University of Alberta

The Experiences of the Younger Head and Neck Cancer Client

by

Kathryn S Grattan

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

©Kathryn S Grattan
Fall 2013
Edmonton, Alberta

Permission is hereby granted to the University of Alberta Libraries to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only. Where the thesis is converted to, or otherwise made available in digital form, the University of Alberta will advise potential users of the thesis of these terms.

The author reserves all other publication and other rights in association with the copyright in the thesis and, except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatsoever without the author's prior written permission.

Abstract

Head and Neck squamous cell carcinoma rates are rising in younger populations, largely related to the sexually transmitted infection, human papillomavirus (HPV). Clinically I observed that this subset of clients had unique physical, psychosocial, and sexual concerns not currently being addressed by healthcare providers. I conducted this study using a simultaneous mixed-method design to better understand the experiences of these clients. Unstructured interviews were conducted with ten participants between the ages of 18-65. Three important themes emerged as common for this group: employment/financial considerations, a change in social patterns, and intimacy/sexuality. To augment the qualitative data, participants completed the University of Washington Quality of Life tool designed for HNC clients. A comparison was made between the interview data and the tool to identify both consistencies and gaps. The data is viewed through King's (1981) conceptual framework for nursing. This is followed by recommendations for clinical practice, education, research and policy.

Acknowledgements

As I take time to reflect on this work, and the journey it has taken to arrive to this point, I am humbled with gratitude. I would like to take a few short lines to acknowledge the contributions of the many people who have supported, encouraged, shared, and constructively critiqued this work. You have helped it develop into something I hope will be meaningful to the patients who experience this, and the healthcare providers who work so hard to care for them.

Thank you to Dr. Vera Caine, who has provided invaluable insight into the challenge of stigma in healthcare systems and encouraged a practice of active reflection in my work. Thank you to Dr. Catherine Kubrak, who shared my enthusiasm for this population and provided immeasurable guidance, both practical and theoretical. Thank you to Dr. Dan O'Connell, who brought both clinical insight and relevance to the work. Thank you to Karmen Schmidt NP and Oksana Zimka who volunteered their assistance in recruitment processes. I am fortunate to have been guided by a gifted and generous supervisor, Dr. Karin Olson. I stand in grateful admiration of your work and dedication to the profession of nursing, to oncology patients, and to the many students who have benefitted from your wisdom and encouragement.

Thank you to the participants and families who have openly shared their stories with me throughout this journey. It has been a privilege to walk alongside you, even for a brief moment. Thank you to my mother, my editor and biggest fan. Thank you to my colleagues who have offered fresh ideas, perspectives, and support. Thank you to my husband Mike whose tireless support got me through.

Table of Contents

Section 1:

"The Experience of the Younger Head and Neck Cancer Client"

Prepared for Publication in the Journal: Head and Neck

Tables and Figures

Section 2:

List of Abbreviations

HNSCC – Head and Neck Squamous Cell Carcinoma

HPV – Human Papillomavirus

HRQofL – Health-related Quality of Life

STI – Sexually transmitted infection

UWQofL – University of Washington Quality of Life Questionnaire (Version 3)

Prologue

While working as a Registered Nurse on an Otolaryngology Surgical unit in a teaching hospital in Ontario, I had the privilege of caring for individuals after their operations. It can be a very vulnerable time, as clients experience pain, voicelessness, feelings of isolation, and fears for their future. It was not uncommon for these overwhelming feelings to rise to the surface in the middle of the night, when their families had gone home and it became quiet.

I cared for a woman in her forties who had just undergone excision of her oropharyngeal cancer and a neck dissection. Her family had left earlier in the evening, after ensuring she was settled. While providing the basic mouth and incision care required for the evening and offering her analgesia for her pain, we began a conversation that was not new to me, having worked there for several years. However, this particular moment changed how I saw her, this disease, and many others afterwards. We discussed those everyday life things that have renewed importance for clients when the future is vulnerable. She spoke of her children, the job from which she was forced to take a sick leave, and her doting husband. She had only been recently diagnosed with oropharyngeal cancer, and it had come as a shock to all of them. She described the agony of explaining cancer to her children. She expressed her fear of not being able to return to her work in full capacity.

What struck me most about our brief exchange was the frustration and anger of having cancer without an explanation. She desperately desired to know why. She had never engaged in what she perceived as bad or risky behaviour.

Tears were shed by both of us as she unraveled all the fears and concerns she had for herself and her family within this new reality. The question of ‘why’ still hung in the air, unanswered.

Later on, she received the pathology report of her cancer at a follow-up appointment. Her pathology indicated human papilloma virus was involved. She had her answer; it led to many more questions for us both. The situation made me wonder what the meaning of ‘causation’ is to a client living with cancer, and how HPV would further impact the individuals and families I cared for.

I have since cared for many clients and families with this disease. Questions and concerns have repeatedly presented themselves. For example, “Is it my fault that I have cancer?”, “Who gave me HPV in my mouth/throat?”, “Is the infection still present?”, and “Is my partner at risk for developing HPV and this or other types of cancer?” They were experiencing feelings of guilt, confusion, and concern for themselves and their loved ones. Although I tried to find credible information to assist these clients, there was a lack of literature to address these questions.

My eyes were opened to the significance of HPV pathology in head and neck cancer, intrapersonally, interpersonally, and socially. This study was born from clinical practice and my goal is that its findings will be framed in a relevant, timely way to support and inform clients, families and healthcare providers managing with this disease.

Purpose of the Study:

The purpose of the study is to explore the experiences of younger clients living with head and neck cancer, and to determine any specific needs before, during and after treatment. This study will explore the research question: What is the experience of the younger adult client (age 18-65) living with head and neck cancer? Additionally, the study will include a comparison of the themes identified in the study with the subscales of the current tool utilized to measure quality of life of these clients. I am interested in finding out whether the concerns of my study participants, as reflected in the themes I identify in interview data, are included in the quality of life tool I have selected, and in comparing the Quality of Life scores of the individuals in my study to established norms for individuals with head and neck cancer.

This thesis is structured as three sections. In Section 1, I outline the problem I studied and the methods used. Section 2 is the culmination of my results, formatted for publication in a peer-reviewed journal. Section 3 is a discussion of the results in relation to the current literature through a disciplinary lens. In it, I also discuss implications for nursing practice, education, research and policy. I make recommendations for moving forward with this work. The sample patient contact letter, consent forms, and revised University of Washington Quality of Life tool are included as appendices.

Section 1: Introduction

Head and Neck Cancer Rates Rising in Younger Populations

Head and Neck Squamous Cell Carcinoma (HNSCC) rates, specifically the rates for cancers that occur at the base of tongue, tonsils, and oropharynx, are rising in younger client populations (Chaturvedi, Engels, Anderson, & Gillison, 2008). Approximately 25% of all new HNSCC is attributable to the sexually transmitted human papilloma virus (HPV) infection in the oropharynx; HPV infection is increasing due to the evolution of sexual practices in recent times (Chaturvedi et al., 2008; Evans & Powell, 2010, Cohan et al., 2009). HPV is a sexually transmitted infection (STI) that is often asymptomatic, that infects skin and mucous membranes, and that produce genital warts, or neoplasms, which may be benign or malignant (Reichman, 2008).

Chaturvedi et al. (2008) reported statistically significant increases in the incidence of HPV-related oral squamous cell cancers in individuals 40-49 and 50-59 years old from 1976 to 2004. HNSCC rates in clients less than 65 are expected to continue to rise (Chaturvedi et al., 2008). Also, men are more likely to have an HPV-associated HNSCC diagnosis (Chaturvedi et al., 2008; Stenson, 2010). Although not fully understood, this is thought to be for several reasons. Males do not mount the immune response that females do when exposed to the virus (Guiliano, Palefsky et al 2011). As a result, males have a continued risk over their life span, while the risk for females decreases with age (Guiliano, Lee et al 2011). Also, HPV has shown an increased prevalence in cervical tissue compared to penile tissue; therefore, males performing heterosexual oral-genital sex have greater risk of acquiring oral HPV infection (Marur, D'Souza, Westra, & Forastiere, 2010).

Significance to Canadians

The significance of HPV and HPV-associated cancers are highly relevant to Canadians as it is estimated that, in their lifetime, seventy-five percent of Canadians will have an HPV infection (Society of Obstetricians and Gynaecologists of Canada, 2009). This implies that a large portion of the population is potentially at risk for developing HPV-associated cancers. Understanding HPV-associated HNSCC is also important for health care providers as we strive to offer treatment and support to these clients through their cancer journey. From an economic perspective, there is a significant financial burden to the health care system to treat HPV-associated cancer clients (Kim & Goldie, 2008).

Current Research in HPV-Associated HNSCC

The impact of HPV and the subsequent epidemiological evolution of HNSCC clients are currently being explored in relation to the medical plan of care (Rischin, 2010; Marur et al., 2010). Individuals with HPV-positive HNSCC appear to have an improved response to chemotherapy when compared to individuals with HPV-unrelated HNSCC (Marur et al., 2010). The psychosocial and physical needs of the general HN cancer client have been explored in relation to quality of life, functional impairment, and pain (Semple, Dunwoody, Kernohan, McCaughan & Sullivan, 2008; Sayed et al., 2009; Onakoya, Nwaorgu, Adenipekun, Aluko & Ibewke, 2006; Zeigler, Newell, Stafford, & Lewin, 2004).

However, no research explores the experiences and needs of the unique subset of HNSCC clients with HPV pathology. As our understanding of HPV-associated HNSCC is evolving, it is important not to overlook the psychosocial, interpersonal, and relational experiences of these clients. Exploring these concepts may assist clients and caregivers during and beyond their cancer journey.

Quality of Life Considerations

Because cervical cancer is also associated with HPV infection, we can gain a deeper understanding of the quality of life concerns by examining the literature about these two populations.

Quality of life in cancer associated with STIs

As no qualitative research is available exploring the experiences of individuals living with HPV-associated HNSCC, we can draw on the existing literature of the more established, parallel experiences of women with HPV-associated cervical cancer. The diagnosis of HPV and HPV-associated cervical cancer in women has been shown to significantly impact the lives of these women by altering their intimate and social relationships, and exposing them to the stigma that occurs with STIs (Newton & McCabe, 2008; Clemmens, Knafl, Lev, & McCorkle, 2008; Waller, McCaffery, Kitchener, Nazroo, & Wardle, 2007). The impact of a diagnosis of HPV-associated HN cancer may be similar but has not yet been explored.

Concurrent quality of life considerations with HNSCC.

HNSCC is often diagnosed in more advanced stages (National Cancer Institute, 2008), and thus may require significant chemoradiotherapy and surgical interventions (Marur et al., 2010). These can lead to devastating consequences such as loss of voice, inability to swallow, pain and facial disfigurement (Semple et al., 2008; Onakoya et al., 2006). Both the disease and its treatments can profoundly affect the quality of life of these patients (Semple et al., 2008).

Impact of age on a diagnosis of cancer.

The basic needs and concerns of cancer patients in younger and middle adulthood differ from those of older cancer patients (Corbeil, Laizner, Hunter, & Hutchison, 2009). For example, they may be experiencing the loss of a job or long-term earning potential, or raising a family (Semple et al., 2008). HNSCC clients also experience additional challenges beyond that of other cancer clients such as changes to physical appearance, impaired speech and impaired swallowing (Sayed et al., 2009). As this subset of clients present at younger ages, it is important to understand that their responsibilities, development, and quality of life indicators may be unique.

Impact of gender in the experience of HPV-associated cancer.

Although both males and females are diagnosed with HPV-associated HNSCC, males are diagnosed 2-4 times more frequently (Chaturvedi at al., 2008; Stenson, 2010). Due to the earlier understanding of the association of HPV and cervical cancer, most available qualitative literature in this field focuses on women. The influence of being diagnosed with an HPV-associated cancer may be different for men and women, but this has not yet been explored.

Implications for Nursing

The newly discovered association between HPV and HNSCC is significant to nursing on several levels. At the micro level, nurses are caring for these clients in acute care and home care settings. They are responsible for providing holistic, evidence-informed care to meet the unique needs of these clients but there is little literature to guide their work. Attention to the complexity and uniqueness of this cancer diagnosis through future research could provide the needed information and enhanced experiences for clients and families.

At a community level, nurses are in a position to participate in the promotion of health and prevention of disease. Nurses have a responsibility in public education regarding safer sex practices, including the newly identified risks associated with oral sex. Presently, the association between unsafe sex practices and HNSCC is not well understood within health care professions. Therefore, health professional education will need to adequately address this issue so that appropriate public health measures can be taken. This could be done through initial practitioner, ongoing educational sessions such as academic conferences, or through self-directed learning such as reading research or online modules through interests groups.

At the political level, nurses are in a position to advocate for the prevention of HPV infection in both males and females. The quadrivalent vaccine ("Gardasil") was approved by Health Canada in 2006 for girls and women, ages 9-26 for the prevention of HPV (Types 6, 11, 16, 18) causing genital warts as well as cervical, vulvar, and vaginal cancers (Health Canada, 2006). It was approved for use in males in 2010 for the prevention of genital lesions (Health Canada, 2010). Vaccination of males with Gardasil has been shown to be equally safe and reliable compared with females (Guiliano et al., 2011; Food and Drug Administration, 2009). Canadian provinces currently vary in their policy and funding structures on vaccination of males. Informed by data regarding HPV infection and its association with other types of cancers including HNSCC, the Alberta Provincial Gynecologic Oncology and Head and Neck Oncologists Tumor groups published a position statement supporting equitable access to vaccination (2013). Nurses should be advocating for increased Canadian research data regarding safety and efficacy of the vaccine for males, and equal access to government funding for vaccination. Cervarix, a bivalent vaccine for the prevention of HPV Types 16 and 18, was also approved for the vaccination of females in Canada in 2010, but is not recommended for males (Health Canada, 2010 “Cervarix”;).

With both advocacy and public education by nurses, upstream prevention strategies decrease the spread of HPV and the longer-term consequences associated with it. Kim (2011) argues that vaccination of boys and young men not only protects them directly, but also enhances the effects for women by reducing the overall prevalence rates of HPV.

The association of HPV with HNSCC is relatively new and there is a lack of literature available to health care professionals support clients or inform important clinical decisions in this younger population. These clients have unique physical, emotional, social, and educational needs that have not yet been explored, and therefore may be unmet by health care providers. The information gathered in exploring these issues could inform future research direction as well as support the creation of holistic care plans for and with these clients.

This study was designed to better understand the unique experiences of younger head and neck cancer clients. Improved understanding will hopefully lead to improved experiences for the individuals and families, as well as more comprehensive supportive care from healthcare providers.

