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## GETTING TO THE OTHER SIDE: AN EXPLORATION OF THE HEAD AND NECK CANCER TREATMENT EXPERIENCE

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Dr. John Watkins, Director of Graduate Studies

GETTING TO THE OTHER SIDE: AN EXPLORATION OF  
THE HEAD AND NECK CANCER TREATMENT EXPERIENCE

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in Gerontology  
at the University of Kentucky

By

Heather Marie Wallace

Lexington, KY

Director: Dr. Graham D. Rowles, Professor,

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## ABSTRACT OF DISSERTATION

### GETTING TO THE OTHER SIDE: AN EXPLORATION OF THE HEAD AND NECK CANCER TREATMENT EXPERIENCE

Diagnosis of head and neck squamous cell carcinoma (HNSCC) presents a multifarious problem. Late stage diagnosis, uncertainty regarding appropriate clinical treatment, as well as the high potential for disfigurement and functional loss resulting in diminished quality of life, contributes to anxiety, stress, fear, and uncertainty throughout the cancer treatment experience. This qualitative study sought to explore the cancer treatment experience of adults with newly diagnosed HNSCC, including laryngeal, esophageal, and oral cancers. Study participants were recruited from the University of Kentucky Ear Nose and Throat Clinic in Lexington KY. Participants agreed to be interviewed after receipt of their cancer diagnosis and again after completion of their cancer treatment. Socio-emotional Selectivity Theory, and Leventhal's Self-Regulation Model provided the theoretical foundation for exploring the ongoing emotional, psychological, and physical aspects of the cancer experience while also recognizing the role of age and time perception. Forty-one patients completed two in depth semi-structured interviews. Transcripts were coded for key themes. Findings indicated that HNSCC in older patients is often preceded by lifelong alcohol, tobacco, and substance use. Despite frequent interaction with health and substance abuse treatment professionals, very few patients had prior knowledge of HNSCC risk or had been screened for these cancers. Experience with addiction treatment programs and perceptions of time seem to influence cancer treatment experience. The following themes were identified: (1) dynamic time perspectives including *taking time*, *making time*, *junk time* and *time out*; (2) recovery vs. cure from disease; (3) the role of reconciliation, hope, self-inventory, reflection, and spirituality in navigating the cancer experience; (4) the role of healing vs. cure; and (5) patient's moving forward to a life

after cancer. Findings from this investigation suggest that patients with a history of lifelong substance use could benefit from earlier detection and improved awareness and knowledge of HNSCC risk. Findings can be applied to improve access to cancer screening through addiction and cessation programs, reduce lags in diagnosis, improve prognosis and contribute to the development of clinical tools. Additionally, the intersection of advancing chronological age, comorbidity, and perception of time warrants further investigation.

**KEYWORDS:** cancer, cancer experience, coping, cancer treatment, aging

Heather Marie Wallace

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03/26/2013

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GETTING TO THE OTHER SIDE: AN EXPLORATION OF THE HEAD AND NECK  
CANCER TREATMENT EXPERIENCE

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03/26/2013

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Date

This dissertation is dedicated to my parents and dearest friends,

James David Wolny and Judy Mae Wolny

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I would like to thank the many people who have had a part in my graduate education and in particular, this dissertation. The success of this endeavour would not have been possible without the ongoing and persistent support of my family and friends, the generosity, willingness, and trust of the participants, and the University of Kentucky Faculty of Gerontology that provided endless faith, patience, guidance, and motivation.

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This dissertation would not have been completed without the assistance of my family and friends. They endured this journey with me and deserve credit in this



accomplishment. I want to thank my parents for picking up the pieces and helping me put my life together when things fell apart early in my academic journey. They reminded me of who I was, where I came from, and helped me find the strength to move forward in my personal and academic life.

Finally, I'd like to thank the patients and family members who generously participated in this project. They provided their time and stories with authenticity, dignity, and bravery. Through their stories I not only gained insight into their cancer journeys and treatment experiences, but also learned deeply about respect, humility, faith, and forgiveness. I hope that this dissertation gives a voice to their silence and that the information shared is useful and helpful to other patients and providers.

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## I. Making the Journey

In the summer of 2006, I had just completed my second year of graduate school and the seventh year of a failing marriage. I felt beaten, alone, and altogether hopeless. That summer I retreated to Alaska, a place as far and foreign as my resources would allow, seeking solace and inspiration in order to regain my equilibrium and dedicate myself to the successful completion of my doctoral work. While there, I met Ben, an Aleutian Indian with stage III laryngeal cancer, and my dissertation journey began.

As I left a meeting at the Alaskan Native American Hospital in Anchorage, I saw a man in the side yard. He was in his late fifties with black oiled hair, spinning round and round, laughing, or perhaps humming in low guttural sounds. He tapped out a strange rhythm, moving back and forth, flapping his filthy red coat – the emblem of a black raven on the back of his coat seemingly alive as it hopped and twirled, while his large obsidian eyes seemed to stare back at me. As I headed for the sidewalk, the man suddenly stopped, and after a moment of hesitation took several steps to my side. I turned away, a little scared and nervous, wanting to flee from this strange dancing man.

“You won’t get far without these,” he murmured, in a voice that sounded like it came from the bottom of a well. “You drop, I pick,” he said, withdrawing a grimy hand from his pocket and dangling a familiar thing, a key ring with a small pewter kayak and 4 keys. I wondered to myself, “How and why does this man have *my* keys? What does he want?”

As if reading my mind, the smiling toothless man said, “I’m Ben, I find these, I think you belong them.” A genuine sincerity and kindness seemed to emanate from Ben and my fear and nervousness fell away as I retrieved my keys from his outstretched hand.

I wanted to know more about this man: who he was, why he was here, and how he came to reunite me with the keys I hadn't realized were gone.

To express my thanks and to learn more, I invited Ben to lunch. On the way, I discovered that Ben was legally blind. As we crossed the street together on this first occasion (and the many more that would follow), I pointed out objects he could not see, while he brought to my attention the things I had not heard or felt.

On my way into the hospital that morning I had deposited my keys into a jacket pocket that had an undiscovered hole. Ben had been dozing on a bench nearby and had heard the keys fall and immediately made an effort to associate the fallen object with the footfall of the probable owner. He retrieved the keys and waited, dancing to make the time go by and to force his concentration, until the matching footfall returned.

In the brief three months that I spent in Alaska, I met Ben for lunch every week. We talked of the "old ways" and old people. He became my friend and teacher, a source of motivation and courage, and a mirror for my own intellectual and personal reflections. Ben shared his life story, beginning with boarding school 1,000 miles from his home and family at the age of 12, and ending with chronic homelessness, addiction, diabetes, and late stage laryngeal cancer, along with an array of other complex health and social problems.

The preceding semester before my arrival in Alaska, I had been accepted into a National Cancer Institute pre-doctoral training program focusing on rural cancer control and prevention at the University of Kentucky. Among other things, I was struggling to identify a specific cancer site or patient population to study. Ben helped me unlock my imagination, summon my courage, and explore the complex challenges, injustices, and



triumphs of a life lived with head and neck cancer, multiple co-morbid conditions, and low personal agency. I certainly could not claim to know the feelings and fears that came with the cancer that Ben endured. Having suffered the shattering of my own dreams with the all too recent death of my marriage, I could relate to the fear, pain, and hopelessness that he spoke of so freely and with deep sincerity.

Talking about living and dying with Ben ignited a curiosity and a drive to examine the lives of people with head and neck cancers. Ben's laryngeal cancer, a type of head and neck cancer, was associated with profound physical, mental, social, and spiritual consequences that I had not seen in other more common cancers of the breast and colon. Few cancers have the potential to deliver such significant shifts in functional ability, aspects of identity, and physical appearance as those of the head and neck. Likewise, few, if any other cancers are as deeply entrenched in the embodiment of social mores, norms, and behavior. As the experiences of Ben and many other patients will illustrate, head and neck cancers are largely linked to tobacco and or alcohol use, and are cultivated and perpetuated by a deep and complex array of social phenomena.

At the end of the summer, I returned to Kentucky and my graduate studies ready to embark on a new journey. Ben had taught me about humility, forgiveness, defeat and triumph in the face of humiliation, blame, incredible loss and personal recovery. Newly armed with these sentiments, I broadly aimed to focus my work on exploring the lives of older adults with squamous cell carcinomas of the head and neck. Specifically, I wondered about the treatment decision-making processes of newly diagnosed patients. Ben had been diagnosed two months before I met him. He had elected to forego treatment, despite access to potentially free, effective, available and accessible services at

the Alaskan Native American Hospital. Like me, Ben's doctors, caregivers and many friends struggled to understand his choice and to support him through his own journey in living, and in dying. Ben's decision was in part based on his perception of the treatment experiences of several other aboriginal patients with advanced cancers, including oral cancer. I wanted to understand the factors that shaped the journey toward making and living with a treatment decision and to tell the stories of patients with similar cancers.

## **Chapter 1. Introduction**

Ben's cancer is one type of head and neck cancer, a family of cancers that generally include sites of moist mucosal lining in the head and neck region (Health, 2012). This includes the nose, oral cavity, salivary glands, tongue, tonsils, larynx, sinuses, and sites of the pharynx (Sanderson, Ironside, & Martin, 2002). Cancers in this region can impart profound and complicated consequences to form and function due to the anatomical complexity of the area (Lung, Tascau, Almasan, & Muresan, 2007). Tumor growth may encroach on dozens of other anatomical structures, which compromises optimal functional capacity and may limit treatment options (Derks, de Leeuw, & Hordijk, 2005). The progression and treatment of head and neck cancer may impede or alter the patient's ability to breathe, speak, swallow, eat, and control facial movements (Murphy, 2009; Ronis, Duffy, Fowler, Khan, & Terrell, 2008), forcing consideration of the most basic aspects of daily life and personal identity. Facial disfigurement and pain is often collateral damage to treatment, imposing additional physical and psychological trauma in survivorship (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010).

As many as 52,000 Americans will be diagnosed with head and neck cancer (HNC) in 2012 ("Cancer facts and figures 2012," 2012). While incidence rates are relatively low in the United States, cancers of the head and neck have long reflected higher mortality rates and secondary tumor site development than many other cancers. As compared to other cancer populations, HNC patients are more frequently diagnosed at advanced stages, exhibit higher rates of smoking and alcohol use, have higher levels of mental illness, and are the most likely among all cancer populations to commit suicide

within three years of diagnosis (Haddad, Annino, & Tishler, 2008; Reid, Warren, & Rozier, 2004).

Receiving a cancer diagnosis creates turbulent emotions and often changes the trajectory of a patient's life. The period of time between cancer diagnosis and treatment initiation is one of the most emotionally demanding stages within the cancer journey and has both immediate and long-term consequences to length and quality of life, functionality, and survivorship. The treatment decision often represents the juncture between being a patient and becoming a survivor and is often viewed as the pinnacle decision for cancer patients and their providers. While treatment decision-making is a justified focus for patients, providers, and researchers, decision-making must be understood within the larger context of the cancer experience. It is the experience of becoming a cancer patient that evokes and necessitates ongoing consideration of many domains that affect one's immediate, short, and long-term existence. The treatment decision is just one of many decisions, both implicit and explicit, that must be made as individuals negotiate and play out their lives with cancer. The larger context of one's life experiences, goals, perceptions, and cognitive capacity are internal, individual factors that shape the response to living with cancer.

### **Purpose of the Study**

This qualitative dissertation seeks to provide a model of the cancer treatment experience specific to older head and neck cancer patients by identifying and describing factors that may be central to that experience. Because HNC often imparts overwhelming consequences to quality of life and physical functioning and because of increased risk of death and secondary tumor occurrence, improved understanding of the experience may

lead to improvements in the detection and treatment of cancer while also improving patient satisfaction with care. Because living with and surviving cancer is largely tied to medical intervention and treatment, investigating the treatment decision provides a central focus for contextual exploration of the larger cancer treatment experience. For patients and their families, a lack of understanding inhibits the ability to satisfactorily negotiate the cancer treatment experience and perpetuates uncertainty and fear in decision-making.

