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“I would have told you about being forgetful, but I forgot”: The experience of cognitive changes and communicative participation after head and neck cancer

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Abstract

Purpose: Survivors of head and neck cancer have reported difficulties with memory, attention, verbal fluency, and processing speed sometimes persisting years after treatment. Self-perceived cognitive function is an important predictor of communication outcomes in this population. This study explores the lived experience of cognitive changes in survivors of non-nasopharyngeal head and neck cancer and how these changes affect communication in their daily lives.

Materials and methods: In the phenomenological tradition, five adult survivors of non-nasopharyngeal head and neck cancer participated in individual semi-structured interviews. The interviews were audio-recorded, transcribed, coded, and summarized into themes.

Results: Two major themes emerged: (1) *I would have told you about being forgetful, but I forgot*, and (2) *It's such a journey that much of it is uncharted*. Participants described problems with memory, focus/attention, and task initiation along with slowed processing and language difficulties. These difficulties affected communication at work, socially, and at home. Participants expressed feeling unprepared for the possibility of cognitive changes, not knowing why they were happening or what to do about them.

Conclusions: Results of this study have implications for counseling and treatment of individuals with head and neck cancer, as well as advocating for these patients to receive appropriate information and intervention.

Keywords

head and neck cancer; communicative participation; cognition; quality of life; qualitative research

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Introduction

Head and neck cancers are primarily squamous cell carcinomas that occur in the oral cavity, pharynx, larynx, nasal cavity, and paranasal sinuses - all critical structures for swallowing, respiration, and communication. Patients treated for head and neck cancers often experience lasting difficulties with verbal communication [1]. In fact, among head and neck cancer survivors, speech outcomes have been identified as the strongest predictor of overall health-related quality of life [2]. Specifically, difficulty communicating in everyday activities, or “communicative participation,” may affect a person’s ability to return to work, establish or maintain relationships, or participate in social contexts [3]. Head and neck cancer patients have identified these roles and activities as extremely important priorities during and after treatment [4, 5].

The most conspicuous barriers to communicative participation in patients with head and neck cancers include impaired voice quality and reduced speech intelligibility, but these may be only moderately related to communicative participation in this population [6]. Beyond speech and voice function, communication success may also be affected by contextual factors related to the environment (e.g., familiarity of communication partners, background noise) or the person (e.g., age, sex, educational background) [7]. In exploring these additional factors, one recent study found that self-perceived cognitive function was second only to self-perceived severity of speech symptoms in predicting communicative participation in survivors of head and neck cancer [8]. Those reporting lower levels of perceived cognitive function also reported lower levels of communicative participation. Despite the limitations of the study design being cross-sectional and measures being limited to patient report, the results from this study highlight the importance of cognition in the everyday communicative experiences of patients with head and neck cancer [9].

While posttreatment cognitive status and its relationship with health-related quality of life has received little attention in head and neck cancer, it is well established in other cancer populations, such as those undergoing treatment for breast, colorectal, testicular, and hematologic cancers [10, 11]. Across these cancer types, the most commonly reported cognitive changes during and after treatment occur in the areas of memory, attention, executive function, and processing speed. These changes may manifest in unusual disorganization, confusion, fatigue, and difficulties with concentration, learning, memory, attention, and word finding [12]. Colloquially, this constellation of symptoms often is referred to as “chemo brain” [11]. However, cognitive decline also has been reported in cancer patients not receiving chemotherapy, suggesting that “chemo brain” may result from radiation, surgery, and perhaps even the body’s response to the cancer itself [13, 14]. Consequently, the term “cancer-related cognitive impairment” has emerged. Qualitative studies completed with individuals with breast cancer to explore their experiences living with the condition have revealed that impairments in memory, word finding, and speed of processing led to difficulty following conversations, particularly in groups. In some cases, this created a barrier to communicative participation as individuals avoided conversations in both personal and professional situations [15, 16].