Research Question

This study was designed to obtain a description of the experience of being diagnosed with HNSCC. The research question for the study was: What is the experience of the younger adult (age 18-65) living with head and neck cancer?

Research Design

To answer the research question, I used a simultaneous mixed method design with a qualitative drive, as described by Morse (2003). In this design, the sampling procedures were driven by a primary qualitative design, and supplementary quantitative elements were added to enrich the answer to the research question.

The primary qualitative design that was used in this study was Interpretive Description as developed by Thorne (Thorne, 2008). I conducted unstructured interviews with ten participants. Participants were welcomed to include a family member in the conversation if they wished. Five of ten participants elected to have their spouse participate in the interview. To analyze the qualitative data, I used constant comparative analysis and coded line by line for themes using

King’s (1981) conceptual framework for nursing as a disciplinary lens. To obtain a complete description of the phenomenon, participants were continually added to the sample until no new dimensions were found. For this study, no new dimensions were found after eight interviews. I conducted two additional interviews to confirm that I had a complete description.

For the supplementary quantitative portion of this study, participants completed the University of Washington Quality of Life Tool (UWQofL). Each client completed this tool prior to beginning the interview. The quantitative data was analyzed descriptively. This data was used for two reasons: first, to ensure that my sample was similar to those in previous studies involving HNSCC clients, and second, to identify similarities and gaps between the assessment tool and the themes from the interviews.

Rigor

I adhered to Thorne’s (2008) process for ensuring rigor in qualitative work by recording analytic decisions made by the research team. For example, at the time of consent one of my participants met the inclusion criteria; however, at the time of the interview he had a known recurrence. He wished to participate, and the decision to include him was supported by all committee members. To ensure epistemological integrity, ongoing evaluation of my positioning within the research was recorded and reflected upon in a research journal. Journal entries varied, but included reflections such as the concept of hope during remission compared with recurrence. I considered how the participant with recurrence and his wife had renewed strength and a sense of hope; however, my clinical experience made me doubtful. I considered how positional differences such as this impact patient-healthcare provider dyads or participant-researcher dyads.

My data is formulated in a description that identifies potential issues encountered by my participants but does not generalize these to all HNSCC patients. In regard to the quantitative component, I have not made claims about the reliability or validity of the tool with this population, but highlighted some themes that are not captured in the tool.

Ethics

Ethical approval was obtained from the Research Ethics Board at the University of Alberta. To protect this potentially vulnerable population, participants were invited to be involved of their own accord, involve a family member if they wished, and decline to speak about any subject they did not wish to discuss. Written consent was obtained from all individuals with HNSCC. Upon analysis of the data, it was clear that data from family members who participated in the interviews needed to be included in order to provide a more complete description of participants' experiences. Therefore, an amendment to the original ethics application was obtained, and verbal consent (witnessed by a member of the study team) was received over the phone from family members. Each participant was made aware of supportive resources available to them free of charge should they experience additional burdens as a result of participating in the research. To the best of my knowledge, no participant required these resources.

Summary

In Section 1, I summarized the rationale for conducting this study and how the study was conducted. Section 2 constitutes a paper prepared for submission to the journal ‘Head and Neck’. In it, I highlight key findings of my study and discuss the implications of these findings for healthcare providers.

Section 3 is comprised of three parts: a review of the data through King’s conceptual framework for nursing; implications and recommendations for clinical practice, education, research, and policy; and a final summary.

References

Chaturvedi, A., Engels, E., Anderson, W., & Gillison, M. (2008). Incidence trends for human papillomavirus-related and –unrelated oral squamous cell carcinomas in the United States. *Journal of Clinical Oncology, 26(4),* 612-619

Clemmens, D., Knafl, K., Lev, E., & McCorkle, R. (2008). Cervical cancer: patterns of long-term survival. *Oncology Nursing Forum, 35(6),* 897-903. doi: 10.1188/09.ONF.897-903

Cohan, D., Popat, S., Kaplan, S., Rigual, N., Loree, T., & Hicks, W. (2009). Oropharyngeal cancer: current understanding and management. *Current Opinion in Otolaryngology & Head and Neck Surgery, 17,* 88-94. doi: 10.1097/MOO.0b013e32832984c0

Corbeil, A., Laizner, A., Hunter, P., & Hutchison, N. (2009). The experience of uncertainty in young adults with cancer. *Cancer Nursing*, *32(5),* E17-E27.

Evans, M. & Powell, N. (2010). The changing aetiology of head and neck cancer: the role of human papillomavirus. *Clinical Oncology*, *22*, 538-546.

Food and Drug Administration. (2009). *Gardasil.* US Department of Health and Human Services. Washington: DC. Retrieved from: www.hhs.gov.

Guiliano, A., Lee, J., Fulp, W., Villa, L., Lazcano, E., Papenfuss, M., Abrahamsen, M., Salmeron, J., Anic, G., Rollison, D., & Smith, D. (2011). Incidence and clearance of genital human papillomavirus infection in men (HIM): a cohort study. *The Lancet*, 377:932-40. Doi:10.1016/S0140-6736(10)62342-2

Guiliano, A., Palefsky, J., Goldstone, S., Moreira, E., Penny, M., Aranda, C., … & Guris, D. (2011). Efficacy of quadrivalent HPV vaccine against HPV infection and disease in males. *New England Journal of Medicine, 364*, 401-411.

Health Canada. (2006). *Summary Basis of Decision: Gardasil. Merck Frosst* Canada. http://www.hc-sc.gc.ca/dhp-mps/alt_formats/hpfb-dgpsa/pdf/prodpharma/sbd_smd_2007_gardasil_102682-eng.pdf

Health Canada. (2010). *Health Canada approves CERVARIX™, new GSK cervical cancer vaccine. GlaxoSmithKline.* Retrieved from: http://www.gsk.ca/english/docs-pdf/FINAL_Press_Release_Cervarix_EN.pdf

Health Canada. (2010). *Summary basis of decision gardasil quadrivalent human papillomavirus (Types 6, 11, 16, 18). Recombinant vaccine. Merck Frosst Canada.* Retrieved from: http://www.hc-sc.gc.ca/dhp-mps/alt_formats/hpfb-dgpsa/pdf/prodpharma/sbd_smd_2007_gardasil_102682-eng.pdf

Kim, J. (2011). Weighing the benefits and costs of HPV vaccination of young men. *New England Journal of Medicine*, 364(5), 393-395.

Kim, J. & Goldie, S. (2008). Health and economic implications of HPV vaccination in the United States. *The New England Journal of Medicine, 359(8)*, 821-832.

King, I. (1981). *A Theory for Nursing: Systems, Concepts, Process*. New York: Wiley.

Marur, S., D'Souza, G., Westra, W., & Forastiere, A. (2010). HPV-associated head and neck cancer: a virus-related cancer epidemic. *Lancet Oncology, 11(8),* 781-789. doi: 10.1016/S1470-2045(10)70017-6

Morse, J. (2003). Principles of mixed methods and multimethod research design. In Tashakkori, A. & C. Teddue. (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 189-208). Thousand Oaks: Sage Publications.

National Cancer Institute. (2008). Stage distribution and 5-year relative survival by stage at diagnosis for 1999-2006. *Surveillance Epidemiology and End Results.* Retrieved from: http://seer.cancer.gov/statfacts/html/oralcav.html

Newton, D, & McCabe, M. (2008). Sexually transmitted infections: impact on individuals and their relationships. *Journal of Health Psychology, 13(7),* 864-869. doi: 10.1177/1359-05308095058

Onakoya, R., Nwaorgu, O., Adenipekun, A., Aluko, A., & Ibekwe, T. (2006). Quality of life in patients with head and neck cancers. *Journal of the National Medical Association*, *98(5),* 765-770.

Provincial Tumor Team (2013). *Provincial Tumor Team Position Statement: HPV Vaccination in Alberta.* Retrieved from: http://www.albertahealthservices.ca/hp/if-hp-position-statement-hpv-gyne.pdf

Reichman, R. (2008). Chpt 178: Human Papillomavirus Infections. *Harrison's Principles of Internal Medicine*. 17 ed. McGraw-Hill.

Rischin, D. (2010). Oropharyngeal cancer, human papilloma virus, and clinical trials. *Journal of Clinical Oncology, 28(1),* 1-7.

Sayed, S., Elmiyeh, B., Rhys-Evans, P., Syrigos, K., Nutting, C., Harrington, K., & Kazi. (2009). Quality of life and outcomes research in head and neck cancer: a review of the state of the discipline and likely future directions. *Cancer Treatment Reviews, 35*, 397-402. doi: 10.1016/j.ctrv.2009.03.001

Semple, C., Dunwoody, L., Kernohan, W., McXaughan, E., & Sullivan, K. (2008). Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. *Journal of Advanced Nursing*, *63(1),* 85-93.

Stenson, K. (2010). *Epidemiology and risk factors for head and neck cancer*. UpToDate. Retrieved from: http://www.uptodate.com/contents/epidemiology-and-risk-factors-for-head-and-neck-cancer?source=search_result&selectedTitle=1%7E150

Society of Obstetricians and Gynaecologists of Canada. (2009). *Overview of HPV: Incidence and Prevalence in Canada.* Retrieved from: http://www.hpvinfo.ca/hpvinfo/professionals/overview-3.aspx

Thorne, S. (2008*). Interpretive Description*. Walnut Creek, California: Left Coast Press.

Waller, J., McCaffery, K., Kitchener, H., Nazroo, J., & Wardle, J. (2007). Women's experiences of repeated HPV testing in the context of cervical cancer screening: a qualitative study. Psycho-Oncology, 16, 196-204. doi: 10:1002/pon.1053

Ziegler, L., Newell, R., Stafford, N., & Lewin, R. (2004). A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making. *European Journal of Cancer Care, 13*, 119-126.

Section 2: The Experience of the Younger Head and Neck Cancer Client

Formatted for the Journal: Head and Neck

The Experience of the Younger Head and Neck Cancer Client

INTRODUCTION

Head and Neck squamous cell carcinoma (HNSCC) rates, specifically the rates for cancers occurring at the base of tongue, tonsils, and oropharynx, are rising in younger populations (ages 40-59).[1] Although both genders are affected, HNSCC occurs more often in males.[1,2] Approximately 25% of all new HNSCC is attributable to the sexually transmitted human papilloma virus (HPV) infection in the oropharynx, HPV infection is increasing due to the evolution of sexual practices in recent times.[1,3,4]

Research is being conducted to determine the biomedical implications of HPV on HNSCC.[5,6] Individuals with HPV positive HNSCC appear to have an improved response to chemotherapy and radiation compared to those with HPV-unrelated tumors, as well as an improved overall survival rate.[2,6,7] This prognostic difference raises issues related to quality of life and survivorship.

The physical and psychosocial needs of the general HNSCC client have been previously explored in relation to quality of life, functional impairment, and pain.[8-11] To date, only a few studies explore the experiences of younger HNSCC patients.

Middle adulthood is often a time where individuals must balance work and parenting responsibilities. HNSCC patients parenting young children experience fear of death and missing milestones, fear of telling their children, impact of hospitalization, changing roles within the family, challenges maintaining employment, re-establishing routines after treatment, increased appreciation for life, and living with uncertainty.[12,13] Also, degree of depression and distress in HNSCC patients decreased with increasing age.[11]

Sexual health is an important component of quality of life. Limited studies are available on the impact of an HNSCC diagnosis in which the tumor is HPV positive on sexuality or psychosexual wellbeing. Parallel literature in cervical cancer suggests women experienced: confusion regarding severity, prognosis and treatment; emotional responses such as stigma, fear, self-blame, powerlessness, and anger; and challenges with disclosure to partner(s).[14] Both males and females have been shown to experience stigma, negative impact on relationships and sexuality, and negative feelings around disclosure of sexually transmitted infections.[15]

Our study was designed to obtain a description of the experience of being diagnosed with HNSCC. The research question for this study was: What is the experience of the younger adult client (age 18-65) living with head and neck cancer?

MATERIALS AND METHODS

Design

We used a simultaneous mixed methods design with a qualitative drive, as described by Morse.[16] This design is comprised of a primary qualitative design that directs sampling, data collection, and data analysis procedures, and supplementary data collected using strategies from some other design that are obtained in order to more fully answer the research question. The primary qualitative design in this study was Interpretive Description.[17] Supplementary quantitative data were collected using the University of Washington Quality of Life Tool (UWQofL).[18,19] Interpretive Description is a design that was developed for use in applied health disciplines that seek to answer clinical questions.[17,20,21] These answers are obtained by generating detailed descriptions from a group of individuals who have some experience in common.

Sample

The sample was obtained using purposive sampling as described by Field and Morse[22], with recruitment through surgical and oncologic units of two hospitals in a large Canadian, urban centre. Our inclusion criteria were: males or females between the ages of 18 and 65 at time of initial diagnosis, finished treatment within the past 3 years, able to speak English, living in the surrounding urban region, and able to provide informed consent. We included individuals with or without confirmed HPV pathology because our centre had only recently implemented routine testing and we were targeting those who had already completed treatment. Participants with known recurrent or metastatic disease, or those with cognitive impairment were excluded. One participant met the inclusion criteria at the time of consent, but was subsequently found to have recurrent disease. At that time, both the study team and the participant agreed he would remain in the study. In studies using an Interpretive Description design, the sample size is determined by the number of individuals needed in order to obtain a complete description of the phenomenon under investigation.[17] Participants are added to the sample until the description is complete and no new dimensions are found.

Data Collection and Analysis

Following ethics approval by Research Ethics Board at the University of Alberta, Nurse Practitioners on each unit identified 18 individuals who appeared to meet the inclusion criteria. A research assistant sent a contact letter to these individuals explaining the purpose of the study and asking them to sign and return an enclosed form if they were interested in learning more about the study. Twelve people returned the form and were subsequently contacted. The principal investigator met with 10 of these individuals (nine males, one female), and answered any questions. Individuals were advised that psychological support was available to them at no cost if they experienced additional stress associated with participation in this study, but to the best of our knowledge, no additional psychological support was required. All 10 interested individuals provided written consent. We were unable to arrange a meeting with the remaining two potential participants. One individual who met inclusion criteria at the time of consent had recurrence prior to our interview. This individual wished to continue his participation, and he was therefore included. The descriptions of the experience were remarkably consistent, with no new dimensions added after recruitment of the eighth participant. The two remaining participants were recruited primarily to confirm findings. Demographic data is presented in Table 1.

