


# Experiences of Head and Neck Cancer Patients in Middle Adulthood: Consequences and Coping

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## Abstract

The head and neck cancer (HNC) rate is rising among the middle-aged adult population. This trend has been attributed primarily to human papillomavirus exposure. An HNC diagnosis and its complex treatments may trigger life-changing physical, emotional, and social consequences. An interpretive descriptive study was conducted to describe the experiences of a purposive sample of 10 middle-aged adults who had experienced HNC. Two main themes were identified: consequences of HNC and coping with HNC. Subthemes of consequences of HNC included: voicelessness; being or looking sick; shifts in family dynamics; and sexual practices, sexual feelings, and stigma. Subthemes of coping with HNC included seeking information, discovering inner strengths, relying on a support network, establishing a sense of normalcy, and finding meaning within the experience. Supportive nursing interventions were identified by considering results from the standpoint of King's theory of goal attainment.

## Keywords

cancer, psychosocial aspects, coping and adaptation, families, caregivers, interpretive description, nursing

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## Introduction

Head and neck cancer (HNC) is the sixth most common cancer worldwide (Mallen-St Clair, Alani, Wang, & Srivatsan, 2016) and the eighth most common cause of cancer death (O'Rorke et al., 2012). Traditionally, an HNC patient was an older man (>65 years old) with certain risk factors including smoking and alcohol use. However, incidence rates related to this etiology have declined because of tobacco cessation efforts (Sturgis & Cinciripini, 2007). The incidence rates of HNC to the base of tongue, tonsils, and oropharynx are rising in adults between the ages of 40 and 59 (Chaturvedi et al., 2011), with more than 60% of new cases attributable to human papillomavirus (HPV) exposure worldwide (Ang et al., 2010; Lewis, Kang, Levine, & Maghami, 2015; Mehanna et al., 2013). Most HPV infections are asymptomatic; therefore, it is difficult to know true prevalence rates. However, in developed countries including Canada, the United States, and Australia, several groups have estimated that 75% to 80% of sexually active adults will have an HPV infection at some point during their lives (Australian Government Department of Health, 2017; Centers for Disease Control and Prevention, 2017; Society of Obstetricians

and Gynaecologists of Canada, 2017). In underdeveloped countries, HPV infection incidence and prevalence rates are even more difficult to determine, but may be even higher given that research has demonstrated even higher rates of HPV in women based on cervical cytology results, particularly in Africa and Oceania (Serrano, Brotons, Bosch, & Bruni, 2017). Most HPV infections resolve spontaneously; however, persistent infection in some people can cause development of HPV-associated cancers such as cervical, penile, rectal, and HNC (Serrano et al., 2017; Society of Obstetricians and Gynaecologists of Canada, 2017). Individuals who develop HNC under these conditions tend to present with advanced disease and be in middle adulthood (fourth and fifth decades) at the time of diagnosis, male, and from a higher socioeconomic status (D'Souza, Zhang,

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D'Souza, Meyer, & Gillison, 2010; Gillison et al., 2008). HPV-related HNC is associated with behavioral risk factors such as marijuana use, open-mouth kissing, having an increased number of oral sex partners, higher numbers of sexual partners, being  $\leq 18$  years old at the time of first oral sex, and having a history of cervical HPV infection (Pickard, Xiao, Broutian, He, & Gillison, 2012). The good news, however, is that individuals with HPV-related HNC respond better to cancer treatments and have better survival rates than individuals with HNC unrelated to HPV (Chaturvedi et al., 2011; Fakhry et al., 2008).

## Background

Many authors have explored the physical and psychosocial challenges faced by individuals with HNC that were caused mainly by smoking or alcohol use (Onakoya, Nwaorgu, Adenipekun, Aluko, & Ibekwe, 2006; Sayed et al., 2009; Semple, Dunwoody, George Kernohan, McCaughan, & Sullivan, 2008; Ziegler, Newell, Stafford, & Lewin, 2004). There is limited research exploring challenges faced by middle-aged adults with HNC or the ways nurses can best support them.

HNC and its treatments are associated with frequently irreversible physical issues including impairments in speech, swallowing, and saliva production; and prolonged pain and fatigue. Individuals with HNC also experience social and psychological issues associated with disfigurement/body image, inability to return to work, resistance to eating in public, and stigma associated with having a disease that is increasingly transmitted through sexual practices (Dwivedi et al., 2009; Fingeret et al., 2013; Hunter et al., 2013; Logan, 2009). Patients may also experience increased levels of depression and anxiety when compared with individuals with other types of cancer (Chen et al., 2013; Chen et al., 2009; Singer et al., 2012). Some patients and their spouses have even been shown to experience severe psychiatric symptoms consistent with a diagnosis of posttraumatic stress disorder. These symptoms can include intrusive negative thoughts, avoidance of negative thoughts and behaviors, and hyperarousal symptoms (Posluszny et al., 2015). A recent retrospective study showed that 31 of 69 (44.9%) HNC patients had a positive depressive screen at diagnosis, but no obvious risk factors (including HPV status) were identified (Qualliotine et al., 2017).