Among head and neck cancer survivors receiving different treatment modalities, deficits in memory, attention, verbal fluency, and processing speed have been identified through neuropsychological testing [17, 18, 19]. These cognitive impairments have been more commonly investigated among those with nasopharyngeal cancer due to the proximity of these tumors to the central nervous system and the exposure of brain structures to radiation beams during treatment [18]. However, there is a paucity of data related to those with non-nasopharyngeal head and neck cancer. In one of the few studies examining cognitive changes in non-nasopharyngeal head and neck cancer, Gan et al [17] found that while few study participants reported cognitive symptoms, 70% demonstrated impaired performance of at least one standard deviation on numerous neuropsychological tests of cognition. In a separate, larger, multicenter study involving similar participants, Wilbers, et al [19] also found significant impairments in memory and processing speed, with additional impairments in verbal fluency for those reporting abnormal levels of fatigue. Together, these results demonstrate that patients with non-nasopharyngeal head and neck cancer may experience cognitive impairments posttreatment and that these impairments should be considered when evaluating long-term outcomes.

To better understand how cognitive impairments manifest in a person's daily life, qualitative research methods can provide further insight. In one study, focus groups were used to compare the perceptions of head and neck cancer survivors, family members, and healthcare professionals regarding rehabilitation needs [20]. While not discussed by survivors or healthcare professionals, cognitive changes represented one of eight rehabilitation needs identified by family members. In another study [21], eight survivors at least one year post treatment for non-nasopharyngeal head and neck cancer were asked in interviews to describe their supportive care needs during and after treatment. Within the theme "Returning to a normal life" participants reported challenges posed by difficulties with memory, concentration, and word finding as they returned to work after treatment. Additionally, difficulties related to speech have been identified as a barrier to returning to work after treatment for head and neck cancer [22].

While the qualitative studies reported here provide preliminary evidence for the presence of cognitive changes among survivors of non-nasopharyngeal head and neck cancer, the topic of cognitive changes was not the focus of these studies. A deeper and more thorough understanding of the nature and lived experience of cognitive changes in survivors of head and neck cancer may be important to inform healthcare providers, particularly speech-language pathologists, about a potential challenge and need for intervention that heretofore has been overlooked in this population. Expanding this type of inquiry among non-nasopharyngeal head and neck cancer survivors is especially relevant as the incidence of head and neck cancers related to human papillomavirus continues to rise in a younger population who will live longer with the consequences of modern combined-modality treatment [23]. The purpose of this study, therefore, was to qualitatively explore the lived experience of a sub-group of head and neck cancer survivors with self-reported cognitive changes. Specifically, we posed the following questions: Among a convenience sample of people with non-nasopharyngeal head and neck cancer who experience cognitive changes during and after treatment, how do these changes manifest? And how do these changes affect communicative participation in daily life? Results of this study will inform patient

education, approaches to assessment, and the development of future interventions (e.g. compensatory and/or facilitatory strategies) for survivors of non-nasopharyngeal head and neck cancer.

Materials and methods

This study followed the qualitative tradition of phenomenology, or the study of the “lived experience” [24]. Phenomenology holds that reality is inextricable from consciousness; ergo those who experience a particular phenomenon are the experts in that phenomenon [25]. This makes purposeful sampling of those said experts appropriate for obtaining full and detailed descriptions of the phenomenon in question, allowing for in-depth exploration and identification of common themes [26]. All procedures were approved by the institutional review board at the University of Washington. Informed consent was obtained from all participants included in the study.

Participants

Participants were recruited through cancer support groups in the greater Seattle area. Inclusion criteria were for participants to be adults (age 21 and older), at least one year post-treatment for any type of non-nasopharyngeal head and neck cancer, including oral, oropharyngeal, hypopharyngeal, or laryngeal cancer, and reporting a history of having experienced cognitive changes during their cancer treatment and/or recovery (e.g. feelings of confusion or mental foginess, unusual disorganization, and/or difficulties with memory, attention, word-finding, and learning) [12]. Participants also needed to be fluent in English and use speech as their primary method of communication. Exclusion criteria were self-reported history of communication disorder, mental illness, other cancers, or psychological disorder existing prior to their cancer. All participants were compensated for their time. While the ultimate goal for participant recruitment was saturation, meaning that subsequent interviews did not yield additional novel information, the anticipated enrollment for this exploratory study was 10–12 participants.

Data Collection

Interviews.—Each participant engaged in an individual face-to-face semi-structured interview session, lasting 1 – 2 hours. Two interviewers (SB and CB) were present at all interviews, which took place at the University of Washington, Seattle. Both interviewers were speech-language pathologists who had experience assessing and treating patients with head and neck cancer. In addition, the lead interviewer (CB) had extensive experience in performing qualitative research. Neither interviewer had personal or professional relationships with any of the participants. The semi-structured interviews started with an open-ended question inviting the participants to describe their experiences with any cognitive changes that they had experienced during their cancer treatment and recovery. Keeping with the phenomenological tradition, participants were free to lead the discussion in directions most meaningful to them [24]. They were invited to share stories and examples of experiences with cognitive changes in their daily lives. Additional follow-up questions, provided in the interview guide in Table 1, were raised by the interviewers if participants did not bring them up spontaneously. These questions were used to gain as detailed of an

account as possible of participants' experiences living with cognitive changes. All interviews were audio recorded for later transcription.

