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What Are The Survivorship Information and Care Needs of Patients from Vancouver Island Centre Upon Completion of Curative Intent Radiotherapy for Locally Advanced Head and Neck Cancer?

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Introduction

Head and neck (HN) cancer includes cancers of the base of tongue, tonsil, and soft palate. Dual Modality treatment which includes radiotherapy (RT) and chemotherapy (CX), is the primary treatment for advanced HN cancer and may result in long term and often permanent morbidity because of xerostomia, sticky saliva, trismus, dysphagia, airway and speech problems, and shoulder dysfunction (De Graeff et al, 2000). According to de Graeff (2000) treatment is a strong predictor of HN symptoms, whereas low performance status and depression symptoms are predictors of poor general functioning. In a study conducted in 60 HN patients, the group receiving aggressive nutritional intervention had statistically smaller deteriorations in weight, nutritional status and global (quality of life QoL) compared to those who received usual care (Isenring et al, 2004). During RT, nutritional interventions positively influence outcomes. Only nutritional counseling, however, exerts a significant impact on patient outcomes in the long term (Ravasco, 2005). Isenring (2004) recommends patients at risk of malnutrition, such as those receiving RT to the HN area should receive regular and individualized nutrition support that continues post RT. According to Murphy (2009) the greatest increase in swallowing dysfunction was identified at 3 month following dual modality treatment and this dysfunction continued on to 12 months post treatment. Furthermore, Isenring (2004) suggests that where staffing levels are not sufficient to allow for this level of nutritional care, it is recommended that screening and triage systems be implemented to ensure that those patients most in need of care receive support. Also improvements were necessary in psychosocial care and in the communication between care providers (Ledeboer, 2006).

It follows that addressing patient needs for information and support may in fact help to reduce morbidity and mortality in this population. Although it is recognized QoL is jeopardized after treatment for HN cancer, the factors determining QoL and information needs of patients after treatment have not been extensively studied. A first step toward improving care of HN patients in the post-treatment phase is learning about their needs for information and support. This information may help health-care providers plan appropriate survivorship rehabilitation programs.

The goal of this study is to provide an expanded view and understanding of the complex care needs of HN Cancer patients beyond their diagnosis and medical treatment. Inclusion of patients and a project team member from Nanaimo in this research will aid in the dissemination of the findings in local settings and in the uptake of the survivorship care strategy for head and neck cancer patients across the region.

Objective

1.To use research interview techniques on an individual basis to explore the experience of VIC HN cancer patients immediately following radical RT and chemotherapy.

Material and Methods

This research received Research Ethics Board Approval. A total of 9 patients who were 4-17 months post completion of curative intent radiotherapy for advanced base of tongue or tonsil cancer were recruited by convenient sample; 4 who live in the Victoria area and 5 who live in the Nanaimo area. A mixed methodology was employed for this qualitative research. Their information and care needs in the survivorship phase were assessed through interviews conducted by a research assistant on an individualized basis. Patients were interviewed with a series of questions that invited candid open-ended discussion by respondents. Data collected include interview transcripts and observational field notes and patients' medical and general social profile. (eg. Diagnosis, treatment, marital status)

Grounded theory-based Atlas ti 6 data analysis software was used to code and categorize transcribed interviews and notes. A comparative analysis of respondents was enhanced by the use of this software.

The transcripts were analyzed and coded to identify recurring themes/categories, while bearing the research questions in mind. The multi-disciplinary nature of the research group benefited the analysis to reflect the multi-faceted needs (medical, nutritional, psychosocial) and experiences of HN patients. Thematic categories identified in interviews subsequently were cross-checked with the data gleaned from previous interviews, to ensure the themes are exhausted and reach a point of 'saturation'..

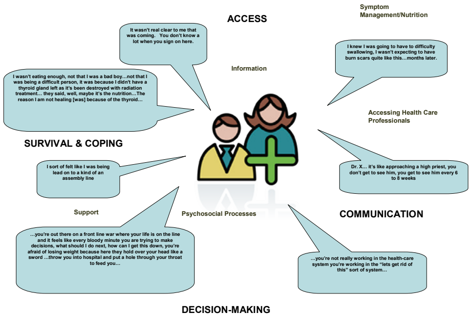
Table 1. Descriptors of patients accrued to study.

Descriptor	Age	Cancer site	Treatment-RT	Treatment-CX	Duration Post-treatment
Victoria cohort n=4	Mean 57 yrs (54-61 yrs)	Lt tonsil (n=3), T2N2 (b/c) Base of tongue (n=1), T1N2c	IMRT 70 Gy/56 Gy (n=3), IMRT 60 Gy (n=1)	Cisplatin 2 cycles (n=1), Cisplatin 1 cycle (n=1)	Mean 9 months (4-17 months)
Nanaimo Cohort n=5	Mean 66 yrs (54-83 yrs)	Lt tonsil (n=2), Rt tonsil (n=2), T2N2 (b/c) (n=1), T4aNo (n=1) Base of tongue (n=1), T1N2c	IMRT 70 Gy/56 Gy (n=4), IMRT 60 Gy (n=1)	Cisplatin 2 cycles (n=2), Cetuximab 3 cycles (n=1)	Mean 11 months (6-16 months)

Results

There were three principle themes identified from the patient interviews which include: high need for disease-related information regarding diet, financial assistance, symptom management and anxiety-reduction; high need for support during the first 6 weeks following discharge; and improved coordination via care manager with contact information .

Figure 2. Themes emerging with quotes from one patient transcript.



Conclusion

The survivorship care and information needs of HN cancer patients identified with this research are many and are spread across the care continum. The information obtained from this qualitative study is an important first step in improving our understanding of the survivorship needs of this patient population. The identified survivorship care and information needs of HN cancer patients will be used to develop a strategy for care for patients during and after treatment for HN cancer for Vancouver Island. This research was grant-funded via BCCF/Vancouver Island Research and Development-Catalyst Program.

Figure 1. VIC Head and Neck Survivorship Research Team – *Left to right, front row*: Helen Wong, Jennifer Gait. *back row*: Cheri Cosby, Bev Gerbis. *Missing from photo*: Tracy Lister, Sally Smith and Andréa Fimrite.

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