



Pilot Telephone Intervention to Improve Survivorship Care in Patients with Head and Neck Cancer

Thanh P Ho¹, Mary Jewison², Kathryn J Ruddy² and Katharine AR Price^{2*}

¹Department of Internal Medicine, Mayo Clinic, Rochester, Minnesota, USA

²Department of Medical Oncology, Mayo Clinic, Rochester, Minnesota, USA

Abstract

Background: Multimodality treatment for Head and Neck Cancer (HNC) is associated with significant impact on quality of life and underscores the importance of comprehensive survivorship care.

Objective: A pilot phone intervention was conducted in HNC survivors to improve coordination of care by addressing core problems: dysphagia, lymphedema, neck pain, fatigue, emotional distress, financial concerns, and nicotine dependency.

Methods: Patients who had completed curative intent therapy for HNC were identified. One month prior to an upcoming appointment, patients were called by a nurse who asked about common long-term side effects and offered services and additional appointments as indicated.

Results: Forty-eight patients (38 males, 79%) with a median age of 60 years (range 41 to 78) were contacted. Most were stage IVA HNC (34 patients, 92%), squamous cell carcinoma (44, 92%) and located in the oropharynx (28, 58%). Patients were contacted between 6 to 77 months from definitive therapy, with conversations ranging from 3 to 30 minutes. Common symptoms included neck pain (52%), dysphagia (46%), and lymphedema (19%). Fatigue (33%) and emotional/psychological concerns (27%) were also noted. Financial matters (10%) and smoking cessation (4%) were infrequently reported. Ultimately, 31% of conversations led to referrals or other interventions resulting in a change in management.

Limitations: The sample size was small, and no direct patient outcomes were reported.

Conclusion: This study demonstrates the need for comprehensive and coordinated survivorship care for patients with HNC.

Keywords: Head and neck cancer; Survivorship; Dysphagia; Lymphedema; Fatigue; HPV; Oropharynx

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*Correspondence:

Katharine AR Price, Department of Medical Oncology, Mayo Clinic, 200 First Street SW, Rochester, MN, 55905, USA,
E-mail: Price.Katharine@mayo.edu

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Abbreviations

HNC: Head and Neck Cancer; HPV: Human Papillomavirus; HPV-OPC: HPV-Positive Oropharynx Cancer; IRB: Institutional Review Board; OS: Overall Survival

Introduction

Historically, Head And Neck Cancer (HNC) was associated primarily with tobacco and alcohol use, with 40% to 60% Overall Survival (OS) rates for most patients with locally-advanced disease [1-3]. However, in recent decades, the incidence of Human Papillomavirus (HPV)-associated oropharyngeal cancer has been steadily increasing; in men in the United States, this is now the eighth most common cancer [4]. The prognosis of HPV-Positive Oropharynx Cancer (HPV-OPC) is significantly better, with three year OS in never-smokers approximately 90% [5]. In addition, patients with HPV-OPC are typically younger, healthier, and have less history of tobacco use than patients with HPV-negative HNC. As a consequence, patients with HNC are being cured at higher rates and most will be expected to live decades with treatment-related side effects. Treatment for locally-advanced HNC typically involves a combination of surgery, radiation, and chemotherapy. This multimodality therapy is associated with long-term treatment-related side effects such as xerostomia, dysphagia, pain, lymphedema and fatigue.

Improved survival rates for many patients with HNC combined with substantial treatment

Table 1: Demographics and Tumor Characteristics (n=48).

Sex	
Male	38 (79%)
Female	10 (21%)
Race	
White	47 (98%)
Other	1 (2%)
Smoking history	
No	27 (56%)
Yes	21 (44%)
Location	
Hypopharynx	6 (13%)
Larynx	2 (4%)
Nasopharynx	2 (4%)
Oral cavity	4 (8%)
Oropharynx	28 (58%)
Sinus	3 (6%)
Thyroid	1 (2%)
Unknown primary	2 (4%)
Cancer type	
Anaplastic carcinoma	1 (2%)
Esthesioneuroblastoma	1 (2%)
Neuroendocrine carcinoma	1 (2%)
Salivary duct carcinoma	1 (2%)
Squamous cell carcinoma	44 (92%)
HPV testing for oropharyngeal cancer ^a	
Negative	2 (7%)
Positive	19 (68%)
Unknown	7 (25%)
Stage ^b	
I	2 (4%)
II	2 (4%)
III	6 (13%)
IV	37 (79%)
IVA	34 (92%)
IVB	2 (5%)
IVC	1 (3%)
Surgery	
No	18 (38%)
Yes	30 (62%)
Radiation therapy	
No	1 (2%)
Yes	47 (98%)
Systemic therapy	
No	2 (4%)
Yes	46 (96%)