Although the definition of middle-aged varies in the literature, in this study, we define middle-aged adults as those 40 to 65 years old. According to the developmental theorist Erik Erikson, middle adulthood is the stage of generativity, a time during our lives when we give back to society, raise children, become involved in community, become productive in our work, and understand ourselves within a bigger picture (Erikson & Erikson, 1998). Failure to achieve this milestone is called stagnation, and results in feelings of dissatisfaction or being unproductive. The physical, social,

sexual, and psychological consequences of HNC may place a significant burden on middle-aged HNC survivors who are trying to manage developmental milestones such as maintaining a relationship with a spouse or significant other, raising a family, supporting aging parents, and managing career-related issues (Katz, Peace, & Spurr, 2012).

Given the significant changes to HNC etiology and the resultant change in patient demographics, there is a need to improve our understanding of the experiences and concerns of middle-aged HNC survivors. The purpose of this study was to begin addressing this knowledge gap by describing the experience of middle-aged adults with HNC. The research question was as follows:

**Research Question 1:** How do middle-aged adults with HNC describe their experience?

## Method

### Design

This study was designed using interpretive description as developed by Thorne (2008, 2016). We chose this approach because our goal was to begin describing the experience of patients seen in the clinical practice of the principal investigator and to explore potential nursing interventions to support those patients. Interpretive description was developed for qualitative research in applied health disciplines that seek to answer clinical questions (Thorne, 2008, 2016). The answers are obtained by generating a thick description of the experience and subsequently interpreting the description through a disciplinary lens. In this study, nursing interventions were identified by considering the findings from the standpoint of the theory of goal attainment developed by King (1981).

### Sample

A purposive sample (Field & Morse, 1985) was obtained from the surgical and oncologic units of two hospitals in a large Canadian urban center between May and November 2012. By recruiting from the two selected sites, we increased the likelihood that we would be able to recruit individuals receiving all available treatment modalities (chemotherapy, radiation, or surgery). Eligibility criteria included being diagnosed and treated (any combination of surgery, chemotherapy, and radiation) for HNC within the previous 3 years, being between 18 and 65 years of age, living in the surrounding urban region, and being able to read, write, and speak English sufficiently to be understood by the interviewer. Many patients have temporary or chronic changes in their speech, and so the ability to speak/be understood was initially assessed when contacting the patient over the phone, and reassessed during the consent procedure. Exclusion criteria included undergoing current treatment for HNC, and having a

recurrent form of the disease. We did not incorporate HPV status in the inclusion or exclusion criteria as it had only recently become standard practice to test for HPV pathology in our setting and, thus, HPV status was not uniformly available for all HNC patients. Although we attempted to recruit men and women, most of the eligible individuals were men, reflecting the epidemiology of the disease (Chaturvedi, Engels, Anderson, & Gillison, 2008). Recruitment continued until a clear and comprehensive description of the experience of HNC was obtained (Thorne, 2016).

### *Ethics*

The study was approved by the Research Ethics Board at the University of Alberta. Written consent was obtained by all patients. Verbal consent was recorded on tape by the spouses who attended the interview in a support role. We had not initially planned to include spousal contributions but when it became evident that including the spouses helped patients convey their experiences, an ethics amendment was submitted and granted to include spousal contributions. Written consent was then obtained retroactively from four spouses who had already participated in interviews. Written consent was obtained prospectively from the one spouse who attended an interview after the amendment had been approved.

### *Data Collection and Analysis*

Nurse practitioners at each recruitment site identified a total of 18 individuals (15 men, three women) who met the inclusion criteria. A contact letter explaining the purpose of the study was sent to these individuals. Individuals interested in obtaining more information were asked to contact the principal investigator. The principal investigator provided a more detailed description of the study to those who contacted her, answered any questions, obtained written consent, and scheduled all interviews. Patients were told that they were welcome to bring a spouse or other support person to the interview if they wished. As all support persons self-identified as “spouse,” we will refer to them in this manner going forward. As the study progressed, the spouse who attended spoke up during the interviews primarily to clarify context or language on behalf of the patient, particularly in cases where a patient had a speech impairment.

All interviews began with an unstructured approach to allow the patient to direct the conversation and describe the experience in the way that best suited him or her. A general introduction to the study was provided and then patients were invited to describe their experience with a broad statement: “Please tell me what it has been like for you to have head and neck cancer.” Patients generally described their personal experiences in the form of a story beginning before their diagnosis and continuing through treatment and recovery. Follow-up questions were asked throughout the

interview for clarification. Interviews were digitally recorded, transcribed verbatim, and checked for accuracy. The contributions from the spouse were indicated as a third speaker in the transcript. The principal investigator took field notes to document the general context of the interviews as well as nonverbal aspects of communication, clarifications obtained through gestures, and writing from those with speech impairments.

