

The Information Needs and Preferences of Younger Head and Neck Cancer Survivors

by

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Abstract

The purpose of this study was to determine the unique information provision needs and preferences of younger HNC survivors in the post-treatment phase of recovery. Participants were asked about information considered most important, sources of information used during recovery, sources considered most helpful, and ideal features of an online information resource. Age, sex, years of education, and time since completion of treatment were also correlated with information content considered most important, sources of information used, and sources of information considered most helpful. Data was collected using a self-administered questionnaire that participants either completed on paper and returned by mail or completed online. The questionnaire utilized The Head and Neck Information Needs Questionnaire as well as 24 other items relating to sources of information used during recovery. Of 511 eligible participants, 206 surveys were returned and analyzed. Results indicated that although many information topics regarded as most important remained similar to those of older individuals with HNC, some unique themes, such as detailed information on signs and symptoms of recurrence, chances of being cured, rehabilitation after treatment, treatment and recovery timeframes, and financial assistance emerged as being very important to the people in this study. The internet as a mode of information was identified as a useful source among HNC patients. Finally, a reliable online information resource was regarded as very helpful by the vast majority of participants. The contents of this study could provide the ground work for designing a reliable internet-based information resource for recovering HNC patients.

Keywords: head and neck cancer, information needs, sources of information, internet

Preface

This thesis is an original work by Oksana Zimka. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, “The Information Needs and Preferences of Younger Head and Neck Cancer Survivors: A Total Population Survey”, No. Pro00043075, October 8, 2013. Reciprocal approval was granted by the Health Research Ethics Board of Alberta – Cancer Committee, “The Information Needs and Preferences of Younger Head and Neck Cancer Survivors: A Total Population Survey”, No.26205, January 09, 2014.

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Chapter I: Statement of the Problem

Background

There are an estimated 10,650 new cases of head and neck cancer (HNC) diagnosed each year in Canada (Canadian Cancer Society, 2012). Of these, approximately 4,000 originate within the oral cavity, and oropharynx (Canadian Cancer Society, 2012).

Changing head and neck cancer population.

Historically, the mean age at diagnosis of HNC was 65 and the primary risk factors included excessive alcohol and tobacco use (Johnson-Obaseki, McDonald, Corsten, & Rourke, 2012; Chaturvedi, Engels, Anderson, & Gillison, 2008). However, in the past decade, several subtypes of HNC, most notably oropharyngeal squamous cell carcinoma, have been associated with sexually transmitted human papillomavirus (HPV) infection (Chaturvedi et al., 2008). These HPV-associated subtypes of HNC are more common in men with no history of excessive alcohol consumption or tobacco use (Marur, D'Souza, Westra, & Forastiere, 2010). The largest increase in HPV-associated HNC in both Canada and the United States has been observed in the 40-59 age group (Forte, Niu, Lockwood, & Bryant, 2012; Chaturvedi et al., 2008). In addition to affecting younger males more, HPV-associated HNCs also tend to be diagnosed at later stages, respond better to chemo-radiation, have decreased risk of recurrence, and have better survival rates than HPV-non associated HNCs (Heath et al., 2012; Mannarini et al., 2009; Marur, D'Souza, Westra, & Forastiere, 2010).

Decreased age at diagnosis and increased survival contribute to prolonged survivorship, shorter productive work years, and increasing numbers of high-needs populations (Deboer et al., 1995; Johnson-Obaseki, McDonald, Corsten, & Rourke, 2012). Although survival rates among patients with HPV-associated HNC are high, up to 90%, the physiological and psychosocial

complications of HNC treatment have a negative effect on quality of life (QOL) (Nichols et al., 2013). Furthermore, younger survivors face unique challenges with relationships, their return to employment, financial stability, and family rearing during recovery. Our clinical conversations with younger HNC patients suggest that the information developed for older HNC survivors may not adequately address the unique needs of younger clients. Addressing this problem may have a positive impact on QOL.

Information provision.

The correlation between appropriate information provision and improved survivor outcomes, and improved QOL, is widely accepted in literature (Husson, Mols, & van de Poll-Franse, 2011). The issue here, though, is about more than just the information itself. Timing, quantity, quality, and mode of delivery are all important determining factors of successful information provision (D'Souza, Blouin, Zeitouni, Muller, & Allison, 2013; Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013). According to the literature, the information needs and preferences of cancer survivors are influenced by a number of additional factors, including age, sex, time since treatment completion, and amount of education (Matsuyama et al., 2013; Rogers, Rozek, Aleyaasin, Promod, & Lowe, 2012; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Thus, exploring the unique needs of this newly emerging HNC population becomes a critical step in designing appropriate survivorship support services.

Preliminary results of a recent study suggest that the information needs of the younger HNC survivors, many with HPV-associated HNCs, may be different than those of older individuals with HNC (K. Grattan, personal communication, April 2, 2013). In my own nursing practice, I have noticed that younger individuals with HNC have unique information and service provision needs, particularly upon completion of treatment and re-integration back into their

family and work roles. They typically ask more questions, want more in-depth information, and feel more comfortable accessing internet-based resources. Colleagues working with HNC populations also comment that younger patients frequently prefer to use e-mail to communicate with their cancer care providers as opposed to their older counterparts, who tend to prefer to communicate in person or over the phone.

Little research in Canada has explored the information needs and information provision preferences of HNC survivors during recovery from treatment, and no studies on the information needs of younger individuals with HNC have been identified in Canada or elsewhere. Our research aimed to fill this gap. Findings from this study will be used to develop an information support service specifically geared toward younger HNC survivors in Alberta.

Purpose of the Study

The overall purpose of this study was to determine the unique information provision needs and preferences of younger HNC survivors in the post-treatment phase of recovery. The findings formed the needs assessment phase of a future information support program.

Research Questions

Primary Research Questions:

- a. What types of information are considered most important for younger HNC survivors to receive after they have completed treatment for HNC?
- b. What modes of information delivery are most frequently used by younger HNC survivors to obtain information about HNC recovery after they have completed treatment for HNC?
- c. What modes of information delivery are considered most helpful by younger HNC survivors after they have completed treatment for HNC?

- d. What kind of features/functions would an ideal information support service include?

Secondary Research Questions:

Among younger HNC survivors who have completed treatment for HNC:

- e. Are age, sex, time since treatment completion, and years of education associated with the types of information considered most important?
- f. Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery used?
- g. Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery considered most helpful?

Operational Definitions

For the purpose of this study, key terms utilized are defined as follows:

Head and Neck Cancer (HNC): this term specifically refers to oral (lips, front 2/3 of tongue, cheeks, floor of mouth, hard palate, retromolar trigone) and oropharyngeal (soft palate, base of tongue, tonsils) squamous cell carcinoma (SCC). These sites are most consistently associated with HPV infection and thus more frequently diagnosed at a younger age.

Younger: clients who were diagnosed with HNC at 18 to 64 years of age.

Survivors: clients who successfully completed curative treatment with no evidence of tumor recurrence or metastases.

Treatment: Curative treatment includes primary surgical resection which can include neck dissection and/or reconstructive surgery followed with adjuvant radiation treatment with/without concurrent chemotherapy; or primary chemoradiation with/without salvage surgery.

Information: specifically refers to any knowledge communicated between a source and a recipient which aims to improve recovery, health status, and health behaviours of cancer survivors.

Information Support Service: a service developed by health care professionals to convey health information through text, multimedia, or personal communication between cancer survivors and health-care providers.

Mode of Information Delivery/Source of Information: refers to ways of communicating information between health care professionals and cancer survivors which includes but is not limited to, verbal, written (such as information leaflets and brochures), internet, television, radio, magazine articles, books, and medical journal articles. Information may also come from support groups, or other cancer patients, and family and friends.

Internet-Based Information Resource: Information which is accessible to public or a specific patient population that can be accessed from an electronic computer device. This may include but is not limited to websites, patient portals, and applications which relay information over the internet.

Study Significance

Rates of HPV-associated HNC continue to steadily rise, forecasting a growing population of HNC survivors with many needs associated with their cancer treatment (Auluck et al., 2010; Johnson-Obaseki et al., 2012). In the face of budget cutbacks and technological advances, innovative programs must be developed to effectively and efficiently provide long-term support to recovering cancer survivors. A needs assessment is an important step in any program development because it helps to identify stakeholder preferences, and provides a framework for structuring the system according to the needs of users (Weigl et al., 2012). In addition to

potentially saving Canadian healthcare dollars, the needs assessment conducted in this study helped identify information needs unique to younger HNC populations. This study is the beginning of a research program. This program of research will be designed so that the results could potentially be used across Canada to provide more personalized information to cancer survivors.

As a registered nurse, I was well positioned to undertake this study. I had clinical experience with HNC and developed a broad network of nursing colleagues in Alberta who also work with HNC patients. Nurses are critical members of the head and neck interdisciplinary team. They provide direct patient care in acute care and outpatient settings, educate patients and families on what to expect and how to manage treatment side-effects, and act as important sources of support within the healthcare system. As such, nurses are in an ideal position to directly improve patient experiences by tailoring information to the unique needs of each individual and incorporating information from all relevant health disciplines. By equipping HNC survivors with survival skills such as management of finances during sickness, re-establishing close intimate relationships with partners, and child rearing during cancer, nurses can help patients become self-sufficient and achieve an optimal QOL during recovery (Gold, 2012; Scarpa, 2004).

Nurses also act as advocates at the systems level of healthcare. As their understanding of the unique needs of younger HNC grows, nurses will be able to advocate for better ways of providing information at all levels of care. By contributing to program development, nurses can also ensure the user-friendliness and relevance of programs to both patients and healthcare practitioners.

Conclusion

A brief outline of the problem under study has been introduced in this chapter. The following chapter, the literature review, will include a summary of current and seminal research relevant to the issue under study. I first outline important HNC and HPV trends developing internationally and in Canada. I then discuss the HNC recovery experience as it relates to QOL outcomes. Next, I discuss the potential unique information needs of younger HNC survivors, followed by a discussion of information provision preferences and previously implemented electronic information support programs. In the third chapter, Methods, I outline the design, population, data collection, instrumentation, data analysis, and dissemination strategies of this project.

Chapter II: Literature Review

The increased incidence of HPV-associated HNCs has dramatically transformed the traditional HNC population: patients are increasingly younger, well-educated, Caucasian males (Callaway, 2011). A substantial change in characteristics of the HNC population has the potential to result in a mismatch between HNC survivor information needs, and information provided upon discharge. In Canada, at the time the study was conducted, there was little available research reporting on HNC patient experiences and information needs upon completion of treatment. No research was identified that focused on younger HNC populations. Thus, the purpose of this literature review was to explore the aforementioned change in population characteristics and its potential implications for information needs, sources of information, and information provision preferences of younger survivors recovering from HNC after completing treatment. Additional literature on QOL, treatment outcomes, and rehabilitation experiences was included in this review to frame the context of the issue under study.

Search Strategy

Relevant literature was identified by searching MEDLINE, PsychINFO, CINAHL, Science Direct, PubMed, and Web of Science. Search terms varied by database but included head and neck neoplasms, head and neck cancer, larynx*, pharynx*, nasopharynx*, oropharynx*, throat, tumour*, tumor*, malignan*, human papillomavirus, cancer, HPV, internet, sources of information, quality of life, QOL, “psychosocial”, psych* support, support network*, support group*, self help group*, TI support*, "information need*", information seeking, information seeking behavior, education need*, TI information, rehabilitation, post-treatment, trends, epidemiology, Canada. Inclusion criteria were: English language, academic journals, publication year 2000-2013 (except Web of Science where seminal research was sought), cancer survivors or

HNC survivors are the main population studied. Articles were excluded if they focused on: caregivers or families of cancer/ HNC patients, patients who were not yet treated, esophageal cancer patients, thyroid cancer patients, and nutritional support. The search yielded a total of 1119 articles. After title and abstract screening, addition of references from key papers, and removal of duplicates, 98 articles were selected for full text screening. A final 54 relevant articles were considered for appraisal and inclusion in this literature review. The 28 most relevant articles are discussed in detail in this review and 14 articles are discussed as part of supporting literature.

Global Head and Neck Cancer Epidemiology

Each year, there are approximately 600,000 new cases of HNC worldwide including 263,020 originating in the oral cavity, and 136,622 in the pharynx (Joseph & D'Souza, 2012). Two-thirds of HNCs occur in the developing world where tobacco and alcohol consumption remain the primary risk factors. Geographical regions like South Asia, Western Europe, and South America tend to have the highest incidence and mortality from HNC (Warnakulasuriya, 2009). Nevertheless, North America is frequently noted as a region contributing to the global burden of HNC. HNC has a two- to nine-fold higher incidence among men than women (Joseph & D'Souza, 2012). Despite decreasing incidences of most types of HNC in the last 20 years, the incidence of oropharyngeal HNC, particularly in younger males ranging from 20-60 years of age, has increased in many developed nations including Denmark, the United Kingdom, Finland, Sweden, Slovakia, the United States, and Canada (Heath et al., 2012; Joseph & D'Souza, 2012). Recent evidence suggests HPV as the probable causative agent for this change (Heath et al., 2012). As a result of widespread increases in HPV-associated HNC incidence, several countries including Australia and the Netherlands have launched initiatives to better understand the

information needs of HNC patients during recovery (Dall'armi et al., 2013; van den Brink et al., 2005).

Human Papillomavirus

HPV is a common, sexually transmitted infection (STI) affecting over 70% of sexually active Canadians at some point in their lives (Canadian Cancer Society, 2012). Most infections are transient and cleared by the body's immune system with no lasting effects; however, about 10% of infections become persistent and, depending on infection strain, can lead to anogenital warts or cancer (Garnock-Jones & Giuliano, 2011; Tota, Chevarie-Davis, Richardson, Devries, & Franco, 2011). The most common oncogenic strain currently associated with more than 90% of HPV-associated HNCs is HPV 16 (Marur et al., 2010).

The link between HPV and HNC was first suggested by Syrjänen et al. in 1983, and later substantiated by Miller and Johnstone in 2001 in their large scale meta-analysis of 94 reports completed between 1982 and 1997 (Miller & Johnstone, 2001; Syrjanen, Syrjanen, Lamberg, Pyrhonen, & Nuutinen, 1983). Since then, numerous reports have confirmed the relationship between HPV and a variety of HNC sites (Mannarini et al., 2009). In 2009, the International Agency for Research on Cancer (IARC), a part of the World Health Organization, released a monograph summarizing infectious agents which are recognized as carcinogenic to humans; for the first time, HPV type 16 was listed as a causative factor for oral cavity and oropharyngeal cancer (Bouvard et al., 2009). This international acceptance of the link between HPV and HNC has sparked an influx of research in the area, largely focused on etiology and treatment implications. Research has yet to focus on supportive care and information needs of HPV-associated HNC survivors, particularly those under the age of 65.