The primary source of data collection was unstructured interviews. Participants selected where they were most comfortable being interviewed (home, workplace, or the researcher's office). Interviews ranged from 33 to 108 minutes (mean = 56 minutes). Participants were advised that they could include a family member in the interview if they wished. Consequently, five spouses were also involved in the interviews. Interviews were digitally recorded. As some participants had impaired speech, interview notes were taken, and non-verbal communication such as gestures was also noted. Second interviews were not conducted, as all required data were obtained in one interview.

At the beginning of each interview, participants completed the UWQofL version 3, as this is the version commonly used in our setting. The tool was originally published in 1993, and has undergone three iterations since that time.[18,19,23,24,25] It is a reliable, validated tool that has been shown to have a high Cronbach's α internal consistency over a 3-year follow-up (0.74-0.84) and an overall internal consistency of 0.81.[19] The quality of life data were collected for two reasons. First, we wanted to compare our participants' scores with published norms to ascertain whether they were similar to or different from the scores published by other researchers (Table 2). Second, we wanted to compare our themes with the elements of the tool to identify whether the tool addressed all of the main areas of importance to our participants.

Each interview was transcribed verbatim, checked for transcription accuracy, and coded line by line for themes. Data collection and analysis occurred concurrently, and thus information obtained in early interviews was used to inform interviews later in the study. We adhered to Thorne's[17] process for ensuring rigor in qualitative work by recording analytic decisions made by the research team. Mean, median, standard deviation and range were calculated for the quantitative data set.

RESULTS

The experience, as described by our participants, was multi-faceted and complex. In this section we focus on the most common features of our participants' experience. Beyond the significant physical ramifications, participants experienced changes in the social (family, friends and employment), sexual and financial domains of their lives. Results pertaining to financial changes have been included in the discussion of changes pertaining to employment.

Changes in Social Patterns

HNSCC and its treatments can cause significant challenges related to all domains of quality of life. Participants discussed the social impact of these changes in relation to family, friends, and employment.

Impact on Family

Participants generally described their family as including a spouse, children, and their parents, but sometimes also included extended family members and/or close friends. One participant described how he could not think about his family while undergoing treatments, only about himself.

"I went through some dark days, I'm not going to lie. When I was sick there were some dark days where, you know, where I didn't think about anybody – I didn't think about my kids, I didn't think about my wife. I thought about myself and how I had to get through this... And that was hard for her to hear" (Participant 5)

His statement highlights not only the effects on him, but also the potential effects on the members of his family.

Impact on Spouse/Partner

Participants described how HNSCC and its treatments had influenced their relationship with their intimate partner by shifting the roles in the family, had impacted the health of their spouse/partner, and had changed their sexual life.

Every participant with a spouse spoke of shifting of roles in their partnership. This was described as ‘participant shifts to patient’, and ‘spouse shifts to caregiver’. Spouses described feeling ‘more like a nurse than a wife’ (Spouse of Participant 6). The focus of the couple was on ‘just surviving’ the experience. Interestingly, participants 2, 3, 6 and 8 also noted that when they began to recover, the relationship required another adaptation. One participant described the challenge during recovery for both her and her spouse:

“He would always be feeling very helpless I guess sometimes, like ‘what can I do for you’, trying to do everything for me… Finally I said ‘Hey, back off… There are some things now that I want to be able to do’. And I said ‘If I need your help I will ask you for some of the things’. I appreciate everything you are doing for me and all of that… kind of let me try to do some of these things by myself again”. (Participant 2)

The family considered this second shift as a sign of moving toward recovery.

The diagnosis and treatment experience were both physically and emotionally taxing on the spouse. Several participants (3, 4, 5, 6, 8, and 9) acknowledged their spouse had taken on the burdens of family, home, finances, and caregiving. Two spouses (6 and 8) experienced significant bouts of exhaustion and unintentional weight loss. One participant said that, despite being a year post-treatment, his spouse was still very upset and fearful of recurrence (Participant 5). Several spouses echoed this experience, saying that they now always worried about what may happen next (Participant 2, 3, 6, 9).

One participant did discuss direct implications to the couple's sexual relationship in terms of libido and function. Fatigue impeded sexual activity during treatment but libido increased with time during recovery. Depending on the disease and its treatments, some sexual activities such as kissing or oral sex were affected. One person described an inability to 'pucker' despite the desire, and had to re-learn this with physiotherapy exercises. Unfortunately, the participant had to bring these concerns forward, as they had not been broached by healthcare providers.

Interestingly, despite the challenges and shifts, two participants (6 and 8) specifically reported their relationship was stronger than before their cancer diagnosis. No participant reported feeling their relationship had suffered, and no one had experienced an end to their relationship since diagnosis.

Impact on Children

Parents found it difficult to discuss their cancer diagnosis with their children and noted that this part of the experience was influenced by the age and maturity of the child, patterns of communication, and the parents' beliefs about what was right for them. Two participants had school-aged children living at home. Despite different approaches, both indicated the experience had impacted their children.

"Our (daughter) would start pulling out bibles. She would start reading. She would start wanting to buy things. … our son, he would deal with things in the fact where he wouldn't say anything, he would hide, he wouldn't eat – you know things like that… Yeah, so you'd see things more in his development, you know he wouldn't communicate as much." (Participant 5)

"She actually physically separated herself at times and stayed away from me, which was a good idea. I looked bad, I sounded bad, I'm pumping food into myself. It's just nothing that a kid needs to see." (Participant 8)

"I really told my kids… to find a way to disregard this part of their lives – like it's not their issue, it's not their problem. They're kids – I'm going to be fine… And so they kind of carried on life around me." (Participant 8)

Participants 2, 3, 4, 9 and 10 had teenage or adult children described included their children in their care plan. They described how their children experienced feelings of fear.

"I would imagine it scared the bejesus out of them but... we talked a little bit, and again I was open and candid with them" (Participant 10).

Several participants indicated their adult children became involved in their decision-making and rehabilitation. Participant 2's son and daughter-in-law urged her to have a feeding tube. Participant 9's adult children came nightly to the hospital to assist with mobilization. This involvement made them feel supported. As well, children of all ages served as a motivator for expedient recovery.

Impact on Older Parents

Three participants (2, 3, and 5) described challenges that arose in their relationship with their own parents. For the participant, it was difficult to be unable to help his/her aging parent if needed. One person was a substitute decision maker for his mother and found he could not fulfill this responsibility (Participant 3), which increased his anxiety and sadness during his HNSSC treatment.

From another view, the older parent was described as being affected by witnessing their adult child face cancer. One person indicated his father had been diagnosed with cancer at the same time as him but disregarded his own health because of his concern for his son. The son felt it was important to include his parents in his healthcare despite being an autonomous adult. Their two cancer experiences were entwined in his story.

Friendships

Participants reported having varied experiences in terms of support from their friends. Most participants indicated that their friendships were important in their coping. One participant (2) reported friends attending appointments with her. Another participant stated,

"it was good to have lots of… you find out who your friends are for sure. Got lots of friends, lots of phone calls. Lots of people come visit. We would email and we had a big list of people we email, they all, you know, they were all pulling for us. It was a really good. (Participant 6)

Participant 9 indicated that he felt humbled because his work colleagues had created a fundraising event in his name. Participant 7's work colleagues assisted him by acquiring for him necessary equipment during his convalescence. Conversely, one participant indicated that his cancer diagnosis was a dividing point in his closest friendship. He hypothesized the reason:

"It was one of my best- or I thought was one of my best friends. I don't know whether I suddenly made him feel mortal or what, but he just….he pulled completely away" (Participant 10)

Some participants indicated that their difficulty eating became a barrier to maintaining their social interactions with friends.

“After something like this happens you realize how much of your life revolves around food. You know, like you say the social thing… and you just don’t do that anymore. It’s not the same… you have to stop and you have to sort of be in a space or place to accommodate me to be able to [use the feeding tube] and I don’t want to do it in front of other people” (Participant 9)

Many participants (1, 2, 3, 4, 7, 9, and 10) described eating as a struggle or a source of stress. Nearly all participants described a time they had to ‘force’ themselves to eat. One participant describes this:

“I didn’t even go on a liquid diet. I forced myself to eat… everything was tasting like crap, like glue… But I mean I had to do it” (Participant 1)

Three participants (4, 5, and 8) indicated their family meals and mealtimes were impacted. Many described limiting their social lives due to embarrassment or frustration about food. Participant 3 had stopped being social because it took him hours to eat a meal and his tube feeding equipment was cumbersome. Participant 9 had bought a house with a large kitchen to host parties but rarely used it now. Both perceived these changes as contributing to depressed moods. Although the challenges associated with food are not unique to the younger HNSCC participant, the patterns associated with food and importance of socializing may be.

Several participants (2, 5, and 8) indicated they benefited from attending a feeding support group during treatment. The program took place weekly at no cost, and was provided by a nurse practitioner and a dietician. Discussions went beyond food and swallowing function. Participants spoke of the benefits of shared experiences, successes, and camaraderie. They described friendly challenges to try new foods or activities they found scary. Participant 2 described it as a place to discover what 'normal is now'. She continued to attend beyond her own treatments to act as role models for new patients. It was an opportunity to provide encouragement to new patients and give back to the program. Interestingly, two participants (5 and 8) indicated they were not interested in attending the support group after returning to work. They indicated the scheduling was not flexible for them. Also, they found returning to the hospital weekly was hard for them emotionally as they were trying to move forward in life.

Employment

Prime earning years are generally between the ages of 18-65. Of the 10 participants we interviewed, 8 had employment of some kind (full time, part time or contract), and 2 were retired at the time of their diagnosis. Every working participant said their employment was impacted by their health. All working participants required time off work at some point during the course of their illness and/or treatment.

Participants primarily indicated their reasons to stop work were feeling too sick or too tired. Some participants stopped work at the time of their diagnosis. Others discussed trying to maintain a work schedule during treatments but stopped part way. Working while receiving treatment was difficult. One participant noted that treatment took away his breath, his spirit, his hope and his energy.

“I’ve heard of it before and it’s odd, people are just tired or whatever, it’s not bad at all. It really does take your breath away and it takes your spirit away which is even worse. So, yeah, you just really – it’s one of those no-hope things… I just thought that my body had completely collapsed to the point of having no energy at all … So there was days that I had difficulty getting up the stairs.” (Participant 8)

Some participants stated they returned to work shortly after treatment was completed while others took more time to recover. Reasons for a prompt return included: financial constraints, a desire to return to work, lack of social interactions, and a desire for a sense of normalcy. One participant returned to work just three weeks after completion of treatment due to financial concerns, despite being exhausted.

“I didn’t have any choice – I didn’t have any money… I went right back into 12-hour shifts… It was very tough… I was exhausted, just absolutely exhausted. ” (Participant 10)

Participant 8 indicated he was motivated to return to work between treatment regimens but experienced worsening symptoms. Participant 1 had contract work prior to diagnosis was unable to maintain work commitments due to treatment schedules. Although motivated to find new work, he felt unsure of his future health and risk of recurrence, which he felt limited his work prospects. This sense of uncertainty emerged as particularly relevant to the people with insecure or temporary employment positions.

Several participants described positive aspects of work, as it provided a different focus, something that was unrelated to having cancer or going through treatments. Two participants said returning to work brought a sense of normalcy and productivity. One of these also stated his work was an outlet for creativity.

“It was like because it’s bringing you back into a normal life, right? It’s like these are normal things that you normally do. I needed my mind to work again and, like, I design… The first design I did was like, it feels so good to be back doing this.” (Participant 5)

Despite the initial challenges, most people wanted to return to work. Three participants who had previously worked had not yet returned at the time of interview. One of these individuals planned to return to work shortly after the interview (Participant 7). He felt reassured about returning, as his return would be gradual, with lighter duties. Participants 3 and 9 had significant ongoing speech and swallowing difficulties. One felt he would be unable to travel and work in sales again as he felt people would not be able to understand him or may think he was less intelligent because of his impairments.

"I can't sell now. Not the way it is. I can't speak properly and I can't eat properly… And there's a lot of travelling involved in my job, there's a lot of sitting face to face with a lot of important people ... you know I think that people would look at me in my business world as you know not as intelligent because of the way I speak" (Participant 3)

Work emerged as a significant aspect of the experience of being diagnosed with HNSCC as a younger person, particularly the participant's self-perception of health. Participants used work as a marker of the healing process and a way to draw a line between treatment and life.

Intimacy/Sexuality

Initial Response to Diagnosis of HPV

HNSCC and its treatment have implications on intimacy and sexuality. This can be both functional and psychosexual. Six participants indicated that HPV added to the complexity of their experience. Responses to their pathology results ranged from experienced shock/surprise and embarrassment to acceptance.

"I was absolutely surprised; I mean apparently it's just a new thing that they found that it actually is contractual from HPV. And I've told other people, like…… nah, bullshit!... (I was) Shocked! And I was a tad embarrassed as well, but it is what it is." (Participant 10)

Most participants indicated that knowing the cause of their cancer was important to them. This was particularly important to participants who had no smoking or alcohol history. Two specifically stated they wanted to know the cause but it did not change the experience for them.

Several participants described being told by their physicians that HPV positive results improved their prognosis. One participant assumed his HPV status was bad news, but changed his view after hearing the prognostic significance. Of note, the participant who had a recurrence had been told his HPV status would improve his prognosis.

"It was supposed to be a good thing that it was probably HPV because it was less likely to spread" (Participant 4)

His spouse indicated that his recurrence was ultimately more disappointing because their hopes had been raised.

Lack of Knowledge or Information about the Relationship between HPV and HNSCC

Of the six participants who discussed HPV, none knew about the link between HPV and HNSCC prior to their diagnosis. Participant 7 jokingly said he previously thought HPV was a breakfast cereal. Nearly all participants indicated they had sought information about HPV on the internet. Two participants discussed the lack of reliable information on HPV and HNSCC.

“You can go online and research all that. But it’s still sketchy, like there’s – you know, they’re pretty positive that it’s all related but nobody really understands what the steps are” (Participant 5)

“No one seems to know anything about it. I have looked online, you know to gain a little bit of knowledge about it but there’s a lot of unknown about the virus” (Participant 7).

Participant 10’s partner had questioned whether she should be tested for HPV.

Experience of Stigmatization

Several people said that close family and friends questioned how they had developed this type of cancer. This was a source of anxiety for several participants. One person called HPV the elephant in the room. Participants 7 and 10 indicated they deliberately kept their HPV diagnosis private. Another participant stated:

“I think it’s a bit of a stigma about it because it is a sexual type of disease but I think that people need to know… Just because it’s sexuality it doesn’t mean it’s a bad thing; it’s part of human life, right?” (Participant 5)

The reactions of telling others ranged from embarrassment to fascination. In our study, those with a steady partner did not worry about the burden of disclosure. For single participants, being faced with the prospect of telling a new partner evoked anxiety and uncertainty. They discussed both partner response and fear about the risk of spread as concerns to them.