Data were collected and analyzed concurrently. Data were analyzed by hand and managed using Excel software. Data analysis occurred in four steps, each of which included the primary investigator and at least one, but often several, other authors: (a) We began by reading the first four interviews for broad themes and developed definitions for these themes; (b) with these in mind, we examined and coded the same four transcripts line by line to more clearly understand these themes, identify any subthemes, and determine whether any data did not fit within the broader themes; (c) we then applied these codes and themes to all subsequent interviews, with new ideas added as the study proceeded; (d) investigators together discussed and compared the transcripts, and organized the data into two major themes and several subthemes. Although the data are presented in this way, it should be acknowledged that the themes sometimes overlapped and intersected, as is the complex nature of the health/wellness/illness experience.

Field notes were used to provide more information about the emerging themes and subthemes. They primarily provided a general context for the interview and speech clarification for those with an impairment. Spouses’ contributions were considered in relation to the information the patient was trying to convey and helped to clarify the patient’s experience.

### *Rigor*

Thorne (2008, 2016) describes four criteria to establish rigor: epistemological integrity, representative credibility, analytic logic, and interpretive authority. Epistemological integrity was ensured by documenting a clear, logical, and defensible line of reasoning from the research question through to the nursing implications. For example, we understood that our question was broad and required the patients to identify their own concerns. Therefore, we conducted unstructured interviews that allowed them to direct the conversation and describe their experience in as much detail as they wished. We achieved representative credibility by acknowledging that our results reflect the experience of a specific group: middle-aged adults experiencing HNC. We ensured analytic logic by reflecting on and documenting all decisions made by the research team in the form of an audit trail. The audit trail included a timeline of the project, any questions or challenges that we encountered, and the resolutions we decided with our associated rationale. Finally, to demonstrate interpretive authority, we engaged in ongoing reflection of our

positioning within the research including acknowledging the clinical backgrounds of several of the authors who cared for this patient population. To minimize clinical bias and avoid potentially altering the patients' responses, the principal investigator did not recruit patients for whom she provided care. To minimize potential influence, the research team reviewed and discussed all transcripts with a minimum of two authors present, and only after anonymization. In addition, we anchored all our identified common themes with direct quotes from study patients.

## Results

Of the 18 potential patients who were sent an initial contact letter, 10 contacted the investigator for further information. All 10 consented to participate in the study. Nine of the 10 were men. The age range was 42 to 65 years (median = 54 years). As our sample did not include any patients between the ages of 18 and 42 years, the study was focused on the experiences of middle-aged adults. Time since the start of treatment ranged from 2 to 19 months (median = 14 months). Eight of the 10 patients lived in an urban area, and two lived in a rural area. All had access to universal health care services in a specialty oncology center. Five of the 10 patients had undergone surgery followed by chemotherapy and radiation, two had undergone radiation and chemotherapy without surgery, and three had undergone surgery followed by radiation only. P16 immunohistologic testing, a surrogate marker for HPV, confirmed HPV pathology in five patients and HPV-negative pathology in one patient. The remaining four patients were not tested for P16. Although we did not focus on HPV pathology specifically, the pathology results are included because most patients discussed HPV as an important aspect of their experience regardless of the testing results. Between the consent date and the time of the interview, one patient was found to have recurrent disease. The patient wished to continue with the study. After discussing the situation with the research team, we chose to continue with the interview. During data analysis, we considered this aspect potentially unique.

We did not exclude any patients based on speech ability. Three patients had ongoing moderate-to-severe speech challenges requiring the interviewer or spouse to clarify words or phrases during interviews. Four patients were still employed in the jobs they had held when diagnosed. One had been unemployed before diagnosis but secured employment after treatment, two were retired by choice, and three were unable to return to their previous work or any employment. As noted above, all five support persons identified themselves as the patients' spouse. Four spouses were women and one was a man.

All patients were interviewed once, with interviews ranging from 33 to 108 minutes ( $M = 56$  minutes). The descriptions of the experience of having HNC cancer at this age were remarkably consistent, with no new aspects to add to the description after the eighth patient. The final two patients

were included to confirm the description we developed based on the first eight patients. Initially, we had considered follow-up interviews. However, we elected not to do so because the description developed based on the first interviews was felt to be sufficiently comprehensive. The study findings are presented under two main themes: consequences of having HNC and coping with HNC.

## Consequences of HNC

Although the interviews made it clear that there are many consequences of HNC, the following four subthemes were identified as being particularly important: voicelessness, being or looking sick, a shift in family dynamics, and sexual practices, sexual feelings, and stigma. Patients said they had to adapt in these areas as a result of their HNC diagnosis and treatment.

**Voicelessness.** Nearly all patients described experiencing voicelessness during treatment. For some patients, the changes to their physical voice were temporary. For others, the changes were permanent. Patients who underwent surgery said that speaking was impossible because of a tracheostomy tube, swelling, or poor tongue movement. Patients who underwent radiation described changes in saliva production and, subsequently, to their voices. They were often misunderstood on the phone or when speaking in crowded places. Consequently, it was difficult to undertake many tasks related to their jobs, and some were unable to return to work. One patient stated,

I honestly thought I would be fine and that I'd be back at work in six months doing what I had always done. I worked in sales . . . but I can't go back. I have to sit in front of all these important people you know, they would look at me in my business as not as intelligent because of the way I speak.

