



Partner's survivorship care needs: An analysis in head and neck cancer patients



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ABSTRACT

Purpose: To determine the number, type and predictors of unmet needs for head and neck cancer (HNC) survivors' partner's.

Methods: Partners of HNC patients were invited to complete the Cancer Survivors' Partners Unmet Needs Survey (CaSPUN). Analysis determined number, proportion and factors associated with greater unmet needs using linear regression. Agreement between the unmet needs of patients and their partners was determined.

Results: Among the 44 partners participated 29 reported ≥ 1 unmet need and 4 had a very high number of needs (31–35). The most common unmet needs were related to concerns about cancer returning, coping with supporting someone with cancer, and the changes cancer has caused. The highest reported needs were in the Relationships domain. Increasing patient unmet needs was significantly associated with increasing partner unmet needs ($p < 0.01$).

Conclusions: A significant proportion of head and neck cancer partners experience unmet needs, which often differ from the patient's needs.

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Introduction

There are approximately 5000 new cases of Head and Neck cancer per year in Canada [1]. Head and neck anatomy plays a critical role in an individual's function, body image and socialization. The nature of treatment for head and neck cancer thus places patients at a particularly high risk of psychological, physical and emotional morbidity [2–4]. Treatment often leads to physical disability, psychological distress and increased health care needs when compared with other cancers [5]. HNC patients are at risk of significant side effects, such as xerostomia, neck fibrosis, and swallowing dysfunction, which can often be permanent [6,7]. Additionally, the majority of head and neck cancer patients are men with significantly different socio-demographic features and side effect profiles relative to other more studied groups, such as those with breast or gynecological cancers. With advances in treatment more

patients are living longer with a diagnosis of HNC or being cured of their cancers [8,9] thus the need to investigate and address cancer survivorship in HNC patients is essential to comprehensive management. Cancer survivorship refers to the journey experienced by any individual with cancer from the point of diagnosis through treatment and beyond [10]. Individuals affected by cancer report a wide range of functional, clinical and psychosocial needs throughout survivorship. An unmet survivorship need refers to a gap between expectations of services and supports required for wellbeing and actual services and supports received [11]. Identifying patients' and their partners' met and unmet survivorship needs through comprehensive assessment is essential to survivorship program development, as these help pinpoint where support deficiencies lie. Addressing needs deficits is necessary to service advancement and subsequent improvement of the functional, clinical and psychosocial states of patients and their partners throughout their cancer journey.

We have recently reported on the significant burden of unmet survivorship needs in HNC patients [12]. However, much of the focus in supportive cancer care to date has concerned only the

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patient diagnosed with cancer. Far less attention has been directed towards the needs of partners and whether these needs are routinely met. The course of disease can have profound impacts on the well-being of those caring for individuals with cancer by imposing countless physical and emotional burdens [13,14]. During treatment, patients may become dependent on their partners for many basic needs such as feeding and physical mobility. Partners are often required to manage illness-related symptoms, make care decisions, respond to emergencies and provide emotional support [15]. Despite successful treatment, failure of the patient to resume previous functionality may have long-term financial and psychosocial impact on the partner [6,16]. There has been a growing recognition of the complex and multifaceted role performed by partners, but the impacts of such responsibilities remain inadequately understood. It has been shown that the higher the unmet supportive care needs of patients, the greater the burden the partner experiences [5]. Recent studies suggest that partners have unique needs [17] that may exceed those of the patients for whom they are caring, in turn adversely impacting on patients' distress [18,19]. While these preliminary studies have begun to categorize the unmet needs experienced by partners in general [20], little is understood about the specific needs of partners supporting specific groups of patients such as those with head and neck cancer.

The complex course of head and neck cancer and its treatment thereby necessitates a heavy reliance on support from partners throughout diagnosis, treatment and recovery. Head and neck cancer survivors and their partners are therefore likely to experience unmet needs that are different from, and potentially in excess of, the rest of the cancer survivor community. It has been shown that partners with greater levels of support tend to have a lower burden related to their support role [21]. Understanding the specific burdens experienced by this group of partners is essential in prioritizing head and neck cancer survivorship program resources to meet the unmet needs of both partners and survivors. The purpose of this study was to determine the number, type and predictors of the unmet needs for head and neck cancer survivors' partners, to examine how they correspond to the unmet needs of the survivor for whom they care.