Quality of Life

We used the UWQofL tool to quantitatively assess the participants' self-perceived quality of life. Our results appeared similar to scores published by others using earlier versions of the tool[25-27] indicating that our population was similar to those previously studied.

In general, participant's scores were consistent with their described health status. Those who had significant functional or psychological impairments had lower scores. Those who had minimal functional or psychological impairments had higher scores.

In part 2 of the tool, participants are asked to identify 3 of 10 items as the 'most important' items to them over the past 7 days. Four participants indicated that swallowing and speech were most important to them, which was consistent with our interviews. Participants also discussed challenges with taste and saliva. Participants had median scores below 70 for all four of these domains (taste, saliva, swallowing, and speech).

The general questions in Part 3 are broad and incorporate 'many other factors such as family, friends, spirituality, and leisure', asking the participant to rate their overall health-related quality of life (HRQofL) on a scale from very poor to outstanding. Compared to their quality of life before cancer, half indicated their HRQofL was now worse. Interestingly, all but one person rated this reduce HRQofL as good, very good or outstanding. Eight out of ten participants indicated their overall HRQofL as good, very good, or outstanding.

ANSWERING THE RESEARCH QUESTION

Participants described the experience of living with HNSCC as multi-faceted and complex. Beyond the significant physical and functional effects of HNSCC and its treatments younger participants experienced changes in the social, and sexual, and financial areas of their lives. These changes significantly impacted their quality of life. Despite the challenges they experienced, most participants indicated their quality of life was now good and they had adapted to their perceived ‘new normal’. They described a need for further support and guidance from healthcare providers to openly attend to the social and sexual implications of the disease and its treatments.

DISCUSSION

As healthcare providers strive to deliver comprehensive, patient-centered care, it is important to remember that younger individuals who are diagnosed with HNSCC require a care plan that also highlights the issues of changes in social patterns, intimacy/sexuality, and financial concerns. These issues are in addition to the concerns shared with other HNSCC patients in the areas of symptom management, nutrition, and function.

Changes in Family Patterns

Our results highlighted the importance of understanding the impact of HNSCC on families. Family nursing theory identifies the importance of assessing the individual client as both an individual system and part of a family system.[28] This systems theory implies that as one member of the family experiences a change, the other members are also affected. Our results aligned well within this theoretical perspective. Spouses or adult children became caregivers and younger children often reflected the changes in the roles of other family members through their behavior and development.

Spouses are often identified as the primary support for a person diagnosed with cancer.[29] Similar to previous literature in the general cancer patient population[30,31], this support role was sometimes associated with both physical and psychological morbidity. Participants in our study described challenges with role adaptation, caregiver health, and sexuality.

The majority of our participants were male and in heterosexual relationships. Little research is available on the impact of caregiving on female partners of male cancer patients.[32] Nijboer et al[33] found that female caregivers reported greater loss of physical strength and reduced self-esteem. As well, younger caregivers report a more negative impact of disrupted schedules.[35] Our participants indicated that the spouse, most often a wife, took on greater home and financial responsibilities and experienced high levels of distress and fear, which extended beyond treatment.

Hodgkinson et al[31] developed a tool to aid clinicians to psychometrically assess the supportive care needs of partners in the general cancer population. Further research on the experience and needs of caregivers may assist healthcare providers in supporting the younger HNSCC patient and his/her spouse.

Limited literature is available to understand the experience of children who have a parent with cancer.[34] Parents in our study discussed talking to their children about the diagnosis and their fears of immediate and longer-term consequences for the children. In a study exploring the experience of parents with HNSCC, parents' hospital stays led to a separation from their children, which was identified as a difficult experience, and also family activities around eating were negatively impacted.[12] In that study, researchers found that parents had an increased appreciation for, and a desire to return to normal life but this was difficult to do because of the uncertainty associated with rehabilitation.[12] Our results were consistent with this study. We did not interview any participants who were single parents of young children. However, the illness of a single parent could pose additional challenges for families of young children.

How can healthcare providers support parents caring for their children from diagnosis through to recovery? In a study of mothers with breast cancer, the authors suggest that trained healthcare workers should focus on the whole family by establishing ongoing assessments of all members.[35] Rauch, Muriel, and Cassem[36] proposed a guideline for clinicians working with parents with cancer which included: learning about the children, maximizing the child's support system, facilitating honest communication, addressing common questions, preparing for hospital visits, and saying goodbye. Local and online resources are also available. For example, the National Cancer Institute has resources and online support groups for teens with parents with cancer.[37] Clinicians need to be educated and proactive in making recommendations for parents about child development in understanding illness.[34]

Rarely does cancer literature include the older generation as part of the family. However, it is common in many cultures for multiple generations to be living in one home. Wright and Leahey[28] discuss the developmental milestones of families throughout the life cycle. In middle adulthood, people are often said to be in the sandwich generation, caring for both their children and their parents. Participants in our study indicated an additional stress maintaining care for their parents during treatment and rehabilitation. This is consistent with Wright and Leahey's position that illness may hinder the ability of younger families to realign relationships to include children and grandparents.[28]

A paucity of literature is available on the experience of older parents who have an adult child living with cancer. Dean et al[38] explored the experiences of older parents who had an adult child die from cancer. Prior to the death, the parents experienced tensions between the desire to parent and allow their child autonomy, as well as feeling helpless and excluded from the process.[38] Our participants' parents had similar experiences, which could hinder the developmental processes of their families. The tensions experience as they struggled between wanting to help their adult child, while also appreciating their child’s autonomy, is an example of a potentially impeded developmental process.[28]

Social support for the older parent and psychological distress of the adult child with cancer affected the parents’ adjustment to the situation.[39] Given the increasing incidence of younger individuals with HNSCC, it may become important to include and support older members of the family unit.

The majority of our participants indicated they received adequate social support from family and friends. Lack of social support has been shown to be a predictor of decreased disease-specific quality of life in head and neck cancer.[40] This suggests that psychosocial interventions that promote social support may be beneficial in this population. Participants in our study noted that the feeding support group was beneficial for both patients and their spouses because it created opportunities for patients to interact with each other to provide ‘peer’ support, to be understood, and to move forward in their recovery. However, the timing and location of the program created a barrier for those who had returned to work. Flexible delivery of support groups, such as web-based groups, could be a practical solution for these patients as participation might be more conducive to work schedules. Younger patients may be more comfortable with this approach. A web-based support group would also be suitable for patients with voice dysfunction and would provide greater anonymity when discussing intimate subject matter.

Changes in Employment Patterns

Historically, most individuals with cancers of the head and neck were retired. The participants in this study, however, were in their prime earning years and faced discontinuing work, either temporarily or indefinitely. Change in work because of cancer can impact self-esteem, quality of life, and social or family roles.[41] Previous researchers have reported that 28-52% of previously employed HNSCC patients were disabled by their illness.[42] This has significant personal, social, and economic implications for the individual with HNSCC and their family.

Buckwalter et al[42] identified fatigue, eating, pain or discomfort, and appearance as reasons why HNSCC patients did not return to work within one year. Fatigue and eating were consistent issues with our participants, but pain and appearance were not identified as primary concerns. This discrepancy may be related to the time since diagnosis and treatment, as our participants were further from treatment. Time may allow for adaptation to a 'new normal' or improved cosmesis.

Participants in our study noted several reasons for returning to work, including financial need, social value, sense of normalcy and an outlet for creativity or focus. These are consistent with the work of Main et al[43], who found that economic concerns, physical effects, and a positive focus on something else were a part of cancer's survivors' return to work experience. This study raises further questions about the optimal timing for return to work, factors affecting decisions about return to work, and ways healthcare providers could support those patients who need or wish to return to work. This is particularly relevant to younger patients who are not yet close to retirement age or who have young children at home for whom they need to provide. Employment concerns should be considered when planning treatment and rehabilitation.

Intimacy/Sexuality

Literature examining the problems with intimacy in HNSCC is scarce despite the degree of disfigurement and loss of function that occurs.[44] In a study piloting a sexuality question for the UWQofL tool, one third of patients reported substantial problems with sexual interest and enjoyment and one quarter of patients reported problems with intimacy.[44] Only one of our participants discussed functional concerns related to intimacy. This may have been due to the sensitive nature of the subject. If asked directly, results may have been different.

Interestingly, body image did not emerge as a significant component of our participants' experience. Cancer and its treatment have been shown to negatively affect the body image and sexuality of the patient, and also the partner.[45] This inconsistency may have been related to the length of time since initial treatment, the positive mortality outcome, or the overshadowing of other personal concerns.

The connection between HPV exposure and diagnosis with HNSCC was a significant component of the experience for some of our participants, with responses, ranging from surprise to frustration to acceptance. Consistent with prior research, our participants indicated they had unasked and unanswered questions about HPV after discussion with their clinician and the Internet was their next source of information.[46] Concerns about transmission dominated rationale for altering intimacy patterns for our single participants. Further research to understand transmission patterns would be beneficial in supporting client's understanding of their disease, and health behaviours for the future.

There is a strong ethical argument for full disclosure of HPV in HNSCC.[47] Our results are consistent with prior research finding younger HNSCC patients wonder about and can become frustrated with the lack of information about the cause of their cancer.[48] Clinicians may not feel comfortable discussing links between HPV exposure and HNSCC, given the sexual practices involved. Of note, our participants indicated that when HPV was disclosed, it was given a positive spin in terms of prognosis. Unfortunately, the sole patient with recurrence felt additional frustration and disappointment in relation to this, so health care providers engaged in this conversation must carefully discuss the uncertainties regarding recurrence.

Similar to previous work, some of our participants experienced a sense of stigma or embarrassment about the diagnosis.[46] Although there is a lack of public knowledge about the HPV link to HNSCC, public perception of sexually transmitted infections is acutely negative. No participants discussed actual negative responses to disclosure but the sense of perceived stigma in the wider community was enough to increase anxiety and distress. Their response to this 'felt stigma' was sometimes one of concealment.[49,50] Conversely, some patients felt obligated to share the relationship between HPV and HNSCC as a means to prevent HNSCC in others. For example, some participants were motivated to engage in meaningful conversations with friends on this topic.

Open dialogue about intimacy concerns may need to be initiated by the clinician. Helping to prepare clients for discussions with family and friends about HPV would likely be helpful, particularly for those who wish to embark on new intimate relationships.

Quality of Life

We found that those whose description of their experience was more positive also had higher scores on the UWQofL instrument than did those who described their experience in negative terms. Participants rated their overall quality of life as ‘good’ or ‘very good’ (mean score 66/100, part 3 question 3 of UWQofL tool). This appeared somewhat contradictory to part 3 question 1 when participants were asked to compared their current quality of life to one month prior to diagnosis. Their average response was between ‘poor’ and ‘fair’ (mean 37.5/100). This may be reflective of efforts to reframe the illness experience and begin the process of creating a “new normal” following treatment. Further exploration of this issue is warranted.

Two of the themes identified in our study, financial/employment and sexuality concerns, are not included in the version of the UWQofL tool used in this study. Interestingly, employment was an independent element of previous versions of the tool but was removed as it was found to lack internal consistency, had wide variations in response, and had a bimodal distribution.[19] Some items in the tool, such as appearance and pain, were rarely discussed as concerning to our participants. One benefit of using a quality of life assessment instrument is that it allows a comparison over time. Clinicians and patients are able to see if progress is being made during follow-up visits. The risk is, however, that only the questions on the instrument used get answered. Information about other domains of quality of life such as sexuality, which can be more difficult to measure, do not get assessed. This tool, while well-regarded, does not capture the complexity of the experience or the implications of HNSCC for patients and their families.[51]

Strengths of the study

This study is the first published work focused on the experience of the younger HNSCC client from their perspective. In this article we describe the complexity of the experience. A 56% response rate indicates participants are interested in sharing their stories. We included the perspective of several spouses, adding to the richness of the data and used a clinical tool that has been validated in HNSCC patients for nearly two decades to augment our findings.

Limitations of the study

Despite the relevance of these findings, there are some limitations to the study. Although we tried to recruit both men and women, most participants were men, and hence the descriptions provided may not fully outline experiential aspects more relevant to women. Differences may exist between men and women with HNSCC in the areas of body image/appearance, sexuality, employment, and family concerns. Further research studies should target differences between men and women in these areas.

Our sampling strategy may have inadvertently excluded patients who were more disabled, and therefore, had different concerns. Our data collection strategy required participants to be able to speak. Additionally, we used 3 years post-treatment as a broad starting point for this research. Time since diagnosis/treatment could have an impact on what is relevant to these patients. Longitudinal studies, both qualitative and quantitative, could help to improve our understanding of the influence of time in this experience.

The centre we recruited from did not routinely test for HPV until recently. We, therefore, could not include HPV status in our description of the sample. As testing has now become routine, future researchers should deliberately recruit from both those who are positive and those whose cancers are unrelated to HPV, in order to explore potential differences in experience.

CONCLUSIONS

In conclusion, our study highlights the complexity of the experience for younger HNSCC patients. We found that beyond the physical effects of HNSCC and its treatments, younger clients experience changes in the social, sexual and financial areas of their lives. These changes influenced the quality of life of our study participants. As there is improved survival in this population, quality of life is an important focus in this population. Health care providers should ensure that they consider the changes in the social, sexual, and financial areas when planning care with younger individuals diagnosed with HNSCC.