Alternative methods of communication such as writing or gesturing were used, but were time consuming and exhausting. Patients said the alternative methods led to delayed self-expression, confusion, and frustration.

Patients said that initially they experienced feeling voiceless as a physiological condition. However, throughout the journey, they also experienced a psychological or metaphorical voicelessness. One patient described the terror of choking on secretions and being unable to yell for help. Another patient described being unable to effectively advocate for pain medication. These experiences led to increased feelings of fear and vulnerability, and translated into feelings of being unimportant, unheard, or unsafe. One patient wondered, "would the nurses even hear me if I was choking all by myself?" He felt unable to speak for himself. Those with chronic impairment discussed ongoing feelings of frustration, anger, and sadness related to losing their voices.

*Being or looking sick.* Each patient said that being or looking sick changed his or her self-image. Prior to their diagnosis, the patients perceived themselves as healthy, busy, productive, and engaged in their families or communities. HNC shattered these perceptions. A common initial reaction to receiving an HNC diagnosis was denial, shock, or anger. “I heard about cancer because of smoking and all this stuff but I don’t, maybe most people are like me and they think I’ll never get that . . . I was one of *those* people.” For all patients, this was their first health crisis. They described how difficult it was to go from feeling healthy, productive, and independent to sick, dependent, or, as one patient labeled it, *idle*. Another patient described this:

When I was so healthy and could *do* and was into sports and we had farms and working and kids and volunteer, you know it’s busy, we were busy all the time. To go from there to just . . . being sick.

The effects of treatment perpetuated the perception of being sick. One patient described debilitating fatigue during radiation therapy:

It’s a very odd thing because 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-hoper things . . . I just thought that my body had completely collapsed to the point of having no energy at all and it just needed time to come back. So there was days that I had difficulty getting up the stairs.

Initially, looking sick was about outward appearance such as scars and disfigurement or what other people could see. However, self-image broadened to include not just the disfigurement but how each patient felt about it.

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—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 honor, you know—I don’t have to be so insecure about it. What I see and what other people see are two different things.

Another patient saw his surgical scars as a metaphor. “They just cut so many things,” he said of the surgeons. “I think they cut up my emotions.” Overall, the patients said that their self-images during treatment were poor, but as they reached the recovery stages, they moved closer to acceptance.

*Shift in family dynamic.* Middle adulthood is a time when people often have multiple responsibilities including raising children, caring for older family members, working, and engaging in their communities (Katz et al., 2012; Wright & Leahey, 2013). Patients described being unable to manage

these responsibilities, and said that they had to shift their focus toward themselves. Although this shift felt unnatural and was unwelcome, it enabled them to endure treatments. They viewed this change in their responsibilities as temporary. One patient said,

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 (pointed to spouse) to hear.

*Relationship with spouse.* Every patient with a spouse spoke of role changes in the relationship. The primary focus for the couple was *just surviving*, as several patients put it. They described feeling like a patient and not a partner in their relationship. The spouse became the caregiver. By way of confirming this, one spouse said, “I was just his nurse to get through it.”

Experiencing the diagnosis and treatment was both physically and emotionally taxing on spouses. Spouses took on additional home and family responsibilities. Two spouses experienced significant bouts of exhaustion and unintentional weight loss. Four patients also noted that their relationship with their spouse required further adaptation after treatments were finished, as they tried to determine how to return to their previous ways of life.

. . . (spouse name) 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.

Having survived HNC treatment, patients described an ever-present uncertainty about the future. Living with that uncertainty, which seemed almost a part of their relationship, provoked anxiety and fear for both patient and spouse. Despite the challenges and changes, no patient reported that their relationship suffered, and no one had experienced an end to their relationship. Two patients specifically reported their relationships became stronger than before their cancer diagnosis because they had truly relied on each other to get through the experience.

*Relationship with children.* Parenting responsibilities were a significant concern for patients, regardless of the age of their children. Discussing their cancer diagnosis with their children was difficult and was guided by the age and maturity of the child, the child’s communication style, and the parents’ beliefs about what was right for the child. All patients felt the need to protect their children. Some included their children in the experiences, whereas others tried to shield

them from it. Inevitably, the children were affected. Some younger children exhibited behavior changes, as described by these two patients:

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.

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 . . . 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.

Patients with teenage or adult children described including them in their care.

My son was there, holding me . . . that helped. I was holding onto the poles . . . making my way, I couldn't talk . . . I didn't have a lot of air. I didn't have a lot of strength. But we kept moving.

**Relationship with parents.** Several patients described challenges that arose in their responsibilities for their own aging parents. Patients in this study found it frustrating and difficult that they were not well enough to help their aging parents. One patient was a substitute decision maker for his mother and found he could not fulfill this responsibility, which increased his anxiety and sadness. Another patient's father disregarded his own health to focus on the patient. This left the patient feeling guilty and responsible for the father's health decline.