Data listed as number (percentage)

^aPathologic staining for p16 antibodies or HPV in-situ hybridization studies^bStage not applicable for esthesioneuroblastoma

morbidities create a need for comprehensive survivorship care for this patient population. In elderly patients with laryngeal squamous cell cancer, higher quality care has been associated with both improved survival and reduced cost [6]. One challenge in clinical practice is to identify and offer referrals to manage long-term side effects in an efficient and coordinated fashion. In October 2013, Mayo Clinic in Rochester, Minnesota began an HNC survivorship initiative to better address the needs of these patients. A multi-disciplinary team of clinicians compiled an extensive list of survivorship issues with potential interventions. Of the 52 clinician-identified survivorship issues, seven were chosen to be addressed in a clinical phone pilot based on the fact that 1) They are common problems in clinical practice and 2) established clinical interventions or referrals exist to address these issues. These even survivorship issues included: dysphagia, lymphedema, neck pain, fatigue, financial concerns, emotional distress, and nicotine dependency.

At this comprehensive cancer center, standard follow-up care after completion of treatment for HNC includes multidisciplinary follow-up with otolaryngology-head and neck surgery, radiation oncology, and medical oncology visits every three months for the first two years after treatment, then every six months for three years, and then annually after five years. These appointments offer point-of-care opportunities to intervene on long-term side effects of treatment. In the current practice, many patients travel from distant locations for follow-up care, and it can be challenging to get appointments at short notice when an active issue is identified during the clinic follow-up visit. In February 2014, a phone pilot was initiated to proactively identify symptoms prior to a patient's appointment, with the focus on dysphagia, lymphedema, neck pain, fatigue, financial concerns, emotional distress, and nicotine dependency. The goal of the phone pilot was to improve coordinated survivorship care. This manuscript reports the results of this clinical phone pilot.

Methods

The phone pilot was conducted by a dedicated HNC nurse in the Division of Medical Oncology at Mayo Clinic in Rochester, Minnesota. Patients were identified for the pilot based on the following criteria 1) Had completed definitive (curative-intent) therapy for a HNC and 2) Had a follow-up appointment scheduled in medical oncology within one month after the pilot phone call. During the phone call, the nurse inquired about the patient's overall health status and asked specifically about the seven above-specified target areas. A data collection sheet was completed at the time of the phone call that documented patient responses to the target questions and whether the phone call resulted in any additional appointments, referrals, or other actions. Additional data such as cancer stage and therapy were abstracted from the electronic medical record using retrospective chart review. The study was approved by the institution's Institutional Review Board (IRB). Descriptive studies were performed using JMP® (Carey, North Carolina).

Results

Demographics: Forty-eight patients (38 males, 79%) were contacted; the majority were white (47 patients, 98%; Table 1). Over half (27 patients, 56%) did not have a significant smoking history. The median age at diagnosis was 60 years (range 41 to 78). The median time since definitive treatment was 21 months (range 6 to 77 months).

Cancer characteristics: The majority of patients were stage

Table 2: Results of Phone Calls.

Symptom/Concern	Yes to Symptom/Concern	Intervention Offered
Dysphagia	22 (46%)	4 (8%)
Emotional/psychological	13 (27%)	7 (15%)
Fatigue	16 (33%)	2 (4%)
Financial	5 (10%)	0 (0%)
Lymphedema	9 (19%)	1 (2%)
Neck pain/stiffness	25 (52%)	6 (13%)
Smoking	2 (4%)	1 (2%)

Data listed as number (percentage)

IVAHNC (34 patients, 92%; Table 1), predominantly squamous cell carcinoma (44 patients, 92%) and located in the oropharynx (28 patients, 58%). Human Papillomavirus (HPV) positivity, per pathologic staining for antibodies to p16 or HPV *in-situ* hybridization studies, was reported for 19 patients (68%) with oropharyngeal squamous cell carcinoma. Most patients received surgery (62%), radiation (98%), and systemic therapies (96%).

Pilot intervention: Phone conversations lasted 10.37 ± 7.13 minutes on average (median 7 with range from 3 to 30 minutes). Thirty-seven individuals (77%) expressed concern about at least one topic (Table 2). This led to 15 referrals or other interventions (31% of conversations) with 10 messages sent to providers in other disciplines (21%) and 8 changes in upcoming appointments (17%).