### **Theoretical and Philosophical Foundation**

It has been argued that a significant objective of geriatric oncology is to optimize the cancer experience (Bellizzi, Mustian, Bowen, Resnick, & Miller, 2008). Similarly, the field of gerontology seeks to enable and empower older adults to thrive throughout the life course and to experience a positive, if not, growing sense of personal well-being into advanced age (Alkema & Alley, 2006). The realization of these goals rests on the development of gerontological theory and perspective that acknowledges and allows for exploration of the entire context of the lifespan. As a framework, naturalistic decision-making (NDM) can offer rich insights into the important and complex tasks involved in real world cancer experience and decision making. NDM arose out of questions related to the generalizability and applicability of traditional, rational research on decision-making (Klein, 2008; LeBoeuf & Shafir, 2001). Studies based on laboratory and hypothetical situations fail to transfer to the real world settings of decision makers (Berryman, 2008; Steginga & Occhipinti, 2004; Tetley, Grant, & Davies, 2009). In contrast to decision-making studies carried out in simulated settings, NDM based research takes place in the context and domain of the decision maker (Pruitt, Cannon-Bowers, & Salas, 1997), which

is at the core of this dissertation's focus. The NDM approach has become a valuable framework for studying "real life" decision-making by acknowledging constraints of time limits, stress, information and personal experience (Klein, 2008). The cancer literature identifies many of these same factors as relevant to the experience of coping and managing cancer (Thomsen, Rydahl-Hansen, & Wagner, 2010). How a cancer patient uses experience and knowledge to make a decision within the context of living with cancer, is a fundamental aspect of the NDM approach (Currey & Botti, 2003).

The gerontological literature suggests that numerous factors related to the experience of aging, may have an influence on the experience of cancer (Given & Given, 2008; Hewitt, Rowland, & Yancik, 2003; Lichtman, Balducci, & Aapro, 2007; Tomaka, Thompson, & Palacios, 2006). Socio-emotional Selectivity Theory (SST) and the concept of an age-related positivity effect are particularly applicable to examining the relationship between age-related perceptions of time that may be unique to older cancer patients and their decision-making goals (Carstensen, 1992b; Carstensen, Isaacowitz, & Charles, 1999; Lockenhoff & Carstensen, 2004). The cancer experience requires patients to manage ongoing physical, emotional, and psychological aspects of their condition and its treatment, as well as lifestyle and daily aspects of living. Managing, or coping with cancer is in itself a series of ongoing decisions, both conscious and unconscious in which patients appraise these threats, deliberate, and execute actions. (Bellizzi et al., 2008; Given & Given, 2008; Thomsen et al., 2010; Witt, Elwyn, Wood, & Brain, 2012). Lazarus and Folkman explained coping as "constantly cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person (Folkman & Lazarus, 1985, pg. 141)." Clearly a

diagnosis of cancer and its treatment can elicit such a response. The process of appraisal inherent to coping requires a person to evaluate the source of stress (i.e. cancer) and its effect upon well-being and quality of life and to decide what to do in response (Thomsen et al., 2010). SST is applicable to a study of cancer treatment experience and associated decision making in that it suggests that age may influence how stressors and information is perceived (appraisal) and what strategies are employed in response (coping).

The theory suggests that decision-making goals change throughout the life course and vary depending on differences in perceptions of time. The goals of young adults are future oriented and focused on information seeking and network building. On the other hand, in old age the focus shifts to positive emotion regulation, increasing importance of close social ties, and other activities producing quick, positive emotional payoffs. These tendencies result in distinct and predictable age-related differences in goals that affect decision-making. Goal shifting is a function of individual perceptions of the amount of time left to live (Carstensen, Pasupathi, Mayr, & Nesselroade, 2000). Future orientation becomes abbreviated, and present-oriented goals emerge as time passes, maximizing emotional meaning and its relevance to decision-making. Research has suggested that in advanced age and terminal illness situations, present oriented goals may serve to alleviate negative symptoms or consequences of the disease and provide a means for participation in emotionally meaningful activities (Lockenhoff & Carstensen, 2004).

Confidence in the relationship between the concept of time perspective in SST and health behavior is constrained by conceptual and methodological limitations. Conceptually, researchers have been inconsistent in defining time perspective. Time perspective has been operationalized in numerous ways, often varying by the field and

purpose of study. Such conceptualizations include: (a) the length of future time an individual has and how that individual sets goals (Klineberg, 1968; Lessing, 1972); (b) a motivational construct referring to the act of appraising required costs and time when setting goals (di Volder & Lens, 1982); and (c) the degree to which an individual's future years are perceived as meaningful, long-lasting, and opportunistic (Lang & Carstensen, 1994).

While scholars have demonstrated that age and experience can influence time orientation leading to changes in emotional regulation and cognitive processing of information (1992a; Carstensen, 1992b; Zimbardo & Boyd, 1999), health behavior research has shown that decision-making and illness experience is further shaped by other determinants. According to Leventhal's Self-Regulation Model (SRM) (Leventhal, Leventhal, & Contrada, 1998) there are five domains of illness representation: identity, timeline, consequences, control, and cause. Each domain is comprised of multiple variables originating from a complex, dynamic social system in which societal norms are continually evolving. Individual appraisals of disease experiences and social and cultural factors contribute to the illness representation (Cameron & Leventhal, 2003; Leventhal & Cameron, 1987; Leventhal et al., 1998). Furthermore, SRM is one of several theories distinguishing between cognitive and emotional processes involved in coping with illness. Emotional processes in decision-making and risk perception have been largely neglected in the literature (Finucane et al., 2002). One of the advantages of Leventhal's model is that it delineates two parallel and potentially independent processes. Cognitive processes regulate objective health threats through thinking. For example, a woman who detects a lump in her breast may begin thinking about the lump, what caused it, and what



next steps or actions to take. On the other hand, a parallel emotion-focused process regulates the emotional consequences of the lump's discovery, such as fear or sadness (Leventhal, Meyer, & Nerenz, 1980). These processes interact as individuals adapt to illness by creating coping strategies to manage both symptoms and emotions (Leventhal, Brissette, Leventhal, & Cameron, 2003; Whitmarsh, Koutantji, & Sidell, 2003), which are salient to decision making and treatment. Individuals construct representations of illness based on these pathways and generate goals of self-management, at which point they derive feedback criteria to evaluate response efficacy.

The manifold use of NDM, SST and SRM provides a theoretical jumping off point for the exploration of head and neck cancer treatment experience. Cancer introduces ongoing and evolving emotional, mental, physical, and psychological stress, which according to theories of coping, is managed or alleviated through the coping process of appraising information, deliberating on an action, and execution of an action (Finucane et al., 2002; Folkman & Lazarus, 1985; Thomsen et al., 2010; Witt et al., 2012). This process relies on individual's perceptions of a threat and identification of coping strategies that optimize well-being and or personal goals. Furthermore, the process of coping occurs within the filter of the person's "real life" experiences, knowledge and information that is gleaned from the life-course. Finally, as individual's age, their perceptions of threat as well as goals and thus coping strategies may shift, producing differences in coping, decision-making and ultimately, cancer treatment experience.

## **Specific Aims**

The specific aims of this dissertation are to: 1) explore the treatment experience of head and neck cancer among older adults with newly diagnosed HNC; 2) explore how elements of time and age influence coping and the cancer treatment experience; 3) elaborate a model of the HNC cancer treatment experience; and 4) propose strategies or tools that could be applied by health providers and patients to improve the cancer treatment experience, and related outcomes.

Exploration of the contextual nature of the HNC treatment experience (Specific Aim 1) will begin to build information and knowledge that can be used to better understand cancer patients at the point of care. What provokes help seeking, medical compliance, or acceptance of one treatment over another? What factors impede timely decisions or perceptions of effectiveness? Are the setting, format and content of treatment information and cancer care important? What are the goals or priorities of patients in seeking care? The answers to these questions will suggest which factors degrade or enhance the cancer treatment experience and how they do so. Themes that emerge are expected to reflect the relationships among factors salient to the cancer experience and to inform the development of a HNC model (Specific Aim 3).

Exploring how elements of time and age affect coping and the cancer treatment experience (Specific Aim 2) is critical to broadening current knowledge regarding the intersection of advanced chronological age, perception of time, and the cancer treatment experience (Specific Aim 1) observed among HNC patients. Such knowledge would be a valuable contribution to understanding how age related changes in perception of time influence the goals and behaviors of older adults, particularly when facing life-

threatening illness. Additionally, information about how elements of time and age influence goals and coping strategies could be used to develop treatment and care tools that are salient to the needs of older cancer patients (Specific Aim 4).

The development of a HNC treatment experience model (Specific Aim 3) that is sensitive to an age-related time perspective (Specific Aim 2) and factors salient to HNC patients (Specific Aim 1) may help to enhance the development of treatment tools (Specific Aim 4) and provide a framework for assisting providers, patients and families in supporting patients throughout the illness experience. Such a model would help structure the process by which HNC patients navigate the cancer experience and identify points in the process in which assistance and/or support could be offered or enhanced.

## **Summary**

A limited number of research publications specifically address the experience of cancer treatment in older adults. These papers largely explore issues of medical symptoms, geriatric assessment of cancer patients, and treatment side effects and tolerance. Less attention has been given to studies that increase our understanding of how older cancer patients perceive and experience risk detection, diagnosis, treatment and survivorship. Methodological and theoretical consistency and clarity are also lacking, and rarely is the congruency of findings with patient perspectives discussed. I begin Chapter 2 by introducing the epidemiology of HNC and its treatment. I also explore health risk behaviors specific to the development, treatment, and survivorship of head and neck cancer. I also present literature relevant to aging and coping with cancer, including health decision-making. In Chapter 3, I present the research design and methodology for the present study. In Chapter 4, I discuss the study's findings, including emergent themes

related to the experience of HNC treatment. In Chapter 5, I elaborate on these themes by presenting a series of case study vignettes. These vignettes provide an experiential backdrop for the presentation in Chapter 6 of a conceptual model of the treatment experience. I expand on the conceptual dimensions of the model in Chapter 7. This dissertation concludes with a summative discussion of study findings, implications, limitations, and areas for future research.

## **Chapter 2. Literature Review**

The following literature review serves to situate the experience of head and neck cancer within the context of aging. In order to achieve this aim, I begin with a comprehensive description of the epidemiology, etiology, and treatment specific to head and neck cancer. In order to situate the geographic and sociocultural context of the present study, a review of literature related to health and health behavior among older patients is also provided. I then discuss literature related to factors and strategies for coping with and adjusting to life with cancer. The findings, conclusions and implications of the reviewed literature assisted in the establishment of the qualitative design used in the present study.

### **Head and Neck Cancer**

Cancers of the head and neck generally include sites of moist mucosal lining in the head and neck region (Health, 2012) including the nose, oral cavity, salivary glands, tongue, tonsils, larynx, sinuses, and sites of the pharynx (Sanderson et al., 2002).

Cancers in this region can impart profound and complicated consequences to form and function due to the anatomical complexity of the area (Lung et al., 2007). Tumor growth may encroach on dozens of other anatomical structures, which may limit treatment options and or compromise optimal functional capacity (Derks et al., 2005).

### **Epidemiology**

Globally, HNC is the tenth most common cancer and the seventh most common cause of mortality linked to cancer (Mehanna, Paleri, West, & Nutting, 2011). Incidence and prevalence increase with age, and the majority of patients are men over the age of 65 (Rezende, Freire, & Franco, 2010). In the United States, rates of HNC and other tobacco

related cancers have begun to slowly decline (Westra, 2009). Mortality rates have also dipped, albeit slightly, due to improved detection and treatment strategies (Marur & Forastiere, 2008).

Survival among HNC patients is lower when compared to other types of cancers, particularly among older adults and those with certain types of HNC. Figure 2.1 shows the 2, 5, and 10 year survival rates (%) by Surveillance Epidemiology and End Results (SEER) area, ages 20 and older from 1988 through 2001.