**Sexual practices, sexual feelings, and stigma.** For this study, sexual practices refers to physical sexual acts such as oral sex or intercourse and stigma refers to the actual or perceived "disqualification from full social acceptance which discounts or taints the individual" (Goffman, 1963, preface; Scambler & Hopkins, 1986). Patients discussed the physical and psychological ramifications of the disease and treatments and how those ramifications affected their sexual feelings and intimacy. Fatigue impeded sexual activity during treatment, but libido improved during recovery. Depending on the disease and its treatments, some sexual practices such as kissing or oral sex were affected. One patient described an inability to pucker for kissing, and had to relearn this with physiotherapy exercises. These types of concerns were not openly discussed by health care providers, and were sometimes uncomfortable for patients to bring forward to their health care providers.

Patients with HPV-related pathology were both surprised and self-conscious when they learned about the connection between HNC and the transmission of HPV through oral sexual practices:

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.

Despite the potential discomfort, nearly all patients indicated that knowing the cause of their cancer was very important to them. This was particularly important to patients who had no smoking or alcohol history.

Of the six patients who discussed HPV, none knew about the link between HPV exposure and HNC prior to their diagnosis. They had many questions and primarily sought information about HPV on the Internet. Two patients discussed concerns about the lack of credible information on HPV and HNC. "You can go online and research all that. But it's still sketchy," one patient explained, adding that the experts "are pretty positive that it's all related but nobody really understands."

One patient's spouse wanted to know whether she should be tested for HPV. 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 patients. One patient called HPV the "elephant in the room." Another patient said he felt stigmatized "because it is a sexual type of disease." Two patients said that they deliberately kept their HPV diagnosis private from everyone. Reactions to disclosure ranged from embarrassment to fascination. In this study, those with a steady partner did not worry about the burden of disclosure. For single patients, being faced with the prospect of having to disclose their illness to a new partner evoked anxiety and uncertainty; their primary concerns were their partner's reaction and their own fear of transmitting the infection.

### Coping With HNC

After describing the experience itself, patients went on to discuss the coping strategies they employed to get through and beyond HNC. Some patients sought professional assistance to address their questions or identify coping strategies before they became overwhelmed by the experience. Others stated they found inner strength that they had not known they possessed. Still others could not identify strategies they had used until several weeks after treatment was finished. Regardless of when the patients identified their strategies, there were five common coping strategies: seeking information, discovering inner strength, relying on a support network, establishing a sense of normalcy, and finding meaning within the experience.

**Seeking information.** During the early stages of their experience, most patients described seeking information about the disease and its treatments from the physician, surgeon, or other health care team members. Several patients said they thought their health care professionals had not fully disclosed

information about issues including cancer staging, pathology results, or prognosis. One patient stated he thought the lack of communication from some health care providers was deliberate. This patient said it seemed like the health care provider was trying to decide how much information the patient and his spouse needed or could process at one time, and even postulated that older patients may not wish to know everything. Three patients said that the perceived withholding of information increased their fears and frustrations. These patients said they wanted full disclosure as early as possible.

Most patients indicated that they sought additional information about their disease and treatments from other sources including the Internet, support groups, family doctor, friends, and counselors. One common frustration was difficulty understanding the information and knowing whether the information was credible, which led to increased stress and fear. One patient describes this:

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.

**Discovering inner strength.** Patients said they discovered inner strength they did not know they possessed. The inner strength was exemplified through humor, maintaining a positive mind-set, and setting attainable goals. Nearly all individuals used humor when discussing their experience. One patient joked, "I thought HPV was breakfast cereal—oh no that's moral fiber." They also discussed how they had tried to find humor during active treatment. One patient laughed at how happy he was that his hair fell out because it saved him from shaving for several months. Another joked that his wife was happy when he (temporarily) lost his voice.

Nearly all patients described how they coped by choosing to confront the experience with a positive mind-set. As one patient said, "It's all mind-set—keeping yourself busy and making sure you stay up. I didn't let myself get down. I danced every week." Another patient described conceptualizing his treatments as a competition:

I went into this with sort of a weird attitude of relating it to a hockey game . . . It was, you know, first period, second period, third period, game for my life. My son is a hockey player, I was a hockey player, and that's something that I can relate to.

Nearly all the patients discussed how setting goals allowed them to cope in the present and focus on the future. Goals included things such as returning to work or participating in family traditions. One patient describes this:

Then the next goal was, I guess, just Thanksgiving, to be able to make the pies for the family . . . I do believe that you have to

have goals because then [you can remind yourself] "Okay, I made it past here and I made it past there."

Overall, setting and achieving goals inspired renewed strength and feelings of accomplishment.

**Relying on a support network.** Beyond immediate family, most patients also discussed relying on friends and colleagues for support. Some patients established relationships with other cancer survivors. Most had attended a support group through the hospital for a period of time. Support groups provided a place to discuss shared experiences and be encouraged to persevere. With the exception of one patient, all patients stopped attending the support group upon completing treatment. Their reasons included going back to work or not wanting to relive the experience. "There's people in there that were five years clean and still upset, and it's like you have to remove yourself from that." Another stated, "I had enough—I can't come here anymore. Like this is ridiculous; I gotta move on from this. . . . I need to find another song to sing here." The one who continued to be involved did so to provide support for others.