Part of the reason HPV-positive HNC is increasingly more prevalent in younger patients may be due to the changing sexual norms of today's society, including younger age at first sexual intercourse and higher numbers of sexual partners (Marur et al., 2010). In fact, accepted risk factors for HPV positive HNC include oral HPV infection, younger age at first sexual contact, higher numbers of lifetime sexual partners, and history of oral sex (Mannarini et al., 2009).

Canadian Head and Neck Cancer Population

A recent study by Johnson-Obaseki, McDonald, Corsten, and Rourke (2012) analyzed national cancer registry data between 1991 and 2007 to examine the changes in age-adjusted incidence, age at diagnosis and survival of HNC patients in Canada. The overall incidence of HNCs in Canada decreased over the study period; however, when examined by subgroup, oropharyngeal cancer was the only subgroup to increase in incidence significantly over the study period (27.1% men, 13.7% women). In the oropharyngeal subgroup, age at diagnosis decreased by 3.68 years in men, and 3.52 years in women. Finally, survival improved for all subgroups, especially for males with oropharyngeal cancers (13.5%). These results support international trends of increases in HPV-associated HNCs, younger HPV-associated cancer populations, and improved survival for HPV-associated cancers in males (Heath et al., 2012; Johnson-Obaseki et al., 2012). This may have a variety of implications for HNC survivorship care; working age individuals with dependents, who survive longer, may have different needs after completing treatment than will the typical older, retired, shorter surviving individuals who have no dependents.

The methodological quality of this study was very good; however it did have several important limitations. First, no data is available in the Canadian cancer registry on HPV status;

the authors make a justifiable assumption that oropharyngeal cancers most accurately represent HPV-associated cancers, so conclusions on HPV incidence drawn from data are tentative.

Second, survival was only reflective of those patients treated up until 2001 (due to a lag of five years to determine five-year survival). Oropharyngeal cancers had the highest improvement in survival, and incidence continued to increase up to 2007; consequently, the results may underestimate the improvement in survival.

In addition to improved survival over time, HPV-associated HNC patients have a higher survival rate than all other HNC subtypes. In a Canadian study analyzing tumor samples and survival from 2003 to 2009, Nichols et al. (2013) found statistically significant differences between disease-free and overall survival of HPV-positive and HPV-negative tumors: 85% vs. 45% and 90% vs. 65%, respectively. This observation of high survival rates in younger patients with fewer co-morbidities, led to an increased emphasis on post-treatment QOL because younger patients may have to endure treatment side effects for decades (Nichols et al., 2013). Thus, research focusing on information needs of this subset of HNCs can provide valuable direction for initiatives aimed at maintaining and/or improving these patients' QOL.

Treatment.

Despite improved survival and different patient characteristics, treatments for both HPV-associated and HPV-non associated cancers have yet to change. There are two main courses of treatment most commonly used to treat oral and oropharyngeal cancer in Canada. These are primary surgery including tumor removal, neck dissection, and in some cases, grafting skin and/or a bone, followed by adjuvant radiation therapy with/without chemotherapy; or primary concurrent chemoradiation therapy followed by salvage surgery if warranted. Treatment options depend on a variety of factors including tumor location, stage, pathological features, and patient

status. However, many treatment side-effects are similar to all treatment pathways (National Comprehensive Cancer Network , 2013) and are directly related to QOL during recovery.

Information on managing these side-effects has the potential to decrease anxiety and increase ability to cope with treatment side effects thus significantly improving QOL for HNC survivors (Deboer et al., 1995).

Survival Outcomes and Quality of Life

QOL is an elusive concept which has a variety of meanings in different contexts. It is a multi-dimensional construct that is defined by subjective experiences, states, and perceptions, and is related to one's overall well-being (Revicki et al., 2000; Sayed et al., 2009). QOL extends beyond an individual's health and is influenced by perceptions of one's physical, psychological, social, economic and political environments (Revicki et al., 2000). HRQOL is more specific and relates to an assessment of the impact of disease and treatment on physical, psychological, social, and somatic domains of well-being (Revicki et al., 2000). QOL and HRQOL are frequently utilized in research and practice to evaluate a patient's response and adjustment to treatment, identify and prioritize problems during recovery, and develop informed rehabilitative and patient education services relevant to individual patient needs (Sayed et al., 2009). These two measures are especially important in HNC populations as the illness and its treatment directly affect vital functions of one's life, including eating, breathing, and socializing, and can significantly compromise well-being and satisfaction with life. Working with the assumption that the primary goal of any support service is to improve patient QOL in some way, survival outcomes and their effect on QOL and HRQOL are discussed in the following sections. Benefits of the proposed information support service are outlined in response to each outcome domain.

Determinants of Quality of Life.

Survival outcomes for HNC clients depend on a variety of features. Infante-Cossio et al. (2009) found that the most significant factors affecting QOL three years after treatment included the site of the tumor, stage of the tumor, and treatment received. Participants with oral tumor sites in stages I-II, who received surgery only, tended to have higher global QOL and functional scores at one year and three years post diagnosis. Participants with oropharyngeal tumor sites in stages III-IV, who received surgery as well as chemo-radiation, had lower global QOL, and lower physical, social, and emotional functioning. They also had more fatigue and pain both one year and three years after diagnosis (Infante-Cossio et al., 2009). These findings indicate that information support needs may be higher in survivors of oropharyngeal cancers caught in later stages and treated more aggressively. It is important to note that HPV-associated cancers more commonly present in the oropharynx at stage III and IV (Marur et al., 2010) further underlining this cancer populations' need for more information.

Physiological and functional outcomes.

A comprehensive, frequently cited study was carried out by Deboer et al. (1995) to assess HNC survivor outcomes and influencing processes. The study included 110 participants diagnosed with HNC who completed a questionnaire between two and six years post-treatment. The authors found that patients with oral and oropharyngeal carcinoma treated with surgery experienced food intake and facial disfigurement problems as well as severe psychosocial distress (Deboer et al., 1995). These findings suggest that patients with oral, and oropharyngeal carcinoma, now thought to be associated with HPV, continue to experience significant physical and psychosocial problems up to six years post-treatment. Although this study was performed in

1995, changes in treatment have not changed drastically, suggesting possibly less dramatic but comparable results today.

Indeed, both Abendstein et al. (2005) and Oskam et al. (2013) observed similar findings. Abendstein and colleagues (2005) found no significant overall improvement in HRQOL from diagnosis to five year follow-up. In fact, the authors found that 25% of participants experienced a decreased overall HRQOL, particularly in relation to senses (taste and smell), sexuality, teeth problems, mouth opening, dry mouth, and sticky saliva. Oskam et al. (2013) followed patients with advanced oral and oropharyngeal cancer into long-term survival. The authors found that long-term survivors had clearly worse HNC-specific HRQOL eight to eleven years after treatment when compared to baseline. For some, it was even worse than during the first year post-treatment. Oral dysfunction and social functioning in particular were significantly worse at eight to eleven years after treatment (Oskam et al., 2013). Although the long-term survivor sample was only 26 of 80 original participants, this article provides valuable insight into long-term functional outcomes of HNC patients.

Mucositis and dysphagia are two other significant complications frequently experienced by patients, and which contribute to diminished QOL in the first year of recovery (Tippett & Webster, 2012). However, the majority of patients return to near-normal swallowing status within the first two years of recovery (Tippett & Webster, 2012). As a result of a myriad of physiological symptoms which persist after treatment completion, it is of little surprise that information needs remain high in the post-treatment period (Rutten et al., 2005). Information on symptom management may be needed most in the first year of recovery, but these studies indicate that it may also be just as needed well into survivorship. In addition, high rates of fatigue and speech impairment may discourage survivors from accessing information support

services in-person, thereby justifying the exploration of other modes of information delivery like the internet.

Psychosocial outcomes.

In addition to physiological complaints, HNC survivors also experience significant psychosocial distress well into recovery. Ziegler and colleagues (2004) carried out a literature review of information needs and outcomes of HNC survivors. They found that survivors experienced the most issues in coping with health problems, fears, communicating with partners, and social relations; in addition, the majority of these psychosocial domains deteriorated markedly over time, in contrast to physiological problems which improved or stayed the same (Ziegler, Newell, Stafford, & Lewin, 2004). Another study reviewed by Ziegler et al. found persisting psychological distress in 30% of survivors between seven and eleven years after treatment, similar to the results found by Deboer et al. (1995). This literature review was extremely useful, cohesive, and quite comprehensive: however, it was limited because it failed to provide evidence of critical appraisal of the articles included, or inclusion criteria for the articles chosen for this review. Ziegler et al. and Deboer et al. both demonstrate the increased psychosocial needs of HNC survivors during recovery. As suggested by these authors, information on available social and psychological support, strategies to improve communication with loved ones, and suggestions to promote healthy coping may all be valuable pieces of information required for optimal HNC recovery.

In relation to younger HNC survivors, Ziegler et al. (2004) also found that survivors under the age of 65 had higher anxiety, depression, and poorer sexual functioning than their counterparts who were more than 65. These findings are supported by Gold (2012), who explains that higher anxiety and depression in younger survivors may be due to the unexpectedness of the

diagnosis, active involvement in careers, fears related to consequences of disease on their young families, fear of stigma associated with a sexually transmitted infection, and feelings of guilt and doubt about their partners' and their own sexual histories.

Younger families.

Semple and McCance (2010) interviewed 12 survivors of HNC who had children under the age of 16 at the time of diagnosis. They found that young families were faced with a set of unique challenges as they progressed through the cancer experience. In addition to the usual physiological and psychosocial difficulties, parents also felt more fear and uncertainty about providing for their families, missing developmental milestones, and guilt for being unable to fulfil their parental roles (Semple & McCance, 2010). Thus, in the recovery phase, parents expressed the desire to receive more information on how to best undertake parental roles in the unique situation of having HNC (Semple & McCance, 2010). Similar to studies previously discussed, the theme of needing information on financial support was also evident in this study. It is important to provide this information to younger survivors especially in the first six months of recovery as they begin re-integrating into day-to-day life. It is interesting to note that survivors who felt they had insufficient information during recovery also felt less emotionally supported and experienced more psychological distress (Semple & McCance, 2010).

The same survivors who felt they weren't being provided with enough information turned to the internet for parenting advice. This qualitative study was very well designed but because ten men and only two women participated in the study, results may not adequately represent unique challenges faced by mothers diagnosed with HNC.

Return to employment.

Verdock-de Leeuw, van Bleek, Leemans, and de Bree (2010) sent out questionnaires evaluating HNC survivors on return to work, and influencing variables. They found that 84% of 53 survivors working prior to diagnosis returned to work, usually within the first six months (Verdonck-de Leeuw, van Bleek, Leemans, & de Bree, 2010). As the majority of younger HNC patients are of pre-retirement age, they are more likely to be employed prior to diagnosis, and thus more likely to return to work within 6 months of treatment completion. This speedy return to work may cause continued stress on survivors as they are recovering from cancer treatment. It is therefore important to better understand the preferred method of acquiring information and support during this hectic time in their lives.

Body image and self-esteem.

Fingeret et al. (2011) carried out a cross-sectional study evaluating body image concerns and their relationship to HNC patients' QOL. Two hundred and eighty surgically-treated patients completed a battery of questionnaires at three different times in the treatment trajectory: prior to commencement of treatment, within one year after commencement of treatment, and more than one year following surgical treatment. The authors found that 75% of participants experienced concerns or embarrassment about bodily changes at some point after the diagnosis. One-third of the sample endorsed behavioural difficulties and social avoidance because of concerns about body image including appearance, speech, or eating changes (Fingeret et al., 2011). Their findings also revealed significant associations with body image concerns and poorer QOL outcomes (Fingeret et al., 2011). Finally, the authors found that younger participants displayed significantly higher levels of body image dissatisfaction.

A strength of the study included the use of multiple validated instruments to measure QOL and Body Image Satisfaction, however, one of the main tools used was specifically designed for the study but was not validated, and it is unclear if it was pilot tested. This may compromise the validity of a portion of the results. In addition, it is unclear whether instruments were completed in an interview setting or if surveys were mailed in, further questioning whether cueing in an interview setting may have altered some results. Nevertheless, due to a lack of studies on the subject, these results remain useful, suggesting that body image remains a concern for a large portion of HNC survivors, particularly those who are younger. It may be that these survivors, in particular, would benefit from internet-based programs where social situations are simulated in a safe, virtual environment, with no trigger to feel self-conscious about body image. Such an environment can also provide needed information to those survivors who may be discouraged from attending more formalized group settings due to body image concerns.

Sexuality.

A recent study carried out by Moreno and colleagues (2012) in Cincinnati surveyed 45 HNC survivors regarding the effect of HNC on their sexuality. All of the participants in their study stated that HNC had negatively affected their sexual relationships, and half of them described the effect as being extremely negative. Males who were over sixty years old had higher sexual satisfaction scores than women, and those younger than 60 (Moreno et al., 2012). Overall, only 31% reported being sexually unsatisfied and the rest were satisfied or extremely satisfied. At the same time, Moreno et al. report that 55% of participants reported that they were rarely or never sexually active. The results of this study seem to suggest that although HNC has a negative effect on patients' sexual activities, the patients either return to a normal sexual relationship through recovery, or redefine the meaning of a happy sexual relationship after completing

treatment. It is interesting to note that participants were interviewed in person about their sexuality. It is possible that some results may be influenced by social desirability and thus may be inflated.

In an unpublished qualitative thesis, Grattan et al. (2013) explored the experiences of younger HNC survivors and found that sexuality was an important theme that was raised repeatedly by participants. She reported that survivors expressed both positive and negative effects of HNC on intimacy and sexuality but seemed more open to discussing negative effects, when compared to participants in the study conducted by Moreno et al. (2012). Limited research on HNC survivor sexuality allows for only tentative claims; however, it seems clear that sexuality is an important topic for HNC survivors. It may be valuable for younger HNC survivors to receive information about re-establishing healthy sexual relationships with partners after treatment or feeling comfortable starting a new relationship.

Driving behavior.