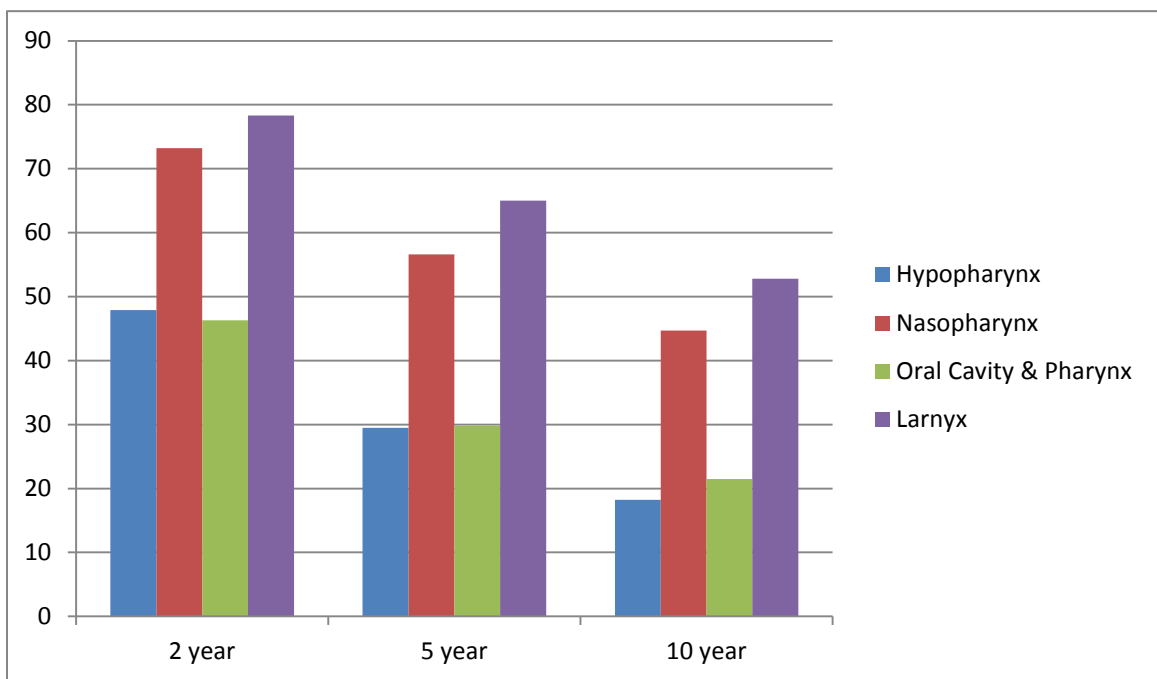


Figure 2.1 The 2-, 5-, and 10-year survival rates (%) by SEER area, ages 20 and older from 1988-2001 (Piccirillo, Costas, & Reichman, 2007).

Likewise, great disparity in prognosis exists by stage of cancer. Figures 2.2, 2.3 and 2.4 show the relative survival rate at years 2, 5, and 10 by stage for selected sites.

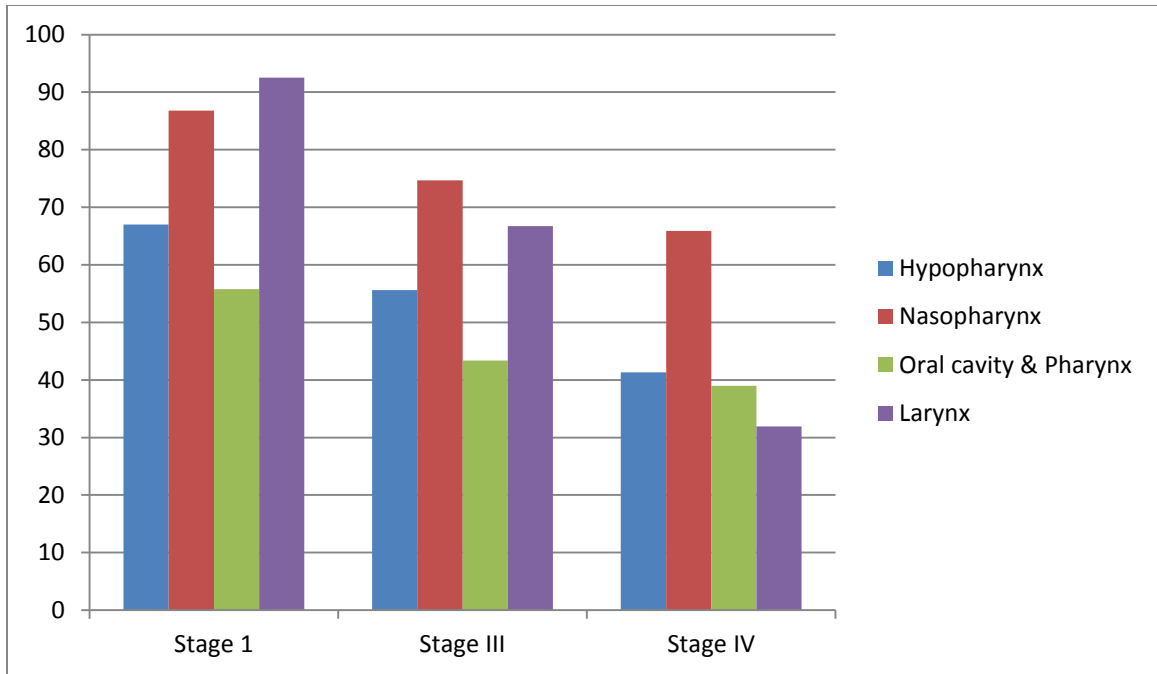


Figure 2.2 Two-year survival by site and stage (Piccirillo et al., 2007).

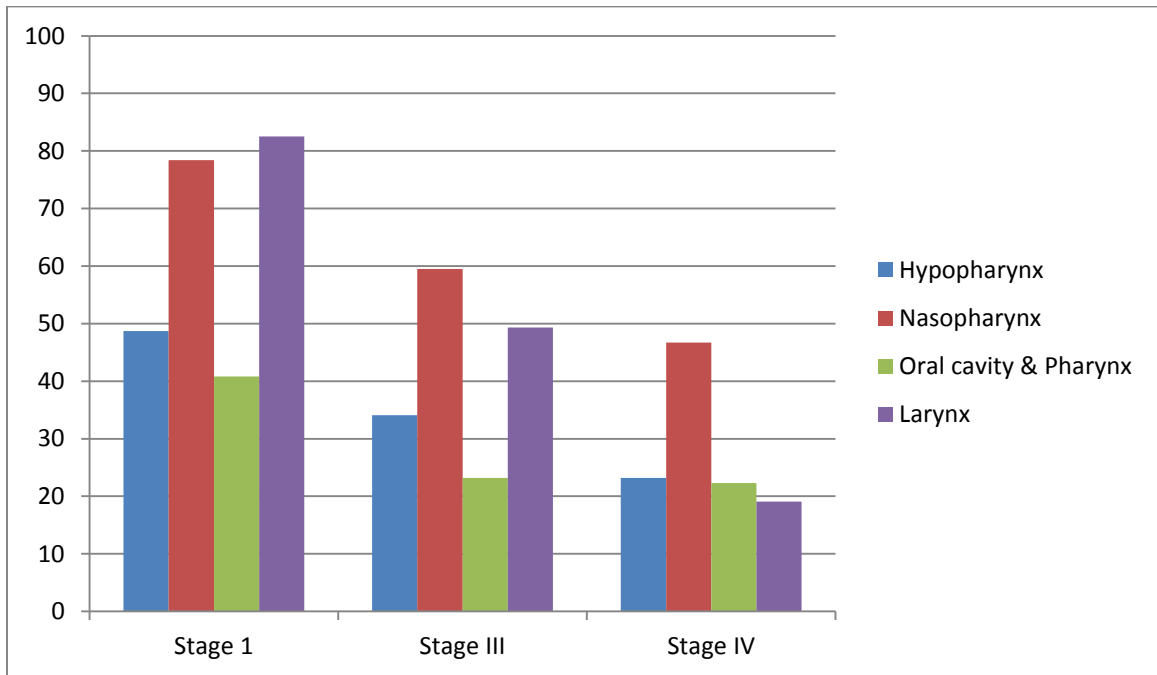


Figure 2.3 Five-year survival by site and stage (Piccirillo et al., 2007).

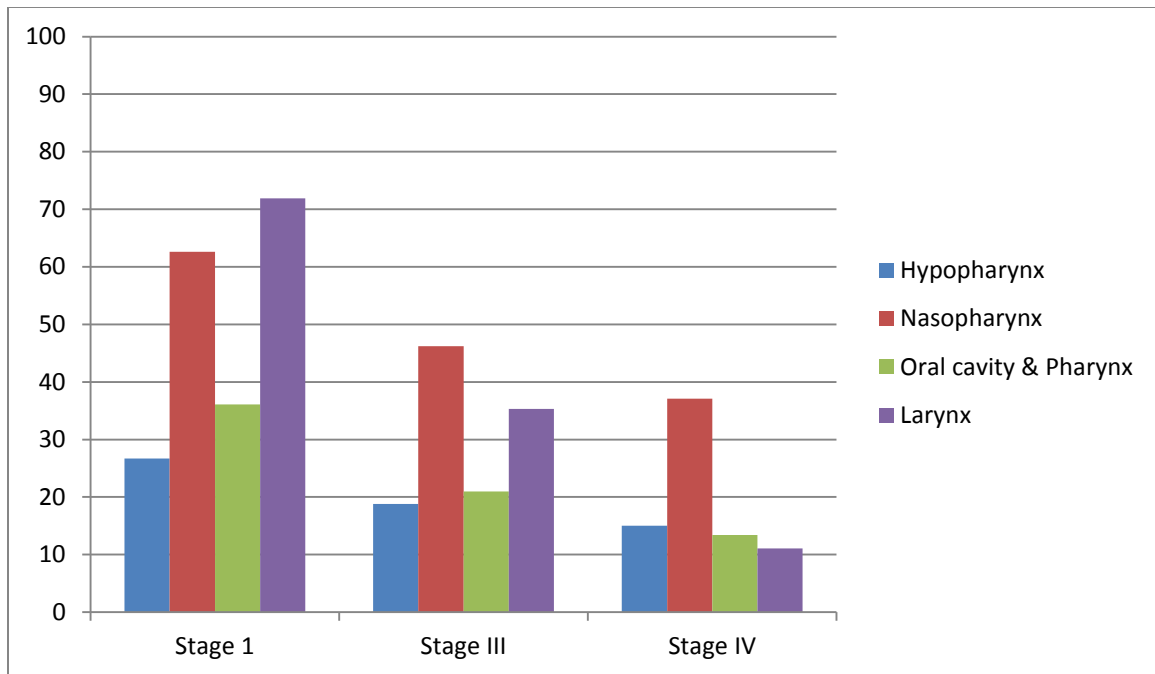


Figure 2.4 Ten-year survival by site and stage (Piccirillo et al., 2007).

### Etiology and Risk Factors

**Tobacco and alcohol use.** The most important risk factors for HNC are tobacco and/or alcohol use (Argiris, Karamouzis, Raben, & Ferris, 2008; Marur & Forastiere, 2008). The long-term use of tobacco weighs heavily in risk for HNC development. In a pooled analysis of 17 case control studies representing 27,389 HNC patients from America and European countries, Hashibe et al. (2009) determined that the population attributable risk (PAR) for tobacco or alcohol was 72% for HNC, with tobacco alone accounting for 33% and alcohol alone accounting for 4%. A total of 35% was attributable to combined use of tobacco and alcohol (Hashibe et al., 2009). The significance of tobacco and/or alcohol use to HNC tumor development differs by site, sex, and geographic region. For example, across all regions, laryngeal cancer has the highest risk (PAR = 52%) among male tobacco users (Olshan, 2010).



Additionally, risk is related to the amount of smoking, or pack-years over a person's lifetime. For example, Wight et al. (2003) found that male cigarette smokers were 23 times more likely than males who had never smoked to develop laryngeal cancer; this disparity was less severe, but still present among women. In addition to cigarette smoking, other forms of tobacco and tobacco use such as Hookah, snuff, cigars, pipes, and environmental tobacco smoke, have been identified as causal agents in the development of oral cancers as well as other forms of head and neck cancer (Anwar Merchant et al., 2000; Dahlstrom et al., 2008; Goldenberg et al., 2004; Lewin et al., 1998; Shopland, 1995).

**Oral health.** An increasing number of studies have investigated the relationship between oral health and overall health (Chattopadhyay, 2008; Guha et al., 2007; Locker, 1992; Makhija et al., 2006; Newton, 2006; Newton, 2007; Patrick et al., 2006). A number of scholars have illustrated that certain dental conditions such as periodontal disease and edentulism may be associated with some types of head and neck cancers (Guha et al., 2007; Macpherson, 2005). In a recent case control study with 2,785 participants, Divaris et al. (2010) found a modest association for periodontal disease, but not tooth loss. Poor dental health (as measured by number of cavities, edentulism and periodontal disease, among others) is apparent in many patients with oral cancers (Divaris et al., 2010). Recent studies suggest that the causal mechanism may be linked to increases in certain salivary enzymes such as acetaldehyde among individuals with poor dental hygiene, which may work synergistically with alcohol to increase the risk of oral cancer (Homann et al., 2000).