Self-reported questionnaires.—Following the interview, participants completed questionnaires to obtain demographic and descriptive information about current level of communicative and cognitive function. The questionnaires were administered at the end of the interview session to allow participants to tell their stories free of any biases that might come from content contained within the questionnaire items.

Communicative participation was assessed using the *Communicative Participation Item Bank Short Form* (CPIB) [27], a validated 10-item self-report measure that asks participants to rate how much their “condition” (i.e. head and neck cancer) interferes with communication in everyday situations (e.g. conversing in small groups). The CPIB short form has demonstrated strong construct validity in head and neck cancer [6].

To assess cognitive function, participants completed the *Neuro-QOL Cognitive Function Short Form* (Neuro-QOL) [28]. On the Neuro-QOL short form, participants rate difficulties with everyday cognitive abilities (e.g., memory, attention, and learning) in terms of frequency and degree of magnitude. While not specifically validated in head and neck cancer, it has been validated across a large population representing multiple health conditions [28].

Data Analysis

Interviews were transcribed verbatim from the audio recordings by members of the research team. A second researcher or lab assistant reviewed each transcript for accuracy, with discrepancies resolved through consensus of the team. Errors that changed the meaning of a statement were rare and tended to be the result of the speaker using an idiom unfamiliar to the transcriber (e.g. “stark-raving mad” transcribed as “star craving mad”).

Authors then analyzed the data according to the phases of thematic analysis outlined by Braun and Clarke [29]. All of the authors had doctoral level training in qualitative research, and three of the four authors had several years of experience conducting research using the phenomenological approach.

After multiple readings of each transcript to obtain a general sense of the whole, individual segments in the transcripts were identified and coded according to topics and ideas conveyed [30]. The codes and their definitions were not established a priori but were generated from the content of the interviews. All authors independently coded the first transcript, and then met to compare and discuss their results. The authors met as a team to compile a preliminary code dictionary based upon common emerging topics (e.g. descriptions of cognitive symptoms, changes over time, reactions of others). The investigators used this dictionary to independently code at least 20% of a second transcript. Results were discussed, and the dictionary was refined. This process was repeated twice more until full agreement was achieved and no further changes were made to the code dictionary. Using this final schema, all of the transcripts were independently coded by the first author (SB) with at least 20% checked by additional authors (CB and MB) for consistency and continued agreement. All

transcripts were coded and organized using Dedoose, a web-based qualitative data analysis software program [31].

Transcript excerpts were sorted by codes and summarized by the first author. The summaries were reviewed by two additional authors (CB and MB) to ensure accuracy and agreement. Multiple authors then independently analyzed the summaries for common themes and subthemes in participants' experiences and together developed the final thematic framework[29]. An additional author (TE), involved in the development of the code dictionary but not the thematic analysis, reviewed this framework and agreed that it represented the participants' perspectives and comments. In this way, the development of themes was an iterative process involving the exploration of alternative interpretations and modification of themes as needed to ensure that the final themes reflected all interviews commensurately.

Several steps were taken to ensure the trustworthiness of the data and analysis. Trustworthiness in qualitative research is established through the criteria of credibility, confirmability, and transferability [32]. Credibility is the extent to which a study authentically represents the perspectives of its participants, and, closely related, confirmability is the degree to which the participants' perspectives are presented without bias from the researchers. Multiple investigators were involved in every step of data collection and analysis to ensure accuracy of interview transcription, and to challenge each other on the coding, analysis, and interpretation of the data. Member checking was conducted in that all participants were e-mailed a 3-page summary of the study findings and were invited to provide feedback regarding the accuracy of the interpretations. Only one participant responded, expressing no disagreement with the findings.