Yuen et al. (2007) surveyed HNC survivors on driving behaviour and found that 26.5% of participants drove less or stopped driving after completion of treatment. Instead, these survivors relied on family and friends more often for transportation (Yuen, Gillespie, Day, Morgan, & Burik, 2007). Internet-based information and support services may reduce survivor burden by eliminating the need for extra travel, time for appointments, and scheduling conflicts with work and face-to-face support services. This is particularly important for those who live in rural communities, or small towns without local supports. It is thus important to inquire about what types of functions an information support service specifically designed for younger HNC survivors would encompass to promote optimal recovery.

Information Needs

In this study, I conducted a needs assessment of younger HNC survivor information needs in the post-treatment period. Information needs have been studied extensively in a range of cancer populations in the past two decades. In their well conducted study, Matsuyama, Kuhn, Molisani, and Wilson-Genderson (2013) explored information needs in stage II-IV cancer patients at three time intervals, up to nine months after treatment. In that study, cancer sites that were included were gastrointestinal, breast, lung, and other. One hundred and thirty-eight participants filled out surveys on demographic variables, amount of information needed, and information needs. The vast majority of patients — 88-91% — wanted “everything, including bad news” (Matsuyama et al., 2013). The authors also found that although information needs decreased significantly between the first and last time intervals (approximately 10% for each domain) information needs remained high at the nine month time interval. Finally, Matsuyama and colleagues discovered that women, younger participants, and participants with less education all had higher information needs. Rutten et al. (2005) found that younger patients, women, and patients with higher education all sought more information than older patients, men, and patients with less education, respectively. These findings once again reaffirm that information needs remain high in the recovery period. They also show that survivors seek as much information as possible, and that gender, age, and years of education may be significant variables influencing information needs in cancer survivors.

Cancer survivor information content.

In a frequently cited systematic review of articles published between 1980 and 2003, Rutten, Arora, Bakos, Aziz, and Rowland (2005) summarized cancer patients’ information needs

into 10 categories and 64 subcategories: cancer specific, treatment-related, prognosis, rehabilitation, surveillance and health, coping, interpersonal, financial/legal, medical system, and body image/sexuality. The most frequently needed information in the post-treatment phase was treatment-related (35%) and rehabilitation (22.5%). However, Rutten et al. (2005) noted that the majority of studies evaluating information needs of patients in the post-treatment phase actually asked the patients to also recall what information they needed during diagnosis and treatment. Rutten et al. conclude that the majority of articles therefore report on needs during treatment and diagnosis versus actual needs during recovery.

The application of these study findings to Canada is reasonable as 31% of the studies reviewed were Canadian. However, although a variety of cancer sites were included, HNC was not mentioned specifically in any of the studies reviewed. Limited research on information needs after completion of treatment further underlines the importance of our study. For this reason, I decided to use an instrument specific to HNC – the Head and Neck Information Needs Questionnaire (HaNiQ). Data were collected from individuals who completed treatment one month to five years prior to data collection, and the survey specifically asked survivors about their information needs at the current stage of their recovery. Thus, information gained as a result of this study contributes to a better understanding of information needs following treatment

Younger head and neck cancer survivor information content.

To facilitate a deeper understanding of HNC patient needs and experiences during recovery, a more recent, qualitative study of lifestyle changes after treatment was examined. Semple, Dunwoody, Kernohan, McCaughan and Sullivan (2008) recruited 10 HNC patients who completed treatment six to twelve months prior to data collection. Semi-structured interviews were carried out and lifestyle changes were categorized into physical changes, concerns about

cancer, work and day-to-day tasks, interpersonal relationships, and social functioning. Two themes which may be particularly important to younger HNC populations were work and day-to-day tasks, and interpersonal relationships. Semple et al. (2008) reported that several participants, who had been employed before diagnosis, described choosing to reduce work hours and focus more on family after treatment. However, some participants described being forced to reduce hours due to physical side effects and altered functioning. This was mostly perceived as a negative experience as participants felt a loss of normality and control, had reduced income, and became more dependent on family members (Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008). This loss of financial productivity could place a greater strain on interpersonal relationships with spouses, particularly in families with younger children. Semple et al. (2008) also reported on specific information needs lacking in the post-treatment phase. Participants wanted more information on practical aspects of recovery such as skin care, welfare and social security benefits. They also wanted more opportunities to interact with 'expert patients' who could share practical knowledge. Participants also reported that timely advice reduced anxiety and improved post-treatment experiences (Semple et al., 2008).

In her discussion paper, Gold (2012) also clearly outlined similar potential problems faced by younger HPV-associated HNC survivors during recovery. She argued that providing information was one strategy to help alleviate these concerns. Particularly during initial recovery, Gold suggested that information about HPV transmission, financial management, and partner communication was crucial to promote better adjustment during recovery and into survivorship (Gold, 2012). Deboer et al. (1995) also found that open discussion of illness in the family, social support and adequate information were the most important predictors of positive rehabilitation outcomes. Upon completing their literature review, Ziegler et al. (2004) also concluded that

improved information provision may play a part in determining positive survivor outcomes. These authors' findings suggest that services aimed at involving family members in rehabilitation, provision of social support modalities and effective information provision including themes outlined by Gold (2012) could improve positive rehabilitation outcomes for younger HNC survivors.

Lewellyn, McGurk, and Weinman (2006) tested satisfaction with information prior to treatment in 82 newly diagnosed patients, and followed them up until one month and six to eight months after completion of treatment. Like Gold (2012) and Semple et al. (2008), Lewellyn and colleagues reported that survivors wanted to know more about where to go for financial advice, information about available support groups, and the long-term effects of treatment on the ability to work. In summary, these findings suggest that in addition to cancer information needs outlined by Rutten et al. (2005), younger HNC survivors may also need more information about financial resources, effects of treatment on the ability to work, practical self-care, HPV, and sexuality. Potential functions survivors want in an information support service may include opportunities to seek advice and support from fellow survivors and experienced practitioners.

Linking information needs and quality of life.

A multitude of studies has confirmed the importance of appropriate information provision to HNC patients. When information needs are satisfactorily addressed in an appropriate timeframe, individuals with HNC report better QOL, greater self-esteem, lower loss of control, and lower depression/anxiety during recovery (Husson, Mols, & van de Poll-Franse, 2011; Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008; Llewellyn, McGurk, & Weinman, 2006; Yu, Fielding, Chan, & Sham, 2001; Deboer et al., 1995). Conversely, when information provided is inadequate, patients experience higher anxiety, depression, and increased

psychological difficulties (Ziegler et al., 2004). This relationship is well recognized by clinicians, and remains a priority for healthcare providers when preparing patients for discharge. However, the recovery period is sometimes characterized by a significant drop in support and professional guidance as cancer survivors leave the secure environment of the cancer center and re-integrate into independent day-to-day life, and so the opportunity to provide information required is limited.

Larsson, Hedelin, and Athlin (2007) conducted an in-depth qualitative study using interpretive phenomenology. Nine participants were interviewed approximately six to eight weeks after completing radiotherapy treatment. The authors concluded that the essential structure of the experience of daily life during and after treatment completion was “Needing a hand to hold,” composed of three interrelated themes, one of which was “Left to one’s own devices” (Larsson, Hedelin, & Athlin, 2007). The authors found that after treatment completion, survivors felt that they were not prepared and had insufficient information to manage treatment side effects by themselves. They struggled to regain normality in their lives without the usual active support they became accustomed to receiving from healthcare providers during treatment. One participant stated “After that [,] you were released from the hospital[;] you were all alone just knowing that you would get an appointment for an x-ray and that they would be in touch. But then you had thousands of questions...” (Larsson et al., 2007). This comment powerfully demonstrates the feelings of dependency on healthcare professionals, as if support needed to be withdrawn gradually, rather than jarringly at discharge.

Although this study was conducted in Sweden where the healthcare structure may significantly differ from that in Canada, these results fit with my clinical observations of HNC survivors leaving the safe environment of structured care settings. In Alberta, survivors typically

have frequent phone follow-up in the first two weeks and appointments are gradually scheduled further apart. However, even in the time period of one day, or one week, concerns and questions can begin to pile up. Follow-up appointments are typically focused on treatment-specific concerns, and health professionals may have limited time to address less emergent concerns such as bowel management, or unrelated medical conditions. Perhaps one function of an information support intervention would be asynchronous discussion with healthcare professionals. Questions could then be asked as they came up, and designated healthcare professionals could respond to questions and concerns in a virtual environment (forum), ideally within a few hours. Not only could this be more convenient for survivors struggling with treatment-related health problems, it would likely be a more efficient use of healthcare professionals' time. In addition, as previously discussed, timely information provision is associated with reduced anxiety and depression, and improved HRQOL (Husson et al., 2011).

Although the relationship between information provision, positive survivor outcomes, and improved QOL are well documented in literature, few studies have been conducted with HNC populations to directly evaluate effects of information based interventions. In one important study conducted in Montreal by D'Souza et al. (2013), a non-randomised, controlled study was designed to evaluate the effect of a patient tailored HNC information intervention on depression and anxiety scores at 2 time points. The multi-media based intervention was administered shortly after diagnosis to the test group while control participants received the usual HNC information mostly administered by healthcare practitioners (D'Souza et al., 2013). The authors found that test group participants had significantly less anxiety than the control group at both time periods. Although the study was non-randomized and only had 103 participants, thereby compromising

the validity of the results, it nevertheless provides preliminary results suggesting potential benefits of individually tailored information services.

Modes of Information Delivery

Only one study was identified that specifically evaluated the sources of information used by HNC survivors. Dall'Armi, Forstner, Simpson, and Simpson (2009) found that HNC survivors used written information, other cancer patients, the internet, and family and friends most frequently to gather information about their cancer. The authors stressed the importance of guiding HNC survivors to good quality internet-based information and including family and friends in patient education (Dall'Armi, Forstner, Simpson, & Simpson, 2009).

A broader search of the literature on cancer patients made it possible to better understand trends in information-seeking behaviours. It is well documented that the majority of cancer patients utilize sources other than healthcare professionals when seeking information about cancer treatment and recovery (Walsh et al., 2010).

In the previously discussed literature review by Rutten et al. (2005), the authors found that between 1980 and 2003, information sources most utilized by patients in the post-treatment phase of cancer recovery included: health professionals (40.6%); printed materials (21.9%); interpersonal including support groups (25%); and media, including internet (15.6%). Because the data included more than 20 years of research, reported sources of information may not be as representative of current information seeking behaviours. The accelerating popularity of the internet as a source of information suggests that current cancer populations may rely more heavily on this source.

In a more recent study conducted in the United States by Walsh et al. (2010) data were gathered as part of the Assessment of Cancer Care and Satisfaction study between 2006 and

2007, the authors found that 69% of participants obtained information from a source other than healthcare practitioners, and that 31.9% of participants reported using the internet to obtain cancer related information. They also reported that 93.5% obtained information from healthcare practitioners, 41.2% from family members, and 30.1% from books. Finally, the authors found that younger age, more education, and higher income were all positively associated with using the internet to influence treatment decisions (Walsh et al., 2010). Although data were analyzed from more than 1,800 participants, only survivors of breast, colorectal, lung, and prostate cancer were invited to participate in the study. Thus, results may not be representative of HNC survivor experiences.

Rogers, Rozek, Aleyaasin, Promod, and Lowe (2012) explored the way that HNC survivors use the internet. The authors surveyed 482 HNC survivors in the North West of England on internet use and access, and other sources of HNC information. Access to internet increased from 32% in 2006 to 54% in 2010. Increased access to and use of internet was associated with younger age (especially under 55 years of age, 83% increased access and 50% higher use), higher education (i.e., leaving school after 18 years of age), and male gender. Main sources of information for survivors under 55 included: leaflets (55%), patient's own use of internet (51%), any use of internet (60%) and healthcare professionals (35%). Rogers et al. (2012) also found that survivors who already used the internet in relation to their HNC used it primarily to get information on HNC (45%), learn about treatment or side-effects (38%), and renew prescriptions (19%). In the future, participants said they would like to also use the internet to contact doctors (44%), and get advice from other health care professionals (47%).

Such trends in internet use in England suggest that younger HNC survivors in Canada may also currently rely more heavily on the internet as a source of information than previously

reported by Rutten et al. (2005) and Walsh et al. (2010). The quality of this observational study was very good. More than half of survivors were diagnosed after 2007, indicating that results are likely representative of current internet use trends. Sample size was sufficiently large. Two potential limitations included a lack of testing of the survey instrument used (although it was primarily based on a previously validated survey), and a lack of reporting of funding sources. If funding was provided by an agency strongly promoting e-Health, a potential bias could be introduced.

Head and neck cancer information on the internet.

Although it appears that the internet is quickly becoming a more common source of information for HNC survivors, the vast majority of information found on the internet (by searching in a search engine) is of poor quality. López-Jornet and Camacho-Alonso (2009) evaluated websites generated by the Google and Yahoo search engines using the search term “oral cancer.” The first 100 sites were screened using the following inclusion criteria: sites that were in English, operational, relevant to oral cancer, and not abstracts of journal articles. The authors found that only two of the websites found in Google met criteria of reliable information according to JAMA benchmarks. No websites had a full score on the DISCERN tool, and 72.5% of websites reviewed had serious deficiencies. Similar results were seen for the Yahoo search engine (Lopez-Jornet & Camacho-Alonso, 2009). The authors concluded that the quality of many websites found through search engines is questionable. They suggested that HNC clients should be guided by healthcare practitioners towards appropriate websites, and reliable information online. This suggestion could be integrated into a feature of an information support service. For survivors seeking information other than what is offered in the service, a list of reliable websites and resources could be provided to guide their independent reading.

It is important to note that although information was evaluated against three separate tools (HON, JAMA, and DISCERN), one researcher evaluated all the websites. There is a possibility that results could be biased as there was no second reviewer of information.

Electronic Information Support Programs for Cancer Survivors

The idea to create an electronic information support system for cancer survivors is not new. Two good quality studies were found which evaluated the implementation of electronic support systems for cancer patients. The first was implemented by van den Brink and colleagues (2005) in The Netherlands between 2000 and 2002. The research team designed an information support system for HNC patients and their health care providers. The system was designed to facilitate communication between multidisciplinary health care providers, and between health care providers and patients; provide information to health care providers and patients; facilitated contact with fellow HNC patients; and facilitated the early detection of recovery problems by means of monitoring assessment questionnaires (van den Brink et al., 2005).

