior (43.5%).

Caregiver-Reported Severity of Neuropsychiatric Symptoms

The severity of the neuropsychiatric symptoms observed by caregivers was high. Nine of the 20 symptoms were rated as moderate to severe (scoring between 2.0 and 3.0). These included: trouble with appetite/eating, altered nighttime behaviors, decreased alertness, inattention, apathy/indifference, anxiety, disorganized thinking, motor disturbance, and euphoria. Of the remaining 11 symptoms, seven had a severity score that ranged from 1.7 to 1.9, thus approaching a moderate level. Only four symptoms had an average severity rating of mild (1.0). These included disinhibition, hallucinations, hyperactive behavior, and illusions.

Caregiver Distress with Neuropsychiatric Symptoms

Among the 20 symptoms, none were scored in the range of moderate to extreme distress (3.0 to 5.0). The vast majority of the neuropsychiatric symptoms caused mild to moderate levels of caregiver distress (2.0 to 2.9). Seven symptoms were associated with minimal to mild caregiver distress (1.0 to 1.9). One symptom, euphoria, was not associated with any distress (score of 0).

While irritability/lability and agitation/aggression were among the least severe symptoms, they were among the most distressing for caregivers. The mean level of distress associated with irritability/lability and agitation/aggression were 2.7 and 2.6, respectively. Trouble with appetite and eating, the most frequently reported symptom, was also one of the most distressing symptoms for caregivers (M = 2.6), followed by anxiety (M = 2.5), depression/dysphoria (M = 2.5), apathy/indifference (M = 2.4), inattention (M = 2.3), and altered nighttime behaviors (M = 2.1). Although frequently reported, slowed behavior and decreased alertness caused less caregiver distress. The mean distress levels for these symptoms were 1.9 and 1.8, respectively.

Qualitative Findings

Depression/Dysphoria—Caregivers reported that patients experienced symptoms of depression, such as being withdrawn, crying, verbalizing depression, wanting to give up, and having suicidal ideation. They described detailed accounts of how this depression severely impacted the emotional and functional wellbeing of the patients and themselves, as caregivers.

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> "He never stopped being himself until the depression. And when he became depressed, it was like we had lost a child. I mean, he cried every day. He was just consumed with the fear and death, and there's no way to describe it."

> "I think the biggest one was the suicide thing. That was really very traumatic and trying to stay on top of it all the time. To make sure that he didn't do something as soon as I turned my back. You know, making him talk about it. Telling him that this was all going to be better soon. Not to even think like that. 'You'd be better off without me' - you know, that kind of thing."

Anxiety—Caregivers conveyed that patients exhibited high levels of anxiety. Specifically, patients commonly expressed concerns about being left alone. This resulted in a need for increased supervision, which was confining for the caregivers.

> "He did not want me to be away from him for any time at all because he was afraid to be by himself or afraid he would need me and me not be there. He was very, very anxious."

> "I couldn't get out of his sight. If I got out of his sight, he would come looking for me."

Caregivers also reported that patients had panic attacks, social anxiety, and fear of being in closed spaces or in crowds.

> "He called me and said "I called an ambulance….I think I'm having a heart attack… I think I'm dying."… And I started going down the questions of what is an anxiety attack and panic attack, and when I was done asking that questions, that is what it was. I knew that is what it was."

> "He's on medication for it, but it don't always cure the anxiety. His anxiety is really, really bad. Like being in small places or being in places with a lot of people. He won't do that at all hardly any more."

Irritability/Lability—Caregivers noted that patients were easily irritated and tended to become upset over minor issues. Often the anger was directed at family members creating significant discord.

> "And he was just hateful. I mean everything he said was just so hateful. By the time we left the clinic I was crying."

> "Very irritable with… little situations that didn't go his way. You know he would just really blow up over [them]. I mean, it was hard on all of us."

Agitation/Aggression—Caregivers noted that patients had increased levels of aggression. Agitation and aggression affected family relationships.

