


ORIGINAL ARTICLE

Survivorship support in head and neck cancer: American Head and Neck Society survey

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Abstract

Background: The value of supporting cancer survivors beyond formal treatment has become increasingly recognized among clinicians who care for patients with head and neck cancer.

Methods: A survey was developed by the American Head and Neck Society (AHNS) Survivorship Committee and distributed to members of the AHNS electronically.

Results: The survey was distributed to 1403 AHNS members, with 202 responses (14.4%). Among survivorship topics, respondents were most likely to address detection of recurrence/second primary malignancies (97.5%), dysphagia (93.1%), and thyroid function (90.1%) with their patients; they were least likely to address sleep disturbance/apnea (27.7%) and body and self-image issues (29.7%). Less than half provide patients with a written treatment summary (43.1%) or follow-up care plan (36.9%).

Conclusions: These results highlight the need for improved survivorship care planning and offer an opportunity for the development of educational and survivorship research in head and neck cancer care.

KEYWORDS

head and neck cancer, surveillance, survivorship, treatment plan

1 | INTRODUCTION

Cancer can have a devastating impact on its victims and their families. In addition to the physical toll, cancer and its treatment often result in psychological, social, and financial burdens. This is especially true of malignancies of the head and neck, given the aesthetic and functional importance of this area. As such, it is appropriate that as the treatment of head and neck cancer has shifted from radical ablation to curative treatment that also focuses on the preservation and restoration of function, the importance of quality of life after therapy has become increasingly recognized.¹ In 2005, the Institute of

Medicine (IOM) published the landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition* that highlighted the increasing number of cancer survivors who were understudied by the research community and often lost to follow-up by care providers.² In this report, guidelines for strategies to improve the quality of life of cancer survivors are provided. A notable recommendation was the provision of a written survivorship care plan. Until recently, there were no standardized care plans or treatment summaries for head and neck cancer survivors although the Commission on Cancer (CoC) of the American College of Surgeons has adopted this as a quality benchmark for cancer programs. The American Head

and Neck Society (AHNS) recently published a primer on survivorship in head and neck cancer that includes a head and neck cancer treatment summary template.³ Additionally, the American Cancer Society (ACS) also recently published a consensus statement outlining the potential issues experienced by head and neck cancer survivors.⁴ Therefore, given the recent interest in head and neck cancer survivorship, this study was designed to assess the current knowledge and attitudes pertaining to survivorship among members of the AHNS.

2 | METHODS

The Survivorship Committee of the AHNS sponsored this project. Members of the committee developed a 16-question survey. The survey covered respondent demographics, practice patterns, and familiarity with current recommendations related to survivorship in head and neck cancer. The survey was electronically distributed to 1403 members of the AHNS. Data were collected anonymously via an online SurveyMonkey poll. Descriptive statistics were used to summarize variables of interest. Subgroup analysis based on demographic responses to fellowship completion, practice type, and years in practice was performed using Fisher's exact test.

TABLE 1 Information on respondents

Characteristic	No. of respondents (%)
How long ago did you complete training?	
<5 years	40 (19.8%)
5–14 years	63 (31.2%)
15–25 years	46 (22.8%)
>25 years	53 (26.2%)
What is your primary practice?	
Academic	157 (78.1%)
Private practice	28 (13.9%)
Government	10 (5.0%)
Managed Care	6 (3.0%)
What percentage of your practice involves head and neck cancer care?	
<25%	18 (8.9%)
25–50%	20 (9.9%)
50–75%	38 (18.8%)
>75%	126 (62.4%)

3 | RESULTS

Respondent characteristics

Responses were received from 202 of the 1403 recipients for a response rate of 14.4%. The characteristics of the respondents are summarized in Table 1. The vast majority of respondents were otolaryngologists (80.7%) and completed fellowship training (84.1%).