Van den Brink et al. (2005) evaluated the frequency of use of the system and the number of times a complication was detected and early intervention ensued. Thirty-six patients participated in the study. All 36 patients, most three to four times a week, and 17 physicians and 8 other various interdisciplinary staff used the system to communicate. In 17 cases of interaction, an extra appointment was made for the patient as a result of the monitoring questionnaires and in 8 of these cases, the head and neck surgeon considered it necessary to undertake direct further action, including antibiotics for a wound infection, and insertion of a nasogastric feeding tube. Comments from patients regarding the system were overwhelmingly positive with the majority of negative comments being related to technical difficulties.

This relatively old intervention is surprisingly ahead of Canadian informatics integration. The authors comment that physicians in The Netherlands were at that point quite used to integrating information and communication technology (ICT) into patient care. Patients participating in the intervention were relatively inexperienced users, 56% had no previous computer experience. Despite the lack of experience with computers, all patients actively used the system, and rated it positively with an average of 8/10. This may indicate that a similar intervention, especially geared toward younger HNC survivors, may have similar positive acceptance. By conducting the study described in this thesis, we hoped to have the information needed to develop interventions that were responsive to survivor needs and preferences.

A smaller scale support system was implemented in Montreal by Attack, Luke, and Chien (2008). Usability testing was conducted with an individualized patient information support website, where healthcare providers could “prescribe” information for their patient. In addition to prescribed information, participants could browse through the library of available information in the database. The website was also equipped with an in-built map of community resources where patients chose what resources they were interested in (for example, support groups, or medical supply stores) and typed in their postal code. They were then provided with a list of resources closest to their home, generated by the system. Eight chronically ill patients participated in this study, two of whom had HNC. Overall satisfaction with the system was high, with an average of 86.5 % satisfaction. Some aspects of the system received even higher scores; “usability” was rated at 92.8% (Attack, Luke, & Chien, 2008).

Although this was a small scale study, the results indicate that some electronic information support initiatives are beginning to be implemented in Canada. Multi-center collaboration could help conserve limited healthcare resources, and a pre-designed template

developed in Montreal could be modified to fit the needs of multiple chronically ill populations. In addition, the study showed preliminary results of the largely positive reception of ICT initiatives for chronically ill patients in Canada, including HNC survivors.

Features of Electronic Information Support Programs

In their discussion paper on supporting cancer patients in an age of social-networking, Bender, O'Grady, and Jadad (2008) offered a few more suggestions. They explained that Computer-Mediated Communication (CMC) is a series of applications that have been used for many years to facilitate the exchange of information before, during, and after cancer treatment (Bender, O'Grady, & Jadad, 2008). CMC includes e-mail communication, asynchronous discussion forums (also known as message boards or bulletins), and synchronous discussions (also known as chat-rooms). Such CMC strategies with healthcare providers can help capture early complications, as identified by van den Brink et al. (2005) in their study. In addition, they can help cancer survivors achieve better survival outcomes. Online support groups have been shown to reduce depression, stress, and contribute to better emotional well-being and social support (Bender et al., 2008). Although research has indicated the many benefits of such technologies, it is important for healthcare providers to assess the receptiveness of their cancer population to such technological initiatives, once again reinforcing the importance of the present study.

Literature Synthesis and Gaps in Knowledge

The population characteristics of people with HNC are undergoing a dramatic change. Incidence rates of all HNCs are decreasing steadily, however HPV-associated cancers, namely oropharyngeal squamous cell carcinomas, have steadily risen in the past decade (Johnson-Obaseki et al., 2012). Age at diagnosis for oropharyngeal cancer is decreasing, and survival is

increasing, resulting in prolonged survivorship and shorter productive work years (Johnson-Obaseki et al., 2012). Improved survivorship results in increasing numbers of high-needs populations who continue to experience physiological concerns and psychosocial distress up to six years post-treatment (Deboer et al., 1995). Consequently, information needs remain high in the post-treatment period (Rutten et al., 2005). Furthermore, younger HNC survivors may have different information needs than other cancer patients in the post-treatment period. For example, survivors who are of working age sometimes experience reduced incomes, strained relationships with family, and financial instability, and consequently want more information on welfare and social security benefits (Semple et al., 2008). Younger HNC clients are also more likely to have HPV-associated tumors, and may need information on HPV transmission, re-establishing healthy relationships with spouses, and family rearing (Gold, 2012). Such differences were further explored in this study, in order to ensure appropriateness of information content provided by healthcare providers to this population.

Limited literature is available on post-treatment needs of HNC survivors, as most researchers ask participants to recall information needed during the diagnosis and treatment phases (Rutten et al., 2005). Furthermore, no literature exists which specifically examines younger HNC survivors' information needs in the post-treatment period, making it difficult to gauge whether service and information provision post-treatment is adequate for this new patient population. Social support, adequate and timely information provision, and contact with fellow survivors have been found to all positively affect survivor outcomes including decreased anxiety, depression, and improved quality QOL (Deboer et al., 1995; Husson et al., 2011; Llewellyn, McGurk, & Weinman, 2006; Semple et al., 2008). Mode of delivery preferences for such support have evolved over time and now HNC patients, those younger in particular, increasingly rely on

the internet as a primary source of information (Rogers et al., 2012). Healthcare providers and fellow survivors are two other important sources of information; HNC survivors already using the internet want to use this medium to access advice from healthcare providers and other HNC survivors, thereby forecasting an increased use of electronic health services (Rogers et al., 2012). Several successful electronic information support systems have already been trialed with cancer patients with overwhelmingly positive results (Atack et al., 2008; van den Brink et al., 2005). Features such as electronic monitoring questionnaires, discussion boards, chat rooms, and local resource maps could help both cancer survivors and healthcare providers to identify early complications, and promote social support and emotional well-being (Bender et al., 2008; van den Brink et al., 2005). The majority of good research on HNC populations has emerged from Europe, Scandinavia, and the United States. Although healthcare structure in some of these regions is similar to Canada, findings may not necessarily be transferrable to the Canadian context. This further reinforces the need to carry out more research of HNC survivor experiences within the Canadian context.

Concluding Remarks

Based on the literature included in this review, I think it is important to learn more about the potential implications of HPV-associated cancer in relation to population characteristics, information needs, and preferences of HNC survivors. This study was designed to fill the portion of this gaps pertaining to younger HNC survivors, with a specific emphasis on post-treatment information needs, and Canadian survivor preferences for information provision.

Chapter III: Methods

Design

In this study I used a simple random sampling survey design. Data were collected using a self-administered questionnaire that participants either completed on paper and returned by mail or completed on the internet.

Purpose and Research Questions

The purpose of this study was to discover the type of information HNC survivors considered most important during recovery, the modes of information delivery used most frequently by HNC survivors during recovery, and the modes of information delivery found most helpful. The specific research questions were:

- a. What types of information are considered most important for younger HNC survivors to receive after they have completed treatment for HNC?
- b. What modes of information delivery are most frequently used by younger HNC survivors to obtain information about HNC recovery after they have completed treatment for HNC?
- c. What modes of information delivery are considered most helpful by younger HNC survivors after they have completed treatment for HNC?
- d. What kind of features/functions would an ideal information support service include?

Among younger HNC survivors who have completed treatment for HNC:

- e. Are age, sex, time since treatment completion, and years of education associated with the types of information considered most important?

- f. Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery used?
- g. Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery considered most helpful?

Population

The target population of interest included younger individuals with HNC who: were between 18 and 65 years of age at the time of diagnosis, were diagnosed with squamous cell carcinomas (SCC) of the oral cavity or oropharynx, had no history or recurrent or metastatic disease, completed treatment in the last 5 years, resided in Alberta, and were able to read and write in English. This population likely included a significant proportion of HPV-associated HNC survivors, but this could not be confirmed as initial HPV status testing protocols were not in place until part way through this study. This study is a total population study, and therefore aimed to survey all individuals who meet the inclusion criteria, estimated to be 550 individuals.

Inclusion and exclusion criteria.

I chose less than or equal to 65 years of age at time of diagnosis as an inclusion criterion because literature indicates that the average age of HPV-positive HNC survivors is 61 (Chaturvedi, Engels, Anderson, & Gillison, 2008). In addition, as previously discussed, those below the normal age of retirement generally have a set of unique needs due to having younger families, and having higher chances of being employed and subsequently losing income as a result of cancer and its treatment (Vartanian, Carvalho, Toyota, Kowalski, & Kowalski, 2006).

I chose to include survivors who completed treatment 1 month to 5 years prior to data collection. I excluded participants who had completed treatment in the past several weeks because I thought they were likely still adjusting to daily life, and still experiencing significant

acute symptoms. In Alberta, patients are followed for at least the first 5 years after completion of treatment to assess recurrence; therefore, patient records and addresses dating back at least 5 years were readily accessible. Also, Deboer et al. (1995) found that HNC survivors experienced significant physical and psychosocial problems up to 6 years post-treatment, indicating that information needs may continue to exist up to 6 years post-treatment. I limited HNC survivors to those diagnosed with SCC of the oral cavity or oropharynx as these types of cancers were most consistently associated with HPV (Chaturvedi et al., 2008).

I chose to exclude those survivors who developed metastatic disease or a recurrence of HNC, as the treatment goals for these patients typically shifted from cure/survival to palliation, and hence this population would have different information needs from the general HNC survivor populations.

Target population size.

The purpose of this study was to understand the aforementioned information types and information provision preferences of younger HNC survivors residing in northern Alberta. As the target population was the same as the study population, no sampling method was needed in this study. Using information from the Alberta Cancer Registry, I estimated that the population would include 550 eligible participants. The demographic features of the total population of HNC patients were available through the Alberta cancer registry and so it was possible to determine whether those who volunteered to participate in this study were statistically different from the total population. To access the total population, we utilized Alberta Cancer Registry data to target participants who met the inclusion criteria. We manually recruited those diagnosed in 2013 through the Cross Cancer Institute as they had not yet been added to the registry. With the exception of those who had no permanent address, or those who changed addresses since the

last recorded address in the Alberta Cancer Registry, all eligible members of the population were contacted to participate in the study.

Based on the total population size, sample population was calculated. A sample of 206 patients collected provides a margin of error of 5.28%, meaning that the study is 95% sure that the true percentage is between 44.72% and 55.28%.

Data Collection

Data were collected using a self-administered mail-in questionnaires, or alternatively with an internet-based survey option. Mail-in questionnaires are the most inclusive method of data collection for this population, and therefore were the primary method of data collection. Mixed-mode surveys combine two modes of data collection, such as mail-in and internet-based, and are typically used to improve response rates, thereby reducing non-response bias, and to reduce respondent burden (Link, 2008). According to the Nurse Practitioner working with the target population, internet correspondence was a frequently used method of communication for many HNC survivors (Schmidt, personal communication, April 3, 2012), and hence was offered as an alternative to the mail-in questionnaire. The internet-based questionnaire was designed on Google Forms and imbedded into a password protected study website. The format of the internet-based survey and mail-in survey remained the same to avoid bias. In contrast to interviews, self-administered surveys are not susceptible to changes in interviewer emphasis from one survey to another, allow for greater privacy of responses; they also allow respondents to fill in responses at their own pace, and more feasibly cover a large geographical area (Link, 2008; Wood & Ross-Kerr, 2011). This method of data collection was selected because HNC survivors often experience a variety of physiological symptoms including fatigue, altered voice and speech quality, mouth dryness, excessive phlegm, and facial disfigurement up to six years

post-treatment (Deboer et al., 1995) that may make it more difficult for them to participate in an interview.

Questionnaire.

The questionnaire consisted of 4 demographic items (age, sex, years of education, and time since completion of treatment), a pre-validated measurement tool, the HaNiQ, two pre-tested sections on modes of information delivery, and 4 open ended information provision preference questions. Enough literature existed to identify an existing instrument to measure information needs and compose questions that effectively measured preferences for modes of information delivery.

The HaNiQ was developed by Dall'Armi and colleagues (2009) and has good internal consistency and reliability (Cronbach's alpha = 0.95), and has been tested multiple times with HNC populations (Dall'Armi et al., 2013). It contains 33 items, grouped into five domains: disease profile, treatment, side effects, psychosocial, and survivorship. Respondents rate the importance of accessing information on each of the 33 items on a four point scale (1=very important to 4=not important) (Dall'Armi et al., 2013). An example of a question is "How important is it for you to get information on: Dental check-ups and care?" or "How important is it for you to get information on how family and close friends will be affected by the disease?" The scores for each domain can be calculated in two ways. The method primarily used to answer the descriptive questions of this study was to calculate the percentage of items endorsed as "very important," and then calculate the average percentages for the 5 domains. The secondary questions were answered by using the second scoring method, adding up the total scores for each item and domain where "Not Important" = 1, "A little important" = 2, "Important" = 3, and "Very Important" =4. The higher the score for each item/domain, the higher importance

respondents placed on the item/domain. An open ended question was included at the end of the HaNiQ to ask for any information needs participants deemed to be important but were not addressed in the tool.

The mode of information delivery questions asked participants to rate on a 4 point scale (4=often, 3=sometimes, 2=rarely, 1=never) how often they accessed information about recovery from each of 10 sources; and how helpful each of these sources were on a five point scale (5=very helpful, 4=helpful, 3=a little helpful, 2=not helpful, 1= did not use). There were also two open ended questions and one “yes or no” question. These questions were used to assess where participants planned to obtain information in the future, whether an internet-based information resource would be helpful to their recovery, and why it would be helpful or not. For example, “What sources of information would you like to use in the future, in addition to those you already use?” The final two questions instructed participants to select what kind of functions an ideal internet-based information resource would include. A pre-determined list of possible functions was provided for participants to check off. Features from systems designed by van den Brink et al. (2005) and Attack, Luke, and Chien (2008) were incorporated into the list of functions.

The questionnaire was pre-tested for clarity and understanding. Because the study population is already very small, the pre-test was conducted with five colleagues, who were asked to review the questionnaire content and make written suggestions to improve clarity and understanding.