Table 2.1: Demographics	n=10 (%) except when otherwise indicated
Sex: Male	9 (90)
Age at Diagnosis, years: (mean ± SD, median, range)	53.8 ± 6.75, 54, 42-65
Marital Status: married/common-law	7 (70)
Time since Treatment, months: (mean ± SD, median, range)	13.5 ± 5.10, 14, 2-19
Staging by Participant	TNM staging as per AJCC guidelines
1	T1N2bM0
2	T2N2cM0
3	T2N0M0
4	T1N3M0
5	TxN1M0
6	T2N1M0
7	T2N2cM0
8	TxN2cM0
9	T3N2cM0
10	T1N2bM0
HNSCC Risk Factors	
p16 positive	4 (40)
p16 negative	1 (10)
p16 not stated/not tested	5 (50)
Smoking history (current or previous)	5 (50)
Alcohol history (current or previous)	3 (30)
Treatment Regimen	
Surgery followed by Radiation only	3 (30)
Radiation and Chemotherapy, without surgery	2 (20)
Surgery followed by Chemotherapy and Radiation	5 (50)*

* one participant did not complete chemotherapy regimen

Table 2.2: University of Washington Quality of Life v 3 Results

Part 1:	
Scores (out of 100)	Domain, score (out of 100): mean ± SD, median, range
Pain	85 ± 17.5, 87.5, 50-100
Appearance	80 ± 15.8, 75, 50-100
Activity**	73.8 ± 22.4, 75, 37.5-100
Recreation**	78.8 ± 22.1, 75, 37.5-100
Swallowing	71 ± 25.6, 70, 30-100
Chewing	65 ± 33.7, 50, 0-100
Speech	78 ± 22.5, 70, 30-100
Shoulder	71 ± 25.6, 70, 30-100
Taste**	61.5 ± 33.0, 70, 15-100
Saliva	63 ± 21.1, 70, 30-100
Total Score (average of all domains)	72.7 ± 15.1, 77, 40.5-90
Part 2:	
Which issues have been the most important to you during the past 7 days? (Check up to 3 items)	Frequency the item was identified
Activity	4
Swallowing	4
Speech	4
Taste	4
Chewing	3
Saliva	3
Shoulder	2
Pain	1
Recreation	1
Appearance	0

* (0 = ‘poor’ quality of life; 100 = ‘excellent’ quality of life)

*Several participants indicated 2 items on the scale – score was averaged

Table 2.2 continued: Part 3:	
Scores (out of 100) *	Domain, score (out of 100): mean ± SD, median, range
Compared with month before you developed cancer, how would you rate your health related quality of life?	37.5 ± 27.0, 37.5, 0-75
In general, would you say your health related quality of life during the past 7 days has been:	68 ± 16.9, 60, 40-100
Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your overall QofL during the past 7 days.	66 ± 25.0, 60, 20-100

* (0=poor quality of life; 100=excellent quality of life)

References

1) Chaturvedi A, Engels E, Anderson W. Gillison M. Incidence trends for human papillomavirus-related and –unrelated oral squamous cell carcinomas in the United States. J Clin Oncol 2008;26(4), 612-619.

2) Chaturvedi AK, Engels EA, Pfeiffer RM, et al. Human papillomavirus and rising oropharyngeal cancer incidence in the United States. J Clin Oncol 2011;29(32):4294-4301.

3) Evans M. Powell N. The changing aetiology of head and neck cancer: the role of human papillomavirus. Clin Oncol 2010;*22:*538-546.

4) Cohan D, Popat S, Kaplan S, Rigual N, Loree T, Hicks W. Oropharyngeal cancer: current understanding and management. Curr Opin Otolaryngol Head Neck Surg 2009;17:88-94.

5) Rischin, D. Oropharyngeal cancer, human papilloma virus, and clinical trials. J Clin Oncol 2010;28*(1):* 1-7.

6) Marur S, D'Souza G, Westra W, Forastiere A. HPV-associated head and neck cancer: a virus-related cancer epidemic. Lancet Oncol 2010;11(8):781-789.

7) Fakhry C, Westra WH, Li S, et al. (2008) Improved survival of patients with human papillomavirus-positive head and neck squamous cell carcinoma in a prospective clinical trial. J Natl Cancer Inst 100:261–269.

8) Semple C, Dunwoody L, Kernohan W, McXaughan E, Sullivan K. Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. J Adv Nurs 2008;*63(1):*85-93.

9) Sayed S, Elmiyeh B, Rhys-Evans P, et al. Quality of life and outcomes research in head and neck cancer: a review of the state of the discipline and likely future directions. Cancer Treatm Rev 2009;35:397-402.

10) Onakoya R, Nwaorgu O, Adenipekun A, Aluko A, Ibekwe T. Quality of life in patients with head and neck cancers. J Natl Med Assoc 2006;98(5):765-770.

11) Ziegler L, Newell R, Stafford N, Lewin R. A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making. Eur JCancer Care 2004;*13*:119-126.

12) Semple C. McCance T. Experience of parents with head and neck cancer who are caring for young children. J Adv Nurs 2010;66(6)*:*1280-1290.

13) Corbeil A, Laizner A, Hunter P, Hutchison N. The experience of uncertainty in young adults with cancer. Cancer Nurs 2009;32(5):E17-E27.

14) Perrin K, Daley E, Naoom S, Packing-Ebuen J, Rayko H, McFarlane M, McDermott R. Women's reactions to HPV diagnosis: insights from in-depth interviews. Women Health 2006;43(2):93-110.

15) Newton D, McCabe M. Sexually transmitted infections: impact on individuals and their relationships. J Health Psychol 2008;13(7):864-869.

16) Morse J. Principles of mixed methods and multimethod research design. In Tashakkori A, Teddue C, editors. Handbook of mixed methods in social and behavioral research. Thousand Oaks: Sage Publications; 2003. p 189-208.

17) Thorne S. Interpretive Description. Walnut Creek, California: Left Coast Press; 2008.

18) Hassan SJ, Weymuller EA. Assessment of quality of life in head and neck cancer patients. Head Neck 1993;Nov-Dec;15(6):485-496.

19) Weymuller EA, Alsarraf R, Yueh B, Deleyiannis FWB, Phil M, Coltrera MD. Analysis of the performance characteristics of the University of Washington quality of life instrument and its modification (UW-QOL-R) Arch Otolaryngol Head Neck Surg 2001;127:489-493.

20) Thorne S, Reimer Kirkham S, O'Flynn-Magee K. The analytic challenge in Interpretive Description. Int J Qual Methods 2004;3(1):1-21.

21) Thorne S, Reimer Kirkham S. MacDonald-Emes J. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. Research in Nursing & Health 1997;2:69-177.

22) Field P, Morse J. Nursing research: the application of qualitative approaches. Rockville, MD: Aspen; 1985.

23) Rogers SN, Laher SH, Overend L, Lowe D. Importance-rating using the University of Washington quality of life questionnaire in patients treated by primary surgery for oral and oro-pharyngeal cancer. J Craniomaxillo Surg 2002;30:125-132.

24) Rogers SN, Lowe D, Yueh B, Weymuller EW. The physical function and social-emotional function subscales of the University of Washington quality of life questionnaire. Arch Otolaryngol Head Neck Surg 2010;126(4):352-357.

25) Rogers SN, Lowe, D, Brown JS, Vaughan ED. A comparison between the University of Washington Head and Neck disease-specific measure and the

medical short form 36, EORTC QOQ-C33 and EORTC Head and Neck 35. Oral Oncol 1998;34(5);361-372.

26) Weymuller EA, Yueh B, Deleyiannis WB, Phil M, Kuntz AL, Alsarraf R, Coltrera MD. Quality of life in patients with head and neck cancer: lessons learned from 549 prospectively evaluated patients. Arch Otolaryngol Head Neck Surg 2000;126;329-336.
27) Kubrak C, Olson K, Jha N, et al. Clinical determinants of weight loss in patients receiving radiation and chemoirradiation for head and neck cancer: a prospective longitudinal view. Head Neck 2013;May:695-703.
28) Wright LM, Leahey M. Nurses and Family: A Guide to Family Assessment and Intervention, 6th ed. Philadelphia: F.A. Davis Company; 2013.
29) Badr H, Carmack CL, Milbury K, Temech M. Psychosocial interventions for couples coping with cancer: a systematic review. In Carr BI, Steel J, editors. Psychological Aspects of Cancer 2013. New York: Springer; 2013. p 177-198.
30) Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. J Am Med Assoc 1999;282(23)2215-2219.
31) Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G. Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the cancer survivors' partners unmet needs measure. Psychooncology 2007;16:805-813.
32) Carlson LE, Bultz BD, Speca M, St. Pierre M. Partners of cancer patients: part 1. Impact, adjustment, and coping across the illness trajectory. J Psychos Oncol 2000;18(2):39-63.

33) Nijboer C, Triemstra M, Tempelaar R, Mulder M, Sanderman R, van den Bos GAM. Patterns of caregiver experiences among partners of cancer patients. Gerontologist 2000;40(6):738-746.

34) Rauch PK, Murial AC. The importance of parenting concerns among patients with cancer. Crit Rev Oncol Hematol 2004;49:37-42.

35) Elmberger E, Bolund C, Lutzen K. Transforming the exhausting to energizing process of being a good parent in the face of cancer. Health Care Women Int 2000;21:485-499.

36) Rauch PK, Muriel AC, Cassem NH. Parents with cancer: who's looking after the children? J Clin Oncol2003;21(9):117s-121s.

37) National Cancer Institute. When your parent has cancer: a guide for teens. 2011. Retrieved: http://www.cancer.gov/cancertopics/coping/when-your-parent-has-cancer

38) Dean M, McClement S, Bond JB,m Daenink PJ, Nelson F. Parental experiences of adult child death from cancer. J Palliat Med 2005;8(4):751-765.

39) Gilbar O. Parent caregiver adjustment to cancer of an adult child. J Psychosom Res 2002;52:295-302.

40) Penedo FJ, Traeger L, Benedict C, Thomas G, Dahn JR, Hernandez Krause M, Goodwin WJ. Perceived social support as a predictor of disease-specific quality of life in head-and-neck cancer patients. J Support Oncol 2012;10(3): 119-123.

41) Steiner JF, Cavender TA, Main DS, Bradley, CJ. Assessing the impact of cancer on work outcomes: what are the research needs? Cancer 2004;101(8):1703-1711.

42) Buckwalter AE, Hynds Karnell L, Smith RB, Christensen AJ. Funk GF. Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. Arch Otolaryngol Head Neck Surg 2007;133:464-470.

43) Main DS, Nowels CT, Cavender TA, Etschmaier M, Steiner JF. A qualitative study of work and work return in cancer survivors. Psychooncology, 2005;14:992-1004.

44) Low C, Fullarton M, Parkinson E, O'Brien K, Jackson SR, Lowe, D, Rogers SN. Issues of intimacy and sexual dysfunction following major head and neck cancer treatment. Oral Oncol 2009;45:893-903.

45) Carr SV. The impact of cancer and its therapist on body image and sexuality. In: Carr BI, Steel J, editor. Pyschological Aspects of Cancer. New York: Springer; 2013. p 199-212.

46) Baxi SS, Shuman AG, Corner GW et al. Sharing a diagnosis of HPV-related head and neck cancer: the emotions, the confusion, and what patients want to know. Head Neck 2012; doi: 10.1002/hed.23182.

47) Shuman A, Wolf G. Human papillomavirus status in head and neck cancer: the ethics of disclosure. Cancer 2010; 4221-4226. Doi: 10.1002/cncr.25210

48) Grant E, Silver K, Bauld L, Day R, Warnakulasuriya W. The experiences of young oral cancer patients in Scotland: symptom recognition and delays in

seeking professional help. Br Dent J 2010;208:465-471. doi: 10.1038/sj.bdj.2010.450

49) Scambler G. Hopkins A. Being epileptic: coming to terms with stigma. Sociol Health Illn 1986;8:26-43.

50) Scambler G, Heijnders M, Van Brakel W. Understanding and tackling health-related stigma. Psychol Health Med 2006;11(3):269-270. Doi: 10.1080/13548500600594908

51) Laraway DC, Rogers SN. A structured review of journal articles reporting outcomes University of Washington quality of life scale. Br J Oral Maxillofac Surg 2012;50(2):122-131.

Section 3: Discussion and Recommendations

In this section, I first examine the results discussed in Section 2 through the lens of a nursing theory, as suggested by Thorne (2008, 2010). I chose to use the conceptual framework developed by King (1981) because it structured and supported the complexity and interwoven nature of health and illness at multiple systems levels, which fit well with the experiences described by my participants. Based on this analysis, I discuss implications for nursing practice that follow from my results and that are rooted in King's framework. I also discuss the implications of my results for education, policy and research. Additionally, I have commented on potential clinical implications for other members of the interdisciplinary healthcare team. Finally, I provide a summary of the study and some concluding remarks.

The Disciplinary Lens of Nursing as described by King (1981)

In Interpretive Description, Thorne (2008, 2010) stipulates that the researcher view their results through a disciplinary lens. I decided to use King's (1981) conceptual framework for nursing because her framework appreciates the dynamic, interwoven influences of individuals, families, and groups on the wellness/illness experience. King stipulates that human beings are open systems that constantly interact with their environment, of which the nurse can be part (King, 1981). Her conceptual framework is comprised of three systems, which are dynamic and interacting (King, 1981). She labels the three systems as personal systems, interpersonal systems, and social systems.

Understanding the Experience through King's Disciplinary Lens

Personal systems.

Individuals, such as the client or nurse, are examples of personal systems. King (1981) says that many dimension of the personal systems are important, including self, perception, body image, growth and development, time, and space. All these elements impact both wellness and illness.

Some elements of this description were particularly relevant to the participants in this study. Considering the nature of HNSCC and its treatments, one could reasonably suspect that body image would emerge as a relevant theme. Many patients do experience changes to the most visible parts of their body. Interestingly, few participants discussed this as part of their experience, and if so, discussed it primarily in relation to treatment. On the UWQofL, appearance was never identified as a current priority. It is possible that the timing of data collection had an impact on why this was not a more prominent concern. One participant discussed his initial reactions looking in the mirror post-operatively and noted that his impression of his appearance evolved over time:

> At first, yeah, certainly when fresh out of surgery I had a hard time looking at myself. From the incision when they had to split my lip open and my jaw so the one on my chin was a little bit of a – not that I'm vain or anything – but it was a little bit tough to look at. The scars on my neck from the incisions I felt that I had to cover them up. As I've learned now I just wear them like a badge of honour, you know – I don't have to be so

> insecure about it. What I see and what other people see are two different things. (Participant 7)

This statement fits well with King's view about body image and time as components of a personal system of health. This participant's perspective of his body image evolved over time from one of illness or difficulty to strength or pride. He shifted his focus away from what others may think and valued his own perception of self.

Sensitivity to where clients are at in their acceptance of their appearance is critical to successfully supporting them. Acknowledging the temporal implications of this evolution in body image is relevant to both individuals experiencing this disease and their healthcare providers.

Within King's model, she describes nurses as being their own personal system as well as within interpersonal systems with clients. As the nurse has his/her own personal system, exploring one's own feelings and perceptions about body image is important as well. Nurses should reflect on how their perceptions of body image could impact their patients, negatively or positively, and incorporate this understanding in their practice.

Interpersonal systems.

King (1981) explains that groups of individuals, such as the client and nurse dyad, are examples of interpersonal systems. Concepts such as role, interaction, communication, transaction, and stress are relevant for the nurse to consider at this level of system as they are key elements in the development and wellness of groups of individuals. Also, these elements can impact the personal system level and the overall health and wellbeing of the individual patient.

Interpersonal systems were evident throughout all participants' interviews. Participant's spoke of their role as a spouse (included married or in committed relationship), parent, peer or patient. These roles were described in relation to another person. For example, the role of spouse implied a partnership with another person; the role of parent implied a relationship with a child.