Current practice

Respondents were questioned regarding their familiarity with the ACS Care Guideline. This guideline details key recommendations for assessment and management of long-term issues common to survivors of head and neck cancer. Only 55.9% of respondents expressed familiarity with the ACS care guideline. However, when asked whether specific survivorship issues outlined by the

TABLE 2 Assessed conditions

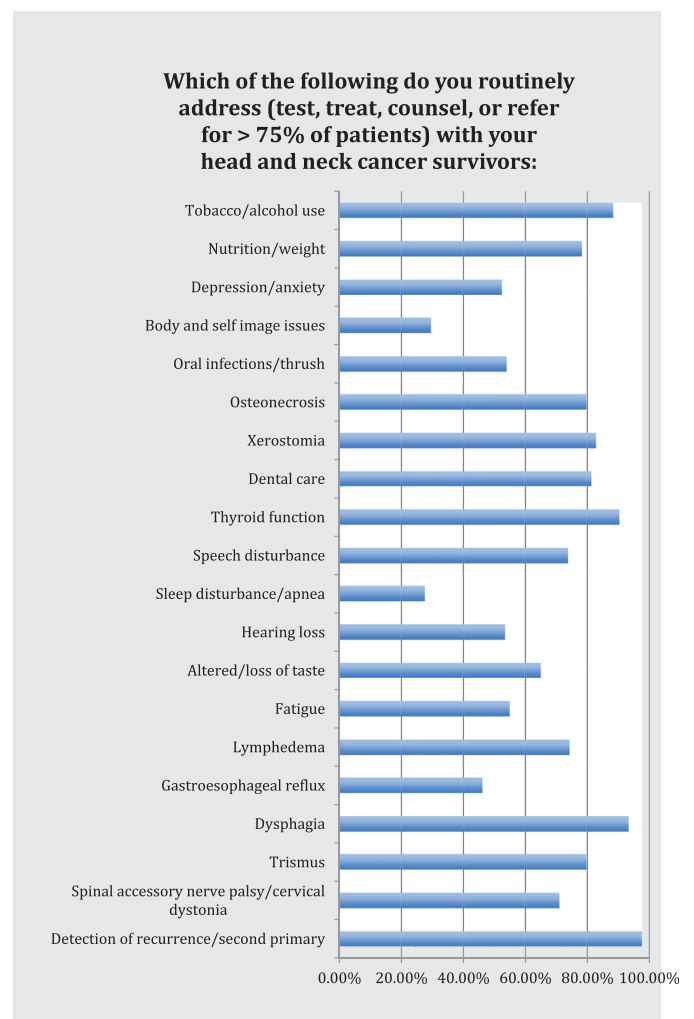


TABLE 3 State of survivorship

Question	No. of respondents (%)		I do not know/in development
	Yes	No	
Are you familiar with the American Cancer Society Survivorship Care Guideline?	113 (55.9%)	89 (44.1%)	0
Does your institute have a dedicated head and neck survivorship clinic?	51 (25.2%)	127 (62.9%)	24 (11.9%)
Do your patients receive a written treatment summary at the completion of therapy (from you or any member of treatment team)?	87 (43.1%)	92 (45.5%)	23 (11.4%)
Do you patients receive a written follow-up care plan at completion of therapy (from you or any member of the treatment team)?	73 (36.9%)	99 (50.0%)	26 (13.1%)

guideline were addressed by respondents, a higher proportion reported routinely addressing them in practice for 13 of the 20 assessed issues (Table 2). Of the survivorship issues evaluated, respondents were most likely to address detection of recurrence/second primary malignancy (97.5%), dysphagia (93.1%), and thyroid function (90.1%) while they were least likely to address sleep disturbance/apnea (27.7%) and body and self-image issues (29.7%).

Respondents reported maintaining close surveillance of patients early after completion of cancer treatment. The most frequent intervals for follow-up appointments during the first year for patients who had completed their cancer treatment were every 2 months (40.8%) and every 3 months (41.3%). Only three respondents (1.5%) reported seeing patients at 6-month intervals during the first year with none reporting that they did not follow the patients. The remaining 16.4% saw patients at 1-month intervals for the first 12 months. Similarly, the majority of respondents provide active involvement in long-term surveillance with 62.9% reporting that they never discharge survivors from their practice and only two respondents (1.0%) reporting that they discharge survivors prior to 5 years.

Consistent with the patterns of surveillance, 77.7% of respondents reported the head and neck surgeon as primarily responsible for survivorship care of head and neck cancer survivors. A survivorship nurse or nurse practitioner was reported as primarily responsible by 12.4% of respondents. Primary care physician (PCP), general otolaryngologist, radiation oncologist, and medical oncologist were reported as primarily responsible by less than 3% of respondents each. Respondents who completed fellowship training (vs those who did not) reported a higher percentage of head and neck surgeons (80.5% vs 62.5%) and survivorship nurse/nurse practitioner (13% vs 9.4%) as primarily responsible for head and neck survivorship care at their institution ($P = .005$.) Respondents in Academic practice (vs those in private practice) reported a

higher percentage of survivorship nurse/nurse practitioner (15.3% vs 0%) as primarily responsible ($P = .013$.) Years in practice did not produce a statistically significant difference in who was primarily responsible for head and neck survivorship care.