> "He even would snap to children, other family, especially our youngest child was afraid to go near him. He didn't … hit no one or anything, but he was very verbal, sometimes abusive."

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Apathy/Indifference—Caregivers observed that patients lost interest in normal activities. Of particular importance, patients handed over control of health-related issues and self-care to caregivers, substantially increasing caregiver burden.

> "But, he gave up complete control during that time. He started giving up control very early on. When he started feeling very, very badly, he made absolutely no decisions whatsoever."

> "But, we just had a period there where he was just shut down…. He had a lack of interest of all the activities he used to do… I mean he would have the TV on, but no interest in anything. … I probably could have gone off and left him all day long and he wouldn't have said a word about it… because he couldn't have cared less."

Inattention—Patients were noted to have lost the ability to focus. Caregivers commented on two specific issues: 1) inability to attend to routine activities such as reading, watching TV, or playing video games, and; 2) generalized lost awareness of events in their immediate surroundings.

> "Well, he didn't pay attention to much of anything. As I said, he is a real TV buff, but he didn't pay attention to TV or anyone talking or anything like that."

> "He paid no attention to things that were going on around him really. Just didn't know what was going on really. Most of it was he didn't care what was going on. It was just whatever was going on around him was just … so far down his priority list that it didn't even matter, so he didn't pay attention to it."

Decreased Alertness and Slowed Behavior—Caregivers noted a general state of lethargy and drowsiness. Patients were described as "out of it." The symptoms were of such severity that patients were noted to "nod off" easily.

> "He was just extremely… lethargic…. he was kind of just out of it."

> "When we were back at Hope Lodge, he was down, he was out of it, he really wasn't aware too much about what was going on with him."

> "You would catch him falling asleep, he would drop his cigarette, you know, you would have to stay with him 24 hours. You had to be there with him because he was just real dazed and confused then."

Caregivers indicated that patients exhibited slowed behaviors particularly slowed walking. One caregiver recounted how she "would have to stop and wait for him [her husband] to catch up."

Altered Nighttime Behaviors—Some patients had alterations in their sleep-wake cycles with increased daytime sleep and nighttime arousal. Caregivers also reported extreme levels of hypersomnia. The total number of hours patients slept was increased. The marked increase in daytime sleepiness was most concerning to caregivers. Furthermore, sleep was noted to be of poor quality with frequent arousal.

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> "Yeah, he slept pretty much a lot of the time as the treatment intensified. Um there were days that he would be up for an hour and the rest of the time he'd be in bed."
>
> "His circadian rhythm was completely flip-flopped. He went from sleeping at night and being up during the day to sleeping all day long and being up all night long. And for a while it kind of scared me."
>
> "Because during the worst, (patient's name) really could only sleep like in 20 minute increments."

Discussion

We examined the caregiver-reported frequency, severity, and level of distress associated with neuropsychiatric symptoms in patients with head and neck cancer. All caregivers reported that patients exhibited at least one neuropsychiatric symptom during treatment. The average number of symptoms per patient was 7.5 (median = 8.0; range 1 – 12). Overall, the symptom severity was high. The average rating for nine of the 20 symptoms was moderate to severe. Most of the reported symptoms caused mild to moderate levels of caregiver distress. The qualitative data highlight how neuropsychiatric symptoms negatively affected caregivers and patients. Although preliminary, the data indicate that neuropsychiatric symptoms are a major issue for both patients and their caregivers.

Our findings demonstrating a high prevalence of treatment-related neuropsychiatric symptoms in patients with head and neck cancer are consistent with currently available data. Although rates of depression and anxiety vary among studies, depression and anxiety are common in this population.[6–10] We also identified prevalent neuropsychiatric symptoms that have not been previously reported or studied. For example, irritability was highly prevalent. Although its severity was reported as mild to moderate, irritability was associated with high levels of caregiver distress.