Results

While initial recruitment targets were not met due to feasibility challenges, meaningful themes were derived from the data using the phases of thematic analysis outlined by Braun and Clarke [29]. As a result, a convenience sample of five survivors of head and neck cancer, henceforth referred to individually as P1 – P5, provided the results for this study (Table 2). Participants ranged in age from 43 – 67 years. All were native speakers of American-English and reported holding advanced academic degrees. Time since treatment ranged from 1 – 8 years. All were treated with chemo-radiotherapy; three reported also undergoing surgery for their cancer.

Four out of the five participants scored within one standard deviation of the mean on the CPIB short form, indicating a perceived level of communicative participation consistent with a communication disorder. Three of the participants scored more than one standard deviation below the mean on a validated patient-reported measure of cognitive function (Neuro-QOL) [28], indicating a perceived level of cognitive function below that of the general population.

Thematic analysis from interviews

Two major themes and six subthemes emerged from the analysis of the interview data (table 3). The first theme, *I would have told you about being forgetful, but I forgot*, is drawn from

participants' descriptions of their experiences of cognitive changes during and after treatment for head and neck cancer. The subthemes contained therein describe cognitive symptoms experienced, the impact of those symptoms on participants' daily lives, and how participants dealt with those changes. The second theme, *It's such a journey that much of it is uncharted*, focuses on the participants' descriptions of the cognitive symptoms being an unforeseen and often un-acknowledged phenomenon. Subthemes under this second theme are divided by stakeholder: patients, friends/family/coworkers, and healthcare providers. These themes and subthemes are described in detail below.

Theme 1: I would have told you about being forgetful, but I forgot (P5)

Participants described experiencing a range of cognitive changes during and after their treatment for head and neck cancer. These changes affected communication and other aspects of their daily lives both at home and at work. As a result, participants found different ways of coping with and compensating for these changes.

1.1. It's not the same. My cognition is not the same (P4)—Many examples shared by participants focused on the effect of memory difficulties on communication. P3 and P4 described repeating conversations because they had not remembered the prior conversations. P5 talked about the need to speak an idea before forgetting it, even if the conversation might have moved on to another topic:

You know, I have an idea, so I kind of have to blurt it out otherwise I'll forget what it was. So I might dive in and seem inattentive perhaps because it's like, if I don't say this it's going to be gone.

Additionally, difficulties with focus and attention created barriers to communication:

I would hear people talk, having a conversation and I remember thinking, I'm doing everything I can to look like I'm paying attention. I've given all the cues. (laughs) I stopped really being able to focus on what you were saying like a minute ago, and even now that I'm thinking about that I'm getting less of it. (P4)

Language difficulties were experienced by most participants. On the expressive side, participants talked about difficulties with word finding, "... the inability to grab the right word" (P2). Receptively, participants talked about difficulties parsing written language. While P5 referred to it as "word salad," P4 talked about not being able to read prescription bottles:

I remember looking at pill bottles like how much do I take? Looking at it, reading it and thinking it doesn't make sense. ...I should be able to decipher this, and yet I can't figure out when to take this. And you know that was such a bizarre feeling.

The time course of these symptoms varied across participants, both during and after treatment. Two participants, P1 and P3, notably the two furthest out from treatment, talked about noticing cognitive changes during treatment, feeling like they got better, and then worsening more recently. Both participants felt that perhaps they had learned to adapt but now find they are working harder to function at the same level.

The other participants talked about really becoming aware of cognitive changes as the physical symptoms abated and they started to resume what had once been normal activities. P2 said that he didn't notice any cognitive changes during treatment (2 years prior) but noted that he really didn't do anything during his treatment other than go to treatment. In his case, he had significant difficulty with his speech, so he didn't talk much for a while. He said he started to notice problems with word-finding when he became more confident in his speech and started talking more: "So I guess because I started talking more, then I became more aware of my ability or inabilities."

1.2. I'm just like a shell of who I was (P5)—Participants linked perceived cognitive changes with changes in what they do, how they do it, and how they feel about themselves. Four out of the five participants continued to work following treatment; at the time of his cancer diagnosis, P2 chose to retire, which he had been considering for a few years prior. P4 and P5 returned to work after treatment but found that problems with memory and slowed processing interfered with their success. P4 stepped down from a management position to a part-time position with a different employer: "I did go back to work about a month after treatment and I lasted in that role, in that management role, for about a year, feeling like I was failing the whole time." P5 left his job as an attorney and went on disability after a colleague commented to him about his cognitive changes. He "didn't realize how little I had in the tank, energy wise and cognitively."

