



## An assessment of patient burdens from head and neck cancer survivorship care

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### ABSTRACT

**Objectives:** To assess head and neck cancer (HNC) patients' perspectives on the value and burdens of routine cancer follow-up care.

**Materials and methods:** Data was obtained from HNC patients (n = 100) at an urban, tertiary head and neck cancer clinic. A novel 15-question survey tool evaluated the logistic, financial, and psychosocial burdens associated with clinic visits. The clinical characteristics and survey responses of demographic groups were analyzed with comparative statistics. Linear regression modeling was utilized to identify predictors of overall stress.

**Results:** A majority of study participants were male (74%), white (83%), and had histories of tobacco (77%) and alcohol (77%) use. Most participants were satisfied with the frequency of their office visits (75%). Patients with laryngeal cancer, advanced stage disease, or who underwent multimodality therapy more often desired increased appointment frequency. These patients also rated the burdens of travel cost and overall stress higher, compared to patients desiring visits less often (41.5% vs 28.4%, p = 0.047 and 46.6% vs 38.3%, p = 0.003, respectively). Travel stress was associated with highest overall stress (beta 0.6, CI: 0.4, 0.7).

**Conclusion:** The HNC survivor population is uniquely disenfranchised in several social and economic ways. While most patients are satisfied with their follow-up care, a significant subset of patients – those with limited social support, high financial stress, functional deficits, and those with transportation burdens – desire more frequent care. Survivorship care plans should incorporate the perspectives of current survivors.

### Introduction

Head and neck cancers (HNC) are a heterogeneous group of cancers characterized by lesions of the upper aerodigestive tract. In the United States, approximately 63,000 new HNC cases are diagnosed annually, accounting for 3% of adult malignancies [1]. As the population of HNC survivors grows, addressing unmet needs in survivorship care becomes increasingly important [2]. The question of survival is no longer the sole focus; rather, coping with the effects of HNC and its treatment demands attention. As a result of treatment, HNC patients face long-term challenges beyond surveillance for recurrent or secondary cancer. These include adapting to disfigurement, managing dysphagia and developing alternative speech [3,4]. Over time, new worries and challenges—aside from the late physical effects of treatment—maysurface. Fear of recurrence, lack of social support, and return to employment all contribute to the hardships faced by HNC patients [5].

With an emphasis on cancer surveillance, the financial demands associated with follow-up care visits, including out-of-pocket cost-

sharing for services, travel expenses, and time off work may be overlooked [6–9]. Low-income cancer survivors may be disproportionately affected by these costs; yet, little data is available on the financial and psychological cost-impact generally experienced by HNC survivors.

Several guidelines for HNC follow-up appointment frequency and duration have been proposed; however, the recommendations vary and all admit to limited evidence base [10,11]. The available literature is observational, conflicting, and in some cases, argues against any mandatory follow-up [12–15]. Additionally, the utility is debated for routine surveillance, by physical exam or imaging, beyond the immediate post-treatment period [10,16,17].

Nonetheless, HNC patients benefit from ongoing rehabilitation and social support [18,19]. Though appointments can be stressful, inconvenient, and expensive, visits may also be reassuring and feel worthwhile. Individual reasons for returning for follow up visits vary but are centered around strong relationships built with the cancer treatment team, a sense of security afforded by these social bonds, desire to address specific symptoms, and reassurance about tumor recurrence [20].

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Despite the wealth of literature on cancer outcomes, surveillance testing, quality of life, and patient needs, no studies to date have directly surveyed patients' attitudes towards follow-up care after HNC treatment. Therefore, this study aims to assess HNC patients' perspectives on the value and costs of routine cancer follow-up appointments.

## Methods

Following Institutional Review Board (IRB) approval, patients were recruited from an outpatient Head and Neck Cancer clinic based in an urban, tertiary referral cancer center from May to October of 2017. Eligible patients were identified based on a history of mucosal squamous cell carcinoma of the head and neck, who completed treatment between 3 months and 5 years prior to study enrollment. Patients were excluded who had a diagnosis of head and neck cancer prior to the index cancer, a history of head and neck radiation other than for treatment of the index cancer, age less than 18 years, and lack of English language proficiency. Written informed consent was obtained from those patients who met study criteria.

A novel survey tool comprised of 15 questions was developed for this study (Appendix 1) after a literature review failed to reveal other previously validated tools which were useful for assessing the study questions of interest. The questions were designed to both assess the patients' support systems and quantify the logistic, financial, and stress burdens related to clinic visits. Sources of support and transportation were identified by ranking the top three sources. Potential causes of financial burden and stress were ranked separately. Stress was also quantified on a visual analogue scale and reported as a percentage with 100% representing "extremely stressful". Patients were directly asked their preference for more, similar, or less frequent visits, and were furthermore allowed the opportunity to provide open-ended feedback regarding visit satisfaction. Phrases from patient free-text commentary data were categorized according to major concepts and themes, including: (a) transportation barriers, (b) financial barriers, (c) patient-provider communication issues, (d) timing of appointments, (e) recurrence worry, and (f) miscellaneous. The responses were then reformatted into codable segments for qualitative data analysis.