Roles were fluid and required adaptability both by the participant and the other person (spouse, child, healthcare provider). For example, several participants described feeling like a patient and noted that their spouse became their caregiver. Spouses described becoming a nurse, a taxi driver, and an advocate in their role as caregiver. Some couples described a shift in their relationship at this time. It was described as necessary to survive the experience, but some found it frustrating. This was challenging both for the participant and the spouse. Several participants mentioned it was exhausting for the spouse to be caregiver and simultaneously manage their household responsibilities. Two spouses had physical health challenges after the active treatment phase was complete. The experience of HNSCC disrupted their interpersonal system, and ultimately impacted the health of both the participant and his/her spouse.

Interestingly, navigating back to previous roles following recovery was also described as difficult for both partners. One participant said is was frustrating not being 'allowed' to perform many of the household responsibilities during her recovery. She felt she finally had to demand these responsibilities be shared again during remission, to prove to herself and her spouse that she was ‘recovered’. Being able to regain some of the daily household chores was important to her sense of self, her personal system. This is one example that aligns well with King’s assertion that one system can impact another.

Participants also discussed communication as important to how they perceived their experiences. Good communication was described as empowering while poor communication was a source of frustration or fear. Access to timely information was mentioned by nearly everyone as a priority.

Notably, several participants indicated that when and how a healthcare provider communicated with them impacted their sense of trust and their hope for a cure. For example, one participant entered his initial visit with the healthcare team with very little hope. An optimistic comment by a healthcare provider elevated his hope and solidified his willingness to engage in treatments. Another participant was frustrated when, after being told he would lose only 3 or 4 teeth, he was now having all teeth removed. This inconsistency proved to be very stressful to him. Both of these examples illustrate how interpersonal communication with healthcare providers impacted the perception of health of the patients, and how interpersonal systems can impact personal systems.

Several participants mentioned they felt they were not offered full disclosure of their health information. This ranged from cancer staging, to pathology results, to prognosis. One participant stated he felt a lack of communication from some healthcare providers was deliberate, and speculated that this was a result of the average patient “not wanting to know the possibilities”

(Participant 8). He, and two others, stated several times how this increased their fears and frustrations. To prepare themselves mentally, they had wanted full disclosure in the beginning.

One participant stated he felt that different age generations wanted different amounts of disclosure. He had discussed this concept within a support group, and discovered the younger patients, in general, wanted to know all possibilities. By comparison, the older generations had "been through a lot in life and didn't want to know what could happen… just what to do when they did have symptoms" (Participant 8). This observation is interesting, and one to consider as the age cohorts of HNSCC patients are changing.

Most participants indicated they sought additional information about their disease and treatments from other sources, i.e. internet, family doctor, friends. One common frustration was a lack of credible information. This led to increased stress and fear:

> So you end up getting a piece of paper that says squamous cell carcinoma on it. You don't know what it is; you have to do your own research on the internet which is very complicated and very hard to get through. I feel, for myself, though quite educated and quite intellectual, there is so much medical technology on the internet – some of it says you're going to die tomorrow, some of it says you probably won't die…. (Participant 8)

This comment has two important messages when viewed from King's lens. The first is that participants may have significant fears associated with the unknown about their disease process. They have questions about their own health and mortality. And, they seek to have them answered. The second is that they may search for answers from multiple sources. The answers, from whatever source, have an impact on their levels of fear and stress. Timely, reliable communication by healthcare providers could serve to mitigate these fears. As healthcare providers are a component of an interpersonal system dyad, how we navigate and support patients has an impact on their health and wellbeing.

Social systems.

Finally, social systems, such as family or work systems, can change the environment and influence behaviours, interactions, perceptions and health. Participants included detailed descriptions of the influence of their diagnosis on both their families and their employment.

Family systems.

Most often, participants described their family and/or close circle of friends as their most important social system. However, two participants were socially isolated. By comparing participants with a strong family system to those without one, we can better understand the influence of the family on the person's health and wellbeing.

One participant lived in a rehabilitation centre where people stayed for weeks to months. For the most part, his social system was transient. Most people with whom he interacted left the facility within a few weeks. Initially, there were a few individuals with whom he connected during treatments. Later, when he was no longer interacting with these individuals, he described feeling a loss of social support. As well, he felt disconnected from newer patrons who had not been part of his treatment journey. In comparison, the participants who had close friends or families who participated in their care felt supported. One participant described how his family had ‘gone through it with him’ by pureeing food, preparing medications, or suctioning his tracheostomy. There was a ‘shared experience’ that the participant acknowledged as a strength.

All participants spoke of how the cancer and the treatments had affected family life and routines. This ranged from frustrations around not being able to have ‘a normal family dinner’ to adapting the family menu to softer foods, to feeling closer emotionally for having gone through the struggle together, to spending more time in relaxation or vacation.

Children were an important element in the cancer experience. Participants with children described the impact of the cancer on children. Several of the participants had school-aged children. Participants described how they disclosed their diagnosis to their children, how much information they had provided to them, and how they had involved their children. Approaches varied from attempting to shield children to having open conversations. Those with older or adult children more often included their children in their treatment and rehabilitation.

Participants also described the impact of their cancer diagnosis on their parents. Several of our participants had aging parents who had their own health concerns. This added stress or complexity to the daily life of these participants, as they were not able to fully engage or support their parents. They also reported that it was difficult for their older parents to see their adult child, the participant, endure a significant health challenge. One participant noted that his father had ignored his own prostate cancer because he was too focused on his son with HNSCC. As patients with HNSCC are often in middle adulthood, it is important to remember that their family social system may be multi-generational.

Family Nursing Theory could provide some insights about how to approach the complexities of supporting a family experiencing HNSCC. According to this approach, each individual is their own system, but also a member of bigger systems, i.e. spouse, parent/child, siblings (Wright & Leahey, 2013). This is visually represented by a set of concentric circles, the individuals at the centre, surrounded by a larger ‘family’ circle, surrounded by a larger contextual circle comprised of friends and work relationships. A change in any one circle in this system will require adaptation by the individuals in the other circles.

Family Nursing Theory fits well within King’s conceptual framework of interacting systems. In Family Nursing Theory, however, there is a shift in focus from the individual to the family as a unit of analysis. The frameworks outlined by King and by Family Nursing Theory could be used in an integrated way to inform the nursing approach to individuals with HNSCC and their families.

Work systems.

As discussed previously, employment and financial concerns were highly relevant to our participants during their treatment and recovery. Specifically, participants described when and why they were unable to work, considerations influencing return to work, and the meaning of work. These elements influence the personal, interpersonal, and social systems.

At the personal system level, work was seen as an outlet for creativity and a sense of normalcy. At the interpersonal level, leaving work meant increased stress for some couples due to financial constraints. Returning to work made several participants feel like ‘productive members of society again’ and was seen as a sign of recovery by both the participant and the spouse. Changes in work necessitated accommodation from both partners in the relationship.

At the social systems level, work was a venue for social interaction beyond the immediate family. Most participants felt their work environments and work colleagues were supportive and accommodating. Unfortunately, one participant felt he would be unable to work in sales again as he had significant speech impairment. He described that he felt others would see him as less intelligent due to his speech. This had profound impact on his sense of self as he had lost his ability to financially provide for his family.

Examples of the Influence of Interactions between Systems on Health.

The descriptions of the experiences of individuals with HNSCC in this study provide many examples of the ways in which systems interacted and influenced health. Three of these examples—stigma, gender, and voice—are discussed below.

Stigma.

The understanding of stigma has evolved since it entered psychology literature. Originally, Goffman defined stigma as “the situation of the individual who is disqualified from full social acceptance”, which “discounts or taints” the individual (1963, preface). The person with a stigma is considered different than the normal, is considered inferior, and experiences discrimination (Goffman, 1963). Stigma has evolved to also be understood as a “process shaped by structural and cultural forces” (Scambler, Heijnders & Van Brakel, 2006).

Several participants talked about stigma associated with HPV infection in HNSCC. This was related to the sexual nature of the disease. This is consistent with Newton and McCabe (2008), who explored the experiences of sixty adults, both male and female, with STIs, thirty of whom had HPV infections. Interviews revealed several themes including stigma, impact on sexuality, impact on relationships, and feelings about disclosure. Our participants’ perception of self, their interactions with intimate partners, and their decision about disclosure to family/friends were all affected by a perceived sense of judgment about the sexual transmission of HPV.

Scambler and Hopkins (1986) differentiated between enacted and felt stigma. “Enacted stigma refers to instances of discrimination against people… on the grounds of their perceived unacceptability” (Scambler & Hopkins, 2006). Felt stigma is the fear of enacted stigma, and also includes feelings of shame (Scambler & Hopkins, 2006). When individuals experience these feelings, the response is most often one of concealment (Scambler & Hopkins, 2006).

Felt stigma was described by several participants when discussing disclosure to past, current, or future sexual partners. Those who elected to disclose information about HPV in relation to HNSCC did so with caution. They described being met with varied responses, from shock and surprise, to acceptance. No one described having an actual negative experience in response to disclosure; however, they noted they had been selective regarding with whom they shared the information. Regardless of the response, their perceptions or fears of stigma were enough to cause an increase in anxiety in several participants. The perception of stigma influenced their personal and interpersonal systems. Stigmatization, the response of concealment, and the impact on quality of life and relationships requires further investigation for individuals with HPV-associated HNSCC cancer.

Interestingly, three participants indicated they felt an obligation to share the information about the link between HPV in HNSCC with friends and family. They viewed it as an opportunity to prevent others from experiencing a similar diagnosis. One participant described how he had paid for his son to be vaccinated and was outraged at the inequity of access to vaccines and HPV education. Two participants had been part of public fundraisers that highlighted risks factors and prevention strategies. For these individuals, having had HNSCC influenced their future health behaviours at both the personal and social systems levels.

It is interesting to consider that three participants who spoke openly about the cause of their disease to friends and family were all in stable, long-term relationships. Comparatively, the individuals who concealed their HPV were all single and faced the prospect of disclosure to future partners. All participants indicated they had learned HPV can be indolent for long periods and then can develop cancer many years after the initial infection. Two participants discussed feelings of frustration or anger toward former partner(s) at the time of diagnosis, but their focus shifted to survival quickly when treatment began. In contrast, fears around future disclosures or risk of transmission were often discussed as important, particularly to those who wished to embark on new intimate relationships. Open dialogue about intimacy concerns may need to be initiated by the clinician. Helping to prepare clients for discussions with family and friends about HPV would likely be helpful.

Gender.

For this discussion, gender is considered a socially constructed concept, including roles, relationships, and behaviours typically associated to men and women (Canadian Institutes of Health Research, 2012). By comparison, sex refers to a biological or physiological differentiation (Canadian Institutes of Health Research, 2012).

Gender and social patterns.

Although only one woman participated in this study, her experience of HNSCC seemed different than the experience of the male participants. For example, she described changes in her perceived role within her family with little emphasis on employment, perhaps because she was retired. Her sense of normalcy was found when she began cooking and caring for her grandchildren again. The men in the study, on the other hand, discussed a lack of physical strength, relying on their spouse to do personal care or household work. They described a sense of frustration in being unable to provide financially for their families. Having to stop work created financial hardships and added stress to the participant, whereas returning to work was found to bring a sense of normalcy and satisfaction. In a study about employment issues in HNSCC, significantly more women than men indicated appearance was an important factor in discontinuing employment (Buckwalter, Karnell, Smith, Christensen, & Funk, 2007). The men in our study did not make any reference to appearance as a factor influencing work-related decisions. Rather, they cited functional concerns such as eating and speech as the primary reasons for not returning to work.

Given the lack of women in this study population, it was difficult to fully explore the influence of gender on the experience of HNSCC. Further research focused on understanding the role of gender in HNSCC could assist patients and healthcare providers in development more holistic care plans for this population.

Gender and sexuality.

Questions about the links between HPV exposure, gender and sexuality have yet to be explored in the HNSCC literature. Several studies have examined gender as a variable in the experience of other STIs (Newton and McCabe, 2008; Clemmens et al, 2008, Perrin et al, 2006); however, both men and women have identified psychosocial concerns about sexuality and stigmatization. Concerns expressed included future partner disclosure and transmission risk (Newton and McCabe, 2008). Two of our participants noted that the diagnosis of HPV increased fear or anxiety when embarking on new intimate relationships. One participant indicated his partner changed her health behaviour by engaging in cervical cancer screening. Gender and sexuality could be viewed as interwoven variables of both interpersonal and social systems.

Gender and sex differences.

Gender and sex differences also exist at the societal level. In this situation, males are disproportionately affected with HPV-associated HNSCC (Chaturvedi et al, 2008). Despite evidence to support its safety and efficacy, Health Canada does not currently fund male access to HPV vaccination (Guiliano et al, 2011 Dobson, Deeks & Money, 2007; Health Canada, 2010). Males continue to be vulnerable to HPV and its associated sequelae. On the surface, this may appear solely to be a sex difference. However, it could also be considered gender discrimination and discrimination of sexual diversity. First, it could appear that, by limiting access to sexual health education and vaccination to females only, the health of females is more strongly valued than that of males. Second, by assuming the protection of females is sufficient in the protection of the population, homosexual or bisexual males, who are at increased risk of the infection, remain extremely vulnerable to HPV and its sequelae (Palefsky, 2010). In this way, an already stigmatized subsection of the population is further disadvantaged. Alternatively, perhaps hegemony persists as an extension of discriminatory gender stereotypes in who is principally responsible for sexual health promotion (Rae & Kerridge, 2011). The influence of interactions between gender, sex, and sexuality on the health of a person with HNSCC needs further exploration.

Voice.

In HNSCC, voice is an important issue both literally and figuratively. Many patients experience changes in the function of their voice. During some stages of treatment, they may have a tracheostomy tube, leaving them with no voice. The structures used to salivate and phonate may be affected by surgery or radiation therapies. These challenges make it more difficult for a person to make speech, and, therefore, express him/herself. Writing down every thought takes time, and can increase confusion and cause frustration.

Changes in physical voice may be temporary or permanent. The individual may need to do rehabilitative exercises to improve speech quality and stamina. Several of the participants indicated that not being able to speak was frustrating and sometimes even scary. Three participants had significant, long-term changes to their voice. They discussed challenges with being understood in phone conversations or speaking in crowded places. They needed to adapt their social patterns in order to preserve relationships with friends and colleagues. Unfortunately, one participant was unable to do this successfully, and described being socially isolated as a consequence. Changes in physical voice affected their personal, interpersonal and social systems, and consequently, their overall health.