**Establishing a sense of normalcy.** After describing their diagnosis and treatment experiences, most patients went on to discuss their "new normal" lives. In one patient's words,

I said to [a friend] you just have to look at this as "this is my new normal—and my new normal . . . do I necessarily like it? No, but it's a whole lot better than the alternative." He looked at me and said, "You know, that's not a bad way to look at things." And that's the way I am.

Some of the patients experienced lingering physical challenges such as difficulty swallowing, ongoing fatigue, or voice changes, which served as reminders of HNC.

My esophagus is narrower than [an] adult's esophagus so swallowing things takes time—it takes me longer to eat. You know, I just have constant reminders of this. It would be nice to move on totally from it, but I think we're still a ways away from that.

Returning to work was often described as a return to normal. Patients in this study noted several reasons for returning to work, including financial need, social value, sense of normalcy, and an outlet for creativity or focus. Two examples of this are as follows:

I didn't have any choice. I had to go back (to work). I didn't have any money. I went right back to 12-hour shifts which was tough, very tough . . . I was exhausted.

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.

There were changes in how patients made health decisions, how they connected with others, how they planned for their future, and how they chose to spend their time and money. For example, several patients described how they planned to arrange HPV vaccinations for their children when the children reached an appropriate age. Several discussed creating wills or advanced directives as they had ongoing feelings of uncertainty but wanted to feel prepared. Also, one spouse shared this about her partner, a patient:

You take a lot more vitamins; you take care of yourself better, which he didn't before. Now he's taking his vitamins, he's careful that way. We are more relaxed. We spend more money (laughter). We go away more.

*Finding meaning within the experience.* Most patients discussed how they wanted to find ways to create meaning from the experience. They felt grateful to be alive and wished to make a positive impact going forward. Examples of how they accomplished this included participating in research and in public education or fundraising campaigns about HNC, and being a role model and/or confidante for future patients.

That's why I kept coming back, 'cuz now all of a sudden I can do some good. That's the thing that stuck in my head, right. So that's why I said yes . . . you know there were several other studies that came through. I was willing to say yes to, to anything that was happening . . . to help, help out.

I heard about cancer because of smoking and all this stuff but I don't, maybe most people [are] like me and they think "I'll never get that" or they don't understand the full ramifications of what could happen to you in the future and I was one of those people. And so when I did learn, I thought holy shit man, you know. Maybe there's something that I can do to help other people. And maybe, you know, share some of my information, and so maybe if somebody or someone that doesn't have this, [I can] can prevent them [from having] to get this

Patients reported a sense of satisfaction about their roles as advocates for the prevention of HNC and as participants in research that could improve outcomes. "I've chosen other ways to give back through fundraising and speaking at events and stuff on behalf of cancer patients, so I feel like I've contributed in other ways." They described these opportunities as helping them to move them from feeling voiceless to feeling valuable.

## Discussion

### Voicelessness

Our results confirm findings from other research showing that functional speech, what we describe as a physical voice, remains a major concern (Jamal, Ebersole, Erman, & Chhetri, 2017; Vainshtein et al., 2014). However, the implications of impaired speech as described by our patients are

potentially different from those reported in other studies, given the age and developmental stage of our patients. Temporary changes to the physical voice during active treatment are important considerations for basic safety and care needs in patients of all ages. Furthermore, chronic changes in physical voice emerged as particularly concerning for the middle-aged adult population because of the resulting negative impact on employment and social interactions. The impact that changes in voice can have on employment creates long-term financial implications for individuals and families in areas such as meeting mortgage payments, saving for their children's education, and planning for retirement.

The physical changes in voice also made it difficult for patients to advocate for themselves. As they were unable to speak for themselves, they needed to rely on others, which diminished their self-image. This finding is similar to what was reported by researchers who studied patients with short-term speech difficulties and patients who were chronically mechanically ventilated and awake in intensive care (Guttormson, Bremer, & Jones, 2015; Karlsson, Bergbom, & Forsberg, 2012). This finding is relevant for situations involving both temporary and chronic changes in voice, as both affect fundamental values such as patient safety, patient empowerment, and autonomy. It is also relevant, in that, middle-aged adults are aiming to achieve generativity by being actively engaged in home, work, and community, and voice changes can hinder such efforts.

### Being or Looking Sick

Being or looking sick altered patients' images of themselves. This finding is consistent with the results of a meta-analysis of qualitative research that focused on quality of life and survivorship concerns for all HNC patients. Self-image was described as "the diminished self," and was associated with a series of losses related to confidence, self-esteem, self-image, and sense of self (Lang, France, Williams, Humphris, & Wells, 2013). Our patients described negative body-image concerns initially, but then described moving toward a position of acceptance or even strength and pride for having survived HNC treatment.

### Shift in Family Dynamics

Another element that our patients associated with experiencing HNC in their middle-adult years was the impact on relationships and responsibilities within the family. As reported in other studies that looked at the general cancer population, the patients' spouses became caregivers, and assumed additional responsibilities that the patient was unable to carry out (Badr et al., 2016). Other authors have reported adverse physical and psychological consequences of caregiving (Hodgkinson et al., 2007). This was identified in our study but not explored in detail.