Face validity of this tool was assessed by multiple HNC practitioners and patients, then modified based on their feedback during pilot testing. Each study participant completed the survey in a private area of the clinic after their scheduled clinic with assistance from a member of the research team, if needed.

Additional clinical data was obtained by comprehensive chart review following enrollment. Demographic data included year of diagnosis, age, sex, race, distance travelled to appointments and substance use. Substance use coded dichotomously as never or ever use of tobacco or alcohol as it was recorded in the medical record. Tumor variables included site, TMN classification, human papillomavirus (HPV) positivity, treatment, reconstruction type, time since treatment completion and current diet limitations.

The study cohort was summarized with descriptive statistics. Clinical variables and survey responses were then compared based on duration of follow-up, sex, presence of a gastrostomy or tracheostomy tube, and desired appointment frequency. Differences were assessed for statistical significance using ANOVA and chi-square testing for continuous and categorical variables, respectively.

Factors associated with overall stress rating were assessed using univariate and multivariate linear regression models. Univariate models were constructed with demographic and tumor variables, in addition to survey responses. Factors with  $p < 0.1$  in the univariate model, excluding the subcomponents stress measurements, were incorporated into the multivariate model.

Data was collected using Microsoft Access (version 2013, Redmond, WA) and analyzed using R statistical software version 3.2.3 [20]. All statistical tests were 2-sided. Statistical significance was considered  $p < 0.05$ . A Holm-Bonferroni correction was applied across each

**Table 1**  
Cohort characteristics.

Number of study participants (n)	100
Time Since Treatment Completion (n, %)	
< 1 year	23 (23.0)
1–2 years	45 (45.0)
> 2 years	32 (32.0)
Age (mean (sd))	62.29 (9.64)
Sex = Male (n,%)	74 (74.0)
Race (% White)	83 (83.0)
Tobacco use, Ever (n, %)	77 (77.0)
Alcohol use, Ever (n, %)	77 (77.0)
Overall Stage (n, %)	
I	22 (22.0)
II	11 (11.0)
III	22 (22.0)
IV	45 (45.0)
Distance Travelled, miles (mean (sd))	48.55 (48.45)
Treatment (%)	
Surgery only	25 (25.0)
Radiation only	5 (5.0)
Surgery and radiation	26 (26.0)
Chemoradiation	17 (17.0)
Surgery and chemoradiation	27 (27.0)

sd: standard deviation.

survey question to account for multiple comparisons. A sample size of 100 patients was chosen to provide 80% power to discriminate a moderate effect size (Cohen's  $d = 0.4$ ) from the null hypothesis.

## Results

### Cohort description and overall survey results

One hundred patients with a mean age of 62.3 years were surveyed at a median of 18 months after treatment completion (Table 1). A majority of study participants were male (74%), identified as white (83%), and had histories of tobacco (77%) and alcohol (77%) use. Most patients had advanced stage disease (67%) and were treated with multimodality therapies (70%). Patients travelled 2–210 miles (median 28 miles) to attend appointments. Most were away from home for < 3 h (56%), but a few (2%) were away for > 24 h per appointment. A majority were satisfied with the frequency of their office visits (75%) and tests (72%). Meanwhile, 20% of participants reported a desire for less frequent visits, while 7% desired visits more often.

Nearly half (48%) reported less than \$30,000 in annual personal income (Table 2). A slight majority were employed prior to their diagnosis (51%), which decreased to 25% following treatment. Of the patients that continued to work after treatment, most (51.8%) missed one day of work to attend clinic visits.

Regarding social support, a third of patients were accompanied by their spouse at their clinic visit (34%) (Table 2). Approximately 53% of study participants reported living with their spouse, while 29% lived alone. Spouses were identified most as assisting with transportation (34%) and were ranked by patients as the greatest overall source of support (mean 1.73 out of 3). A substantial proportion of patients (19%) relied on public or medical transportation.

Treatments and tests were most often the greatest cause of financial burden (35% and 29%, respectively), whereas tests and transportation were the greatest cause of stress (31% and 27%, respectively) (Table 2). For a significant number of employed patients, lost income due to absence from work represented the greatest financial and stress burden (13% and 18%, respectively). When asked to rate stress from various causes on a 100% scale, patients rated tumor recurrence highest (59.2%), followed by cost of medical expenses (38.9%) and travel (30.6%).

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