Neuropsychiatric symptoms in patients with head and neck cancer may contribute to poor treatment outcomes. Anxiety in patients with head and neck cancer receiving radiation therapy has been associated with treatment disruption[43]; and data indicate that failure to complete head and neck cancer treatment in a timely manner is associated with decreased local control and survival.[44] Furthermore, patients with depression, anxiety, and/or neurocognitive dysfunction often fail to comply with treatment recommendations.[45–47] These patients may fail to complete doctor's visits, fail to take medications as prescribed, and fail to participate in necessary rehabilitation activities. Recovery of swallowing, speaking, and musculoskeletal function following head and neck cancer treatment requires intensive multimodality rehabilitation. Although never formally studied, it is reasonable to suggest that patients who are unable to participate actively in these efforts due to neuropsychiatric symptoms may experience increased long-term treatment sequellae. This is an important area of future study.

In addition, neuropsychiatric symptoms may affect patients' abilities to care for themselves, thereby increasing caregiver burden. Patients with head and neck cancer who are undergoing treatment must actively engage in self-care activities to prevent and manage multiple

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symptom control problems. For example, patients must undertake frequent mouth care, maintain adequate fluid intake and nutrition via feeding tubes, and manage complex pain medication regimens. Data from this study suggest that patients with neuropsychiatric symptoms have difficulty adhering to these complex medical regimens. The data also indicate that patients' inabilities to provide self-care significantly impact caregivers by increasing caregiver task burden and distress. Neuropsychiatric symptoms in patients with primary malignant brain tumors have been associated with increased depression and burden among their caregivers.[39] The relationship between neuropsychiatric symptoms and caregiver task burden in head and neck cancer patients warrants further study.

Finally, neuropsychiatric symptoms also caused tension between patients and their caregivers, and contributed to strained family relationships. One might anticipate that there would be conflict between the patient and the primary caregiver, but a particularly striking finding was that neuropsychiatric symptoms such as irritability and aggression affected relationships with children and other family members. Because clinicians are largely unaware of the frequency, severity, and impact of neuropsychiatric symptoms, they do not foreworn caregivers as part of informed consent. Thus, caregivers are often unprepared to deal with these symptoms. Caregivers indicated that they would have liked more information about the potential for neuropsychiatric symptoms, as well as the opportunity to discuss these with health care professionals.

Although data from this pilot study are preliminary and further study is needed, the findings lend themselves to the following clinical recommendations. Patients and caregivers should be informed about the potential manifestation of neuropsychiatric symptoms during treatment, and the impact on self-care and caregiving. This would allow patients and caregivers to develop strategies for dealing with these issues in a proactive rather than reactive manner. Clinicians should carefully monitor for neuropsychiatric symptoms before, during, and after treatment. Early symptom identification and management with appropriate pharmacologic agents and psychological support is paramount. Consultation with psychiatrists or psychologists may be particularly important for patients with prior histories of psychiatric illness. These strategies could potentially prevent or minimize treatment compliance issues and medical complications, as well as diminish caregiver distress.

Limitations

This pilot study examined a broad array of neuropsychiatric symptoms in patients with head and neck cancer. The study is limited by the small number of caregivers who participated. The caregivers of deceased patients were excluded. Because neuropsychiatric symptoms are common in patients with advanced cancer, particularly near the end of life,[48,49] it is possible that the patients who died during treatment or soon after treatment experienced a high level of neuropsychiatric symptoms. Thus, the prevalence of neuropsychiatric symptoms may be underestimated. The retrospective report of neuropsychiatric symptoms by caregivers is also a limitation. Neuropsychiatric symptoms should be assessed prospectively throughout the treatment trajectory. We chose to query family caregivers because: 1) patients may be unaware of and reluctant to report neuropsychiatric symptoms and 2) caregivers spend a large quantity of time with patients and are best able to observe and report these symptoms.

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However, there are concerns that caregivers may have either under-reported or over-reported symptoms. Studies examining patient and caregiver agreement with symptom reporting suggest that caregivers tend to overestimate symptoms and symptom distress.[50] Agreement is worse for symptoms that are subjective in nature compared to those that are more concrete and observable. Future studies should examine concordance between patient and caregiver reports of neuropsychiatric symptoms.