Further questions directed at the current state of survivorship in head and neck cancer are seen in Table 3. Despite a majority of respondents reporting familiarity with the ACS Survivorship Care Guideline, a minority of them reported that their patients receive written treatment summaries and written follow-up care plans. These practices were not statistically different based on fellowship completion, practice setting, or years in practice. Only 25.2% reported that a dedicated head and neck survivorship clinic exists at their institution. An additional 11.9% reported that a survivorship clinic was in development at their institution. A dedicated head and neck survivorship clinic was much more likely to be present or in development in the academic setting vs private practice (43.3% vs 10.3%, $P = <.001$.) Finally, when asked who should primarily manage long-term and late treatment effects for head and neck patients with cancer, 48.0% of respondents felt it should be the head and neck surgeon and 40.4% felt it should a survivorship nurse/nurse practitioner. The percentage of respondents who felt it should be the radiation oncologist was 5.6% while the percentage selecting PCP, general otolaryngologist, or medical oncologist were less than 2.5% each. These responses were not statistically different based on fellowship completion, practice type, or years in practice.

4 | DISCUSSION

The recent increase in incidence of oropharynx cancers and improved overall survival has led to a significant rise in survivors both in the United States and abroad.^{5,6} The

ACS Survivorship Care Guideline and associated initiatives acknowledge the decline in quality of life that occurs for head and neck patients with cancer both before and after treatment and highlights the need for attention to the sequelae of head and neck cancer diagnosis and treatment well beyond the acute treatment phase.⁷

Our survey indicates that the impact of the IOM's report and the ACS Survivorship Care Guideline among primarily head and neck surgical oncologists has not been fully realized. Just over half of respondents reported familiarity with the Survivorship Care Guideline. Despite treatment summaries and survivorship care plans being a CoC quality standard, only 43% and 37% of respondents report that their survivors receive written treatment summaries and follow-up care plans, respectively. This is consistent with a recent study of oral/oropharyngeal cancer survivors in which only 35% of those who were surveyed between 2 and 5 years after their diagnosis had received a written treatment summary.⁸ This may reflect challenges with implementation of a written process. In December of 2017, the CoC decreased the minimum required percentage of delivered survivorship care plans to eligible patients for accredited programs from 75% to 50% for 2018, an indication of the state of penetrance of this initiative.

While the percentage of survivors who reported receiving a written treatment summary in the above study of oral/oropharyngeal cancer survivors was low, 96% reported that their physician informed them about the need to follow up.⁸ In our survey, while the proportion of respondents who are providing written treatment summaries and survivorship care plans is low, the proportion of respondents who are addressing many of the survivorship issues is high. The detection of recurrence/second primary, dysphagia, thyroid function, and tobacco/alcohol use were of primary interest to the respondents. However, few providers assessed for sleep disturbance/apnea, body and self-image issues, gastroesophageal reflux, and depression/anxiety. Tobacco and alcohol use are established risk factors for recurrence of head and neck cancer, and dysphagia and thyroid dysfunction are common and well-recognized sequelae of head and neck cancer treatments. Therefore, it appears that the most commonly considered survivorship needs by head and neck surgical oncology providers are the well-established morbidities of head and neck cancer and therapy. However, the unmet needs most frequently mentioned by patients are psychological in nature.⁹ A study of long-term caregivers of patients with head and neck cancer also found greatest levels of unmet needs for partners of patients to occur in the emotional and health service domains.¹⁰ Head and neck patients with cancer are at high risk for emotional and financial distress, and in our survey depression/anxiety and the associated body and self-image issues are less commonly

addressed by respondents. The incidence of depression in patients with HNC is as high as 40%.¹¹ Unemployment more than doubles after treatment for head and neck cancer, with unemployment linked to decreased functional and social well-being scores and increased depression scores.¹² Furthermore, the suicide rate among patients with head and neck cancer is three times that of the United States general population, representing the highest suicide rate among all cancer types.^{13,14} Randomized controlled data exist that demonstrate the development of depression can be prophylactically reduced in patients undergoing treatment for head and neck cancer,¹⁵ and an important step in the treatment of any problem is recognizing it. Therefore, our results suggest need for increased attention to psychological and less common morbidities that impact survivors.

