Head and Neck Cancer Survivors

Specific needs and their implications for survivorship care planning

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WITH AN ESTIMATED 436,000 HEAD AND NECK CANCER (HNC) SURVIVORS in the United States (Cohen et al., 2016), long-term survival is increasingly common with multimodality therapy. Rates of remission for early-stage disease and human papillomavirus (HPV)–related cases are as high as 80%–90% (Cohen et al., 2016). The demographics of patients with HNC are shifting to younger ages with the rise of HPV-related cases and decline of alcohol- and tobacco-related squamous cell carcinoma (Young et al., 2015). Although cure rates are high, HNC survivors experience significant sequelae of treatment, including long-term physical symptoms that affect quality of life and societal functioning, such as difficulties with eating, drinking, and communicating, and pain (Funk, Karnell, & Christensen, 2012). In addition to managing chronic and late treatment-related toxicity, careful follow-up is necessary for surveillance of recurrence and secondary cancer development. Oral and eating problems, fear of recurrence, fatigue, and care coordination all have been cited as common unmet needs in this population (Giuliani et al., 2016; Wells et al., 2015).

Given the needs of this growing survivorship population, clinical guidelines have emerged to describe best practices for post-treatment care (Cohen et al., 2016; Nekhlyudov et al., 2017). Recommendations include delivery of survivorship care plans (SCPs), which aim to provide comprehensive treatment summaries and additional educational content to aid patients and their primary care physician when transitioning from acute oncology management. SCPs provide information about the treatment received, short- and long-term side effects, and guidance for follow-up monitoring (Institute of Medicine, 2006). SCPs are hypothesized to benefit patients through improved education. Oncology nurses are well-positioned to play an active role in SCP development and implementation (Corcoran, Dunne, & McCabe, 2015).

Few studies have specifically evaluated the educational and informational needs of the HNC survivorship population. One 65-patient study evaluated interest among patients with HNC in receiving information for certain topics (e.g., speaking and swallowing, coping with anxiety) and found that higher distress was associated with a greater informational need (Fang et al., 2012). A survey of 93 oral cancer survivors within one year of diagnosis found that...
informational needs were highest for how to live a healthy lifestyle after treatment (87%), followed by strategies to improve speaking and eating problems (81%) and information about side effects (76%) (Badr, Lipnick, Gupta, & Miles, 2017). To date, research has been limited about head and neck cancer survivorship knowledge as it relates to treatment side effects, healthy behaviors, healthcare follow-up, and alcohol and tobacco. Although these studies suggest a desire for more resources and information among patients, they do not objectively establish patient knowledge at baseline or opportunities for SCP intervention.

To meet this need, the current authors explored post-treatment knowledge and needs of HNC survivors. These results are expected to facilitate development and provision of comprehensive and useful resources within an SCP.

Methods
This exploratory study was performed at Duke Cancer Center in Durham, North Carolina, after institutional review board determination. Eligible participants included adults (aged 18 years or older) within three months of completing curative-intent treatment for HNC who could read and write English. Nursing staff recruited participants at three HNC clinics at the cancer center, representing three subspecialties (medical oncology, surgical oncology, and radiation oncology) from July to November 2016.

Because the authors found no HNC knowledge instruments, they collaboratively developed a 48-item survey designed to be specific to HNC issues as reflected from the literature and clinical practice. An interprofessional team of HNC specialists reviewed the items for content, accuracy, and relevance. The survey addressed multidimensional aspects of the survivorship period, including cancer and treatment side effect knowledge, alcohol and tobacco usage and knowledge, learning preferences, healthcare providers and care coordination, and caregiver support. This survey was anonymous and took no longer than 15 minutes to complete.

Item responses were entered into Microsoft® Excel. Descriptive statistics were computed using IBM SPSS Statistics, version 24.0, to characterize patient responses. Items specific to certain disease sites or treatments were coded based on participants’ self-reported disease. Participants who circled both “yes” and “unsure” or “no” and “unsure” to knowledge questions were considered unsure. Of 41 participants, 37 completed more than 90% of the survey questions, and 39 completed all 11 knowledge questions.