**Dietary determinants.** Nutritional and dietary factors also have been suggested as etiological agents in HNC cases, although they appear to be less well understood and less significant (Grobbelaar, Owen, Torrance, & Wilson, 2004; van Bokhorst-de van der et al., 1999). In particular, several dietary deficiencies have been found among certain HNC patient groups (Negri et al., 2000). Among individuals with low beta carotene diets, increased rates of various types of cancers, including laryngeal cancer, have been found (Suzuki et al., 2006). Similarly, chronic iron deficiency leading to Plummer-Vinson syndrome has been documented in women with oral and pharyngeal cancers (La Vecchia, Negri, D'Avanzo, Boyle, & Franceschi, 1991). Diets rich in fruits and vegetables that contain nutrients such as iron and beta carotene have been found to protect against HNC (Suzuki et al., 2006; van Bokhorst-de van der et al., 1999). Likewise, inadequate amounts of vitamin C, vitamin E, and zinc have been associated with laryngeal and esophageal cancer (Olshan & Divaris, 2010), while diets rich in these nutrients seem to produce protective effects (Li et al., 2012).

The habitual use of other carcinogenic substances such as areca nuts, khat leaves, betel quid, iqmik, and the tea Yerba Mate are found within various ethnic sub populations within the United States (Goldenberg et al., 2004). Yerba Mate, an increasingly popular drink touted for its health benefits, has been shown to be associated with increased risk of esophageal and laryngeal cancer (Goldenberg, Golz, & Joachims, 2003). Iqmik, extensively popular among Alaskan natives, is frequently used in combination with alcohol and tobacco. A recent study suggested that iqmik may further exacerbate the synergistic effects of alcohol and tobacco in the development of oral cancers (Renner et al., 2005).

**Viral and bacterial determinants.** Human papillomavirus (HPV) is perhaps most well-known for its role in the development of cervical cancer (Walboomers et al., 1999). In 1975, Byers documented a subset of HNC patients that were distinct: they were younger than 30 years of age and had cancers of the tongue (Byers, 1975). While HNC rates as a whole remained consistent, Shantz and Yu (2002) documented a 60% increase in the incidence of tongue cancer among individuals 30 and younger between 1973 and 1997 (Shantz & Yu, 2002). Rates did not increase for other age categories. Recently, the mysterious trend was linked to positive oral HPV status (Kreimer, Clifford, Boyle, & Franceschi, 2005). Certain strains of HPV, mainly 16 and 18, have been documented as the etiologic agent in certain types of oropharyngeal cancers, most notably those of the tongue and tonsil (Kreimer et al., 2005). In the United States, HPV positive oropharyngeal cancer incidence increased 225% between 1988 and 2004 (Kreimer et al., 2005). Most common among young white men (Maden et al., 1992; Ragin, Modugno, & Gollin, 2007), HPV is a communicable, sexually transmitted infection that can be contracted through oral sex. Researchers have cautioned that increased rates of oral sex among younger populations may increase HPV-related oral cancer incidence in coming decades (Ragin et al., 2007).

The role of HPV is particularly relevant to patients with no history of smoking or drinking (Tan, Adelstein, Droughton, Van Kirk, & Lavertu, 1997). While the synergistic effect of tobacco and alcohol use is abundantly clear, researchers are attempting to identify the degree of increased risk for individuals who smoke, drink, and engage in risky sex practices (Maden et al., 1992). Numerous studies have identified HPV DNA in certain tumor sites, most frequently in the tonsils, larynx, tongue, and floor of the mouth,

and less frequently in the esophagus and lips (Reddout et al., 2007). Other studies have also found that HPV positive patients tend to have larger tumors, as compared to non-HPV positive patients, as well as higher incidence rates for lymph node metastasis (La Vecchia et al., 1997). While the presence of HPV has helped to explain HNC among non-smokers and non-drinkers, more research is needed to determine additional causes and risk factors within this population.

Several other potential biological and viral factors have been cited in the literature. The Epstein-Barr virus (EBV), more commonly associated with lymphomas and gastric cancer, has also been linked to nasopharyngeal cancer (Jacobs, 1990). It appears however, that EBV alone is not sufficient to cause the development of nasopharyngeal cancer (D'Souza & Gillison, 2005). Likewise, *H. pylori*, and human immunodeficiency virus (HIV) have been shown to play indirect etiological roles in various types of HNC (Olshan, 2010). General immunosuppression, gastroesophageal reflux disease (GERD), and oral lichen planus (OLP) are three medical conditions that have been identified in a small population of HNC cases (Kleist, Bankau, Lorenz, Jager, & Poetsch, 2004; White et al., 2007). GERD has been suggested as a possible cause of certain laryngeal cancers, since chronic movement of gastric acids and resulting inflammation of the esophagus and larynx region contributes to damage of the mucosal lining, which may lead to cellular dysplasia and eventually cancer (Kleist et al., 2004). Finally, OLP is an inflammatory condition of the mucosal lining (Barnard, Scully, Eveson, Cunningham, & Porter, 1993). Although its role is highly controversial and not well understood, several studies have provided evidence that presence of the condition may lead to the development of malignancies, of the oral cavity (Gonzalez-Moles, Scully,

& Gil-Montoya, 2008; Maraki et al., 2006; Olshan & Divaris, 2010; Winn, Blot, Shy, & Fraumeni, 1982)

**Occupational exposure.** Individuals who spend extended periods of time outdoors, such as farmers and construction workers, have an increased risk of developing lip cancer due to ultraviolet radiation from the sun (Olshan & Divaris, 2010; Winn, Blot, Shy, & Fraumeni, 1982). In fact, the incidence of cancers for this sub-site increases in countries closer to the equator (Davidson, 2001).

Laryngeal cancers have been argued to be more sensitive to occupational exposure than other cancers (Rafferty, Fenton, & Jones, 2001). In particular, some studies have shown that after controlling for smoking and alcohol, workers in occupations involving high and more frequent levels of exposure to chemical fumes, radiation and dust are at significantly higher risk for development of laryngeal cancer (Becher et al., 2005; Laforest et al., 2000; Muscat & Wynder, 1992). On the other hand, a recent meta-analysis of 99 studies concluded that exposure to wood dust, formaldehyde and cement dust were not significantly associated with laryngeal cancer (Paget-Bailly, Cyr, & Luce, 2012). In addition, military personnel and others exposed to mustard gas explosions are at increased risk for laryngeal cancer (Rothman, Cann, Flanders, & Fried, 1980). Among other cancer sites, evidence on the role of these agents and other solvents, gases and chemicals in cancer development is largely inconclusive (Marur & Forastiere, 2008). Issues related to measurement, recall and the presence of multiple confounders cloud the ability of researchers to draw strong conclusions regarding the relative strength and relationship of many occupational exposures.

Other distinct agents found in certain occupations have also been suggested as etiological factors. These include, but are not limited to nickel, asbestos, formaldehyde, cement dust, wood dust, diesel exhaust, benzene, and coal (Marur & Forastiere, 2008; Paget-Bailly et al., 2012). Generally, studies examining the role of these factors have not controlled for the use of tobacco and alcohol and age of study participants. Likewise, most studies suffer from small sample size and other study conditions that render the findings questionable at best (D'Souza & Gillison, 2005).

**Geographical and socio-cultural context.** As many as 85 of the 120 counties of Kentucky are classified as rural (Davis, 2009). These same counties have among the highest rates of smoking and smoking related disease in the country (KY Institute of Medicine, 2007). As such, many study participants were expected to reside in rural and/or Appalachian regions of the state. Rural residents, classified by the U.S. Department of Health and Human Services as a “special population” (Portnoy, 1994) tend to be older, poorer, less educated, suffer higher rates of disease and disability, and are more likely to be uninsured and/or underinsured than their urban counterparts (Portnoy, 1994 ). In addition, certain health behaviors and trends in medical help seeking have been observed. For example, a recent study determined that Appalachian residents may believe that death from cancer is unavoidable, and/or that a person will know or be able to tell if they have cancer without seeing a physician; the same study also pointed out that Appalachian patients often do not seek medical help or treatment even when they perceive that a threat exists (Vanderpool & Huang, 2010). Rural residents are often viewed as self-reliant, self-sufficient, individualistic, and wholesome (Bull, 1998; Krout, 1988; Rowles, 1984; Rowles, 1988; Youmans, 1977). Additionally, there is a perception

that rural Americans are friendly, hospitable, robust, traditional and/or conservative, and even wistful (Lee, Coward, & Neizer, 1994; Youmans, 1977). Similarly, social bonds and networks among rural residents are often considered to span multiple generations and contribute to social insiderness and social capital that may enhance social coping and buffering of negative health and social problems (Arcury, Quandt, McDonald, & Bell, 2000). From a health perspective, literature frequently reflects rural attitudes of fatalism, independence, a belief and faith in God, a reliance on alternative and natural health remedies, and an external locus of control (Arcury et al., 2000; Behringer & Friedell, 2006; Hartley, 2004). In studies of rural farmers, health has been defined as the ability to continue to work and complete daily activities, despite the existence of multiple comorbidities (Lizer & Petrea, 2007).

**Comorbidity.** Aging is the single most important risk factor for the development of cancer and a significant predictor of functional decline, chronic disease, and disability (Rowland & Yancik, 2006). In the largest pooled analysis of comorbidity among HNC patients to date, Boeje and Overgaard (2012) suggested that 44% of all Danish HNC patients between 1992 and 2008 had at least one comorbidity. The most common comorbid conditions within this population are linked to tobacco use, and include cerebrovascular disease (11%), chronic pulmonary disease (11%) and cardiovascular disease (10%) (Boeje & Overgaard, 2012). Reid and colleagues (2001) reported that tobacco and alcohol use, as primary etiologic agents, contribute to the high prevalence of comorbidity and poor survival rates among HNC patients (Reid et al., 2001).

The presence of comorbidities, including addiction to tobacco, alcohol, or other substances may deter initial help seeking for symptoms of HNC (Brouha, Tromp,

Hordijk, Winnubst, & De Leeuw, 2005), and result in tumors that are well advanced before presentation to a health care specialist (Oozeer, Paleri, Benbow, Downs, & Kelly, 2006). As demonstrated above, patients with later stage disease generally have higher risk for death and functional decline. Additionally, the presence of advanced disease combined with comorbidities and overall poor health may significantly limit treatment options and or outcomes, due to the added complexity of treatment, its side effects, and potential for added treatment-related toxicity to the body, particularly among older patients (Oozeer et al., 2006; van der Schroeff, Derks, Hordijk, & de Leeuw, 2007). Comorbidities have been suggested as one reason for high mortality rates and low survival among HNC patients. In a study by Coatesworth et al. (2002), 40% of deaths occurring in the 23 months between diagnosis and time of death were attributed to a comorbid condition. Larger cohort, case-matched studies confirmed the hazard of higher mortality linked to comorbidities (Datema, Ferrier, van der Schroeff, & Baatenburg de Jong, 2010; Piccirillo, Tierney, Costas, Grove, & Spitznagel, 2004; Reid et al., 2004). Finally, comorbidities may also pose a threat to post treatment quality of life (QoL). Terrel et al. (2004) demonstrated that the presence of two or more comorbidities was a predictor of decreased QoL.

## **Treatments**

HNC treatment strategies are similar to other types of cancers, except that these strategies are complicated by the anatomy of the head and neck region. For example, radiation treatment after surgery introduces radiation to adjacent tissues that assist in breathing, swallowing, chewing, eating, and the absorption of nutrients. Post-treatment



side effects may require long term medical management and often influence a patient's physical and social function (Rose & Yates, 2001).

Standard HNC therapies include surgical intervention, radiation, conventional chemotherapy (e.g., cisplatin), and strategies to inhibit the epidermal growth factor receptor (EGFR) (e.g., cetuximab) (Sloan & Goepfert, 1991). Those patients who survive initial treatment often suffer severe morbidity resulting from damage to the upper aero-digestive tract as a consequence of treatment or tumor invasion (Lung et al., 2007). In addition to physical treatment outcomes, a large number of patients also experience psychological distress before, during and after treatment, including anxiety, depression, and fear. Studies have shown that clinically significant depression is often present before diagnosis (29%), as well as at diagnosis (13-40%), during treatment (25-52%) and post-treatment (11-45%) (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009). Pre- and post-treatment distress has been described as moderate to severe among head and neck cancer patients, necessitating supportive care (Chen et al., 2010).

Often, patients are offered multidisciplinary treatment protocols that utilize multiple therapies and medical specialties, resulting in long-term aggressive treatment plans. Generally, the type of treatment is largely dependent upon the stage and location of the tumor. However, research has shown that providers may opt for less aggressive treatment strategies among older and elderly patients, despite clinical evidence that would support more aggressive treatment (Balducci, 2006; Ershler & Balducci, 1994).

During and after treatment, patients may experience a range of physical and emotional side effects that can continue for months or even years. Treatment type and intensity determines the scope of these side effects (Lung et al., 2007). Patients receiving

aggressive surgery and/or radiotherapy and chemotherapy cope with an array of long-term side effects that may affect quality of life (Derks, de Leeuw, Hordijk, & Winnubst, 2004; List & Bilir, 2004). Following treatment, physical symptoms and functional impairment commonly include dry mouth, dysphagia, pain, inability to swallow or eat normally, and impairment to voice and/or speech (Zackrisson, Mercke, Strander, Wennerberg, & Cavallin-Ståhl, 2003).