Protocol

Following approval by the Health Research Ethics Board at the University of Alberta, and the Operational Approval for Alberta Health Services, the project description and a research

agreement was sent to the Planning and Priorities committee at the Alberta Cancer Registry for approval. Upon approval, the Alberta Cancer Registry sent the number of eligible participants to me so that the appropriate number of survey packages could be prepared. These packages included an information and consent letter, questionnaire, and a pre-stamped, pre-addressed return envelope (the contents and purposes of each item in the package are explored in the next paragraph). Including a pre-addressed, pre-stamped return envelope reduces respondent burden and can therefore improve response rates (Dillman, 2011). Each consent letter, questionnaire, and envelope was labelled with a unique identifier number to keep track of surveys returned, identify addresses needing reminders, and check for data completion during data entry (Fowler, 2009). The first question of the internet-based version of the survey instructed participants to enter their unique identifier number found on the information letter. The primary investigator then gave the prepared packages to a representative from the Alberta Cancer Registry who chose a clerical staff member to address and mail the envelopes to each eligible participant on the composed list. The unique identifier of each envelope corresponding to the addressed name was noted on the list of potential participants kept by the Alberta Cancer Registry staff person. In this way, the primary investigator had no access to names of potential participants, only those who returned a signed consent form and survey, ensuring confidentiality of participants who declined to participate.

HNC patients diagnosed in 2013 were not yet inputted in the Alberta Cancer Registry system so recruitment of these participants was done manually. A research assistant was hired to review charts at the Cross Cancer Institute. Patients diagnosed in 2013 who met the inclusion criteria were sent the same packages sent to participants recruited from the Alberta Cancer Registry. The research assistant performed a similar job as the Alberta Cancer Registry

representative so that the primary investigator did not have access to names of patients who declined to participate.

All correspondence including letters, envelopes, and address labels utilized official University of Alberta stationary, to signal importance and legitimacy of the study (Millar & Dillman, 2011). The information letter contained information about the study including: aims of the study, information about the primary investigator, the benefits of participation, information on the purpose of tracking number, and how confidentiality and security of responses would be maintained. Consent for this study was implied. Several statements throughout the information letter stated that by completing the survey the participant is consenting to take part in the study. The letter also contained a password for an online survey if the respondent felt more comfortable filling out a internet-based version of the survey. Providing two compatible modes of administration, such as mail and internet-based surveys (both visual modes) can improve response rates while maintaining reliability of instrument measures (Borkan, 2010; Dillman, 2011). Those choosing to complete the internet-based questionnaire were asked to provide consent by answering a consent question in the beginning of the survey. Upon completion of the mail-in survey, participants were instructed to mail the survey in the pre-addressed envelope with pre-paid postage. The packaged mailed back did not include the participant names, as participants were identified by numbers.

Survey responders were initially given three months to respond. Surveys arrived directly to the Alberta Cancer Registry Office who passed completed surveys to me. The representative from the Alberta Cancer Registry sent one reminder letter to the remaining participants in which the benefits of participation were highlighted. Participants were allowed a further 4 months to return the completed surveys. In total, data collection took place over seven months.

Rigor

Rigor in this study was addressed by utilising a validated and reliable survey instrument, as well as consciously attempting to reduce bias throughout the study design. For example, the format for both pen-and-paper and electronic questionnaires was strictly maintained to reduce delivery method bias. All appropriate communication maintained a grade eight reading level to reduce non-response bias related to lower educational achievements. Although attempts such as these were made throughout the study, a proportion of unavoidable non response bias likely remained due to the nature of the population, data collection method, and feasibility of the study.

Data Storage and Preparation

Completed paper surveys were stored in a locked filing cabinet. Only members of my supervisory committee and I had access to this filing cabinet. Completed internet-based survey responses were stored in a password protected Gmail account. Once data collection was completed, a codebook was constructed to facilitate data entry. Close-ended survey items had a predetermined code, and open-ended questions were analyzed for themes, and coded quantitatively. I manually entered raw data into a password protected SPSS file. All electronic data were entered under a unique patient identifier number; no names were present anywhere other than the master list of names and numbers at the Alberta Cancer Registry. Data verification occurred by randomly checking data from 20% of cases with copies of completed surveys. Data cleaning was achieved by analyzing data for errors such as extreme values, and removing duplicate survey entries and code errors.

Data Analysis

After data entry and cleaning, statistical tests were performed to determine differences between responders and non-responders on key demographic variables such as age and gender.

As select demographic data (such as age and sex) was available in our original list of participants, such a comparison could be made. A percent of missing values was included for each item in descriptive statistics tables. A Cronbach's alpha was calculated for the HaNiQ scale in this population. Frequencies and percentages were reported for categorical variables; mean and standard deviation (SD) were presented for continuous variables. Descriptive statistics were primarily reported for demographic characteristics of the sample, information needs domains, items, and preferred methods of information delivery. Descriptive statistics for demographic variables were displayed in tables. Results were displayed in histograms; this analysis provided information to answer the primary research questions.

The secondary research questions were answered by using standard multiple linear regressions and ordered logistic regressions to test relationships between the aforementioned variables. There were three dependent variables: types of information considered most important, measured by the HaNiQ domains: disease profile, treatment, side effects, psychosocial, and survivorship; mode of information delivery used most often; and mode of information delivery considered most helpful. Independent variables included age, sex, time since completing treatment, and years of education. The parameter estimates and the corresponding 95% confidence interval were reported. A p-value <0.05 was used for all statistical significance. SPSS version 15 was used to conduct all the statistical analysis.

Ethical Implications

There are three general ethical issues in survey research: informing respondents, protecting respondents, and benefits to respondents (Fowler, 2009). As guided by Fowler (2009), I informed respondents by providing an initial information letter with the survey: the letter included the name of the organization and investigator carrying out the research; a brief

description of the aims and purpose of the study being conducted; a description of how data would be handled and how confidentiality would be maintained; an assurance that cooperation was voluntary and that no negative consequences would result if an individual choose not to participate; and the assurance that respondents can skip any question they did not feel comfortable answering. Consent was implied. The information letter contained several repeated statements which stressed that by proceeding to fill out the survey, the participant was consenting to participation in the study, and consenting to having their survey responses used for the purpose of the study. As previously discussed, respondents were told that their information would be securely stored and that confidentiality and anonymity would be maintained. Although unlikely, it was still possible that some questions would be uncomfortable for participants to answer. The information letter contained a statement specifying that any question the participant did not feel comfortable answering could be skipped. In the event that participants experienced any feelings of distress due to recalling their recovery experience, they were instructed to contact the Psychosocial and Spiritual Resources Program at the Cross Cancer Institute. The number for this service was provided in the information letter.

No incentive was offered for filling out questionnaires. However, participants were advised that one of the aims of this research was to gather assessment data for the eventual design of a support intervention. Finally, it is important to recognize that due to the changing protocols of HPV status disclosure in the past several years, some patient may not have been aware of the association of HPV with HNC, or their own HPV status. For this reason inclusion and exclusion criteria were used to attempt to capture a sample most consistent with HPV-positivity, and direct questions about HPV status were not used within the questionnaire to avoid undue distress.

Chapter IV: Results

Using the Alberta Cancer Registry, I found 545 potential participants who met the eligibility criteria. The first mail out occurred on March 29th, April 2nd and April 8th, 2014. A total of 173 completed surveys were returned: 86% mailed back, and 14% completed online. Reminder letters were sent to the 372 remaining cancer survivors on May 23, 2014. A further 33 completed surveys were returned: 91% mailed back, and 9% completed online. Of the 545 surveys sent, 29 did not reach the potential participant due to wrong address, 2 were deceased, and 3 were ineligible, resulting in 511 potential participants. Of these, 3% declined to participate (n=16) and 57% did not respond (n=289). A total of 206 (response rate of 40%) participant surveys were analyzed for this study.

Population

The sample was predominantly male (male n=174, 85%), and the average age was 58 years (SD=6.5, range 35-71). Participants had an average education of 14 years (SD=2.6), and completed treatment an average of 28 months prior to the study (SD=17.9, range 2-61).

Eighty percent of the non-respondents were male (n=271). There was a significant difference in age between female respondents (F=57, SD=6.5) and non-respondents (F=52, SD=8.74; $t(75.7)=-3.05$, $p=0.0032$, two-tailed). The magnitude of the difference in the mean ages for females (mean difference = 5.01, 95% CI: -8.2 to -1.8) was moderate (eta squared=0.1). There was a significant difference in age between male respondents as well (M=58.6, SD=6.5) and non-respondents (M=53.2, SD=7.8; $t(399.4)=-7.6$, $p=0$, two-tailed). The magnitude of the difference in the mean ages for males (mean difference = 5.4, 95% CI: -6.8 to -4.0) was

moderate ($\eta^2=0.12$). Non-respondents were on average 5 years younger than respondents.

Instrument

Data were collected using the HaNiQ. The 33 information items of the HaNiQ were grouped into five domains: disease profile (four items), treatment (eight items), side effects (eight items), psychosocial (nine items) and survivorship (four items). The Cronbach's alpha for survey items in all domains was 0.92. Cronbach's alpha within items of each domain varied as follows: disease profile 0.88, treatment 0.95, side effects 0.90, psychosocial 0.93, and survivorships 0.68.

Research Question One

The first research question was, "what types of information are considered most important for younger HNC survivors to receive after they have completed treatment for HNC?" This question was answered by examining the needs domain of the HaNiQ (see Figure 1). To answer this research question, I chose to first display the mean proportion of respondents who classified each item in this domain as "very important." To derive this figure I added up all the proportions of respondents who classified each item as "very important" in each domain and divided the sum by the number of items in each domain. This helped visualize the information needs respondents considered most important. Predictably, the "survivorship" items were deemed to be most important. However, the "disease profile," "treatment," and "side effect" domains were also important to respondents. The "psychosocial" domain was considered least important

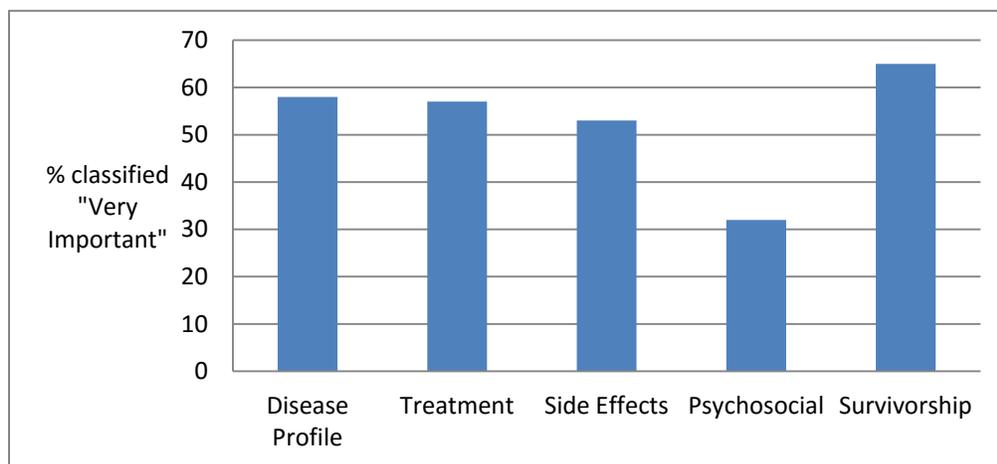


Figure 1: Information Importance Post-Treatment for HNC.

Figure 2 displays item by item frequencies of the participant HaNiQ responses sorted by highest proportion of “very important.” The items rated as overwhelmingly most important include “signs of a recurrence or how to tell if the disease has come back” and “the chances of being cured of the disease. “Staying well after treatment” was considered to be “very important” less often, however 95% of respondents classified this item as “very important or “important.” The items perceived to be least important included “how the treatment may affect my feelings about my body, physical appearance, and sexual attractiveness,” and “support groups or other supports services available for myself and my carer.”

An open ended question was posted after the HaNiQ instrument to capture any additional information respondents felt was important but not included in the content of the HaNiQ items. A total of 71 respondents provided further information topics. Table 1 displays these information topics and the frequency with which they were mentioned by respondents (n=71). These responses were grouped into four overarching themes including “Recovery and Quality of Life,” “Treatment”, “Health System”, and “Additional Supports.” Some topics discussed by respondents were similar to HaNiQ instrument items and thus were not included in this table. It

is interesting to note, however, that financial support was repeatedly discussed by respondents despite already being covered by a HaNiQ item.

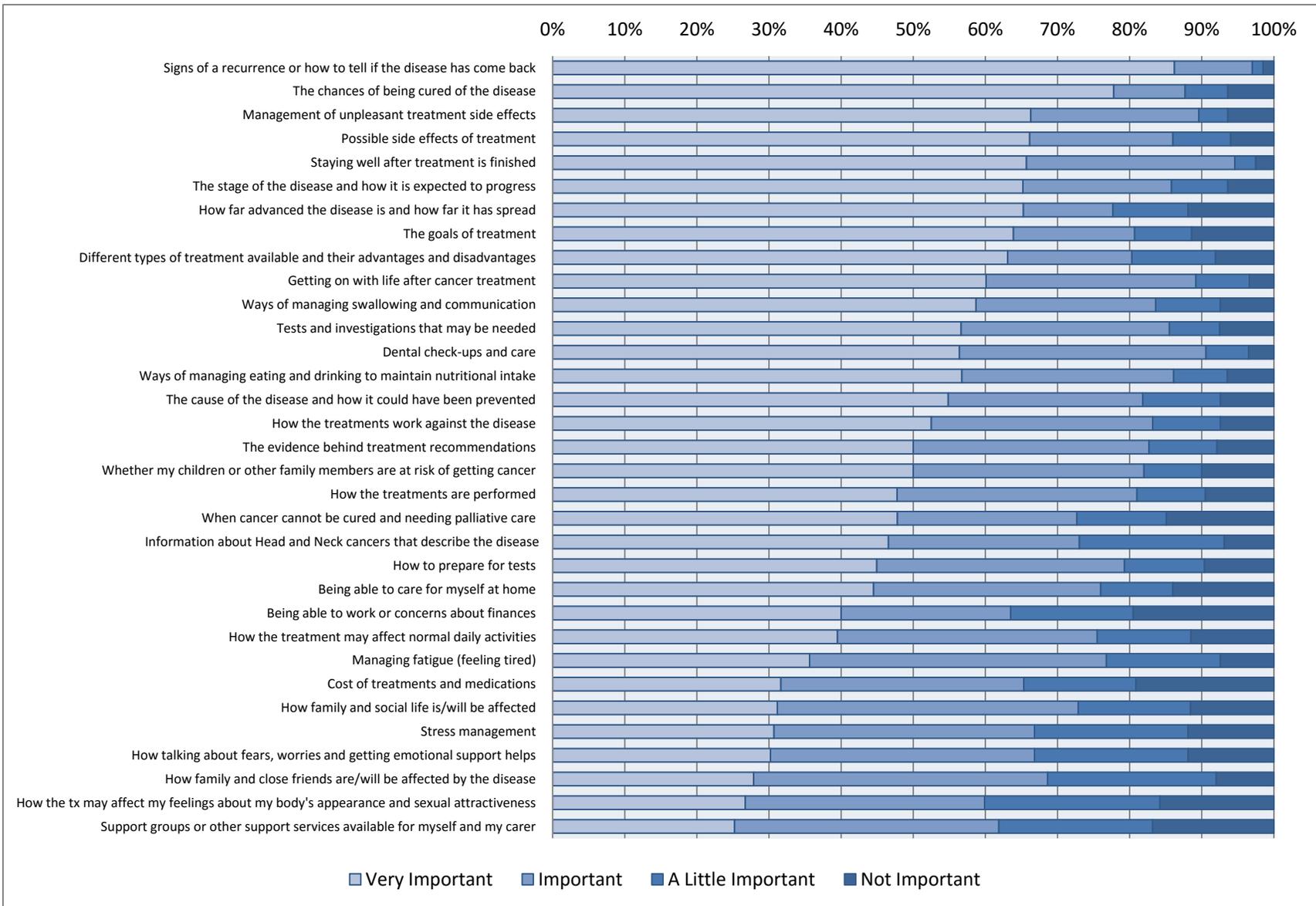


Figure 2: Information considered most important for younger HNC survivors after completion of treatment