Two participants, P1 and P4, found that difficulties with focus and attention created barriers at home and in social situations, particularly those involving eating. Both participants had some level of dysphagia and found that they could not simultaneously attend to safe swallowing strategies and conversation. P1 characterized eating as "a concentrative sport." P4 said of going to a restaurant with friends:

I would just withdraw and, you know, hope to God that the whole table could just keep talking and no one would notice that I wasn't participating. Um, or I would leave early. I would always have an exit plan. [Now] I don't do as much socially.

1.3. I was working much harder than I ever had before to function (P4)—Participants described various ways of planning and organizing to try to remain functional in the context of their cognitive changes. But first, participants had to come to the realization that they just could not sustain premorbid levels of function and had to accept a new level of function. P4 talked about the need to balance work and social activities. She described it as having a "bowl of energy" from which all activities (work, social, physical, emotional) draw, requiring her to budget her physical energy and cognitive resources; if one area demands more, she cuts back in the others. Finding that balance was not always easy however, as participants often found they needed to work harder at tasks that once were simple. P5 talked about having to organize his thoughts before starting something as simple as making a grocery list: "This is now a difficult problem. What used to be something I wouldn't even think about."

Two participants discussed using written strategies such as notes or calendars. P4 said she started out with three calendars, thinking that the more she wrote something down the more

likely she would be to remember it, but now she has just one calendar on which she keeps very detailed notes. P5, however, said that he could not always rely on his notes: “It’s harder to keep track of my thoughts. I do need to take more notes and things, and sometimes my notes aren’t comprehensible afterwards.”

Theme 2: It’s such a journey that much of it is uncharted (P1)

A second major theme that emerged from the data reflected the extent to which the cognitive changes were unexpected and unexplained. Participants talked about how they were not prepared for the possibility of cognitive changes and did not know why they were happening. These unanticipated symptoms affected their experiences with their friends, loved ones, and colleagues, as well as their experiences with healthcare providers. They also shared advice for patients, caregivers, and healthcare providers so that others would not have to deal with so many unknowns.

2.1. I don’t think that I knew I would feel like this (P5)—Participants said that they had not been informed that cognitive changes could occur, so as they started to notice cognitive changes, they did not know what was causing them. P3 feared at first that he was experiencing early signs of dementia, while P4, the youngest participant, said her doctor casually dismissed her cognitive complaints as the result of natural aging.

Most participants questioned whether their cognitive changes were the result of cancer treatments. Some theorized primary toxicity from chemotherapy or radiation. P5 said, “Look, if a cup of coffee can change how you function. I mean lethal, lethal toxins...” Having initially attributed her cognitive changes to narcotic painkillers prescribed during her treatment, P4 noted that she continued to have cognitive problems long after stopping those medications: “So was that cognition? Was that narcotics? Was it a mix of both? I’m not really sure.”

After talking about multiple potential causes of cognitive change, however, P3 stressed that the cause was not his primary concern, choosing instead to focus on the future: “I don’t really worry about [the cause]. What I worry about is trying to suppress it or correct for it. Or try to improve and see if I can keep it from getting worse.” The future and not knowing what to expect were also of concern for P5: “This is actually one of the problems I’m having right now is figuring out will I feel like this forever or in four months am I going to say, ‘Let’s get back.’”

2.2. Some people don’t know what to do, so they do nothing (P1)—Participants talked about whether other people had noticed their cognitive changes and the things that those who noticed did and said. Naturally, these words and actions affected the way participants felt about themselves and about others, and those feelings were not always clear-cut.

For example, P1’s experience interacting with his wife at mealtimes illustrated how navigating the cognitive changes with family members could place strain on relationships. The use of prescribed safe-swallowing strategies to manage his dysphagia placed great demands on his limited energy and attention:

When I started having difficulty eating, it was really getting bad, and she would sit with me at dinner while I was eating. You know she'd try to keep me company. I finally had to tell her, I said, 'I can either listen to you, which I'm happy to do, or I can eat; but I can't do both.' And I think at first it hurt her feelings, because If you think you're helping me you're really not... relationships change because of that. I think eventually she understood

In the work domain, P4 talked about her coworkers' attempts to ease her concerns over memory issues and her own ambivalence about their remarks:

I had a lot of colleagues who would say, and it really bothered me, 'Oh, you know I forget things all the time.' And I really felt like - on one hand I didn't want them to recognize my deficits- I was working hard for no one to see them- but on the other hand I felt like they were really minimizing and not recognizing at all, not validating how hard I'm working - how hard this is for me.