Conceptually, voice also emerged from our data from the standpoint of advocacy as ‘speaking up’ and ‘speaking out’. During treatment and rehabilitation, this often meant speaking up for one’s self about care planning or symptom management. A lack of physical voice makes this difficult but not insurmountable. More concerning was the circumstance of not being listened to or heard. This was described, not as a physical concern, but as a concern of feeling valued or, more specifically, ‘devalued’.

Advocacy raises issues of who is heard, who should be heard and when is/should this hearing take place. During radiation, nearly all participants in this study spoke of debilitating exhaustion. Participants said they simply did not have enough energy to ‘speak up’ about concerns. This was often when the participant’s spouse or friend would ‘speak up’ on their behalf, and was most often for practical reasons, such as advocating for analgesia when pain was uncontrolled, or for hospital admission of a dehydrated patient. Participants and their spouses felt that if they had not ‘spoken up’, nothing would have changed, and more importantly, critical issues would not have been addressed. The importance of advocacy in this context raises two additional issues. First, who would speak up on behalf of the solitary or isolated patient who had no voice? And second, what does this say about the listener? Healthcare providers need to acknowledge the importance of actively listening to patients, and address the barriers that impede this. In this scenario, the listener was the healthcare provider, but it could include employers or governments making decisions about health systems. There is a role for healthcare providers in advocacy at the societal level, to increase awareness and prevention of the disease and conduct research towards improving patient outcomes.

‘Speaking out’ was a slightly different slant on advocacy. It had, within it, a future intention, a ‘pay it forward’ element. It had a promise of action and change. Nearly all participants discussed feeling a responsibility to engage in some type of ‘pay it forward’ activity. This included participation in research, in public education about HNSCC, or in being a role model or confidante for future patients. There was a perceived sense of satisfaction in being able to ‘speak out’. Moving from a position of not feeling heard to being asked to speak about their experience was important to them. Given the rewarding experiences associated with advocacy reported by our study participants, health care providers are encouraged to explore advocacy opportunities with individuals recovering (or recovered) from HNSCC.

Quality of Life Considerations within King's Theory

The definition of Quality of life (and Health-related Quality of Life) varies and has evolved over time. The UWQofL tool is a universally recognized, validated tool used to assess the quality of life in HNSCC patients. Although not stated in the original publication (Hassan & Weymuller, 1993), the authors of the UWQofL tool appear to have initially conceptualized quality of life in HNSCC in relation to physical function. The tool asked questions about pain, disfigurement, activity, recreation, employment, eating, speech, and shoulder function. Newer versions include assessment of anxiety and mood, as well as three general quality of life questions.

My understanding of quality of life stems from the World Health Organization's definition:

> An individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (World Health Organization, 1997)

My understanding of quality of life certainly includes the domains assessed in the UWQofL tool, but appreciates quality of life from a broader perspective. The World Health Organization definition (1997) fits within King's (1981) conceptual framework, as it acknowledges the importance of individual, interpersonal, environmental, and relational influences on health and well-being.

A preliminary discussion comparing the emerging themes in my data with the elements of the tool is in Section 2. The overarching message learned from this comparison is that quality of life is a broad concept that involves many domains. The UWQofL has evolved to more adequately assess quality of life but there are still some gaps. Employment and sexuality are significant components of the experience of younger HNSCC patients not included in the UWQofL tool. It is important for clinicians to initiate discussions with their patients about these elements, as they can be delicate or embarrassing for patients to disclose.

Summary of Results within King's Conceptual Framework

The participants in the study described their experiences as complex and multi-dimensional. In Section 2, I elected to highlight the themes that were most unique to the younger population. These included: a change in social patterns (with family, friends, and work), intimacy/sexuality, and financial concerns. As described above, these elements, as well as many other themes described, fit well within King's conceptual framework for nursing (1981). Particularly relevant, yet difficult to capture, are the ways in which the three systems interact. Stigma, gender and voice were used as examples of how themes became entwined and relevant to various systems.

Implications for Clinical Practice

Nurses are charged with the responsibility of caring for these clients at various stages of their cancer journey. Nurses who work in acute surgical or oncologic settings care for these clients and their families during the active treatment phase. The results from this study, when filtered through King's framework, reminds nurses that although their focus may be on immediate things such as pain management or fluid balances, there are many other important elements for the individual and family. Initiating discussions about health stressors, such as stress from employment changes, disclosing a cancer diagnosis to younger children, or unanswered questions about HPV pathology, are part of providing comprehensive patient-centered care.

Acute care nurses contribute to a patient's safe transition home, often with significant changes to their physical function. For example, these nurses teach clients how to use their feeding tube. The results of this study would challenge the nurse to move the discussion beyond function and technique. Helping patients and families explore what food and eating means to them and finding ways to keep important rituals as they explore adjustments warranted by HNSCC is part of a comprehensive care plan. Involving families in these conversations opens the doors to assess coping strategies and adaptability. In doing so, the nurse is acknowledging the impact of the client's health on the family unit and helping to foster resiliency. Wright and Leahey (2013) describe how nurses can intervene with families to change the affective domain of family functioning (p. 161) by encouraging the telling of the illness narrative. In so doing, families explore not just their illness experience, but stories of resiliency and strength (Wright & Bell, 2009).

Nurses who provide home care are responsible to help clients heal and rehabilitate. This can include the physical components of healing but is not limited to this one dimension. During rehabilitation, the nurse may also need to help individuals overcome a fractured sense of self brought on by the inability to work or to care for elderly family members, recognize the emotional implications of a cancer diagnosis, and work through questions about survival and mortality.

This study has potential implications for healthcare providers in other disciplines as well. Quality of life is an important aspect of care planning and decision-making for the patient and his/her healthcare team. Assessment of quality of life has become an expectation in our healthcare system. There is a strong movement to obtain quantitative data to help healthcare providers assess quality of life. Our inclusion of the UWQofL tool provides a way to engage quantitatively-driven clinicians in discussions about comprehensive care. Our study highlighted some of the strengths of this strategy, but also some of the gaps that exist when assessing a patient's quality of life with numbers alone. The results serve as a reminder to all clinicians that quality of life is a broad concept that includes many domains of health, including financial, social, and sexual and thus individuals recovering from HNSCC may require the assistance of social workers and psychologist, in addition to the usual treatment team comprised of physicians, surgeons, nurses, speech and language pathologists, dentists, dieticians, and physiotherapists.

Implications for Education

Public education.

Nurses in public health roles are responsible for educating the public about their health risks and guiding them into making healthier choices. In relation to cancers of the head and neck, this has traditionally meant encouraging individuals to quit smoking. With our new understanding about the role of HPV in HNSCC, nurses working in health promotion roles are now charged with the responsibility of adapting sexual health education programs and providing HPV vaccinations.

Despite the availability of evidence for several years, public awareness of the relationship between HPV in HNSCC is limited at best. Our participants all indicated they had no knowledge of the relationship between HPV in HNSCC prior to their diagnosis. Most education campaigns about HPV still focus on cervical cancer. This is despite HPV's known role in penile, anal, vulvar, vaginal and HNSCC (Kurdgelashvili et al., 2013).

Unfortunately, as HPV is an STI, it continues to carry with it some measure of stigma. Participants felt this stigma to varying degrees. Future public education campaigns to increase awareness about the infection and its consequences may prove to normalize the disease and, hopefully, reduce some of the stigmatization experienced by those diagnosed.

HPV vaccination has been available and free to Canadian females aged 9-26 through vaccination programs since 2006 (Health Canada, 2006). The program received support from both the National Advisory Committee on Immunization and the Canadian Immunization Committee (Public Health Agency of Canada, 2011). Despite incorporation into existing programs, vaccination rates of girls have been low (MacDonald, Stanbrook, & Hebert, 2008). Research into understanding the reasons for refusing HPV vaccination may help healthcare providers address this issue. Advocacy for universal access to HPV vaccination and education would help protect both men and women (Kim, 2011).

Education for healthcare providers.

As HNSCC impacts all aspects of a person, there are implications for all members of the interdisciplinary team. Physicians, nurses, dentists, and dental assistants have a role in prevention and early identification of HPV-associated HNSCC. Dietitians, Speech-Language Pathologists, Occupational therapists and Physiotherapists work closely with patients during active treatment and rehabilitation. Social workers are often critical in supporting patients experiencing financial and social stresses. Our results about changes to social patterns, intimacy and sexuality, and financial concerns are relevant to the entire interdisciplinary team when considering a comprehensive care plan.

Curriculum in healthcare education should reflect the evolving population of HNSCC and the implications of HPV. Those currently employed should be made aware of these implications through ongoing education opportunities and publications.

Implications for Research

This study provided a preliminary understanding of the experiences of individuals diagnosed with HNSCC at a younger age. This experience was complex and multi-faceted.

Prognostic implications are becoming more fully understood in biomedical research. The individuals are diagnosed younger but living longer. Survivorship considerations are highly relevant in this patient population and would be important research foci for healthcare providers. Our results provided only a preliminary understanding about patient and family adaptation. Longitudinal studies, from diagnosis to remission, would provide insight into quality of life and perceived health and wellness.

Because routine pathologic testing was not performed until recently, it was not possible to include HPV status in the inclusion criteria for this study. Our results indicated patients want to know more about their diagnosis. They have questions about transmission and risk for partners. They were looking for credible sources for this information. Many biomedical questions remain unanswered in this area.

From a psychosocial and sexual health standpoint, further understanding of the implications of HNSCC on sexuality, with the added complexity of HPV, would be beneficial. From a public health standpoint, a better understanding of transmission, prevalence, and efficacy of prevention are pertinent.

Opportunities exist for future work on gender differences in the experience on HNSCC. Unfortunately, we could not make gender comparisons as we only recruited 1 female participant. Targeted studies focused on gender differences may provide valuable insight into their experiences. Exploring the influence of body image/appearance, social and family roles, and sexuality in relation to gender would also be useful.

One of our major findings was related to employment. The trend of younger people experiencing temporary or permanent lack of employment is concerning from both psychosocial and economic standpoints. Further insight into what makes people stop working, what facilitates people returning to work successfully, and what healthcare providers can do to support patients in this domain is highly relevant for individuals and for society.

Another theme that emerged from our participants was that of the importance of family in the experience of HNSCC as well as the family experience of HNSCC. Changes in individuals and in the relationships between family members were seen in spouses/partners, children, and older parents. Further research could be done in exploring what families experience and they adapt to the experience of living with HNSCC. By understanding what families experiences and their perceived support needs, organizational support interventions could be developed to maximize optimal health of these families.

Quality of life in HNSCC is often assessed using validated quantitative tools. Our study identified both consistencies as well as gaps in the UWQofL tool. To date, it has not been tested in this younger subset of patients. Research could be conducted to assess if the current tool adequately meets the needs of these clients or if revisions should be made.

Implications for Health Policy

Organizational policy.

One challenge we experienced was a lack of organizational policy around HPV pathology. Initially the testing was not routine, and was only obtained by some clinicians when their suspicions of HPV were elevated, as in the case of younger men who had no smoking or drinking history. However, a smoking history does not preclude individuals from having HPV positive tumors. Consistent policy around HPV pathology testing is now routine in the setting where this study was conducted. It would be prudent to have routine testing of HNSCC for HPV in all institutions. This would allow for further research on local prevalence, prognostication, and impact to quality of life.

Provincial and National policy.

Adopting the role of advocate is the responsibility of all healthcare providers who care for individuals with HNSCC. HPV prevention through vaccination is both a pertinent and timely concern in national policy development. The National Advisory Committee on Immunizations recommended that HPV vaccinations be given to males (Public Health Agency of Canada, 2012). However, Health Canada does not currently federally fund males to receive HPV prevention through vaccination although some provinces have already adapted their policies to include males in existing programs (Public Health Agency of Canada, 2011). Based on the principles of herd immunity, gender-neutral policy could further protect both males and females from HPV infection (Public Health Agency of Canada, 2012). Advocacy for equal opportunities for education and vaccination should be a top priority for Canadians.

Conclusions

In conclusion, this study highlights the complexity of the experience for younger HNSCC patients. It is evident that beyond the substantial physical effects of HNSCC and its treatments, younger clients can experience social, sexual and financial consequences that impact their experience.

The impact of the experience on social interactions with family, friends, and the broader society emerged as relevant from diagnosis through treatment, rehabilitation, and remission. Employment was frequently identified as a concern both during and after treatments. This may be due to the age and stage of the individuals diagnosed, as well as the improved survival rates observed in this population. Clients may experience concerns related to intimacy and sexuality as a result of the cancer and its treatments. With the added element of HPV infection, there can be additional concerns for patients and families.

Quality of life tools are routinely used in clinical settings. The UWQofL tool addresses many of the functional concerns identified by clients. However, it may not address all of the elements contributing to their perceived health, including social, sexual, and financial concerns.

As there is improved survival in this population, a focus on survivorship issues like social patterns with family and friends, intimacy/sexuality concerns, and financial concerns should be addressed with patients to improve their overall health and wellbeing. Healthcare providers should also consider these elements when assessing and supporting these patients.

References

Buckwalter, A., Hynds Karnells, L., Smith, R., Christensen, A., & Funk, G. (2007). Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Archives of Otolaryngology Head and Neck Surgery*, 133, 464-470.

Canadian Institutes of Health Research. (2012). *What a Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook*. Retrieved from: http://www.cihr-irsc.gc.ca/e/44734.html#aiv

Chaturvedi, A., Engels, E., Anderson, W., & Gillison, M. (2008). Incidence trends for human papillomavirus-related and –unrelated oral squamous cell carcinomas in the United States. *Journal of Clinical Oncology, 26(4),* 612-619

Clemmens, D., Knafl, K., Lev, E., & McCorkle, R. (2008). Cervical cancer: patterns of long-term survival. *Oncology Nursing Forum, 35(6),* 897-903. doi: 10.1188/09.ONF.897-903

Dobson, S., Deeks, D., & Money, D. (2007). Statement on human papillomavirus. *Canada Communicable Disease Report,* 33(ACS-2). Retrieved Nov. 14, 2011 from: http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/07vol33/acs-02/index-eng.php

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Shuster.

Guiliano, A., Palefsky, J., Goldstone, S., Moreira, E., Penny, M., Aranda, C., … & Guris, D. (2011). Efficacy of quadrivalent HPV vaccine against HPV infection and disease in males. *New England Journal of Medicine, 364*, 401-411.

Hassan, S. & Weymuller, E. (1993). Assessment of quality of life in head and neck cancer patients. *Head and Neck*, 15, 485-496.