Methods

Study design

This cross-sectional study recruited partners from among 158 primary head and neck cancer patients who had previously completed a onetime Cancer Survivors' Unmet Needs Measure (CaSUN) survey between January 2013 and May 2014 at the Princess Margaret Cancer Centre in Toronto, Canada. For the purpose of this study, we used the National Cancer Institute definition of cancer survivor as an individual with cancer from the time of diagnosis throughout their life [22]. Patients at any survivorship phase from diagnosis to long term follow-up were eligible. The original patient survey package included a patient demographic survey, the Cancer Survivors' Unmet Needs Measure (CaSUN) [23], The Functional Assessment of Cancer Therapy - Head and Neck (FACT-HN) [24], The M.D. Anderson Symptom Inventory - Head & Neck (MDASI-HN) [25], The EuroQol EQ-5D-5L utility scale [26], the RTOG work status questionnaire, and a study-specific checklist of potential survivorship services. Participants were approached for the study in the waiting rooms of outpatient HN clinics at Princess Margaret and eligible individuals provided written consent. The Cancer Survivors Partners' Unmet Needs Measure (CaSPUN) [4] was included in each package and patients were instructed to provide it to their main partner for completion in clinic or at home (to be returned by mail). Partners were defined as the patients main support person

including spouse, caregiver etc as designated by the patient. No demographic data was collected directly from the partners as ethics approval only permitted collection of patient demographic details. Patients were eligible if they were over 18, could read in English and were being treated or had been treated for head and neck cancer with curative intent. Participants who had serious cognitive or psychological difficulties, were too unwell to participate, or presented in clinic with metastasis to the head and neck from a different primary site were excluded. This study was conducted with research ethics board approval.

Measures

Demographics: Patient's marital status, level of education, employment, primary language, smoking status, age, gender, disease type, location and stage, treatment details and stage of survivorship (<=6 months vs >6 months from the end of treatment) were collected from the self-administered demographic survey. The ECOG performance status was patient reported on a scale from 0 (asymptomatic) to 4 (completely bedbound).

Quality of life – Functional status and symptom severity

To measure quality of life, the FACT-HN was used. The FACT-HN is a self-reported multidimensional quality of life index specifically designed for use with head and neck cancer patients. It consists of a 28-item core with 11 head and neck specific items each rated on a 0–4 Likert type scale over the past week. Items are then combined to describe six areas including physical well-being, social and family well-being, emotional well-being, functional well-being, and head and neck related symptoms. Higher subscale scores correlate with a better quality of life.

To characterize health utility, the EuroQOL EQ-5D scale was used. The EQ-5D is a self-reported tool that consists of both a descriptive and a visual section. The descriptive system asks patients to indicate their health state by selecting one of 5 levels (no problems, slight problems, moderate problems, severe problems and extreme problems) across 5 domains (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) based on how they feel that day. The visual system asks patients to rate their health on a 20 cm vertical, visual analogue scale with end-points labelled “the best health you can imagine” and “the worst health you can imagine” based on how they feel that day.

To measure symptom severity, the MDASI-HN was used. The MDASI-HN is a multi-symptom patient-reported outcome measure that is used to assess the severity of multiple head and neck cancer-related symptoms and the impact of these symptoms on daily functioning [25]. MDASI-HN assesses the severity of symptoms at their worst in the last 24 h on a scale from 0 “not present” to 10 “as bad as you can imagine”. MDASI severity scale is the prorated total of 13 MDASI items (pain, fatigue, nausea, disturbed sleep, distress, shortness of breath, remembering things, lack of appetite, drowsiness, dry mouth, sadness, vomiting, and numbness). MDASI interference scale is the prorated total of 6 interference items (general activity, mood, and work, relations with other people, walking, and enjoyment of life). The MDASI-HN includes 9 items relevant to head and neck cancer: mucus in the mouth and throat, difficulty swallowing/chewing, choking/coughing, difficulty with voice/speech, skin pain/burning/rash, constipation, problems with tasting food, mouth/throat sores, and problems with teeth or gums.

Patient and Partners' Unmet Survivorship Needs: The CaSUN was used to measure the number and type of unmet survivorship needs experienced by head and neck cancer patients. CaSUN assesses and identifies the level of need experienced by cancer survivors within the last month for 35 need items, including 6 positive change items and one open-ended question. Needs items covered five different

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