Results
The authors collected data from 41 patients. The majority of patients underwent multimodality therapy with chemotherapy, radiation therapy, and/or surgery. Patients represented a variety of disease sites, most commonly tongue and tonsil (see Table 1).

Cancer and Treatment Side Effect Knowledge
Correct response rates were less than 50% for items relating to anxiety, fatigue, sleep, and hearing loss after treatment (see Table 2). Although almost all patients indicated that eating well and being physically active were important to health and recovery, 35 of 39 patients agreed or strongly agreed to the statement, “I am interested in learning more about ways to stay healthy after my cancer diagnosis and treatment.” Patients were interested in learning more about their cancer (n = 29 of 40), short-term side effects (n = 32 of 40), and long-term side effects (n = 30 of 39). Thirty-three of 40 respondents agreed or strongly agreed with the statement, “I am likely to start new habits (like stop smoking, begin to exercise, and eat well) if it might help decrease my cancer coming back.”

Alcohol and Tobacco Knowledge and Usage
In the current sample, 24 patients indicated past tobacco use and none indicated current tobacco use. Thirteen patients reported...
drinking alcohol daily in the past, and four reported current daily alcohol use. Of the 24 prior smokers, 11 also used alcohol daily in the past. Only two patients drank alcohol daily in the past without also using tobacco. Thirty-four of 39 patients answered “true” to the statement, “Tobacco products of any kind, including e-cigarettes and vapor products, will increase my risk that my cancer may come back”; 4 were unsure. For the knowledge statement, “Drinking any alcohol products (beer, wine, and liquor) will increase my risk that my cancer may come back,” of 39 respondents, 12 answered true, 11 answered false, and 16 were unsure.

Learning Preferences
Patients could report multiple learning preferences. Patients were most interested in learning via discussions with a nurse or doctor (n = 31) followed by reading written materials (n = 25), looking up information online (n = 13), talking with loved ones (n = 11), watching a video (n = 7), attending classes with others (n = 4), and no response (n = 1).

Healthcare Providers and Care Coordination
Most patients (n = 35) reported having a primary care provider (PCP), and 3 were unsure whether they had one. About half (n = 23) of patients had a dentist they visited regularly, and 18 reported having dental insurance. Of 17 patients who did not have a dentist they saw regularly, 15 did not have or were unsure whether they had dental insurance. Most patients (n = 28 of 35) who had PCPs reported that their PCP knew they had been treated for HNC. Patient perceptions of coordination between primary and cancer care providers was high, with 35 of 39 respondents agreeing or strongly agreeing with the following statement: “My cancer providers and PCP work together to provide the best care to meet my needs.” Most respondents (n = 26 of 37) agreed or strongly agreed that they knew how often they needed cancer checkups after treatment, and 25 of 38 agreed or strongly agreed that they knew what tests they would get at checkups. The majority of patients (n = 38 of 39) endorsed the following statement: “Having written information that describes what tests and healthcare needs I will have long-term would be helpful for me.”

Caregiver Support
Thirty-two patients indicated that they had someone who “gives me the help I need,” six said no, and three did not respond. The majority of the time (n = 25 of 33), the helper lived with the patient and was a spouse or partner. Caregivers came with patients to the clinic most of the time for 28 of 34 patients and received information about diagnosis, treatment, and side effects for 32 of 33 respondents.

Discussion
The needs of patients with HNC are complex. The current study captures a cross-sectional picture of those needs as they relate to providing quality survivorship care plans to patients. The authors explored the nursing implications for addressing healthy behaviors, healthcare access and engagement, and side effect management.