Table 1

Additional Information Needs Identified by HNC Survivors

Recovery and Quality of Life	35.2%
Information on rehabilitation after treatment, including the importance of physical exercise, and daily exercises to improve recovery	10%
Treatment and recovery timeframes	8.5%
Maintaining own quality of life including managing permanent side-effects to maintain quality of life	8.5%
Cooking/tasting food appropriate to swallowing and recovery	4%
Social eating skills/ nutrition while traveling	1.4%
HPV positive cancers, how to prevent oneself from spreading/having a recurrent HPV + cancer	1.4%
How to minimize chances of recurrence	1.4%
Treatment	13%
Minimizing damage to body as a result of treatment	3%
Salivary gland restoration/transplant	3%
Alternative treatments including clinical trials	1.4%
Details about less common side effects such as memory loss, chronic fatigues, sleep apnea etc.	1.4%
Hyperbaric oxygen therapy information	1.4%
Options to battle same cancer a second time	1.4%
The need to remove metal fillings prior to radiation	1.4%
Health System	12.4%
Managing wait times for initial and subsequent surgery/treatment/follow-up	7%
Navigating the system e.g. setting up appointments, and, filling out paperwork	4%
Roles and responsibilities of all HCPs involved	1.4%
Additional Support	8.4%
Where more and/or new information can be found after treatment e.g. websites, or newsletters	4%
Spouse support	3%
Getting to and from treatments/follow-ups	1.4%

Research Question Two

The second research question was, “What modes of information delivery are most frequently used by younger HNC survivors to obtain information about HNC recovery after they have completed treatment for HNC?” This question was answered by examining the Information Source Use items in the survey, displayed in Figure 3. Health care professionals were the most utilized information resource. Family and friends, Internet, and written materials made up the rest of the most frequently utilized resources. An additional question asked respondents to indicate what kind of information resources they would like to use more in the future. Table 2 summarizes future use of information sources (n=77), as well as frequencies of each source mentioned.

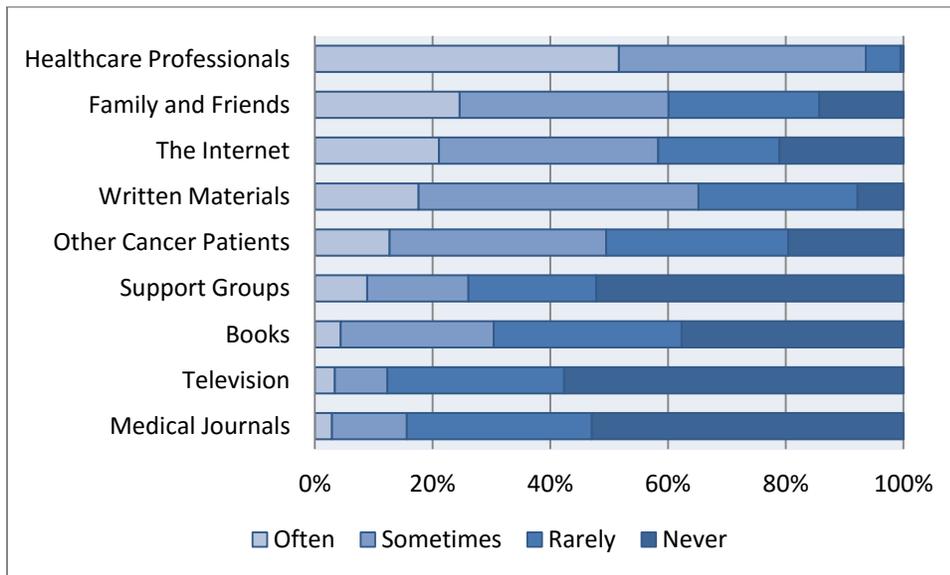


Figure 3: Frequency of information source use

Table 2

Sources of Information HNC Survivors Would Like to Use More in the Future

Internet (Including websites, internet support groups/forums, internet access to own medical records, and e-mail)	40%
Healthcare Practitioners	18%
Support Groups	16%
Other Cancer Patients	10%
Written Materials	8%
Medical Journals	6%
Cancer Center Resources	5%
Books	4%
Videos/You Tube	3%
Faith Based Resources	1%
Family or Friends	1%
Telehealth	1%

Research Question Three

The third research question was, “What modes of information delivery are considered most helpful by younger HNC survivors after they have completed treatment for HNC?” Figure 4 displays the results of the information source helpfulness portion of the survey. Survey respondents considered health care professionals as well as family and friends most helpful sources of information during their recovery. Although the internet, other cancer patients, and support groups were less often used by participants, about half of those who used these resources considered them helpful or very helpful. The rest largely found these sources a little helpful, with a small percentage finding them not helpful.

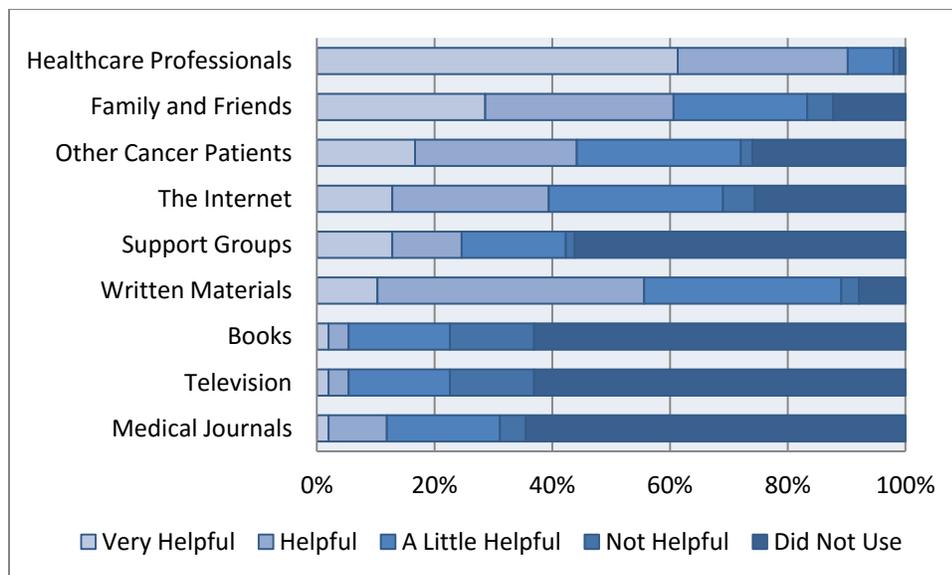


Figure 4: Information Source Helpfulness

One goal of the study was to better understand whether an internet resource would be considered as useful to HNC survivors during recovery. For this reason the question “Would you find an internet-based information resource useful during recovery?” was included in the survey. Of those who answered the question, 81.3% (n=157) answered “Yes.” Logistic regression was conducted to assess the ability of four factors (age, sex, education, and time since treatment completion) to predict the likelihood of finding an internet-based information resource useful (yes/no). The full model was not statistically significant, $\chi^2(5, N = 191) = 7.615, p = .179$. However, individuals who had “high school or less education” found an internet-based information resource less useful than those with more education.

A follow-up question was posed to elicit the reasoning behind why the participant would find this internet-based information resource useful/not useful. Table 3 outlines the answers provided by 182 participants. The most common reasons given by those who considered such a resource useful included ease of access/convenience (n=71), resource would be reliable and

current/up to date (n=26), and resource would be informative and provide more information and varied opinions (n=24). Of those who believed the resource would not be useful most commonly preferred to obtain information in person (n=11), were not computer literate/do not use internet (n=10), or felt that such a resource would be unreliable/misleading (n=8).

Table 3

Reasons for Considering Internet-Based Resource Useful and Not Useful

Useful (n=148)	
Ease of Access/Convenience	48%
Would be current/Reliable	18%
Informative (Gives more relevant information/varied opinions)	16%
Faster to obtain answers to questions	8%
Enables connection with other cancer patients	3.3%
Confidential/Private	2.7%
Interactive	2%
Easier to Communicate (due to difficulty with speaking)	2%
Helpful when HCP not available	2%
Can direct family/friends	0.6%
Personalized	0.6%
Can use at my own pace	0.6%
Not Useful (n=34)	
Prefer to obtain information in person	32%
Not computer Literate/Do not use internet	29%
Internet is unreliable/misleading	24%
I do not have/ Cannot afford a computer	12%
Do not want to know worst case scenario/Do not want to scare self	5.5%
Previously told not to use internet	2.9%

Research Question Four

The fourth research question was, “What kind of features/functions would an ideal internet-based information resource include?” This question was answered by reviewing survey items in which respondents were asked to identify features they thought should be included in an internet-based information resource. Table 4 summarizes the frequency of each feature being chosen. The list of features included an “Other” option. Space was provided for participants to list other features they believed would be valuable for an internet-based resource to contain.

Table 5 outlines these suggestions.

Table 4

Features of an Ideal Internet-Based Information Resource

Easy to read information about my cancer and recovery	89.3%
A way to communicate with a nurse or other HCP online when I have questions	73%
Detailed research articles or article summaries about my cancer	67.6%
Meal plans appropriate to my swallowing	67.2%
Discussion board where I can ask questions and read other people’s questions and answers	63.7%
Videos showing me how to take care of my skin, tracheostomy, or feeding tube	60.3%
A list of support groups and services in my area	53.4%
A chat room where I could chat with other HNC patients	48.5%
A way to schedule all my medical appointments online	43.1%

Table 5

Other Features of an Ideal Internet-Based Information Resource

Easy to navigate	Information on Home Care
A way to view own medical records	Cancer journey inspirational stories
Research Advances	Resource links
To-do lists (to do before, during, and after treatment)	Health promotion web portal
Travel advice (international and to/from hospital)	Volunteer opportunities to work with other cancer patients
Financial resources	Dining out food choices
Childcare/Family resources	Exercise plans
Counselling	Self-help advice on psychosocial issues (Self-esteem, return to work, survivorship)
Photos of cancers	

Secondary Research Questions

I had three supplementary research questions. The first supplementary question was, “Are age, sex, time since treatment completion, and level of education associated with the types of information considered most important?” Standard multiple regression equations were developed to determine the effect of age, sex, time since completion of treatment, and education level on the importance scores of the five HaNiQ information domains (disease profile, treatment, side effects, psychosocial, and survivorship.). A separate regression analysis was conducted for each information domain. Preliminary analyses were conducted for the data in each of the five domains to ensure no violation of the assumptions of normality, linearity, and homoscedasticity, and that multicollinearity did not exist. Descriptive statistics for the independent variables are summarized in Table 6. Results of the multiple regression models are displayed in Table 7. Only statistically significant models are discussed in this and the following sections.

Table 6

Descriptive Statistics for Independent Variables

	Mean(Range)	Standard Deviation	Frequency	Proportion
Age (years)	58.34 (35-71)	6.511		
Time since treatment completion (months)	27.87(2-61)	17.9		
Sex				
Male			173	85.2%
Female			30	14.8%
Education level				
High school and Less			66	32.5%
Certificate or Some Post Secondary			86	42.4%
Bachelor's and Higher			51	25.1%

Table 7

The Effect of Age, Sex, Time since Completion of Treatment, and Education Level on the Importance Scores of Five HaNiQ Information Domains

	R square	F	β	p-value	95% Confidence Interval	
					Lower Bound	Upper Bound
Disease Profile	0.072	3.793		0.005		
Education level			-0.238	0.001	-1.695	-0.462
Treatment	0.073	3.682		0.007		
Education level			-0.202	0.005	-2.922	-0.538
Time since treatment completion			-0.146	0.039	-0.104	-0.003
Side Effects	0.055	2.740		0.030		
Education level			-0.178	0.013	-2.357	-0.277
Psychosocial	0.087	4.483		0.002		
Education level			-0.268	0.000	-3.892	-1.246
Survivorship	0.042	2.114		0.081		
Education level			-0.161	0.024	-0.900	-0.064

The models for the disease profile, treatment, side effect, psychosocial, and survivorship domain analyses explained 7.2%, 7.3%, 5.5%, 8.7% and 4.2% of the variance in each model, respectively. All models other than the survivorship model were significant. Overall, level of education was the only consistent significant independent variable. The importance of information in all domains decreased as level of education increased. Time since treatment completion was only a significant independent variable in the treatment domain, with longer times since treatment predicting lower treatment information importance scores.

The second supplementary question was, “Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery used?” Ordinal logistic

regression was used to determine if age, sex, time since completion of treatment, and education level could explain the frequency of use (never, rarely, sometimes, and often) of nine sources of information (healthcare professionals, written materials, the internet, television, medical journals, books, support groups, other cancer patients, and family and friends). Nine models were constructed, one for each source of information. None of the models were statistically significant as a whole; however some independent variables explained a statistically significant portion of the variance between responses. Table 8 displays a summary of all statistically significant independent variables for each source of information.