2.3. It's all kind of swept under the rug (P4)—None of the participants felt that they had been informed by healthcare providers about the potential experience of cognitive changes during or after their cancer treatment. Additionally, participants did not feel that they knew how to talk about the experience of cognitive changes with their healthcare providers, and when they did talk about it, their healthcare providers did not know how to help them.

When asked for advice to healthcare providers, participants stressed a desire for validation of the experience of cognitive change and better communication about potential risks and options for rehabilitation. Participants said that they did not necessarily understand what was happening or how to talk about it, and that perhaps if they had heard it from their doctors it might have been easier for them to discuss it and get help.

I think the idea of just asking that question and as a healthcare provider making it okay to talk about it. Ask that, you know, how are you kind of getting by day by day? Do you find that it's more difficult for you to remember things? You know, ever feel like you're working harder than you had to before, just mentally? To just kind of put some words to it, to make it okay for the person to say, you know, yeah, I really am. (P4)

All participants talked about being inundated with handouts over the course of their cancer treatment and feeling overwhelmed by information that was not always helpful: "It was all this stuff ...I threw them all away, and that was fun" (P1). P2 believed that much of the information given to him was more about fulfilling legal requirements rather than utility:

When I went to the first session they gave me a bag filled with all this stuff you know. I guess a lot of it has to do with just laws about disclosure and all that sort of stuff. But there was nine million things in there about support and you know family and blah, blah, blah, blah, blah. It's just like-this is just over the top.

Participants reported that the volume of handouts and notebooks provided was so overwhelming they did not read them, so if information about cognitive changes had been

included in those packets, they did not notice it: “Was somebody really advised of something when you’ve given them this boxcar of paper and one line in the middle?” (P5)

Discussion

This study is the first to focus on the lived experience of self-reported cognitive changes among a convenience sample of survivors of non-nasopharyngeal head and neck cancer, specifically how these changes can affect communication in everyday settings. Interestingly, cognitive issues were highlighted as a priority in one previous study, not by survivors of head and neck cancer, but by their family members [20]. Personal communication with the first author of that study revealed that most of their participants were within one year of treatment completion, suggesting the possibility that, for some, cognitive changes may become apparent to other people before they become apparent to the patient. This was acknowledged by one of the participants in the present study (P4) who said of her coworkers, “It would be interesting to interview them.”

Survivors of non-nasopharyngeal cancer in this study reported a range of cognitive symptoms. The most notable symptoms were problems with memory and focus/attention, along with slowed processing and language difficulties. These cognitive symptoms are consistent with those identified by survivors of nasopharyngeal cancer [18], as well as other cancer populations, including breast, colorectal, testicular, and hematologic [10, 11, 15, 16, 33, 34]. The time course of the specific symptoms noted by participants in this study was also similar to what has been reported in other cancer populations [16, 33, 34]. That is, some people become aware of cognitive changes during treatment, and others do not become aware until going back to work or engaging in other life activities [16, 33, 34].

Importantly, the cognitive symptoms reported by participants in this study affected occupational and social activities, including those involving communication. These effects are strikingly similar to those reported in other studies. For example, participants treated for head and neck cancer in a previous study identified communication as becoming more effortful, requiring them to budget their energy, and ultimately changing the way they interacted with people around them up to two years after treatment [35]. Likewise, survivors of breast cancer have noted many of the same difficulties with reading and conversation, and they developed similar coping and compensatory strategies. They also described changes in self-identity, reduced productivity, and the need to work harder to seem normal [15, 16, 33, 34]. As a result, up to half of those who were employed at the time of diagnosis either left the workforce or reduced the number of hours they worked. The effects of cognitive issues on employment are also consistent with reports by participants in the present study. All of these considerations warrant future study and regard in establishing rehabilitation priorities, as employment has been identified as a significant factor in health-related quality of life after treatment for head and neck cancer [21, 36].

Finally, while participants in this study made efforts to adapt and cope over time, they generally felt both unprepared for the cognitive changes they experienced and largely unsupported by healthcare providers and others. Survivors of breast cancer who experienced cognitive changes during and after treatment also commonly expressed similar concerns [15,

16, 33, 34]. In addition, many survivors of breast cancer experienced fear and frustration because they did not understand what was happening or how to deal with it [15, 16, 34]. Together, these results have implications for counseling, inclusion of assessment tools, and approaches to intervention.