Healthy Behaviors
Patients in the current study had a good understanding of the importance of a healthy diet and physical activity to their recovery, but they still desired more information, mirroring results of a prior survey of oral cancer survivors (Badr et al., 2017). Nutrition and exercise guidelines from the American Cancer Society (ACS) (Rock et al., 2012) could provide patients with more detailed guidance (e.g., aim for at least 150 minutes of moderate exercise a week). Nurses may educate patients about the impact of performing physical activities during and after treatment completion and provide materials from the Oncology Nursing Society’s (2018) Get Up, Get Moving campaign.

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Emotional side effects

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Wellness

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Tobacco

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*The correct answer was dependent on the patient-reported disease site; if the patient answered “other” or did not respond to the disease site question, this item was unscored.
Alcohol use and tobacco use account for an estimated 75% of cases of HNC and are the most important modifiable risk factors for HNC recurrence and secondary cancer development (Cohen et al., 2016). Patients’ understanding of the basic relationship between smoking and HNC risk was very high in the current study. However, smoking relapse rates range from 14%–60% (Cohen et al., 2016), and the estimated prevalence of current tobacco use among patients with HNC is 33% (Burris, Studts, DeRosa, & Ostroff, 2015). The ACS HNC survivorship guidelines suggest offering referral to cessation counseling (Cohen et al., 2016). Support resources may benefit current and former smokers.

Patients had less knowledge about alcohol’s relationship to cancer compared with smoking, which also is reflected in four respondents admitting to current daily alcohol consumption. The ACS HNC survivorship guidelines state that PCPs should counsel patients to avoid alcohol consumption but further elaborate that “clinicians must carefully consider several clinical and prognostic factors when advising survivors about alcohol consumption” and note that “consumption of up to one drink per day for women and two drinks per day for men might lower the risk of heart disease” (Cohen et al., 2016, pp. 230–231). However, there are reasons specifically relevant for patients with HNC to avoid alcohol beyond secondary cancer risk, including worsened dry mouth, indigestion or gastric reflux, and increased risk for dental caries (Cohen et al., 2016). The challenge of communicating the nuanced, dose-dependent relationship between alcohol and cancer and general lack of awareness of this risk likely contributes to patient uncertainty regarding alcohol and cancer recurrence.

Healthcare Access and Engagement

Because SCPs are meant to help coordinate care among providers, understanding current healthcare use is particularly important. Primary care use among participants was markedly higher than dental care use, and perceived coordination between providers was high in absence of any formalized SCPs in the clinics studied. Lack of dental insurance reported by patients was a barrier to regular dental care. Infrequent or absent dental care is associated with higher-stage oral and pharyngeal cancer at diagnosis, compared with receiving at least annual dental care (Lane et al., 2012). Regular dental care is important given the increased risk for dental caries, gingival disease, and oral infections after chemotherapy or radiation to the head and neck (Epstein et al., 2012). Care teams can play an important role in documenting whether patients are receiving dental care and connecting patients to community support resources.

Most patients reported having involved caregivers, and some patients preferred learning through conversations with loved ones. A survey of 59 family caregivers at HNC radiation clinics found significant informational needs among caregivers, with more than half having high needs at the end of treatment (Longacre, Galloway, Parvanta, & Fang, 2015). The current authors advocate for providing caregiver-targeted informational resources to improve overall survivorship education.

Managing Side Effects

After HNC treatment, patients may develop side effects that are uncommon in the general population, including neck lymphedema, changes in taste, xerostomia, and neck stiffness and spasms. Patient expectations and early recognition of these symptoms can improve early intervention to manage treatment sequelae. Prior research has not examined patient knowledge of HNC treatment side effects via objective questions. In the current study, participants had more knowledge about certain common physical side effects like dry mouth and changes in physical appearance. However, most patients were incorrect and unsure about the expectation of anxiety, fatigue, and sleep disturbance occurrence after treatment. ACS guidelines suggest screening and assessment for sleep disturbance and fatigue. In particular, depression and anxiety should be screened for three months post-treatment and at least annually (Cohen et al., 2016). Educational initiatives should raise awareness of these psychosocial side effects of treatment in addition to physical side effects.