Conclusion

The data presented in this study suggest that neuropsychiatric symptoms in patients with head and neck cancer are frequent and moderately severe. In addition, they are associated with substantial family caregiver distress. Caregivers expressed the need for information and support surrounding these issues. Additional research is needed to further characterize the wide array of neuropsychiatric symptoms experienced by patients with head and neck cancer and to develop interventions targeting risk identification, prevention, and effective symptom management.

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Table 1

Caregiver Characteristics (N = 23)

Characteristic	**Mean (Range)**	**n**	**(%)**
Age, years	55.1 (31–83)		
Gender			
Male		1	4.3
Female		22	95.7
Race			
Caucasian		23	100
Marital status			
Married		20	87.0
Separated		1	4.3
Divorced		1	4.3
Widowed		1	4.3
Level of education			
Less than high school		3	13.0
High school		5	21.7
Some college		7	30.4
4-year degree		6	26.1
Graduate degree		2	8.7
Relationship to patient			
Spouse/Partner		20	87.0
Sister		1	4.3
Mother		2	8.7

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Table 2

Patient Characteristics (N = 23)

Characteristic	Mean (Range)	n	(%)
Age, years	54.6 (35–68)		
Gender			
Male		20	13.0
Female		3	87.0
Race			
Caucasian		23	100
Marital status			
Single		1	4.3
Married		19	82.6
Divorced		2	8.7
Widowed		1	4.3
Level of education			
Less than high school		2	8.7
High school		9	39.1
Some college		5	21.7
4-year degree		5	21.7
Graduate degree		2	8.7
Cancer site			
Oropharynx		13	56.5
Nasopharynx		4	17.4
Paranasal sinus		2	8.7
Unknown primary		2	8.7
Larynx		1	4.3
Salivary gland		1	4.3
Cancer stage			
III		5	21.7
IV		18	78.3
Treatment			
Chemoradiation		6	26.1
Induction chemotherapy/chemoradiation		16	69.1
Chemotherapy		1	4.3

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Table 3

Caregiver-Reported Neuropsychiatric Symptoms (N = 23)

Symptom	**Frequency n (%)**	**Severity (1–3) *M (SD)***	**Distress (0–5) *M (SD)***
Appetite and eating	22 (95.7)	2.4 (.74)	2.6 (1.36)
Nighttime behaviors	19 (82.6)	2.4 (.76)	2.1 (1.37)
Depression or dysphoria	18 (78.3)	1.9 (.87)	2.5 (1.04)
Decreased alertness[a]	16 (69.6)	2.1 (.77)	1.8 (1.27)
Inattention[a]	14 (60.9)	2.1 (.86)	2.3 (1.20)
Apathy or indifference	13 (56.5)	2.2 (.69)	2.4 (1.12)
Anxiety	13 (56.5)	2.1 (.76)	2.5 (.97)
Irritability or lability	12 (52.2)	1.9 (.90)	2.7 (1.23)
Agitation or aggression	12 (52.2)	1.8 (.87)	2.6 (1.16)
Slowed behavior[a]	10 (43.5)	1.7 (.82)	1.9 (1.6)
Disorientation[a]	4 (17.4)	1.8 (.96)	2.2 (.96)
Inappropriate communication[a]	4 (17.4)	1.8 (.50)	1.2 (1.26)
Disinhibition	3 (13.0)	1.0 (.00)	1.0 (1.0)
Delusions	3 (13.0)	1.7 (.58)	2.3 (1.16)
Hallucinations	3 (13.0)	1.0 (.00)	1.3 (.58)
Disorganized thinking[a]	2 (8.7)	2.0 (.00)	2.0 (1.41)
Motor disturbance	2 (8.7)	2.0 (1.41)	2.5 (.70)
Hyperactive behavior[a]	1 (4.3)	1.0	1.0
Euphoria	1 (4.3)	3.0	0.0
Illusions[a]	1 (4.3)	1.0	1.0

[a] Symptoms added to NPI-Q by the investigators.