Neck pain or stiffness was reported by over half of patients (25 patients, 52%); six of them received interventions including referrals to cancer rehabilitation or physical medicine and rehabilitation, or resources on acupuncture. Two who did not receive interventions had previously tried acupuncture or massage therapy without significant benefit. Lymphedema was a concern for 9 patients (19%), although many also reported that their lymphedema was improving. Concern over lymphedema resulted in 1 intervention (2%), a referral to cancer rehabilitation that included consultation with a lymphedema therapist. Another patient had previously been evaluated by a lymphedema specialist. Of the 25 individuals with neck pain or stiffness, 6 patients also had difficulty with lymphedema.

During these phone conversations, 22 patients (46%) reported difficulty swallowing, resulting in 4 interventions that included prescription for Biotene® as well as patient-specific resources on acupuncture. Two patients already had scheduled endoscopy and swallow study, respectively, at the time of phone call.

Patients also expressed a range of psychological and emotional concerns (13 patients, 27%) including anxiety, depression, anger, cognitive changes related to memory, issues with self-esteem or the workplace. This resulted in 7 interventions (15%). Support groups, stress management brochures, and referrals to psychiatry or social work were offered. Two declined interventions and preferred to discuss their concerns with their oncologist or primary care physician instead. Similarly, energy level was a concern for 16 patients (33%), with 2 (4%) receiving pamphlets on potential solutions tailored to specific patient interest, such as yoga or tai chi. Six patients (13%) endorsed both fatigue and psychosocial concerns.

Less commonly, patients reported financial concerns (5 patients, 10%); no interventions were performed. One patient opted, instead, to discuss these issues during his medical oncology follow up appointment. Two patients (4%) expressed difficulty with smoking

dependence; one was offered nicotine cessation clinic and the other was already utilizing nicotine patches to reduce nicotine use.

These phone calls encouraged patients to discuss other medical concerns as well; for instance, one resulted in physical therapy referral for shoulder pain (without reporting neck pain). In another instance, the nurse spoke with the patient's spouse, who was "extremely happy to get the call", and agreed to receive educational materials by mail.

Discussion

HNC survivors who undergo multidisciplinary therapy may experience significant treatment-related side effects that can impact quality of life. Individuals with late-stage tumors report significantly worst quality of life scores on areas such as swallowing and social contact [7]. Long-term overall quality of life can decline, as reported by a study on 10-year survival [8]. We present a telephone-based pilot intervention to address common side effects experienced by HNC survivors. Our study demonstrates that even for patients several years from definitive treatment, symptoms such as dysphagia and neck pain often persist. The challenges of assessing and treating dysphagia may contribute to this [9]. We found that a medical oncology nurse-based phone call helped to identify patients with specific symptoms (usually related to radiation or surgery) for which targeted interventions (e.g., endoscopy or physical medicine and rehabilitation) could be helpful, if not already scheduled.

Our pilot intervention also identified and addressed important psychosocial concerns in HNC survivors. We found that fatigue, anxiety, and/or depression, present in nearly a third of all participants and often persist long after completion of treatment. Poor body image among this cohort can contribute to depressive symptoms [10], and individuals with HNC, especially those with cancer of the larynx and hypopharynx, are at increased risk of suicide [11]. It remains unclear if psychosocial factors contribute to survival, and others studies have attempted to assess this association or predict survival based on quality of life scores [12,13]. It is apparent, by our study and others, that psychological distress is common in this unique patient population but may be under-recognized or undertreated [14].

This pilot study underscores the importance of coordinated, multidisciplinary survivorship care. Many of the concerns that were reported by these HNC survivors are best addressed by non-oncology specialties including primary care providers, gastroenterologists, physical medicine and rehabilitation specialists, and psychiatrist/psychologists. In addition, the effectiveness of this phone pilot highlights the value of patient contact that is not necessarily a face-to-face evaluation. Although a telephone-based nursing assessment does require staff resources, the average length of each phone call was only ten minutes. It is notable that 31% of the phone calls resulted in a tangible change to a patient's upcoming appointment schedule. In the future, it is possible that text- or web-based communication could serve a similar purpose.

The primary limitation of this study was its small sample size. In addition, no direct patient-reported outcomes were collected due to limited resources. Therefore, we were not able to compare this telephone-based intervention to standard care with regard to patient satisfaction and physical and mental quality of life. However, this hypothesis-generating study did have a wide age range of patients with HNC, from 41 to 78 years old, suggesting that our findings are reasonably generalizable across the age spectrum. Due to the size of the study, sex-specific analysis was not performed. With improving

therapies that may prolong life in HNC, survivorship care should address therapy-related side effects in addition to the impact of emotional and psychological challenges of cancer treatment. In light of rising numbers of cancer survivors, the future of survivorship care will likely involve utilizing resources such as phone interventions and web-based programs to provide comprehensive, coordinated survivorship care.

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