Table 8

Significant Independent Variables for Frequency of Use of Sources of Information

	Estimate	Std. Error	p-value	Odds Ratio	95% Confidence Interval	
					Lower Bound	Upper Bound
Healthcare Professionals						
Treatment Completion ^a	.016	0.008	0.038	1.012	0.001	0.032
Written Materials						
Male ^b	-0.933	0.382	0.014	0.393	-1.68	-1.86
Television						
High school and Less ^c	0.778	0.378	0.040	2.177	0.036	1.52
Family and Friends						
High school and Less ^d	0.675	0.342	0.048	1.964	0.005	1.34

^a Adjusted for age, sex, and level of education

^b Adjusted for age, time since treatment completion, and level of educations

^c Adjusted for age, sex, and time since treatment completion

^d Adjusted for age, sex, and time since treatment completion

Holding all other sources of information constant, I found that:

1. The use of health care professionals as an information source increased 1.012 times for every month since treatment was completed.

2. The use of written materials as an information source was 61% less common in males than females (odds ratio =0.39).
3. The use of television as an information source increased 2.2 times with education level (odds ratio =2.18).
4. The use of family and friends as an information source model increase 1.96 times with each level of education (odds ratio=1.96).

There were no statistically significant variables in any of the other models (internet, books, medical journals, support groups, or other cancer patients).

The third supplementary question was, “Are age, sex, time since treatment completion, and years of education associated with the modes of information delivery considered most helpful?” Ordinal logistic regression was used to determine if age, sex, time since completion of treatment, and education level could explain the modes of information delivery considered most helpful (healthcare professionals, written materials, the internet, television, medical journals, books, support groups, other cancer patients, and family and friends). Nine different models were examined, one for each source of information. None of the models proved to be statistically significant and none of the variables were significantly correlated with information source helpfulness for any of the information sources.

Limitations

One limitation of this study is the fact that only two variables (sex and age) were available to compare the differences between respondents and non-respondents. This means that the respondents may not have been representative of the Alberta population of HNC patients. A second limitation also stems from lack of available data for HPV tumor sample testing has only

become routine in the last several years. This made it difficult to confidently claim that the population in this study contains a significant proportion of HPV positive cancers.

Chapter V: Discussion

To date, there has been limited research in which the information needs and information provision preferences of younger HNC patients has been explored, particularly in the post-treatment phase of recovery. The aim of this study was to better understand information needs and information provision preferences of this population of cancer survivors. Numerous studies have previously demonstrated associations between appropriate cancer-related information provision and improved HRQoL and QoL (Husson, Mols, & van de Poll-Franse, 2011; Mesters, van den Borne, De Boer, & Pruyn, 2001; Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008), further underlying the importance of such research.

Importance of Information Content

Unsurprisingly, I found that younger HNC patients find survivorship information most important in the post-treatment phase of recovery. In particular, signs of a recurrence (86%), the chances of being cured of the disease (78%), and management of unpleasant treatment side effects (66%) were considered the most important topics of information. Dall'Armi et al. (2009) used the same instrument to determine information needs of HNC survivors. They found that 83% of participants rated signs of a recurrence, 87% rated chances of being cured, and 77% rated management of unpleasant side effects as very important (Dall'Armi, Forstner, Simpson, & Simpson, 2009). Although these ratings were comparable, more participants in Dall'Armi's et al. study rated more items as "very important". It is unclear how soon after completion of treatment the study was conducted, but a shorter timeframe between survey and treatment completion might explain the differences in findings.

The findings of my study were analogous to those of several other studies. Chen et al. (2009) found that 37.2% of surgically treated HNC patients had high or moderate unmet needs

“to be fully informed about cancer remission,” and 31% wanted to know more about what a person could do “to be fully informed about things you can do to help yourself get well” (Chen, Lai, Liao, Chang, & Lin, 2009). Shea-Budgell and colleagues (2014) surveyed 411 cancer survivors and found that 29% of respondents sought more information on prognosis or recovery from cancer, and 27% looked for information on prevention of cancer (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). Mistry et. al (2010) also found that 51% of cancer patients in their study wanted more information on cancer prognosis including chances of cancer returning (52%) and chances of cancer spreading (50%).

It is interesting that survivors placed such importance on chances of cure and signs of recurrence. Ghazali et al. (2013) discussed fear of recurrence as a major concern for HNC patients during recovery, which can have a negative effect on survivors’ psychological well-being. They found that 35% of HNC survivors attending clinic visits of one consultant between 2008 and 2011 consistently experienced fear of recurrence throughout the first nine months of recovery (Ghazali et al., 2013). My findings corroborate those of Ghazali and colleagues, suggesting that information on signs and chances of recurrence must be discussed with HNC survivors throughout recovery to facilitate better psychological coping and adjustment (Ghazali et al., 2013).

A less expected finding of this study was that information about the disease, treatment, and side effects of treatment were still considered important by HNC patients in the post-treatment phase. Items scored as least important were still rated as “Very Important” or “Important” by over 60% of respondents. Dall’Armi’s et al. (2009) findings once again support this conclusion, as at least 59% of respondents in their survey rated each of these domains as “very important.” Mistry et al. (2010) also found that cancer patients in the post-treatment stage

still wanted to know more information about the type, cause, and symptoms of the cancer. These findings indicate that most items on the HaNiQ survey are key pieces of information that should be included in educational resources.

Respondents felt that in addition to all the items included in the HaNiQ, Information about rehabilitation, treatment/recovery timeframes, maintenance of QoL, and managing wait times was also considered very important. Information on financial assistance was repeatedly mentioned by respondents. Llewellyn, McGurk, and Weinman (2006) compared information needs of HNC patients pre- and post-treatment. They discovered that 60% of post-treatment HNC patients were not supplied any information regarding where to go for financial assistance/support, and 50% did not receive information on how treatment may impact QoL (Llewellyn, McGurk, & Weinman, 2006). Participants in Dal'Armi's et al. (2009) study also answered an open-ended question where they could express their own views on the most important information needs. Topics mentioned included information on what to expect, recovery and recurrence, and financial support (Dall'Armi et al., 2009). No authors reported finding management of wait times as being an important information topic for HNC patients. This may be due to the unique structure of the health care system in Alberta, which is sometimes characterized by extended wait times for specialist services.

Sources of Information

Respondents used healthcare practitioners (52%) most frequently to obtain information about recovery. Family and friends (25%), the internet (21%), and written materials (18%) were the other primary sources of information. Television and medical journals were used least frequently. Rogers et al. (2012) found that over 75% of HNC survivors in their survey used a hospital doctor to learn about HNC; just under 40% of respondents used leaflets (written

information), and 13% used family/friends. The difference between my findings and those of Rogers et al. may be because Rogers' question regarding information sources asked which sources HNC survivors used, without focusing on frequency of use. If I combine sources used both "often" and "sometimes", my results are comparable to those of Rodgers et al. For example, healthcare practitioners were used "often" or "sometimes" 94% of the time in my survey, comparable to Rogers' results. Walsh et al. (2010) had similar results in their study, with 93.5% of cancer survivors obtaining information from healthcare practitioners, and 41% from family members (Walsh et al., 2010).

The internet was used "often" by 21% and "sometimes" by 37% of respondents in our study. Rogers et al. (2011) found that 25% of their HNC participants used internet "often," and 15% used it occasionally. The number of frequent users of the internet seemed to be consistent between the two studies however the number of occasional users differs significantly. Perhaps the time frame between the two data collection times, 2010 and 2014, could explain the difference. The growing popularity of the internet as well as an influx of health-related information on the internet has opened this medium to a larger proportion of cancer survivors (Crutzen et al., 2014). Shea-Budgell et al. (2014), for example, found that internet was the most popular source of information, used by 57.4% of cancer survivors in their survey. Thus, when asked what kind of sources of information HNC survivors in our study wanted to use in the future, unsurprisingly the largest number of participants (40%) wanted to use the internet more frequently.

Information Source Helpfulness

Survey respondents considered healthcare professionals as well as family and friends as the most helpful resources. Other cancer patients and the internet were used less, however were

still considered helpful or very helpful by over 40% of respondents. Overall Dall'Armi et al. (2009) also found that HNC patients in their study rated healthcare professionals as most helpful, followed by the internet and family and friends. This emphasizes the importance of a reliable information-based resource which can be used by both survivors and their support persons (Dall'Armi et al., 2009).

Over 80% of respondents thought that an internet-based information resource would be useful during recovery. Of those who considered that it would be useful, almost half attributed usefulness to ease of access and convenience. Of those who felt it would not be useful, 32% prefer to obtain information in person, 29% were not computer literate, 24% thought the internet was unreliable/misleading, and 12% did not have access to a computer/internet. These results are similar to those of Rogers et al., who found that 35% were not familiar with computers or lacked the skill to use them (Rogers, Rozek, Aleyaasin, Promod, & Lowe, 2012). An important difference between my findings and those of Rogers et al. is that they found 37% of HNC survivors had no access to a computer, only 7% distrusted information on the internet, and 2% preferred face to face contact. As Rogers' study was conducted between 2007 and 2010 and mine in 2014, access to computers and internet at home and in places of employment may have improved for society in general. The vast popularity of the internet and an immense influx of health information onto the World Wide Web have also sparked a new movement focused on the importance of identifying and using reliable sources on the internet (Kowalczyk & Draper, 2012). This could explain why a higher proportion of our respondents mistrusted information found on the internet. Finally it is difficult to say why 32% of our participants preferred receiving information face to face versus only 2% in Rogers et al. study. This difference may be attributed to differences in the methods healthcare practitioners use to deliver information, or the

user friendliness of information resources available for participants in the UK versus those in Canada. Despite the differences, the majority of respondents in our study would likely use a reliable and trustworthy internet resource which contained a variety of multimedia and communication tools to facilitate a feeling of connection between HNC survivors recovering at home and healthcare professionals or other survivors.

Features of Internet-Based Information Resource

All the features included on the list were chosen for inclusion in an internet-based information resource by at least 40% of respondents. Most consistently chosen were “easy to read information about my cancer and recovery” (89.3%) and “A way to communicate with a nurse or other HCP online when I have questions” (73%). Rogers et al. (2011) also found that HNC survivors wanted to use the use computer resources to get information about HNC (68%), get advice from nurse/dietician/speech therapist (47%), and contact doctors with questions (44%). The increase in desire to use computer resources for such purposes may, once again, be related to the wider availability of internet resources for patients in general. Respondents from our study in 2014 have likely been more exposed to the internet as an information medium than those in Rogers and colleagues’ 2010 survey (Rogers, Rozek, Aleyaasin, Promod, & Lowe, 2012).

Factors Explaining Information Importance

The results of this study indicated that higher education resulted in a decrease in importance to receive information in all domains. Chen et al. (2009) similarly found that HNC cancer patients with lower education had higher information needs. Studies conducted with a variety of cancer populations have derived comparable results (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013; Matsuyama et al., 2011; Mistry, Wilson, Priestman, Damery, &

Haque, 2010). This may be because individuals with higher levels of education are able to find the information they require on their own.

An increase in time since completion of treatment also indicated lower treatment information importance. Mistry et al. (2010) studied cancer patients in the pre-treatment and post-treatment stages and came to the same conclusion; patients who completed treatment needed less information on treatment when compared to those who were pre-treatment or currently finishing treatment (Mistry et al., 2010). In their systematic review, Rutten et al. (2005) also found that needs of information on treatment decreased from 43.8 during treatment to 35% post-treatment. Studies with other cancer populations have demonstrated that although information needs tend to decrease with time, total information needs remain high in the recovery period (Matsuyama et al., 2013); stressing the importance of information provision through all stages of recovery.

Factors Explaining Information Source Use

Health care professionals were used more frequently the more time passed since treatment completion. In their large-scale systematic review, Rutten et al. (2005) similarly found that the use of healthcare practitioners increased from 27% during diagnosis and treatment, to 40.6% post-treatment (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). This suggests that healthcare practitioners continue to play a key educational role in HNC survivor's lives well past treatment. Thus any resources developed for this population must directly or indirectly involve access to healthcare practitioners' advice.

Written information was used less commonly by males than females. The higher the education level of respondents, the more frequently they used family and friends as a source of information. This is a new finding that has not been reported by others.

Factors Explaining Information Source Helpfulness

I found that none of the independent variables (age, sex, time since treatment completion, or years of education) were associated with information source helpfulness. A qualitative study focused on this question should be conducted before further development of information sources is undertaken.

Chapter VI: Implications and Conclusion

In this chapter I will outline implications for clinical practice, education, research, and policy, and some concluding comments.

Clinical Practice

The findings of this study outline the types of information that should be provided to HNC survivors in the post-treatment phase. Existing information appears to be lacking in several major topics that are particularly important for younger HNC survivors such as: signs of recurrence and how to tell if the disease has come back, chances of being cured, and staying well after treatment is finished. Notable information not discussed in the HaNiQ that was deemed to be important by HNC survivors included rehabilitation and exercises, maintenance of QoL post-treatment, managing wait times, treatment and recovery timeframes, and HPV positive cancers. Furthermore, these findings give a comprehensive overview of the cancer-related education needs of Alberta's younger HNC population, and thus can be used to structure patient education after treatment completion and throughout recovery.

Health care practitioners are the most frequently used resource by HNC survivors in Alberta and thus comprehensive HNC information must first come from this source. In addition to being considered the most trustworthy resource, healthcare practitioners also significantly influence cancer survivors' health-related decisions (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014; Walsh et al., 2010). Consequently HNC practitioners must ensure that patient education content is congruent with HNC patient needs.

Despite being the most frequently used resource, healthcare practitioners' information is often being supplemented with internet-based resources. Over half of our participants sometimes

or often used the internet, 40% wanted to use the internet more in the future, and over 80% agreed that an internet-based resource would be useful during recovery. These findings demonstrate the increasing popularity of internet as an important source of cancer information.

Present HNC information on the internet, however, is mediocre, at best. Dall'armi et al. (2009) examined 32 existing and reputable internet resources focused on HNC. Two of the resources included were Canadian: BC Health Guide, and the Canadian Society of Otolaryngology. The existing sources covered only 50% of HaNiQ item topics, and the majority of topics were discussed in only five of the websites. Some topics were barely mentioned in three of the websites (mentioned briefly with inadequate explanation or content). These briefly mentioned topics included information about ability to work, finances, the effects of the disease on family and close friends, and the effects of the disease on social life. Several topics not brought up in any of the 32 internet resources included stress management, risk to children and other family members, and perhaps most alarmingly, signs of recurrence or how to tell whether the disease has come back (Dall'Armi, Forstner, Simpson, & Simpson, 2009).

Accordingly, healthcare practitioners should join efforts with organizations such as the Canadian Society of Otolaryngology, the Alberta Cancer Foundation, and Alberta Health Services to develop comprehensive and trustworthy internet-based resources for HNC patients. Examples of content that should be included in such resources are well outlined in this study. Such an endeavour would certainly benefit the QOL of HNC patients and survivors in Alberta.