In related literature, researchers have shown that treatment negatively affects diet (Grobbelaar et al., 2004); body image, self-image and self-esteem (Dropkin, 1999; Fingeret et al., 2012); as well as the ability to eat, drink, swallow, talk, and breathe (Fingeret et al., 2012; Holloway et al., 2005; Larsson, Hedelin, & Athlin, 2003).

Despite the fact that many older patients with HNC smoke, there is a paucity of research focusing on the effects of tobacco use during and after treatment. A thin body of emerging research strongly suggests that treatment outcomes are less satisfactory for patients who continue to smoke. In one study, Jensen, Jensen, and Grau (2007) found that patients who quit smoking after treatment experience better quality of life than patients who continue to smoke. In another study, researchers found that patients who have smoked or currently smoke are a psychologically at risk group, with higher rates of depression, anxiety, and distress in the first 15 months following treatment (Humphris & Rogers, 2004).

There are many factors to consider when identifying HNC treatment options. One important consideration is tumor stage at diagnosis. Various medical assessments such as visual endoscopic examinations, chest x-rays, computerized axial tomographic (CAT) scans and magnetic resonance imaging (MRI) are used to assess tumor size, shape, and

depth and to identify adjacent areas of pre-malignant or malignant change. This information is then used to assign a descriptive number representing the tumor's size and potential for cure. These stages fall generally into early (stage I), intermediate (stage II) and advanced (stages III and IV). Tumor stage is not based on patient-specific information such as age, overall health status, or other comorbidities, yet it is often viewed as a prime indicator of disease severity that dictates treatment options (Sloan & Goepfert, 1991). Each option has its own potential for success and significantly influences functional outcomes. Many treatment options may be influenced by size and location of the tumor, thus similar treatment strategies could have vastly different outcomes across patients.

The prognosis is best for people with early stage cancers. Survival rates are higher, functionality can usually be preserved, and patients experience less effects on long-term quality of life (Ronis et al., 2008). Most early stage cancers can be eliminated through surgical resection or radiation while minimizing functional deterioration (Marur & Forastiere, 2008). Recent advances in surgical micro-laser and other emerging technologies have greatly improved a surgeon's ability to remove malignancies (particularly those with limited extent) without disturbing surrounding tissue, thus maintaining a patient's physical appearance, voice and swallowing function (Grant et al., 2010). For patients who opt for radiation without surgery, voice may be better maintained, although dry mouth and long-term swallowing problems may occur (Corvo, 2007; Specht, 2002).

Intermediate cancers are more invasive, requiring surgical resection and removal of lymph nodes (neck resection), as well as radiation therapy. Although these procedures

may eradicate a malignancy, preservation of function may be considerably reduced (Syrigos et al., 2009). Patients treated for intermediate cancers through radiation may require future treatment for local recurrence, requiring significant surgical intervention, such as a total laryngectomy for recurrent laryngeal cancer (Lung et al., 2007).

Treatment of advanced stage disease is the most complex and controversial. Treatment options must be identified on a case by case basis and may be focused more on functional preservation than cure. Aggressive treatment includes significant surgical resection combined with radiation and pharmacological interventions (Givens et al., 2009). Loss of voice, swallowing problems, malnutrition, severe physical deformation, and many other subsequent side effects are likely to occur (Curran et al., 2007).

In sum, the standard treatment options for managing HNC include surgery, radiotherapy, and chemotherapy. Unfortunately, many patients are diagnosed in later stages of disease which may significantly diminish the efficacy or viability of available treatments (Lung et al., 2007). For patients not receiving radiotherapy, surgical resection is generally believed to be the optimal treatment approach for curative purposes (Bernier, 2011). For patients with advanced disease and/or recurrence of advanced disease, surgical outcomes may be poor. Irradiation can be difficult and produce unpleasant symptoms and physical challenges while also producing less than optimal results (Cox & Laramore, 1989). Irradiation with concomitant chemotherapy is a continuing focus of research in otolaryngeal surgical practice. In fact, among cancer sites in chemoprevention clinical trials, concomitant chemotherapy for HNC tumors is one of the most prolifically studied (Tsao, Kim, & Hong, 2004).

## **Coping with Head and Neck Cancer**

Coping is the process by which an individual uses cognitive and behavioral strategies to mitigate and manage both internal and external responses to stress-inducing situations (Folkman & Lazarus, 1985). While coping is a significant area of research across the illness experience, some researchers have argued that among head and neck cancer patients, stress and associated coping strategies increase as patients complete and finish treatment (List et al., 2002; Sherman, Simonton, Adams, Vural, & Hanna, 2000). Aside from constituting a significant threat to overall health and cancer recovery, tobacco and alcohol use may be a dominant means of coping for HNC patients who experience-varying rates of distress related to living with cancer. Aarstad et al. (2007) reported that alcohol use was reported as a coping mechanism among HNC patients after one year of treatment. Additionally, the same study determined that as smoking and drinking increased, general quality of life decreased (Aarstad, Aarstad, & Olofsson, 2007). In a study of patients with head and neck and lung cancers, those who continued to smoke after diagnosis were more dependent on nicotine, perceived fewer positive reasons for quitting, had a greater fatalistic perspective combined with emotional distress, and lower self-efficacy (Schnoll et al., 2002).

Additional mechanisms for coping with cancer have been identified in the literature. (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992) identified five broad patterns of coping with cancer. These included: (a) social support, (b) focusing on the positive, (c) distancing, (d) cognitive escape-avoidance, and (e) behavioral escape-avoidance. These findings have been expanded upon over the last 20 years, although the five primary patterns remain significant in the illness coping literature. Social support is

commonly cited in the literature as a means of both instrumental and psychological support among head and neck cancer patients (Aarstad, Lode, Larsen, Bru, & Aarstad, 2011; Deno et al., 2010; Foxwell & Scott, 2011; Gil, Costa, Hilker, & Benito, 2012; Howren, Christensen, Hynds Karnell, Van Liew, & Funk, 2012; Kilbourn et al., 2013; Penedo et al., 2012). Patients and families seek information about their disease, treatment choices, and side effects from trusted sources of social support which may include family members, health care providers, close friends, social internet sites, and members of faith based organizations. In a study of African American men with head and neck cancers, the three most common coping strategies were support from God, seeking emotional support from family and friends, and helping others (Agarwal, Hamilton, Crandell, & Moore, 2010). The concept of helping others parallels Dunkel-Schetter et al.'s concept of focusing on the positive, and has also been conceptualized as one aspect of self-transcendence. Self-transcendence has been defined as the experience of taking on broader life activities, perspective, and purpose through extending one's self boundaries (Reed, 1991). Self-transcendence allows the individual to move beyond concern of self while maintaining or increasing one's self value (Coward & Kahn, 2005). According to Coward & Kahn (2005), self-transcendence may be a powerful means by which patients can reestablish personal well-being and transformative growth in the wake of significant life trauma. In addition to Agarwal et al.'s study, other researchers have begun to identify and report that cancer patients engage in activities that benefit the good of others as a way to stay positive and focus on something other than their cancer (Matthews & Cook, 2009; Thomas, Burton, Griffin, & Fitzpatrick, 2010). Social support and transcendence are considered to be problem-focused coping strategies as the

individual acknowledges and/or accepts the stress and attempts to mediate it by learning new skills and information, or making goals (Lazarus & DeLongis, 1983).

While social support and positivity strategies including self-transcendence may be used as a coping strategy by some, others may employ emotional avoidance strategies such as cognitive and behavioral escape, whereby the person attempts to retreat from the stressor by engaging in other activities, denying or dismissing the seriousness of the stressor, and or intentionally suppressing thoughts and emotions related to the stressor (Endler & Parker, 1990).

Although the head and neck cancer experience brings significant stress before, during, and after treatment, only a small body of literature specifically examines coping and its relationship to the cancer experience among this patient population. This topic will become increasingly relevant as the number of older individuals living with chronic diseases such as cancer who may not be fully relieved of pain and discomfort continues to grow.

Daily life for the head and neck cancer patient occurs within the context of competing health demands (Baijal et al., 2011), limited resources (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006; Lawlor, Patel, Fraser, Smith, & Ebrahim, 2007; List et al., 2004; Vartanian, Carvalho, Toyota, Kowalski, & Kowalski, 2006), tobacco dependency (Argiris et al., 2008), limited HNC knowledge (Sommer, Sommer, Goldstein, & Irish, 2009), low risk perceptions, and an increased likelihood for impaired physical functioning (Haas, Eng, Dowling, Schmitt, & Hall, 2005; Ronis et al., 2008). The stress-coping model (Folkman & Lazarus, 1985; Lazarus & DeLongis, 1983) proposes that the coping strategies one employs to adjust to a stressful situation are based

largely on the personal meaning that the individual has assigned to the situation. Age and developmental stage at the time of diagnosis may influence appraisal, meaning, and thus adjustment through coping (Folkman & Lazarus, 1985; Gotay & Muraoka, 1998; Lazarus & DeLongis, 1983). Qualitative explorations acknowledging and exploring the manifold context of these factors among cancer patients, and specifically head and neck cancer patients, are largely absent from the literature. These models suggest that older cancer patients may respond differently to a cancer diagnosis than their younger counterparts.

**Age.** Northouse (1994) postulated that the impact of cancer and cancer treatment is strongly associated with the patient's age at the time of diagnosis. The normal process of aging may influence adjustment to cancer (Gotay & Muraoka, 1998; Northouse, 1994). Others have asserted that coping strategies change in predictable ways over the life course (Aldwin, 1991; Aldwin, Sutton, Chiara, & Spiro, 1996; Levenson, Jennings, Aldwin, & Shiraishi, 2005; Yancura & Aldwin, 2008). For example, problem focused coping increases with age and is dependent upon the persons' perception that they can successfully mitigate the stressor (Trouillet, Doan-Van-Hay, Launay, & Martin, 2011). Such confidence may be built through experience or may be part of a larger developmental process specific to late life (Yancura & Aldwin, 2008). Several research studies have found that older cancer patients perceive less threat from their cancer diagnoses and experience fewer intrusive and depressive thoughts than younger patients, thereby influencing appraisal of threat (Epping-Jordan, Compas, & Howell, 1994; Schroevers, Ranchor, & Sanderman, 2004; Wenzel et al., 2012). Some researchers have attributed differences between younger and older patients to diminishing cognitive ability in late life (Deary et al., 2009; Pinqart & Duberstein, 2004), associated impairments to



short- and long-term memory (Carstensen, Mikels, Mather, Birren, & Schaire, 2006; Charles, Mather, & Carstensen, 2003; Fung & Carstensen, 2003; Lockenhoff & Carstensen, 2004; Mather & Johnson, 2003; Sehl, Sawhney, & Naeim, 2005), fatalism (White & Verhoef, 2003), and less effective coping skills (Chappell, 2008).

Others have made connections between age and time perspectives that affect cognitive processing related to emotional regulation and influence decision-making (Carstensen & Charles, 1998; Charles, Carstensen, Hess, & Blanchard-Fields, 1999; Rothspan & Read, 1996; Seijts, 1998; Teahan, 1958; Zimbardo & Boyd, 1999). These literature streams are directly applicable to this study since cancer related decisions are typically made by (a) older patients with (b) shortened time perspectives (due to age and illness) during (c) emotionally intense times post-diagnosis.

**Time perspective and emotion.** Conceptualizations of time and timing are manifest both in individual illness experiences and medical practices. For example, individuals with chronic illness have been shown to restructure time and arrange or even rank plans, priorities and goals through a process of framing, organizing, and using time (Charmaz, 1993). Illness often forces patients to consider temporal factors such as time to cure, time to death, and time remaining with high quality of life. In one study, older adults were more likely to make more immediate decisions regarding cancer treatment (Meyer, Talbot, & Ranalli, 2007). Placing the self into linear time-scapes of past, present and future may assist patients in adapting, coping and living with an illness by creating timetables and time-oriented milestones that structure daily living (Charmaz, 1993; Klitzman, 2007).

Individual perceptions of time affect cognitive processing related to emotional regulation, thus influencing decisional approaches and outcomes (Carstensen & Charles, 1998; Charles et al., 1999; Rothspan & Read, 1996; Seijts, 1998; Teahan, 1958; Zimbardo & Boyd, 1999). Carstensen and Turk Charles (1994) found that older adults recall a greater proportion of emotionally meaningful information than neutral information. Furthermore, older adults consistently display a recall bias toward subjective, emotionally relevant information rather than factual information. For example, when asked about a hospital experience, older adults are more likely to describe emotions and feelings associated with the visit, while younger adults are more likely to recall more spatial, factual, and perceptual information (Hashtroudi, Johnson, Vnek, & Ferguson, 1994).