Clinical Implications

Findings from this study have numerous clinical implications for rehabilitation practitioners and others on the multidisciplinary team caring for head and neck cancer patients and survivors. Clinicians should be mindful of the fact that some of their patients may be experiencing cognitive changes which can affect a patient's ability to learn and follow complex treatment regimens, and that written instructions on a handout may not be a sufficient adjunct to, or replacement for, therapy. Consequently, practitioners may want to probe for the presence of cognitive difficulties, including the use of appropriate patient-reported outcome measures, to ensure that cognitive issues are considered when providing information in a way that patients can process and use. In the current study, the qualitative data revealed cognitive difficulties consistent with most of the changes reflected in the patient-reported Neuro-QOL [28] scores, suggesting the value of incorporating such a measure into the rehabilitation process. In addition, rehabilitation professionals have the opportunity to advise their patients regarding available resources should they be experiencing cognitive changes or become aware of them later and can advocate for these patients to receive the acknowledgement, information, and potential intervention they may require.

Similarly, rehabilitation practitioners need to be aware of communication difficulties in non-nasopharyngeal head and neck survivors, even in the absence of speech or voice impairments. In the present study, only two of the participants reported more than mild impairments in speech intelligibility or voice quality. Yet, four out of the five participants scored within one standard deviation of the mean on the CPIB short form, indicating a perceived level of communicative participation consistent with a communication disorder. This illustrates that barriers to communicative participation may exist outside of a functional speech disorder and should be measured as a separate construct.

The consistency of the results reported here with those found in other cancer populations suggests that rehabilitation practitioners may expand their advocacy beyond head and neck cancer patients. Those treated for other cancer types who experience cognitive changes also may benefit from skilled cognitive-communication intervention. The results of clinical trials with survivors of breast and brain cancers have shown significant improvements in memory, attention, processing speed, and executive function after cognitive training delivered in both group and individual formats [37]. This can be an important step in helping these patients achieve their rehabilitation goals and resume meaningful activities.

Limitations and future directions

The primary limitation of this study is the small sample size and the relative homogeneity of participants, which limits the transferability of the study findings. Because of the small sample size, due to unanticipated recruitment problems and feasibility constraints, saturation

of the results was not reached. Consequently, results from this study should be considered preliminary. Yet, while the sample size was small, it is noteworthy that the participants reported a range of perceived cognitive function (as measured on the Neuro-QOL), suggesting that experiences were at least derived from individuals with a wide range of impairments. The relative homogeneity of the sample also poses a limitation. While not reflective of the broader population of head and neck cancer survivors, the racial/ethnic makeup of the sample was consistent with the population of the city of Seattle and surrounding areas, from which participants were recruited [38]. Additionally, people with advanced education are overrepresented in this sample. This may be reflective of those more likely to volunteer for a study or of those more likely to participate in a support group from which most of the sample was drawn. It could be, however, that people with advanced education may be more sensitive to mild cognitive changes, which warrants further research. Finally, because phenomenology requires purposeful sampling of those with experience of a given phenomenon, in this case cognitive changes during and after treatment for head and neck cancer, no conclusions should be drawn with regard to incidence or prevalence within the broader head and neck cancer patient population.

This study brings to light a topic that up to now has received limited attention in the non-nasopharyngeal head and neck cancer literature, and future research is needed. Studies involving larger, more diverse samples are required for understanding the incidence and prevalence of cognitive changes among patients and survivors of head and neck cancer, including those with nasopharyngeal cancer. Such studies could reveal valuable information regarding patterns and predictors of such changes, such as differences related to treatment regimes, tumor site and stage, demographic factors, or other co-morbidities. Longitudinal studies including impairment-based measures in addition to patient report also would provide a better understanding of the time course of cognitive changes and would help identify therapeutic targets. Further study also is needed to determine best practices regarding optimal treatment approaches for cognitive changes experienced within this population.

Conclusions

In conclusion, this study described the cognitive changes, and the subsequent impact on communicative participation, experienced by a subset of individuals treated for non-nasopharyngeal cancer. This is an emerging and novel area of research, which needs future study and has meaningful implications for clinical practise.