Testing of tumor samples post-operatively to establish HPV status has only recently become routine in Alberta. Over half of the participants in this study thought it was very important to get information about the cause of their cancer and ways it could have been

prevented. Thus, in addition to testing tumor samples, discussions about the cause of HNC cancer should be held with each HNC patient as well as their families. Such a discussion could normalize the topic of HPV and potentially prompt further dialogue about safe sexual practices, and risks of HPV transmission. The discussion about HPV transmission and its relationship to past sexual practices of the patient may be difficult for patients and their intimate partners to hear, and support from the psychosocial services should be offered if this is the case.

Education

Many of the topics discussed by participants in this study involve a broad range of healthcare providers including physicians, nurses, radiation technicians, speech and language pathologists, dieticians, physical and occupational therapists, social workers and many more. Providers of educational programs for health science students and professional development programs for existing health care providers could utilize the findings of this study to demonstrate the scope of information required by recovering HNC patients. The large variety in topics could be used to help learners better understand the total disease burden on the various aspects of patients' lives. The variety of information resources used by cancer survivors in this study could be used to teach learners how to aid patients in accessing trustworthy and accurate information from many different sources.

Research

This study was intended to be the needs assessment portion of a larger project to improve information provision for HNC patients in Alberta. The results of this study could be used to structure a preliminary internet-based information resource intervention so that pilot studies could begin. A well designed internet-based information resource could foster e-loyalty

(recurrent visiting of a particular cancer website) in cancer patients and their caregivers, increasing their frequency and confidence in using the resource to make health-related decisions (Crutzen et al., 2014). In addition to having the right content, future research could also focus on strategies to improve efficiency, effectiveness, enjoyment, and active trust in the proposed internet information resource (Crutzen et al., 2014), and relationships between these factors and QOL.

Several relationships discovered in this study have not previously been explored in research. Written information was used less commonly by males than females. In addition, information source helpfulness has not previously been explored in relationship to demographic factors such as age, sex, years of education, and time since treatment completion.

Further research could also explore relationships between other independent variables and information source helpfulness as the amount of variance explained by independent variables in this study was minimal.

Dissemination Strategies

The study will be submitted to at least one professional journal. In addition, I already created a website for the study and anticipate posting a summary report of findings on the study website for survey respondents and practitioners involved with the study. The website will also be available to any practitioners serving the HNC population in Alberta, in the hope that the study findings can help improve information provision for survivors. I also plan to submit abstracts for presentation at national and international otolaryngology and oncology conferences.

Conclusion

HNC is quickly becoming one of the most common cancers in the 40 to 65 year age range. This type of cancer responds well to treatment, but the impact of this treatment on QOL

is significant. Based on the results of this study, current post-treatment education provided to patients may not address some needs unique to this age group. In addition, cancer survivors, including those with HNC, are turning to a wide variety of information sources to supplement the knowledge they receive from health care practitioners. The provision of relevant, accurate, timely, and accessible information via the internet may be useful in improving health outcomes, including QOL, for individuals treated for HNC.

The purpose of this study was to better understand the unique information needs of younger HNC survivors after treatment completion. Results indicated that although many information topics regarded as most important remained similar to those of older individuals with HNC, some unique themes such as detailed information on signs and symptoms of recurrence and chances of being cured, rehabilitation after treatment, treatment and recovery timeframes, and financial assistance emerged as being very important to the people in my study. In addition, the internet as a mode of information was identified as a useful source that is quickly gaining popularity among HNC patients. Finally, a reliable online information resource was regarded as very important by the vast majority of participants.

The information contained in this thesis can help guide clinicians provide more comprehensive education to recovering HNC patients. In addition, the results suggest that HNC patients want reliable internet-based resources where they can read information about the disease and treatment, connect with other survivors, and manage appointments and clinician advice from the comfort of their own home. In addition to meeting the needs of younger HNC patients in Alberta, such a resource could make cancer information and medical advice more accessible to people who live in rural communities, have poor support networks, and who must return to work early due to financial obligations.

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Appendix A: Survey Questionnaire

Information Needs of Individuals with Head and Neck Cancer

Please complete all fill in the blank questions as directed. Any question that asks you to choose an option can be marked with an X. E.g.

Demographic Information

1. Please write your identifier number.

Your identifier number should be three digits long and is found on the information letter you received in the mail. Ex. 642

2. I turned _____ on my last birthday.

Please write your answer in years.

3. I am a _____.

Male Female

4. It has been _____ since I finished cancer treatment.

Please select one.

- | | | |
|-----------------------------------|------------------------------------|--|
| <input type="checkbox"/> 1 month | <input type="checkbox"/> 7 months | <input type="checkbox"/> 2 years |
| <input type="checkbox"/> 2 months | <input type="checkbox"/> 8 months | <input type="checkbox"/> 3 years |
| <input type="checkbox"/> 3 months | <input type="checkbox"/> 9 months | <input type="checkbox"/> 4 years |
| <input type="checkbox"/> 4 months | <input type="checkbox"/> 10 months | <input type="checkbox"/> 5 years |
| <input type="checkbox"/> 5 months | <input type="checkbox"/> 11 months | <input type="checkbox"/> more than 5 years |
| <input type="checkbox"/> 6 months | <input type="checkbox"/> 1 year | |

5. What is the highest level of education you have achieved?

Please select one.

- Less than 6th grade
- Finished 6th grade
- Finished 7th grade
- Finished 8th grade
- Finished 9th grade
- Finished 10th grade
- Finished 11th grade
- Finished 12th grade
- Certification or Diploma
- 1 year of post-secondary education
- 2 years of post-secondary education
- 3 years of post-secondary education
- Bachelor Degree
- Master Degree
- More than a Master Degree

Information Needs

This survey has been sent to patients at many different stages of recovery.

Please complete questions 6 to 38 by choosing the option which relates to how important the following information is for you to know at the current stage of your recovery.

	Very Important	Important	A little Important	Not Important
6. Information about Head and Neck cancers that describe the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The cause of the disease and how it could have been prevented	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The stage of the disease and how it is expected to progress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Very Important	Important	A little Important	Not Important
9. How far advanced the disease is and how far it has spread	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The goals of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Tests and investigations that may be needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. How to prepare for tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The different types of treatment available and their advantages and disadvantages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The chances of being cured of the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The evidence behind treatment recommendations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. How the treatments are performed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. How the treatments work against the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Possible side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Management of unpleasant treatment side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Very Important	Important	A little Important	Not Important
20. Dental check-ups and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Ways of managing eating and drinking to maintain nutritional intake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Ways of managing swallowing and communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Being able to care for myself at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Managing fatigue (feeling tired)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. How the treatment may affect normal daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Being able to work or concerns about finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Cost of treatments and medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. How family and social life is/will be affected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. How talking about fears, worries and getting emotional support helps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Stress management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Very Important	Important	A little Important	Not Important
31. Support groups or other support services available for myself and my carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. How the treatment may affect my feelings about my body, physical appearance and sexual attractiveness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. How family and close friends will be affected by the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Whether my children or other family members are at risk of getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Staying well after treatment is finished	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Getting on with life after cancer treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Signs of a recurrence or how to tell if the disease has come back	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. When cancer cannot be cured and needing palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Is there any other information that is not included in these questions that you think is important during your current stage of recovery?

If so, please list the information you need.

Sources of Information

Questions 40 to 48 ask about the time following your discharge home after you finished treatment.

Please choose the option that relates to how often you used each source to get information about your cancer and recovery after you were discharged home.

	Often	Sometimes	Rarely	Never
40. Healthcare Professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Written Materials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. The Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Medical Journals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Support Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Often	Sometimes	Rarely	Never
47. Other Cancer Patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Family or Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Source Helpfulness

Questions 49 to 57 ask about the time following your discharge home after you finished treatment.

Please choose the option which relates to how helpful each source was when you used it.

	Very Helpful	Helpful	A Little Helpful	Not Helpful	Did not use source
49. Healthcare Professionals	<input type="checkbox"/>				
50. Written Materials	<input type="checkbox"/>				
51. The Internet	<input type="checkbox"/>				
52. Television	<input type="checkbox"/>				
53. Medical Journals	<input type="checkbox"/>				

	Very Helpful	Helpful	A Little Helpful	Not Helpful	Did not use source
54. Books	<input type="checkbox"/>				
55. Support Groups	<input type="checkbox"/>				
56. Other Cancer Patients	<input type="checkbox"/>				
57. Family or Friends	<input type="checkbox"/>				

Information Resources

58. What sources of information would you like to use in the future, in addition to those you already use?

59. Would you find an internet-based information resource useful during recovery?

Yes No

60. Please comment on why you would find this useful/not useful?

Information Resources

61. What characteristics would a good internet-based information resource have?

Please select all that apply.

- Easy to read information about my cancer and recovery
- Detailed research articles/summaries or articles about my cancer
- Videos showing me how to take care of my skin, tracheostomy, or feeding tube
- Meal plans appropriate to my swallowing
- A way to communicate with a nurse or other professional online when I have questions
- Discussion board where I can ask questions and read other peoples' questions and answers
- A chat room where I could chat with other head and neck cancer patients
- A way to schedule all my medical appointments online
- A list of support groups and services in my area
- Other

62. In you chose 'other,' please specify.

Thank you for completing this survey!

Appendix B: Study Information and Consent Letter

Study Information and Consent Letter

Study Title: The Information Needs and Preferences of Younger Head and Neck Cancer Survivors: A Total Population Survey

Research Investigator:

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Dear Sir/Madam,

You are invited to participate in a study looking at information needs of head and neck cancer patients. You are invited because you have been diagnosed with head and neck cancer. We hope to better understand what kind of information you need during this stage of your recovery.

We are contacting you through the Alberta Cancer Registry. They agreed to help us with this study. If you were diagnosed in 2013, our study's research assistant chose you because you met the study criteria.

This study is a part of a requirement for my Master of Nursing Degree. The results of this study will be used to write my thesis. The results might also be published in a journal to help other health care professionals care for individuals with head and neck cancer. Your name will not be used in any published material.

What is the reason for doing the study?

The purpose of the study is to better understand what kind of information is important for head and neck cancer patients. We also want to understand how you got information about recovery in the past, and how you would like to get this information in the future.

We are also interested in finding out if answers to some survey questions are different depending on your age, gender, time since you finished treatment, and number of years you went to school. We hope to use the results of this study to improve how information is provided to head and neck cancer patients.

What will I be asked to do?

In order to help us better understand your information preferences, you will be asked to take a survey. The survey has 62 questions. It includes some questions about you, questions that ask you to rate items, and short answer questions. The survey should take you about 30 minutes to complete. You will have until November 22, 2013 to complete and send your survey.

You can choose to fill out the written survey included in this package, or fill out the same survey on the internet. You can skip any questions you do not feel comfortable answering.

If you choose to fill out the written survey included in this package, you will be asked to:

Follow the instructions to each question. Use a pen to answer questions. After you are finished, use the pre-addressed envelope to mail back the survey. You do not need to pay for postage. Just seal the envelope and drop it into a mail box. By filling out the survey you are consenting to participating in the study.

If you choose to fill out the survey online, you will be asked to:

Go to the website: www.hncalberta.wordpress.com. On the right hand side you will see “Protected: Information Needs Survey” Click on this text. When it prompts you for a password enter headandneckcancer in all lowercase letters with no spaces. Continue to fill out the survey.

The first question will tell you that by filling out this internet survey, you are consenting to participate in the study. Click “Accept” to the first question if you would like to continue filling out the survey. When you are finished, click “Submit.” Your responses will be recorded and sent to the researcher.

How will my responses be recorded?

When we receive a survey in paper form we will enter your survey responses into a computer program. This computer program helps us analyze the data to see patterns. You will notice that each of the pages in this package is labeled with a number on the bottom right corner. This is why your name does not appear anywhere other than the envelope addressed to you. This identifier number helps keep your responses confidential. The survey and the envelope will be separated so that your responses can be kept confidential.

If you choose to fill out the internet survey, you will be asked to enter this identifier number to help us keep track of accidental double responses. This number will also help us to not send you a reminder if you have already completed the survey. This number is linked to your name, but the name corresponding to each number will be stored by the Alberta Cancer Registry.

We will send out two reminders to potential participants who do not complete the survey. If you complete the survey you will not be sent a reminder. If you have decided not to participate in the

study, either answer and mail back the question at the bottom of this letter, or simply ignore the reminders. These are meant to remind participants who want to participate but might have forgotten to fill out the survey.

What are the risks and discomforts?

There are no physical risks to participating in the study but it is possible that remembering your recovery might be emotional or uncomfortable for you. The nature of this disease can be personally and emotionally difficult. You can choose to skip any question you do not feel comfortable answering. If completing this survey brings on any feelings of distress or you find that you are not coping well at home you can contact the Psychosocial and Spiritual Resources Program at the Cross Cancer Institute by calling (780)643-4303 or (780)643-4304.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What will I need to do?

You will need to fill out the 62 question survey either on paper or over the internet. If you fill out the written survey, you will need to mail it in the envelope provided.

What are the benefits to me?

You are not expected to get any direct benefits from being in this research study. It is our hope that this study may help other people with head and neck cancer in the future by helping us better understand what kind of information is needed during recovery. The results may also help design information support programs for head and neck cancer patients.

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop participating in the study at any time, and it will in no way affect the care or treatment that you are entitled to. You can choose not to answer any question you do not feel comfortable completing.

Will I be paid to be in the research?

No, there is no payment for being in this study.

Will my information be kept private?

Your information will be kept confidential. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

We will keep your information confidential by using your own identifier number instead of your name on all surveys and data files. We will have one list of all participants who agree to take part in the study and all their identifier numbers. This master list will be stored at the Alberta Cancer Registry. This master list will be kept separate from the written survey responses. Electronic survey responses will be kept in a password protected computer with the file encrypted. Your name will not be used in any reports or publications.

Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The results of this study will be used to help me write my thesis. These results might also be published in a journal to help other health care professionals. We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

By choosing to complete this survey you are saying it is okay for your survey responses to be used in the way described in this letter. If you choose to withdraw from the study at any time prior to my completing the analysis of the survey data, your survey responses will not be used in the results.

If you have any questions, please feel free to contact me, Oksana Zimka by e-mail hncalberta@gmail.com.

Thank you for your consideration.

Oksana Zimka, RN, MN student
Faculty of Nursing
University of Alberta

Note: The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.