



Head and Neck Cancer Survivorship: Learning the Needs, Meeting the Needs

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Cancers of the head and neck and the treatments required to control them frequently result in serious and persistent impairments that can affect participation and quality of life. Increased recognition of the needs of cancer survivors and their caregivers has prompted research focused on the unique concerns of this complex group. Unmet needs have been identified among 60–70% of patients and a similar proportion of their partners; impacts can include profound social effects, isolation, and psychiatric conditions. Interprofessional teams, supplementing oncology nursing and physicians with physical rehabilitation, occupational therapy, speech-language pathology, nutrition and psychological disciplines is important to address the spectrum of emotional, cognitive, physical and functional, and pragmatic issues. In addition to investigating modified anti-cancer therapy intended to reduce the frequency of long-term toxicities, supportive care strategies that may be effective include physical activity, nutritional intervention, behavioral and cognitive-behavioral therapy, psycho-education and goal management therapy. This article addresses identified needs across varied domains, the current state of research surrounding them, and their impact on quality of life, while also describing one cancer center's approach to head and neck cancer survivorship.
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Introduction

The 2005 publication, *From Cancer Patient to Cancer Survivor: Lost in Transition*,¹ is frequently regarded as the

catalyst to the development of cancer survivorship initiatives. In fact, significant efforts in both research and program development relevant to what we now term “survivorship” pre-date this document. Supportive care research and programs using terms such as quality of life (QOL), psychosocial care, rehabilitation, and pastoral care, among others, have long aimed to meet the holistic needs of cancer patients. However, such programs were frequently insufficiently resourced, fragmented, and/or inaccessible due to cost or geography. Thus, 2005 is a watershed date for increased public discourse regarding the ongoing implications of a cancer diagnosis, for both the individual and those in his or her circle of care. Targeted funding, meetings, and collaborations resulted. Initial efforts focused on common cancers, and in particular breast cancer. However, over time, there has been recognition that needs may differ across cancer diagnoses, related to differences in demographics, the specific disease and treatment-related effects, and differing time courses for active treatment, chronic care, surveillance, and recurrence.

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Head and neck cancer (HNC) is a term usually encompassing primarily squamous cell cancers of the mucosal surfaces of the upper aerodigestive tract (paranasal sinuses, nasal cavity, pharynx, oral cavity, and larynx), often grouped together with major and minor salivary gland cancers, and with more variable inclusion of other rare pathologies occurring in the same anatomic locations (eg, adenocarcinomas, sarcomas, and melanomas). These relatively rare cancers together make up about 5% of all cancers, but patients and families affected by these malignancies experience such profound and numerous disabilities that their morbidity far exceeds their incidence.

In this review, we attempt to outline the unmet needs of HNC survivors and address the current knowledge around managing the major physical, emotional, and cognitive disabilities that affect them. We also describe the ongoing evolution of an interdisciplinary, disease-specific survivorship program under development since 2012 for these survivors at a single large cancer center.

Unmet survivorship needs in HNC patients and their caregivers

Unmet survivorship needs are common and have been identified in over 50% of general cancer patients.² These unmet needs, if they are not addressed, can negatively impact psychological well-being, QOL, and ability to complete daily tasks.³ Recent studies have investigated the specific nature of unmet needs in HNC patients, a group who had been largely excluded from previous work in this area.⁴

There are several validated measures to assess unmet supportive care or survivorship needs in cancer patients, however, a detailed review of these instruments is beyond the scope of this article.⁵ One such measure is the CaSUN, which is a measure of patient-reported supportive care needs for cancer survivors. It was developed and validated in largely female cancer survivors.⁶ It explored unmet survivorship needs across 5 domains: Existential Survivorship (14 items), Comprehensive Cancer Care (6 items), Information (3 items), QOL (2 items), and Relationships (3 items). The CaSUN asks respondents to indicate each item in 1 of 3 categories: no need or not applicable; have need but it is met; or, need is unmet.⁶ The CaSPUN is a companion self-reported tool to the CaSUN for the partners or caregivers of cancer survivors.⁶

A cross-sectional study of 158 HNC survivors at Princess Margaret Cancer Centre was conducted at the Princess Margaret Cancer Centre using the CaSUN.⁶ Among 158 patients sampled, 96 (61%) reported at least 1 unmet need and 6 had a very high number of needs (31-35 out of a possible 35 items). The mean number of unmet needs per patient was 6. The most common unmet needs in those who had completed active treatments were “I need help to manage my concerns about the cancer coming back,” “I need to know that all my doctors talk to each other to coordinate my care,” “I need more accessible hospital parking,” “Due to my cancer, I need help getting life and/or travel insurance,” and “I need up to date information.” In multivariable analysis patients who were younger, closer to the time of their cancer treatment, and

who has reported worse QOL^{7,8} were more likely to have high numbers of unmet needs.⁹

In addition to studying the unmet needs of HNC patients, 44 partners of the 158 patients in the study above completed the CaSPUN. The CaSPUN assesses and identifies needs experienced by partners within the last month over 35 need items, including 6 positive change items, and 1 open-ended question. Of the 44 partners who participated in this aspect of the study 29 reported as least 1 unmet need and 4 had a very high number of needs (31-35 out of a possible 35 items). The most common unmet needs in the partners of HNC patients were “I need help to manage my concerns about the cancer coming back,” “I need more accessible hospital parking,” and “I need help to cope with others not acknowledging the impact that having a partner experience cancer has had on my own life.” An increasing number of unmet needs in patients was significantly associated with increasing number of unmet needs in their partners.¹⁰

The results from these studies are corroborated by a study using the Supportive Care Needs Survey (SF34),¹¹ which reported that 68% of 127 HNC patients had unmet needs. The majority of the most frequently mentioned unmet needs occurred in the psychological domain. These included fears of cancer recurrence, future uncertainty, sadness, and concerns about family/friends.¹² Balfe et al¹³ surveyed 197 caregivers of HNC survivors using the “partners and caregiver supportive care needs survey,”¹⁴ and reported managing fears of cancer recurrence as the most common unmet need.

These compelling data demonstrate significant unmet needs. The development of survivorship programmes for HNC patients and their partners or caregivers will be guided by this information. However, other strategies to meet these needs may be required, especially in smaller cancer centers.

HNC-specific physical rehabilitation issues

Cancer rehabilitation involves coordinated, professional care that enables people to maximize physical, social, and psychological function within the limits of the disease and its treatment effects, and engage in personally valued activities within their social contexts.¹⁵ Health disciplines involved with delivering rehabilitation may include (but are not limited to) occupational therapists, physiatrists, physical therapists, psychologists, registered dietitians, social workers, and speech-language pathologists. Survivors of HNC have among the most complex rehabilitation needs of all cancer survivors due to the anatomical complexity of the head and neck region. In addition to the extremely common speech and swallowing issues (discussed in the next section), they may have lymphedema, pain, stiffness, and/or weakness of the jaw, neck, and shoulder. Radiation (RT) in the area may cause fibrosis and other latent effects. In people requiring neck dissection surgery, there is a risk of damage to the spinal accessory nerve that supplies the trapezius muscle.¹⁶ Even when the accessory nerve is spared, up to two thirds of patients report shoulder dysfunction.¹⁷ Impairments from HNC and its treatments can lead to body-image dissatisfaction, cognitive and behavioral

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