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Declaration of interest

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Implications for Rehabilitation:

- Survivors of non-nasopharyngeal head and neck cancer described experiencing problems with memory and focus/attention along with slowed processing and language difficulties.
- Study participants generally felt both unprepared for the cognitive changes they experienced and, in many ways, unsupported by healthcare providers and others.
- Rehabilitation professionals should be aware that cognitive changes following medical treatment for head and neck cancer may affect a patient's ability to learn and follow complex treatment regimens,
- Rehabilitation professionals can advise and advocate for these patients to receive the appropriate referrals for assessment and treatment of their cognitive symptoms.

Table 1.

Interview Guide

•	What can you tell me about your memory/thinking/attention since diagnosis and treatment for cancer?
•	When did you first notice changes in your memory/thinking/attention?
•	What has been the progression of these changes? (Changes over time – better, worse)
•	To what do you attribute these changes? (e.g. sleep disturbance, fatigue, medications, depression)
•	Impact of changes on ability to communicate
•	Impact on relationships with others (family, friends, strangers)
•	Impact on activities, work
•	What has helped/not helped (compensatory strategies – How do you manage...?)
•	Did you seek/receive help? (medical, therapeutic, professional services)
•	What do you wish you had known?
•	What advice do you have for caregivers/healthcare providers/other patients?

Table 2.

Participant characteristics

Participant ID	P1	P2	P3	P4	P5
Age	67	60	61	43	56
Gender	Male	Male	Male	Female	Male
Race	White/non-Hispanic	White/non-Hispanic	Native Alaskan	White/non-Hispanic	White/non-Hispanic
Employment	Full-time	Retired	Full-time	Part-time (0.8)	Unemployed
Occupation	Claims Manager	Real estate appraiser	System Arts/Designer	Allied Healthcare Provider	Attorney
Cancer Location	Pharynx	Tongue	Tongue	Tongue	Tongue
Cancer Stage	Unknown	III	IV	IV	IV
Time post-treatment (years)	8	2	6	4	1
Smoking history	former	former	Never	never	never
Treatment	Chemo/XRT	Chemo/XRT	Surgery/Chemo/XRT	Surgery/Chemo/XRT	Surgery/Chemo/XRT

Abbreviations: XRT, Radiation therapy

Table 3.

Summary of results

Participant ID	P1	P2	P3	P4	P5
CPIB ^a	51.5	55.3	66.6	51.5	51.5
Neuro-QOL SF v2.0 ^a	46	45.8	39	30	31.5
Themes and subthemes					
Representative quotes					
1: “I would have told you about being forgetful, but I forgot” (P5)					
1.1: “It’s not the same. My cognition is not the same” (P4)	Participants experienced a range of cognitive symptoms: memory, focus/attention, slowed processing, and language difficulties. The time course of these symptoms varied across participants, both during and after treatment.				
1.2: “I’m just like a shell of who I was” (P5)	Perceived cognitive changes affected participants’ daily lives and identities at work, socially, and at home.				
1.3: “I was working much harder than I ever had before to function” (P4)	Participants developed different coping and compensatory strategies for their perceived cognitive changes.				
2: “It’s such a journey that much of it is uncharted” (P1)					
2.1: “I don’t think that I knew I would feel like this” (P5)	Participants didn’t expect it, didn’t know what to attribute it to, and don’t know what to expect in the future.				
2.2: “Some people don’t know what to do, so they do nothing” (P1)	If friends, family, and coworkers noticed cognitive changes, they didn’t know what to do or say.				
2.3: “It’s all kind of swept under the rug” (P4)	Participants felt that healthcare providers did not acknowledge or address the presence of cognitive changes.				
<i>There are things that I remember verbatim that were told to me and then other things perhaps in that same appointment that I have no recollection of... I’m pretty sure they did say that, but you know maybe your brain was memorizing the other thing. (P4)</i>					
<i>I think I did have some people who were accustomed to me doing certain things and I wasn’t doing them. (P1)</i>					
<i>I would spend my whole Sunday evening organizing my week, whereas I had never done that before. (P4)</i>					
<i>I don’t know how long this fog is going to last. It’s hard to make plans. (P5)</i>					
<i>One of my colleagues said, ‘You know, you used to make legal arguments even I couldn’t understand. Now, I just don’t recognize you.’ (P5)</i>					
<i>If you come in and you have something funny on your skin, they’re all over it. But if you come in and sound like you’re a little bit off, they’re just not attuned to that. (P5)</i>					

Abbreviations: CPIB, Communicative Participation Item Bank Short Form;

^aT-scores: mean = 50 (SD = 10); Higher scores represent a higher level of the trait being measured.