Recent empirical work has shown that aging is associated with an increase in attention to emotional content. For example, Carstensen and Turk Charles (1994) asked adults in four different age groups to read and recall stories containing both neutral and emotion-laden content. Examination of the data revealed a linear decline across the four age groups in recall of neutral content with age, but stability in recall of emotional content. Thus, older adults recalled relatively more emotional content than neutral content, supporting the authors' contention that there was a shift in the nature of memory representation toward disproportionate retention of emotional information. Likewise, Fung and Carstensen (2003) examined advertisement memory and found that older adults prefer emotional advertisements more than younger adults. In addition, memory for advertisements with emotional appeals comprised a greater proportion of the total information remembered by older adults compared to younger adults.

While biological aging generally has negative consequences for cognitive and biological functioning, emotional capacity may actually grow and develop (Scott, McGurk, & Grunfeld, 2007). The recognition and study of development into late life provides a fertile area of research with a significant ability to illuminate how older adults perceive, process and use information in adjusting to life with cancer. Emotional maturity may explain the paradox often cited in gerontology literature of shrinking social networks and resources, but stable or improved life satisfaction.

The cancer treatment experience brings with it ongoing, complex, and multidimensional opportunities for decision-making (Noone, 2002), including the treatment decision. Among older adults, factors stemming from the aging process as well as cognitive, functional, and overall health status may influence the head and neck cancer experience including cancer decisions, and their outcomes (Balducci & Extermann, 2000). The link between HNC, comorbidity, late stage diagnosis, and tumor complexity may be exacerbated by factors that permeate coping and thus decision-making for older cancer patients (Davies, Rhodes, Grossman, Rosenberg, & Stevens, 2010).

### **Significance and Implications of the Study**

The HNC treatment experience is embedded within the larger context of one's life experiences, goals, perceptions, and cognitive capacity. The predicted increase in cancer and other chronic diseases related to a rapidly increasing older population warrants research that explores the context of the experience. The research presented in this dissertation adds to the limited knowledge of how HNC patients experience treatment and what factors, including age, may shape that experience. This study has the capacity to

yield valuable insight into the relationship between age-related emotional regulation, illness, and decision-making processes and outcomes in older patients with cancer.

The literature reviewed offers a starting point for examining the complex nature of the head and neck cancer treatment experience. The epidemiology of the disease is entangled in social, behavioral, and clinical risk factors that often emerge or exist alongside an array of comorbidity and advancing chronological age. Furthermore, individual elements related to coping, adaptation, and emotion hint at the deeply personal and individual context of life with cancer. Although the literature clearly identifies these factors, little is known about the experience of living with head and neck cancer and its treatment. The breadth and depth of factors related to head and neck cancer warrant further exploration in terms of how they impact treatment experience (Specific Aim 1). Likewise, elements of time, age, and coping, among other factors remain relatively unexplored, particularly from the perspective of the patient and the context of life with cancer (Specific Aim 2). This study will add to what is known about the intersection of time, age, and coping in relation to cancer treatment experience. The current body of literature lacks a clear model of cancer treatment that focuses on head and neck cancer experience. The development of such a model (Specific Aim 3) shifts the focus to the patient and their living, rather than the disease and its cure. Finally, the literature suggests that HNC risk factors, treatment options, and coping mechanisms are well studied, yet patients and providers still experience less than optimal outcomes. Few tools and strategies are identified and available to patients and their families in navigating the cancer treatment experience. An understanding of treatment experience would lend itself

to the development of such resources (Specific Aim 4), thereby potentially improving experience, satisfaction, and outcomes for patients and providers.

### **Chapter 3. Research Design and Methodology**

This chapter provides an overview of the research methodology used in this study. I justify a qualitative approach and describe the qualitative techniques employed. Also described is the research setting, methods for data collection, and data explication and analysis. A summary is provided at the end of the chapter before findings are presented in Chapter 4.

A qualitative research methodology was selected as the most appropriate approach for this study's aims. The treatment experience is complex and includes an array of elements such as cognitive, affective, and perceptual dimensions that are neither easily nor directly observable (Pierce & Hicks, 2001). As described by Denzin and Lincoln (2000), qualitative research allows for the many intricate pieces of lived experience to come together as a piece of art. Much like a quilt built from many individual pieces, qualitative methods can elucidate the many parts and uncover the whole of human perspective (Denzin & Lincoln, 2000). In other words, qualitative methods provide a means to explore and gain a thick description of the context and reality of treatment experience. Thick description reflects layers of meaning and experience and is sensitive to the complexity of the phenomenon of interest (Creswell, 2003; Geertz, 1973; Hurwicz, 1995; Ryle, 1949; Tibbitts, 1954).

An important element of qualitative research is determination of an appropriate method of data collection (Starks & Trinidad, 2007). Among the various methods of data collection, interviews (a) allow a researcher to establish rapport with study participants (Creswell, 2003), (b) facilitate the observation of participants in their environment

(Starks & Trinidad, 2007), and (c) are conducive to capturing the lived experience of real life situations (Klein, 2008).

### **Research Setting**

Participants were recruited from the Department of Otolaryngology, Ear Nose and Throat Clinic (ENT) at the University of Kentucky's (UK) Chandler Medical Center in Lexington, KY. Medical organizations offering comprehensive treatment options for cancer including HNC are geographically limited in Kentucky. Most patients in need of significant ongoing comprehensive care must either travel to the Chandler Medical Center in Lexington, or obtain care through cancer care services based in Louisville, KY. The UK ENT clinic serves a significant percentage of HNC patients from Kentucky and surrounding states.

### **Data Collection**

Two semi-structured interview guides were developed to collect study data: (a) a pre-treatment interview guide, and (b) a post-treatment interview guide. Each guide was developed specifically for this study and was designed to facilitate an exploration of the HNC treatment experience. The average length for each interview was 74 minutes. This does not include the considerable amount of time that was often spent building rapport with participants prior to and after the formal interview process. As participants were often recruited, enrolled, and interviewed in the context of a clinical visit, I was afforded the opportunity to meet and talk to patients about their potential participation in the study, their treatment and general well-being. In recruiting and preparing for interviewing, I frequently sat and talked with patients and their families before, during and after appointments. Our discussions focused largely on the many stresses and fears associated

with their cancer, clinical appointments, and treatments. While I made no attempt to formally capture the time I spent in these discussions, it was not uncommon for several hours to pass between the time I met a participant, conducted and completed the interview and talked with them more before eventually saying goodbye. In addition, several patients spent additional time with me outside of our formal interviews, either in person or over the phone. For example, many participants frequently visited the medical center to undergo testing, seek care, or complete treatment. If I was in the clinic, I often made time in my schedule to briefly visit with them and stay abreast of their experience. On several occasions I visited participants and their families post-surgery or while undergoing treatment. These interactions provided additional opportunities for me to observe the treatment experience and to cultivate relationships with study participants. Phone calls from participants added limited, although useful additional interaction. In some cases, participants would call me on the phone to add or clarify something that they said in one of the interviews. I had provided my phone number in the event that they needed to reschedule an interview or had questions or concerns about their study participation. In any case, these calls sometimes evolved to include discussions of other aspects of their treatment. For example, one man called to confirm where we would be meeting for the second interview. He also added that he had spoken to his older sister about a childhood illness they both had experienced and was able to tell me more information about the event than he had during the first interview. The conversation also included an update on his last chemotherapy session and meeting his physical therapist for the first time.



Development of the interview guides (see Appendices B and C) incorporated open-ended questions about the HNC treatment experience. I also utilized several scales to further attempt to identify relationships between time and age, as suggested by SST. The Future Time Perspective Scale (Lang & Carstensen, 2002) is a validated instrument used to measure perceptions of future time. Respondents are asked to rate their agreement with 10 statements, such as “There is plenty of time left in my life to make new plans” using a 7-point scale ranging from “very untrue” to “very true.” A final score is calculated and used to determine expansive (higher scores) versus more limited future time perspectives (lower scores).

Degner’s Control Preference Scale (DCPS) (Richmond & Ross, 2009) is a commonly used tool to measure patient preference for decisional control, or the degree to which a person wants to be involved in the treatment decision-making process. Respondents select one of five statements that best fit their personal preference for participation in selecting treatment.

The University of Washington Brief Quality of Life (UW-BQOL) scale is a validated scale used to assess quality of life with regard to common problems experienced by HNC patients (D’Cruz A et al., 2007; Weymuller, 2001). One strength of the scale is that it incorporates a free text or open-ended question that allows patients to record other issues not covered in the structured responses that may be important factors affecting quality of life. The scale asks about health and quality of life in regard to pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder pain and function, taste, salivary production, mood, and anxiety. Finally, the instrument asks

patients to rate their overall quality of life over the preceding 7 days as outstanding, very good, good, fair, poor, or very poor.

The first interview was completed within 2 weeks of the patient receiving a new HNC diagnosis. The second interview was completed after either treatment had ended or the patient had decided to stop undergoing treatment.

**Protection of human subjects.** Approval from the University of Kentucky Institutional Review Board was granted on October 17, 2008. Patients were actively recruited between October 20, 2008, and March 3, 2009, with the enrollment of the forty-first participant. The procedures for informed consent and data protection were strictly adhered to. No adverse events or occurrences were reported. I had given a great deal of thought to incentives for patient participation. I decided to offer all patients who enrolled in the study an honorarium of \$30 cash to be paid upon completion of each interview. Funds for the honorarium were provided through a grant from the Kentucky Cancer Prevention and Control Training Program, National Cancer Institute Grant # R25 CA 098220. Although several patients seemed more interested in participating when they learned about the honorarium, only six patients accepted payment for their interviews. The remaining 35 patients refused payment altogether or asked that their honoraria be donated to a charity. Five participants requested to review the results of the interview findings upon completion of the study. I sent a brief overview of study results to all patients who had provided a mailing address or e-mail address for that purpose. Hand-written thank you cards acknowledging their personal contributions were also given to patients or their families shortly following the last interview.

## **Research Sample**

Patients were eligible to participate in the study if they: (a) had received a primary, recent (within the last 2 weeks) diagnosis of a squamous cell carcinoma of the head and neck; (b) could speak English; (c) were deemed cognitively competent by the treating physician; and (d) were over the age of 18. While the age of study participants was expected to mirror the age of HNC patients at the national level, the age of 18 was used as encouraged by the human subjects review board. Inclusion of any adult (age 18 and over), prevented discrimination on the basis of age and allowed for potential comparisons between younger and older study participants should younger patients be available and recruited. The 2-week window of HNC diagnosis was included as an eligibility requirement to ensure that the first interview occurred early in the treatment decision-making in order to limit the amount of time that had passed since treatment options had been identified. There were two ways in which individuals could be enrolled in the study. The primary way depended upon clinical staff to identify eligible patients and to provide them with information regarding the study. The clinical staff included the Multidisciplinary Head and Neck Cancer Nursing Coordinator, the treating head and neck oncologic surgeons, and/or the clinical services technician at the Chandler Medical Center ENT clinic. Information (visit date and time, as well as patient name) for eligible patients was then communicated to me with the patients' permission if they were interested in learning more about the study. I spoke with each eligible patient either in person or by telephone to assess his or her interest in participation and to obtain informed consent.

The second way a patient could enroll was by contacting their ENT clinic staff member or contacting me directly in response to viewing a recruitment flyer, approved by the Human Subjects Review Board. These flyers were posted in clinic exam rooms, the clinic waiting room, and on clinical research information bulletin boards throughout the Chandler Medical Center and on the center's website. Interested candidates were provided more information and the option to enroll was extended to them.

Since patients were often on the UK Medical Campus for an extended amount of time, I was usually able to contact patients in person before, during, or after their visits. When I was not able to contact patients during initial visits, I contacted them by telephone within 24 hours of their visit. If a patient met eligibility criteria, I met with him or her to provide a brief description of the research, discuss the significance of the study, including the overall goal and the number of interviews involved and time required for participation, the types of questions that would be asked during the interviews, the risks and the potential benefits, procedures to assure confidentiality, and the voluntary nature of participation. Potential participants were encouraged to ask questions about the project and their participation. Candidates interested in participating were then asked to sign and return an informed consent form approved by the University of Kentucky Institutional Review Board (Appendix D) before scheduling or initiating the first interview and were given a copy of the document for their own records.