Health Canada. (2006). *Summary Basis of Decision: Gardasil.* Merck Frosst Canada. Retrieved from: http://www.hc-sc.gc.ca/dhp-mps/alt_formats/hpfb-dgpsa/pdf/prodpharma/sbd_smd_2007_gardasil_102682-eng.pdf

Health Canada. (2010). *Human Papillomavirus.* Retrieved from: http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/hpv-vph-eng.php

Kim, J. (2011). Weighing the benefits and costs of HPV vaccination of young men. *New England Journal of Medicine*, 364(5), 393-395.

King, I. (1981). *A Theory for Nursing: Systems, Concepts, Process*. New York: Wiley.

Kurdgelashvili, G., Dores, G., Srour, S., Chaturvedi, A., Huycke, M., & Devesa S. (2013). Incidence of potentially human papillomavirus-related neoplasms in the United States, 1978 to 2007. *Cancer*, April 11. Doi: 10.1002/cncr.27989.

MacDonald, N., Stanbrook, M., & Hebert, P. (2008). Human papillomavirus vaccine risk and reality. *Canadian Medical Association Journal,* 179(6), 503. Doi: 10.1503/cmaj.081238

Newton, D, & McCabe, M. (2008). Sexually transmitted infections: impact on individuals and their relationships. *Journal of Health Psychology, 13(7),* 864-869. doi: 10.1177/1359-05308095058

Palefsky, J. (2010). Human papillomavirus-related disease in men: not just a women's issue. *Journal of Adolescent Health*, 46(Supp), S12-S19.

Perrin, K., Daley, E., Naoom, S., Packing-Ebuen, J., Rayko, H., McFarlane, M., & McDermott,R. (2006). Women's reactions to HPV diagnosis: insights from in-depth interviews. *Women & Health, 43(2),* 93-110. doi: 10.1300/J013v43n02_06

Public Health Agency of Canada. (2011). *Human Papillomavirus (HPV) Prevention and HPV Vaccines: Questions and Answers.* Retrieved from: http://www.phac-aspc.gc.ca/std-mts/hpv-vph/hpv-vph-vaccine-eng.php

Public Health Agency of Canada. (2012). *Update on Human Papillomavirus (HPV) Vaccines.* Retrieved from: http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/12vol38/acs-dcc-1/index-eng.php#a5

Rae, M. & Kerridge, I. (2011). Vaccines – but not as we know them: an ethical evaluation of HPV vaccination policy in Australia. *Australian and New Zealand Journal of Public Health*, 35(2): 1760179. doi: 10.1111/j.1753-6405.2011.00652.x

Robles, S., White, F., & Peruga, A. (1996). Trends in cervical cancer mortality in the Americas. *Bulletin of the Pan American Health Organization*, 30(4), 290-301.

Scambler, G., Heijnders, M., & Van Brakel, W. (2006). Understanding and tackling health-related stigma. *Psychology, Health & Medicine*, 11(3), 269-270. Doi: 10.1080/13548500600594908

Scambler, G. & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health and Illness*, 8, 26-43.

Thorne, S. (2008*). Interpretive Description*. Walnut Creek, California: Left Coast Press.

Thorne, S. (2010). Toward methodological emancipation in applied health research. *Qualitative Health Research*, 21(4), 443-53.

World Health Organization (1997). *WHOQOL Measuring Quality of Life.* Retrieved from: http://www.who.int/mental_health/media/68.pdf

Wright, L. & Bell, J. (2009). Beliefs and Illness: A Model for Healing. Calgary, AB: 4th Floor Press.

Wright, L. & Leahey, M. (2013). *Nurses and Families: A Guide to Family Assessment and Intervention, 6th ed.* Philadelphia, Pennsylvania: F.A. Davis Company.

Appendix A

UNIVERSITY OF WASHINGTON QUALITY OF LIFE REVISED QUESTIONNAIRE

This questionnaire asks about your health and quality of life over the past seven days. Please answer all the questions by checking one box for each question.

1. Pain. (check one box)
☐ I have no pain
☐ There is mild pain not needing medication.
☐ I have moderate pain-requires regular medication (codeine or nonnarcotic)
☐ I have severe pain controlled only by narcotics.
☐ I have severe pain, not controlled by medication.

2. Appearance. (check one box)
☐ There is no change in my appearance.
☐ The change in my appearance is minor.
☐ My appearance bothers me but I remain active.
☐ I feel significantly disfigured and limit my activities due to my appearance.
☐ I cannot be with people due to my appearance.

3. Activity. (check one box)
☐ I am as active as I have ever been.
☐ There are times when I can't keep up my old pace, but not often.
☐ I am often tired and have slowed down my activities although I still get out.
☐ I don't go out because I don't have the strength.
☐ I am usually in bed or chair and don't leave home.

4. Recreation. (check one box)
☐ There are no limitations to recreation at home or away from home.
☐ There are a few things I can't do but still get out and enjoy life.
☐ There are many times when I wish I could get out more, but I'm not up to it.
☐ There are severe limitations to what I can do. I stay at home and watch TV.
☐ I can't do anything enjoyable.

5. Swallowing. (check one box)
☐ I can swallow as well as ever.
☐ I cannot swallow certain solid foods.
☐ I can only swallow liquid food.
☐ I cannot swallow because it "goes down the wrong way" and chokes me.

6. Chewing. (check one box)
☐ I can chew as well as ever.
☐ I can eat soft solids but cannot chew some foods.
☐ I cannot even chew soft foods.

7. Speech. (check one box)
☐ My speech is the same as always.
☐ I have difficulty saying some words but I can be understood over the phone.
☐ Only my family and friends can understand me.
☐ I cannot be understood.

8. Shoulder. (check one box)
☐ I have no problem with my shoulder.
☐ My shoulder is stiff but it has not affected my activity or strength.
☐ Pain or weakness in my shoulder has caused me to change my work.
☐ I cannot work due to problems with my shoulder.

9. Taste. (check one box)
☐ I can taste food normally.
☐ I can taste most food normally.
☐ I can taste some foods.
☐ I cannot taste any foods.

10. Saliva. (check one box)
☐ My saliva is of normal consistency.
☐ I have less saliva than normal, but it is enough.
☐ I have too little saliva.
☐ I have no saliva.

Which issues have been the most important to you <u>during the past 7 days?</u>

Check up to 3 boxes.

☐ Pain
☐ Appearance
☐ Activity
☐ Recreation
☐ Swallowing
☐ Chewing
☐ Speech
☐ Shoulder
☐ Taste
☐ Saliva

General Questions

Compared to the month before you developed cancer, how would you rate your health related quality of life? (check one box)

☐ Much better
☐ Somewhat better
☐ About the same
☐ Somewhat worse
☐ Much worse

In general, would you say your health related quality of life <u>during the past 7 days</u> has been:

☐ Outstanding
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Very poor

Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being rate your overall quality of life during the past 7 days. (check one box)

☐ Outstanding
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Very poor

Total Score____

Appendix B: Consent Letter - Participant

UNIVERSITY OF
ALBERTA
Faculty of Nursing

Faculty of Nursing
Level 3, ECHA
11405 87 Avenue
University of Alberta
Edmonton Alberta, Canada T6G 1C9

kscoates@nurs.ualberta.ca
www.uofaweb.ualberta.ca/nursing

Tel: 780.492.4506
Fax: 780.492.2551

PARTICIPANT CONSENT FORM

Title of Study: The Experiences of the Younger Head and Neck Cancer Client

Principal Investigator: *Kate Coates, RN*
Contact Number: 780-492-4506
Supervisor: Dr. Karin Olson
Contact Number: 780-492-6403

Research/Study Coordinator: Kate Coates, RN

Why am I being asked to take part in this research study?

You are being asked to be in this study because you have been diagnosed with head and neck cancer at a younger age.

The research study is being done to help nurses and doctors better understand what it is like to have head and neck cancer as a young or middle-aged adult. This disease is becoming more common in younger adults. We want to understand what it is like to have this kind of cancer, how it affects you and your family, and what we can do to help support other people in the future.

This study is being done through the University of Alberta, Faculty of Nursing. There are study members from the Faculty of Nursing and the Faculty of Medicine/Dentistry who will be involved.

Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

The purpose of the study is to better understand what it is like to live with head and neck cancer as a young or middle-aged adult. We hope that the information we gather will help members of the healthcare team understand and support persons with this disease. We also want to know if the questionnaire that we use captures what is important to younger adults.

What will I be asked to do?

In order to help us understand what it is like to have head and neck cancer at a younger age, you will be asked to answers some questions. We will ask to tape-record this conversation, so we can listen to it and try to understand more. If you do not want to be recorded, the researcher can simply take written notes. Also, we will ask you to fill out a questionnaire about your quality of life each time we meet.

You will be asked to meet with the researcher 2-3 times. Each visit will likely take about an hour. The study will last until the end of the summer 2012. The interviews can happen in your home, in the hospital, or near the University. You can decide where you feel more comfortable. Also, if you would like to have a family member present, you are welcome to do that.

Before you meet with the interviewer, we will need some information from your medical record. We will record the following information: name, age, gender, medical diagnosis including location of cancer and type of cancer, timing of treatments (dates of surgery, chemotherapy or radiation). We record this information so we can find similarities and differences among participants. We are interested in learning more about relationships among age, gender, type of cancer, and type of treatment.

What are the risks and discomforts?

We do not anticipate any physical risks to participating in the study. However, it is possible that the conversations may be emotional or uncomfortable for you. The nature of this disease can be personally and emotionally difficult. You will be able to decide what you want to talk about and what you do not want to talk about.

"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 you need to do?

You will need to be available for 2-3 interviews that will last about one hour each over the next few months. You will also need to complete the Quality of Life tool during each session.

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 understand what it is like for you and your family.

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 being in the study at any time, and it will in no way affect the care or treatment that you are entitled to.

Will I be paid to be in the research?
No, there is no payment to be in this study.

Will my information be kept private?
During the study we will be collecting health data about you. 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. 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 health information is kept private.

The study doctor/study staff may need to look at your personal health records held at the study doctor's office, and/or kept by other health care providers that you may have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will be only what is needed for the study.

During research studies it is important that the data we get is accurate. For this reason your health data, including your name, may be looked at by people from:

The University of Alberta

By signing this consent form you are saying it is okay for the study doctor/staff to collect, use and disclose information about you from your personal health records as described above.

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for 5 years after the end of the study.

If you leave the study, we will not collect new health information about you, but we will need to keep the data that we have already collected.

What if I have questions?
If you have any questions about the research now or later, please contact:
Kate Coates, kscoates@ualberta.ca 780-492-4506 or Dr. Karin Olson, Karin.olson@ualberta.ca 780-492-6403

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: The Experiences of the Younger Head and Neck Cancer Client

Principal Investigator(s): **Phone Number(s):**
Study Coordinator: **Phone Number(s):**

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name ____________________	☐	☐

Who explained this study to you? ____

I agree to take part in this study:

Signature of Research Participant ____

(Printed Name) ____

Date:________________________________

Signature of Witness ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee________________________________
Date ___________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix C: Letter of Consent – Spouse

UNIVERSITY OF ALBERTA

Faculty of Nursing

Faculty of Nursing
Level 3, ECHA
11405 87 Avenue
University of Alberta
Edmonton Alberta, Canada T6G 1C9

kscoates@nurs.ualberta.ca
www.uofaweb.ualberta.ca/nursing

Tel: 780.492.4506
Fax: 780.492.2551

Verbal Consent Script for Spouse of Participant

Title of Study: The Experiences of the Younger Head and Neck Cancer Client

Principal Investigator: *Kate Coates, RN*
Contact Number: 780-492-4506
Supervisor: Dr. Karin Olson
Contact Number: 780-492-6403

Research/Study Coordinator: Kate Coates, RN

To: “Participant Spouse”

During my interviews, several participants invited their spouses to be involved in the research process. As I analyzed my data, I realized the information provided by spouses would likely be helpful for others. I would like to include the spouses’ contributions in my final thesis and the potential research presentations and publication(s).

At the time of data collection, I obtained consent from each participant (your spouse), but did not ask you (the spouse) to provide consent. In order to include the data collected from you, I require your consent. I have, and will continue to, keep your information confidential and will remove any potential identifiers from the data. Only members of the study team have access to the research files. As per University of Alberta Ethics policy, the information will be kept in a locked office and filing system for a minimum of 5 years.

We do not anticipate any physical risks to participating in the study. However, it is possible that the conversations may be emotional or uncomfortable for you. The nature of this disease can be personally and emotionally difficult. You will be able to decide what you want to talk about and what you do not want to talk about.

Including your information in the study is your choice. If you decide you do not wish to have your information included, it will not be in my thesis, research presentations, or publications.

I am happy to answer any questions you may have about the nature of the study or how your information will be used. [opportunity for questions here]

If you agree to proceed, I will now go through a series of yes/no questions for you to answer. At the end, I will ask if you agree to have your information included in the study. If so, I will sign and date the form on your behalf. [complete the below questions]

I thank you for your involvement and greatly appreciate your support in this process.

Please refer to the UofA Research Ethics Office at 492-2615 should there be any questions regarding one's rights as a research subject.

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand the benefits or risks to participation?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records?	☐	☐

Who explained this study to you? ____

I agree to take part in this study:

Signature of Research Participant ____

(Printed Name) ____

Date:___________________________________

Signature of Witness ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee_________________________________

Date ___________

Appendix D: Initial Participant Contact Letter

Dear Patient,

I am a nurse and a student in the Masters of Nursing program at the University of Alberta. I am currently conducting a study about the experience of being diagnosed with head and neck cancer as a younger person. I would like to meet with you briefly to tell you more about the study. At that time I will review the study in more detail and answer any questions you may have about it. The purpose of the meeting is to provide you with the information needed in order to decide whether you would like to participate in the study. You are under no obligation to participate, but if you wish to do so, I will ask you to sign a written consent form. Please complete the bottom of this form and place it in the box that says "Study" on the front counter.

If you would be willing to meet with me, please sign the form below and provide your phone number. Please also indicate whether it would be ok for me to leave a message for you at the number you provide, in the event that I am not able to reach you. Thank you for considering this request.

Sincerely,

Kate Coates
MN Student
Faculty of Nursing
University of Alberta

__________ I would like to hear more about the study and can be reached at the number below:

Name ______________________ Phone ________________________ Ok to leave message Yes _______ No _______________

IF YOU RECEIVED THIS AT YOUR CLINIC APPOINTMENT, PLEASE PLACE IN BOX THAT SAYS "STUDY" ON THE FRONT COUNTER

IF YOU RECEIVED THIS VIA MAIL, PLEASE PLACE THE SIGNED LETTER IN THE SELF-ADDRESSED ENVELOPE AND RETURN VIA THE POSTAL SERVICE