Study patients with young children or aging parents had to temporarily withdraw from many responsibilities they had previously undertaken. As in previous research (Semple & McCance, 2010), patients who were parents had challenges and questions about how to talk to their young children about their cancer or how much to include their children in the experience. With more patients experiencing HNC in middle adulthood, this may become a more frequent concern. Patients in our study described being unable to attend to the needs of their aging parents, and their aging parents were concerned about the challenges associated with caring for ill adult children. To our knowledge, this dynamic has not been specifically identified in HNC research, likely because the parents of older individuals with HNC are no longer alive.

### *Sexual Practices, Sexual Feelings, and Stigma*

Patients had questions about the relationship between HPV and HNC. Patients said they had difficulty finding credible resources to address their questions. As previous research found (Baxi et al., 2013), they also perceived a social stigma around HNC's sexual mode of transmission. The relative newness of HPV as an independent cause of HNC explains some of the lack of research and resources available. It will be important to continue to deepen our understanding of this relationship through research to respond to patients' questions about transmission, risk, disclosure, and potential prevention strategies such as vaccination, condoms, or dental dams. It is also likely that health care providers have variable levels of comfort discussing sexual practices and may lack knowledge about the relationship between HPV and HNC (Dodd, Marlow, & Waller, 2016). Ongoing professional development regarding the etiology of HNC is an important way to support patients. There is some discussion in the literature about strategies for counseling individuals and families (Finnigan & Sikora, 2014), but more work is needed in this area.

### *Coping With HNC*

Initial research on coping with HNC identified four common coping strategies: denial, behavioral disengagement/giving up, suppression of other activities, and venting to others (Sherman, Simonton, Adams, Vural, & Hanna, 2000). These have been described as predominantly disengaged styles of coping (Carver & Connor-Smith, 2010). Previous researchers have demonstrated that younger HNC patients use more active coping strategies and feel more internal control over the cause, but not the course, of their disease (Derks, Leeuw, Hordijk, & Winnubst, 2005). However, these findings were used only as a baseline for comparison for older patients, perhaps reflecting the demographics of the era (1998–2001) in which the studies were conducted. Similar to some research in the general HNC and other cancer populations, we found that actively engaged coping strategies such as

humor, a positive attitude, and goal setting were common (Semple et al., 2008; Skeath et al., 2013); however, age was not a focus of these studies. Relying on a support network has previously been identified as an effective coping strategy, and correlated with improved health-related quality of life scores, in particular, better general mental health and less social disruption (relating to pain, employment, and social functioning; Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007). A recent study exploring emotions and coping with HNC in India proposed as primary coping strategies a positive attitude, faith in doctor/God, expressing emotions with family/friends, and indulging in activities to divert attention (Jagannathan & Juvva, 2016). The researchers proposed a conceptual framework for understanding the emotions of cancer survivorship but acknowledged that the framework might be culturally biased as communication and faith may be experienced differently in India than elsewhere in the world. Overall, our findings highlight the complexity of coping with this disease and treatments. Practically speaking, creating supportive interventions in coping will need to be tailored to individuals and families, and may be culturally influenced. A focus on actively engaged coping strategies such as humor, positive attitudes, and goal setting may be beneficial.

### *Work*

Work was an important aspect of several of our subthemes including voicelessness, relying on others, and establishing a sense of normalcy. Consistent with other research, returning to work was sometimes seen as an important time point that separated being sick from embarking on a "new normal" life (Buckwalter, Karnell, Smith, Christensen, & Funk, 2007; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005). Buckwalter et al. (2007) focused on the barriers for returning to work within 1 year of treatment for HNC, including fatigue, difficulty eating, impaired speech, pain or discomfort, and changes in appearance. The patients in our study discussed all these concerns. However, beyond these more functional concerns, our patients highlighted the need or desire to return to work as important for psychological and social reasons, as well as financial. Work helped promote a sense of normalcy. These reasons align with a systematic review that examined factors associated with returning to work after cancer treatment (Chow, Ting, & Su, 2014). However, the majority of the studies reviewed focused on breast cancer survivors (predominantly women), and only four of the 27 studies specifically examined patients with HNC. The findings, therefore, may not fully reflect the return to work experiences of middle-aged adult HNC patients. Some of our patients said they returned to work before they felt well enough to do so, usually because of financial pressures. Therefore, although there may be potential psychological benefits of returning to work, these may be compromised if patients continue to feel unwell or not ready.

With improved survival rates in this subpopulation, supporting a return to work is an important aspect of care delivery.

### Gender

Previous research has demonstrated important gender-related influences in how cancer is experienced. For example, men have been shown to have a tendency to avoid appearing weak or ill, and to maintaining physical activity and involvement in work or communities as coping strategies (Wenger & Oliffe, 2014). Our results describing how patients felt about looking sick, the psychological importance of returning to work, and relying on supportive communities appear in keeping with other findings. However, as we had only one woman in our sample, we were unable to comment on how women's experiences may differ. Additional research would need to be conducted with women who have had HNC to determine whether gender-related influences exist in this population.