The results of our survey reveal that head and neck surgeons are actively involved in the surveillance of their patients. The reported frequencies of patient visits in the first year after completion of treatment are in line with the recommendations by the National Comprehensive Cancer Network guidelines,^{11,16} and the vast majority of respondents continue to follow their patients for at least 5 years. The most frequently addressed topic in our survey was detection of recurrence/second primary cancer. This corresponds with patient reported understanding in a previous survey in which 76% of patients expressed that the most important reason for follow-up care is to check for recurrence.⁸ Interestingly, only 1% of those patients felt that treatment for any symptom or side effect of cancer therapy is the most important reason for follow-up care. However, the yield of surveillance visits in detection of asymptomatic recurrence is low and the impact on survival is questionable, thus leading some to suggest that follow-up visits should focus on other survivorship issues.^{17,18} Furthermore, there is evidence to suggest that the survivorship needs of patients are not adequately being addressed outside of the head and neck specialist's clinic. Although the ACS Survivorship Care Guideline is directed at PCPs, in a recent survey of PCPs, only 32% felt confident they could manage late/long term side effects of head and neck cancer treatment and only 29% felt confident they could provide appropriate cancer screening.¹⁹ Only 3% of respondents in our survey report that the PCP is primarily responsible for survivorship care in their patients with cancer and only 1.5% of respondents felt the PCP should be primarily responsible for managing long-term and late treatment effects. Furthermore, the written treatment summaries and survivorship care plans may not achieve their goal of educating patients and their PCPs. A survey of patients and their physicians between 3 and 4 years after receipt of the survivorship care plan revealed that only 10% of patients and 34% of their

community physicians or dentists were able to locate or recall receiving the survivorship care plan, and 90% of patients were unsure of the value of care plans.²⁰

It may be that utilization of written care plans and the PCP is not the optimal way to address survivorship for patients treated for head and neck cancer. In our survey, 12.4% of respondents report that a survivorship nurse/nurse practitioner *is currently* responsible for survivorship care while 40.4% of respondents feel that a survivorship nurse/nurse practitioner *should be* primarily responsible for managing long-term and late treatment effects. The discordance of these two numbers likely reflect acknowledgement of a role for nurse practitioner led survivorship clinics by respondents of the survey. Interestingly, there was a higher percentage of survivorship nurse/nurse practitioners (15.3% vs 0%) *currently* primarily responsible for survivorship care reported in the academic setting vs private practice, but no statistical difference for the answer of who *should be* primarily responsible between the two settings. This suggests that while academic centers are further along in the establishment of survivorship clinics (as confirmed by the percentage of academic setting vs private practice [43.4% vs 10.3%] who have survivorship clinics active or in development), both settings see a value.

Surgeons may be more apt to reassign their role in follow up if the yield of asymptomatic cancer surveillance is seen as low and the survivorship needs are seen as high and/or better addressed by another. This may increasingly be the case due to HPV-related head and neck cancer. Patients with HPV-related head and neck cancer are on average younger. They also have higher cure rates and likely have lower second primary cancer rates.²¹ These factors would contribute to lower yield of cancer surveillance and longer survivorship periods. The optimal structure for coordination of cancer surveillance and survivorship care between the head and neck surgeon and survivorship nurse practitioner and other care providers warrants further investigation.

We acknowledge the limitations of a survey study, including recall bias. Additionally, it is recognized that the vast majority of members of the AHNS and the respondents to this survey are otolaryngology trained head and neck surgeons, which biases the responses to that perspective.

5 | CONCLUSION

Responding members of the AHNS are actively involved in the follow-up care of their patients with head and neck cancer. However, familiarity with the ACS Survivorship Care Guideline is low and respondents are not meeting the current CoC accreditation minimum for provision of written treatment summaries and survivorship care

plans. While 40% of respondents report that a survivorship nurse/nurse practitioner should manage the long-term and late treatment effects for head and neck patients with cancer, only 25% report that a survivorship clinic currently exists at their institution. The optimal structure to address the unique and unmet survivorship needs of patients following the treatment of head and neck cancer warrants further investigation.

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SUPPORTING INFORMATION

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