Patients who were contacted by telephone received the same information. When patients indicated interest, I arranged to meet with them during their next clinic appointment. All patients provided consent and were first interviewed at the UK Chandler Medical Center.

After recruitment began, I identified several factors that precluded participation. First, patients who were moving from place to place on the medical campus were difficult to find, and speaking with them while preserving confidentiality proved challenging. The medical campus is a large urban teaching campus that requires patients to travel around the campus to obtain various services and procedures. For example, I once visited three different clinical settings on campus before I located a participant who had been sent for lab work. Once I found him waiting for a CT-scan in the radiology department, an interview was not conducted because the location, although quiet and relatively empty at that time, was not immune to interruptions by other patients and staff. Additionally, the patient's wait time was unknown, so it was unclear whether there was enough time to conduct the full interview. Several patients who met eligibility criteria were emotionally distraught and/or acutely ill at the time of their visits. In such a situation, I noted the patient's name and attempted to contact him or her later using the information provided by the clinic. If reachable, I explained more about the study, and then arranged a future time to meet. It should also be noted that an unknown number of patients who appeared to be eligible based on clinic information were not able to be contacted. Frequently, patients missed visits or did not follow through with secondary appointments, eliminating the potential for recruitment and/or follow up. An additional number of patients who had indicated interest in the study were not included, as I was unable to locate or contact them for an interview within the two week window.

My goal was to recruit a sample of 40 patients to ensure not only substantial qualitative data, but also to provide the opportunity to quantitatively evaluate responses to scales that were included in the interview. Obtaining a sample of this size was

challenging for a number of reasons. HNC is relatively rare, patients are often diagnosed with late stage disease, and the number of appropriate and willing patients often fluctuates. At times, one or two weeks would pass in which no patients were identified as eligible. At other times, two or even three eligible patients were seen in the clinic on the same day. Poor weather and high gas prices appeared to coincide with missed or cancelled appointments. Over the course of 4 months and 3 days I enrolled 41 participants from a total of 72 patients who were screened for eligibility. Among the 31 who did not participate, six declined participation, one was ineligible due to advanced Alzheimer's disease, 14 had a cancer other than a squamous cell carcinoma of the head and neck (such as salivary gland or thyroid), and eight were determined to have a cancer that was secondary to a prior diagnosis. Finally, there were two eligible individuals for which my attempts to locate at the clinic and/or reach by phone failed.

**Procedures.** I visited the ENT clinic almost daily from October 2008 through March 2009. I consulted patient appointment lists to identify possible candidate participants and structured my time in order to maximize opportunities to contact patients while they were in the clinic. Once the informed consent process was complete, I either initiated the first interview or arranged a time to interview the participant within the following 2 weeks.

I made an attempt to establish rapport with participants prior to beginning the formal interview process. Often, I sat with patients and their families in the clinic exam room or while waiting for various medical tests or procedures. I also took the time to walk patients to other appointments or helped them navigate back to their cars or to food services. Spending time with them allowed me to indirectly learn about and experience

the clinical setting, observe their families (who were often in attendance), and establish an interview session that was less likely to be interrupted.

Uncertainty about the amount of time and privacy available for interviews was a constant consideration. Clinic staff could interrupt conversations in exam rooms. Likewise, constant logistical changes often led to patients waiting or hurrying unexpectedly from one appointment to another. Thus, interviews were carried out in private ENT clinic exam rooms, a private interview room located in the Graduate Center for Gerontology at the University of Kentucky which was adjacent to the ENT clinic, or in a quiet location on the University of Kentucky campus (i.e., a recovery room, or study area). The location and duration of every interview was documented, as was the presence of other people, interruptions, or other environmental factors that may have influenced the interview process. Interviews were audio recorded with permission from each participant.

***First session.*** The purpose of the first session was to build rapport; assess self-perceived health; explore patient perceptions of HNC, including symptom recognition, severity, and health literacy; and begin to address the range of factors related to perceptions of time and emotions in decision-making. Additionally, I explored treatment decision-making preferences and goals with interview questions guided by SST (Carstensen, 1995; Stevens, Martina, & Westerhof, 2006). Patients also were given an opportunity to discuss perceptions and understanding of their diagnosis and disease by answering questions based on Leventhal's SRM (Leventhal & Cameron, 1987). I ended the first session by collecting demographic information. The session 1 interview guide is provided in Appendix B.

*Second session.* To enhance retention efforts, the second interview took place during the first clinic visit following treatment, when possible. Patient variability and treatment differences were expected to create a time lag of 3 to 6 months following the first interview session. It was anticipated that the majority of patients would be available for a second session within 3 months of the initial interview.

The purpose of the second interview was to explore the decision-making process and allow patients to elaborate on the most salient features of their experiences. I also explored satisfaction with treatment decisions and outcomes. The interview guide for the second session is provided in Appendix C, and was developed based on SRM (Leventhal & Cameron, 1987) and SCT (Bandura, 2001). Interviews ranged from 36 to 127 minutes with the average length being 74 minutes. Interviews were audio recorded with permission from each participant.

### **Data Explication and Analysis**

As my data collection methods included both open ended and semi-structured responses as well as scales, I employed a combination of explicative techniques as well as qualitative data analysis techniques suggested by Creswell (2007). The following section summarizes the process of data analysis that I used for this dissertation. I use the term “analysis” to refer to all steps and activities that led me to my findings, presented in Chapter 5.

**Step 1: Audio taping and transcription (Hycner, 1985).** Upon consent of the participant, each interview was audio taped. A total of eight individuals declined to have their interviews recorded, and thus notes typed on a laptop during the interview were used instead of transcripts. The use of audiotapes enabled me to listen to participants



without the need for extensive note taking or hand recording of information. I did, however, take notes during the interviews, which included my own thoughts and questions as well as characteristics of the interview setting and phrases or comments made by the participants. Following each interview, I wrote additional notes. Note taking followed the scheme developed by Schatzman and Strauss (1973). These included observational notes about interruptions, sounds, or other intrusions that may have affected the interview. My own thoughts and questions that arose during the interviews, such as my curiosity regarding the link between a family member's illness and the participant's reluctance to seek help, were recorded as theoretical notes. Finally, I also noted reminders and feedback to myself regarding the process of interviewing, in methodological notes (Schatzman & Strauss, 1973). The notes and audiotapes were reviewed and selective transcription of the interviews began.

Verbatim transcription of qualitative interviews helps to ensure reliability and validity of data collection, but doing so can consume a great deal of time and resources (MacLean, Meyer, & Estable, 2004). For every recorded hour of an interview or focus group, 6-7 hours of transcription may be required (Halcomb & Davidson, 2006). Additionally, the process and outcome of transcription can be flawed by technical and human error (MacLean et al., 2004). Fasick (1977) asserted that the concurrent use of notes taken during and after an interview could be appropriate, and possibly superior, to the exclusive use of verbatim transcription. One way to mitigate errors and save time while maintaining rigor is by performing selective transcription. Selective transcription requires that the researcher transcribe only the recorded pieces of information that are directly relevant to the research topic, the specific aims, or the emerging codes (Strauss &

Corbin, 1990). Considering that the process of transcription has the ability to generate meaning rather than merely text, selective transcription combined with note taking is a valid and appropriate strategy (Fasick, 1977). Immediately after selective transcription, I listened to each interview at least once and checked the contents against my original notes. The tapes were reviewed and compared to my notes multiple times throughout the coding and data analysis process.

**Step 2: Coding.** Within the context of the dynamic evolution of qualitative data analysis, I attempted to extract meaning by first listing units of relative meaning for open-ended questions (Moustakas, 1994) and also coding the transcripts (Creswell, 2003). Coding involves searching the data to identify textual data relevant to the research aims. The process was repeated for each individual interview and also collectively across cases. Each transcript was reviewed, line by line to look for words, phrases, and monologs used by the participant. Data was then organized into broad categories around each question and each topical area from the interview guide. Continuous clusters of emergent codes were then organized into themes. A code book was kept that organized the codes into categories and subcategories and could be linked to concepts and emergent themes.

**Step 3: Theme development.** The codes that emerged from the data were used to “make sense” of the data through the conceptual development of themes (Moustakas, 1994). This was a cumbersome task as the quantity and content of interviews continually led me to revisit prior interviews and codes in light of new information or knowledge. The largest analytic leap to thematic integration took place after the twenty-first interview. In almost every section of that interview, the participant’s responses reflected a life organized and structured by Alcoholics Anonymous, one of several 12-step

substance abuse recovery programs. After transcribing and coding that interview, I clearly recognized language from several previous interviews as the language of people with 12-step program experience or knowledge. I reviewed the transcripts and codes again, and codes that had seemed somehow incongruent prior to this interview were revealed as dominant concepts within the context (theme) of coping and survival.

**Step 4: Model development.** After completing the coding and the development of themes, I developed a descriptive summary of the head and neck cancer treatment experience (Hycner, 1985) which was then used to build a model of that experience. The model (see Chapter 7) represents the lived experience of cancer treatment among the HNC patients who participated in this study.

Interviewing individuals with newly diagnosed HNC was both fascinating and challenging. Aside from logistical challenges associated with interview timing and location, the patients themselves had experienced significant life events and were often emotionally and physically “shattered,” as one patient described. I struggled to focus on comprehensive experiences, which often were marked by long and complex medical and personal life histories affected by a variety of medical, biological, social and environmental factors.

**Quantitative analysis.** The primary purpose of the quantitative scales was to add greater depth to the descriptions of the patient population. In addition, the scales allowed a limited, but helpful way to explore variations in treatment decision-making between the first and second interviews in terms of time perception, control preference, and indicators of health status. Prior to analysis, I cleaned the data from the socio-demographic questionnaire, the FTP scale, Degner’s Control Preference Scale, and the University of

Washington Brief Quality of Life Scale using range and logic checks, inspected the scales for missing values, and entered the data into a Microsoft Access database. I calculated scores for each scale using the recommended scoring instructions provided by the scales' authors. I also ran measures of central tendency, range, and standard deviation for each scale score and frequencies for health status and socio-demographic variables. In addition, I calculated time between first symptom recognition and medical appointment as well as time to diagnosis.

### **Methodological Rigor**

I took several steps during the data collection and analysis process to ensure intellectual and analytical rigor as well as study validity. The first step was to keep detailed records, including my personal journal of research interactions (Schatzman & Strauss, 1973). My journal was also a depository for thoughts, feelings, emotions, and observations regarding data collection and analysis.

Second, my own ideas and conceptualization of emergent themes and processes were not compared to earlier examples found in the literature until after the data had been completely coded and applied to subsequent interviews. The final codes and themes were only fully developed toward the end of data collection in June 2009. Validity checks were conducted throughout the coding and data collection process by ongoing discussions and meetings with my advisor and mentors. Two colleagues reviewed and coded the transcripts of interviews 1 and 2 for two participants. Consistency of codes (both initial and thematic codes) was compared and differences were discussed until consensus was reached (Strauss & Corbin, 1990). One colleague randomly reviewed four of the selectively transcribed interviews against the audio recordings to check for

accuracy. Participants were invited to read the selective transcriptions and provide feedback. Only two participants requested to view their interview transcripts. One participant reviewed the transcripts from both interviews and offered further elaboration on certain items. One participant reviewed the transcript only from the first interview and commented that he was curious as to how interview data was “coded” to produce data.

### **Summary**

Following Creswell’s (1998) model for developing a research design, a qualitative approach was selected. I have provided an account of the data collection and data analysis process that was undertaken in this study. The next chapter reveals the findings based on data analysis. I begin by describing the demographic characteristics of the research sample before presenting data on overall health, initial illness experiences, and perceptions of current health, time orientations and treatment considerations.

## **Chapter 4. Findings**

The goal of this study was to understand the experience of head and neck cancer treatment among older cancer patients. I sought to investigate aspects specific to the aging process in relation to the treatment experience. In this chapter, I present the findings of the study.

The following section describes and explores the common characteristics and themes among study participants, as revealed through data analysis. Findings presented in this chapter are presented in relation to the interview guides, and move from specific and discrete to broad and abstract. Illumination of these components will serve to orient the reader to the model of treatment experience that is presented in Chapter 7.

### **Demographic and Socio-Cultural Characteristics**

Demographic characteristics of the full sample are presented in Table 4.1. The study sample included 41 individuals (nine females and 32 males). The mean age was 58.4 years with a range from 45 to 91 years. All participants (100%) self-identified as white. The majority of participants (25, 61%) were living with an adult partner and children at the time of the study; 10 (24%) were living without a partner but with adult children. Slightly more than half of the population (21, 51.2%) reported having no health insurance, while 14 (34.2%) were insured through Medicare or private companies and six (14.6%) were covered through company/employer insurance. One pattern that emerged from the data had to do with the past or present occupations of participants. These occupations were largely low education, high-risk jobs that often required shift work while offering little autonomy. The most common types of occupations were military jobs, extraction industry work such as coal mining and forestry, trades including welding

and carpentry, transportation jobs, and blue collar work in manufacturing or agricultural companies. Several participants had also been incarcerated, institutionalized or served in the military at some time in their life. Being in prison, an institution, or military deployment, as discussed in the findings, was significant in that participants identified these as periods of low personal autonomy, power, or choice.

