

Symptom Management in Post-Treatment Survivors: A Qualitative Study on Head and Neck Oncology Clinicians and Survivors’ Perspectives

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Significance

- ❑ Managing symptoms and side effects is one of the most demanding components of care delivery to post-treatment head and neck cancer (HNC) survivors.
- ❑ While some symptoms are temporary after treatment (e.g., mucositis) other symptoms can last longer (e.g., neck fibrosis pain).
- ❑ Due to multimodal and intensive treatments for HNC, many of the side effects can remain throughout survivors’ lives including physical (e.g., swallowing difficulty) and emotional symptoms (e.g., depression) along with the late side effects (e.g., osteonecrosis).
- ❑ It is important to investigate the perspectives of clinicians and survivors regarding symptom management post-treatment in order to facilitate delivery of tailored survivorship care.

Methods

- Study design**
Two studies were conducted separately to examine:
- 1) HNC survivors’ symptom management practice
 - **Data collection:**
 - Demographic and self-management surveys and semi-structured interviews
 - 2) HNC programs’ implementation and practice of survivorship care.
 - **Data collection:**
 - Program characteristics survey; semi-structured interviews with providers including HNC surgeons, medical and radiation oncologists, speech pathologists, advanced practice practitioners, dietitians, and patient navigators involved in treatment and survivorship care
 - On-site observations for clinic workflow; and gathering of survivorship materials.
 - Both studies were conducted in the Midwestern US.

Results

- ❑ Twelve HNC survivors and 38 oncology clinicians across six HNC programs were interviewed. The HNC survivors’ mean age was 59.5 ± 11.3 and half of them were more than five years out of treatments.
- ❑ A majority of HNC survivors reported engaging in management of their symptoms immediately after treatment. While symptom management was a concern, few of them reported maintaining or engaging in managing symptoms that lasted longer than the immediate phase, such as managing xerostomia and fear of cancer recurrence, despite the continuation of symptoms as they moved farther from treatment.
- ❑ Particularly management of emotional symptoms, such as fear of cancer recurrence, was not a priority for participants. Clinicians prioritized management of physical symptoms including swallowing difficulty and lack of nutrition particularly for those in the immediate phase of survivorship (less than a year out of treatment).
- ❑ The focus later shifted to tracking recurrence and second primaries. These prioritizations were related to the survivors’ need for better quality of life, lack of resources in the clinic, and diminishing frequency of follow-up visits over time. A few HNC programs had resources for the early mitigation/prophylactic therapy for emotional symptoms such as depression.

Discussion

Attending to symptom management needs of HNC survivors depends on survivorship timelines and HNC programs’ characteristics. HNC survivors’ priority is to mitigate physical symptoms that last temporarily. While clinicians are aware of the presence of emotional symptoms and late side effects, they prioritize managing physical symptoms so survivors can return to daily activities. Limited clinical and survivorship program resources can shift the focus of symptom management planning to an emphasis on immediate physical symptoms.



Purpose

This paper focuses on analyzing qualitative interview data obtained from these two studies that was merged to investigate the perspectives of HNC oncology clinicians and survivors using thematic analysis