Limitations

The current study had several limitations. The survey is not yet validated. Although several validated instruments measure cancer survivorship needs and quality of life (Hodgkinson et al., 2007; Ringash & Bezjak, 2001), no instruments are available for measuring objective knowledge of survivorship issues specific to the population of interest. Limited research has been performed about cancer survivorship knowledge in general. Only one study has looked at objective, comprehensive knowledge of cancer diagnosis, treatment, long-term side effects, and follow-up.

FIGURE 1.
PRACTICAL TIPS FOR CARING FOR HEAD AND NECK CANCER SURVIVORS

- Encourage activity (at least 150 minutes per week of moderate exercise).
- Ask about smoking and secondhand smoke exposure. Refer to cessation counseling.
- Educate patients about specific side effects of alcohol (dry mouth, reflux, dental caries, risk of recurrence).
- Assess access to dental care; connect to resources as needed.
- Address common emotional health issues, including depression, anxiety, and fatigue.
- Assess nutritional status and refer to a dietitian if appetite is a concern or malnutrition is present.

Note. Based on information from Cohen et al., 2016; Institute of Medicine, 2006; Oncology Nursing Society, 2018; Rock et al., 2012.
recommendations in breast cancer survivors via the creation of a new questionnaire with preliminary evaluation similar to that of the current authors (Rocque et al., 2014). The authors hope to further pursue this research by undergoing survey validation to optimize wording of each question and determine any additional potential needs that should be evaluated.

The current sample size (41 patients) was small and from one institution, limiting the generalizability of the results. The survey included only self-report data, raising concerns about accurate disease site for answer coding and recall bias, particularly for items related to healthy behaviors (e.g., tobacco use). Patient reports of treatment received and cancer risk factors may be unreliable. In some cases, treatment information was incomplete, preventing the authors from fully assessing side effect questions, whose scoring depended on treatment site (e.g., swallowing, talking).

Despite these limitations, the current study does provide insight into the knowledge gaps of HNC survivors and can assist in developing an understanding of the gaps HNC survivors face. The results show that a majority of patients with HNC do have interest in more information and willingness to learn from the healthcare team, as well as interest in written or electronic information for knowledge reinforcement. Within the authors’ facility, patient education regarding symptoms and adverse effects occurs when symptoms requiring management arise; this usually occurs one-on-one with a nurse or provider during treatment, and written information is provided for education reinforcement. Treatment-specific education (e.g., surgical, chemotherapy, radiation therapy) occurs prior to the start of treatment by a provider, pharmacist, or nurse. The results of the current study indicate that patients prefer that education take place at multiple time points throughout the survivorship journey and be adapted to the many learning styles patients express. SCPs can meet this need, and the current study results can affect SCP development with content that is evidence-based.

**Implications for Practice**

The current study showed clear gaps in knowledge among HNC survivors (knowledge deficits related to alcohol, hearing loss, emotional symptoms). In addition, access to dental care was an issue for many patients. Having a better understanding of these issues can aid in the creation of educational materials and provision of resources, and can inform future study of survivorship knowledge. Baseline alcohol and smoking behavior provided a target for future behavioral modification. The active involvement of caregivers in patient visits demonstrates another source for providing educational information (see Figure 1).

**Conclusion**

Nurses are well positioned to create and deliver patient education materials during and after treatment within the context of an SCP to increase patients’ awareness of symptom expectations, management, and engagement in healthy behaviors. The current study highlights many educational needs of patients that could be addressed, in part, using an SCP as an educational framework and tool. Each patient will have a unique pattern of needs, so reviewing potential knowledge and support gaps using the structured format of an SCP may highlight areas for additional nursing support. Providing patients in this high-risk population with resources to stop smoking, perform physical activity, and receive low-cost or free dental care has the potential to reduce unnecessary complications and improve quality of life. Future research will focus on refining and validating knowledge questionnaires and studying the ability of SCPs and other educational interventions to affect knowledge.

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