### Implications for Nursing

To formulate supportive nursing interventions, results were considered from the standpoint of King's theory of goal attainment (King, 1981). This theory was selected because it acknowledges the dynamic, complex, and interwoven nature of health and illness at the personal, interpersonal, and social system levels. Although we will describe nursing interventions within each system, it is acknowledged that there may be implications at other system levels. King stipulates that for a patient to reach his goals, three needs must be met: the need for information, the need for care to prevent illness, and the need for care when illness occurs and the patient is unable to care for himself or herself. The nurse's role is to support the patient in delineating and reaching these goals. This theory provided a lens through which to view the data to formulate supportive nursing interventions.

The personal system includes concepts of perception, self-growth, body image, space, and time (King, 1981). Findings from this study relevant to the personal system include concerns with body image, sexual feelings, or being or looking sick. Nurses could help patients to first work through and then express their feelings regarding changes in body image, sexual feelings such as reduced libido, and distress at being unprepared to be sick at this age. They can help patients understand that these feelings are common and often temporary. They may even be able to help prepare patients beforehand to identify coping mechanisms. Patients may also need validation that it takes time to move from these more negative or isolating feelings to healing or empowerment.

The interpersonal system includes interactions, communication, transactions, roles, and stress experienced within the patient's closest relationships, including those with a spouse, children, parents, or friends (King, 1981). When our results are reviewed from the standpoint of the interpersonal system,

we see the challenges of communication and the implications of shifts in roles within the family. For HNC patients, communication was impaired by the changes in the physical and metaphorical voice. Voicelessness contributed to shifts in the patients' and spouses' normal roles, with patients becoming dependent and spouses becoming providers or advocates. Communication challenges and role changes also influence patients' relationships with their children and their aging parents. Being unable to care for children or aging parents placed additional stress on the patient, which also negatively affected the patient's self-image within his or her personal system. Nurses can help patients and families adapt to these changes by including all family members in the care plan and helping them to identify and address role changes. Nurses may also need to step into the role of patient advocate for the voiceless patient who does not have a support person. The nurse-patient relationship, an interpersonal system in itself, may be a safe space for open discussions about health stressors such as employment, sexual practices or sexual feelings, changing roles within the family, and coping strategies. Nurses may be involved in developing supportive programs for patients to connect with each other during and beyond treatment. These programs could be delivered either traditionally, in person, or online for those who have returned to work or have speech challenges.

The social system includes organization, status, power, authority, and decision making (King, 1981). When our results are viewed at this level, we see the importance identified by some patients of participating in opportunities to reciprocate or "give back" through research, public education, or fundraising. Our patients said that they found these experiences were very meaningful to them and part of their healing journey. Nurses could help patients find ways to engage with a broader social system by using their metaphorical voices, for example, encouraging patients to participate in research or public education campaigns for early detection or improved vaccination uptake for disease prevention. By participating in these programs, patients can experience a sense of control and empowerment. Such engagement may also help reduce the actual or perceived stigma that our patients described.

### Limitations of the Study

The sampling strategy used might have inadvertently excluded individuals who were more disabled and, therefore, might have different concerns. Patients in this study were Canadian with access to universal health care and recruited through a specialized cancer treatment program. Geographically or socially isolated patients may have different concerns. Our data collection strategy required patients to be able to speak, so might not reflect concerns of those unable to speak. We used 3 years posttreatment as a broad starting point for this research. The length of time since diagnosis and treatment could have influenced what patients

considered relevant. Longitudinal studies, both qualitative and quantitative, could help to improve the understanding of the influence of time in the evolving experience of HNC.

The center we recruited from did not routinely test for HPV until the time of study enrollment. Therefore, we could not directly include HPV status in our description of the sample. As testing has since become routine, future researchers should deliberately recruit from both those who have HPV-related disease and those without, to explore potential differences in experiences.

More broadly, the influence on HNC of social constructs such as gender, sexual feelings, and stigma likely differ from one country or culture to another. More research should be conducted to further explore these hypotheses.

## Conclusion

Our study describes the experiences of middle-aged adults with HNC, highlighting the unique consequences that the illness has on this population. These include feelings of physical and metaphorical voicelessness, a self-image altered by being or looking sick, changes in relationships with all generations in the family as well as changes to familiar responsibilities, and concerns with sexual practices, sexual feelings, and the stigma associated with the disease and HPV. For the patients in our study, coping with the disease and its treatments involved seeking information from multiple sources such as health care providers or the Internet; discovering inner strengths such as humor, goal setting, and maintaining a positive attitude; relying on a support network of family, friends, and fellow patients; establishing a “new normal” routine with family or work; and finding deeper meaning in the experience by giving back. Nurses should provide personal and interpersonal support as patients experience the consequences of the disease and its treatment. Nurses can encourage patients to identify and employ effective coping strategies. Nurses can also help patients find ways to advocate at the social system level to help restore the patients’ metaphorical voices, which may reduce the actual or perceived social stigma.

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