Table 4.1 Participant Characteristics (N = 41)

Variable	Frequency (%)	
Age (in years)		
40-49	9	(22.0)
50-59	17	(41.5)
60-69	11	(26.8)
70-79	3	(7.3)
90-99	1	(2.4)
Sex		
Female	9	(22.0)
Male	32	(78.0)
Household Members		
Partner alive/together	2	(4.9)
Children	10	(24.4)
Partner and Children	25	(61.0)
Children and Other	4	(9.8)
Marital Status		
Married	27	(65.8)
Separated	4	(2.4)
Divorced	7	(14.0)
Never Married	3	(4.8)
Education		
Incomplete Elementary ( $\leq 7$ )	5	(12.2)
Completed Elementary (8)	8	(19.5)
Incomplete Secondary (9-11)	6	(14.6)
Completed Secondary (12)	17	(41.5)
Post-Secondary	5	(12.2)

Table 4.1 (cont'd)

Stage of Cancer		
II	11	(26.8)
III	16	(39.0)
IV	14	(34.1)
Site of Cancer <sup>a</sup>		
Esophagus	3	(7.3)
Larynx	18	(44.0)
Mouth	2	(4.8)
Nasal	1	(2.4)
Tongue	4	(9.7)
Tonsil	10	(24.3)
Vocal Cord	3	(7.3)
Health Insurance Status		
Company Sponsored	6	(14.6)
Medicare	7	(17.1)
Private	7	(17.1)
None	21	(51.2)
Perceived Financial Status		
I have just about enough	15	(36.6)
I struggle	26	(63.4)

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<sup>a</sup> site of cancer was reported by participant

Participant counties of residence are shown in Figure 4.1. Participants resided in 28 of the 120 counties in Kentucky. The majority (n = 20, 71%) of these counties have been designated as Appalachian by the Appalachian Regional Commission. The Appalachian region of the United States reflects persistent and historical disparities in health, notably in cancer mortality rates (Wingo et al., 2008). Appalachian Kentucky has the highest cancer death rate of Appalachia and the nation (Huang, Gal, Valentino, & Wyatt, 2007). Rural living, especially in rural Appalachia, is associated with a higher likelihood of being diagnosed with cancer (e.g., breast, cervical) at a later, more terminal, stage (Yabroff et al., 2005).



In the present study, Appalachian culture, beliefs, and characteristics, such as those discussed in Chapter 2 (page 24) colored participant narratives and provided the context in which many participants placed their illness experience. The prevalence of tobacco use, poverty, comorbidity, rural residence is consistent with Appalachian Kentucky.

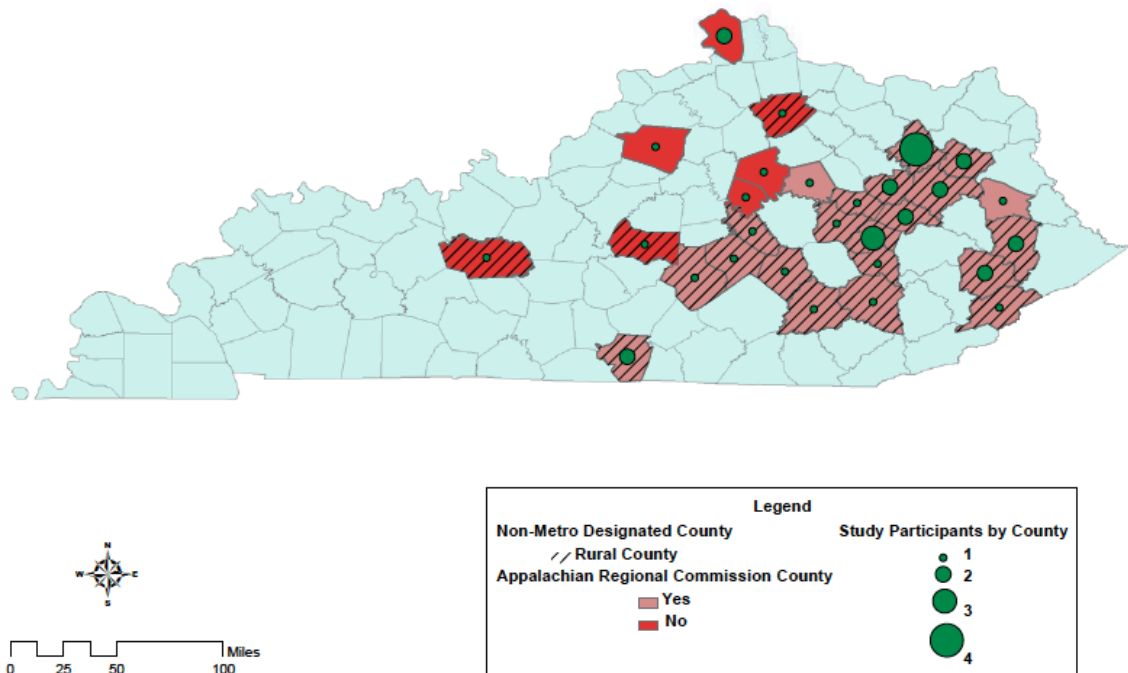


Figure 4.1 County of Residence

### Overall Health

During the first interview, participants were asked to describe and discuss their health over their life course, by reminiscing about events and health behaviors from their childhood and early adulthood to later life. Based on participant self-report of their health status, responses were coded and categorized. Most participants described their health as average (n = 31). Thirty-six participants described at least one serious health event in

their youth or young adulthood that they believed had influenced their current health. These events fell into four categories: diseases (n = 15, 37.5%), occupational injuries (n = 5, 12.5%), unintentional accidents (n = 7, 17.5%), and addiction-related injuries or health crises (n = 13, 32.5%). Several patients described infectious diseases that they experienced as young children or as young adults and recalled with vivid clarity not only the physiological manifestations of their conditions, but the social hardships and suffering they endured. For example, one participant described having what he believes was an abscessed tooth around the age of 10. It caused him severe pain, night sweats, and prevented him from eating. Unable to afford a dentist, his family relied on several “folk remedies” and herbal tinctures for several months, until his health deteriorated substantially. Finally, he was taken to a family doctor who simply “used pliers to pull the tooth out with no anesthetic.” The participant explained that this experience kept him from seeking dental care. In fact, he recalls visiting a dentist exactly three times over 62 years despite the fact that his job provided dental insurance.

Participants reported a broad array of individual level behaviors or actions that they felt contributed to their current overall health status. The largest group (n = 29, 70.7%) identified tobacco use (cigarettes, pipes, and chewing tobacco) as a behavior that affected their current overall health. One participant “smoked a pack a day of cigarettes for 35 years.” Six (14.6%) participants did not smoke, but reported that living with a spouse who smoked was something that had affected their health. HNC literature suggests that despite significant risk, tobacco users lack knowledge and awareness of this disease (White, Chin-Quee, Berg, Wise, & Hapner, 2012). During the first interview session, I asked participants questions related to recent actions in response to their

condition, as well as perceived causes and risk factors. Overwhelmingly, participants (n = 29, 70.7%) stated that they would have smoked less or not at all to prevent the disease. This is not surprising, considering that 20 of the 29 (68.9%) were shocked to learn they had HNC. Even more of them (21, 77.7%) were unable to provide a clinical or medical description of their diseases prior to diagnosis. For example, one participant with uncontrolled diabetes explained that his condition was “a problem with being too nervous.” In contrast, when patients were asked about what health problems they had expected prior to their cancer diagnosis, as much as 78% (n = 32) of the sample had anticipated developing some other type of health condition. Table 4.2 lists the anticipated health conditions and response frequencies.

Table 4.2 Anticipated Comorbid Health Conditions (N = 41)

Health Condition	Frequency (%)	
Unspecified/Did Not Know	13	(31.7)
Cancer (other)	26	(63.4)
Heart Disease/Cardiac	22	(53.6)
Diabetes	15	(36.5)
Alzheimer's/Dementia	14	(34.1)
COPD/Respiratory	14	(34.1)
Alcohol/Substance Abuse Related	12	(29.2)
Arthritis/Pain	4	(9.7)
Car Accident/Accident	2	(4.8)
Fibromyalgia	1	(2.4)
Liver Failure	1	(2.4)

Inadequate physical activity levels were identified by 21 (56.0%) participants while poor diet was acknowledged by 20 (48.7%) participants. Other factors (n = 5, 12.1%) included occupations such as long haul truck driving and mining, in which diet, physical activity, and occupational hazards were seen as threats to health. A few people

(n = 3, 7.3%) identified financial resources, social status, and/or lacking health care resources as factors that had influenced their health.

Twenty-two (53.6%) participants indicated that they received regular yearly cancer screenings, with breast and colon cancer screenings the most frequently cited. Four (18.1%) of the 22 participants said they received screening, but they did not know or were not sure of the cancer type. One participant received bi-annual screening for skin cancer. Only 2 of the women indicated that they received regular cervical cancer screening through pap smears. Of the 22 who reported regular screening, 17 (77.2%) commented that their insurance companies or physicians send mail reminders or call to schedule the appointments. An additional 12 (29.2%) participants reported that they sometimes get screened or have been screened for cancer in the past.

Participants were asked specifically if they had ever been screened for oral cancer, given the relationship between tobacco use and development of HNC. A total of six (14.6%) participants had been screened for oral cancer. Of them, four had been screened after seeking dental or medical care for a self-perceived abnormality. Ten (23.4%) participants did not know if they had been screened. Twenty-five (61%) participants reported that they had never been screened for oral cancer specifically. Indeed, only 52% of the sample reported receiving regular dental exams.

### **Initial Illness Experiences**

The second section of the interview guide was designed to elicit participants' thoughts, ideas, and experiences early in their HNC journeys. Participants were asked about their initial visit(s) and what factors had led them to seek care or information. A majority (n = 34, 82.9%) of the 41 respondents sought medical care at the UK ENT clinic

after receiving a referral from a physician or other health care professional. When asked how they would have described HNC prior to their diagnoses, most participants indicated either they didn't know (n = 12, 29.2%) or had only a basic idea (n = 26, 63.4%); very few had a fairly developed and or correct understanding of HNC (n = 3, 7.3%). In many cases, participants reported that the suspected or confirmed HNC was discovered upon seeking medical care for a different (unrelated) health problem. For example, one participant explained that her diagnosis resulted from a routine physical exam she underwent in order to obtain a medical release so that she could return to work following significant cardiac surgery. Her physician discovered a small white spot in her mouth and referred her to the UK ENT clinic where she learned that she had a rather advanced oral cancer. I was unable to determine how many participants originally may have attributed HNC symptoms or associated problems to "unrelated" health conditions. One participant commented:

I kept losing my voice, and it just kept getting worse. Finally got so bad my wife couldn't hear me hollerin' from the other room... sometimes my throat hurt and then a few weeks ago it was getting hard to swallow. I had to really focus on swallowing... I thought I was allergic. We just finished pulling up old rugs, uh, carpets all dirty and that goo, glue on the back, all up in the air. My son and I did most the work, and we was both coughing and sneezing... thought it was just allergic... I reckoned I just needed some allergy pills.

Participants frequently mentioned or discussed other chronic health conditions, such as diabetes, arthritis, chronic obstructive pulmonary disease (COPD) and heart disease. The physical symptoms of these conditions, mainly pain and fatigue, as well as side effects from medications and tobacco use, were frequently cited as "normal" aspects of daily living. Nineteen participants (46.3%) specifically commented that they

attributed certain symptoms like sore throat, dry mouth, coughing, pain, and fatigue or changes in sleeping patterns to long term cigarette use. For example, one participant commented:

I've smoked about three or four packs a day since I was 12. Everybody I knew smoked when I was a kid... lotta people in my family still smoke. My doctor always is tellin' me to stop. I've had a bad cough all my married life, maybe even before that. I can't breathe good when it's hot or get movin' fast. Had no thought that it was anything else, you know, specially not cancer. Never heard of this before now.

In contrast, some participants were very aware that something was abnormal.

Among this group (n = 6, 14.6%), palpable growths, bumps, or spots often accompanied with pain, burning, or itching were most often cited as symptoms that prompted medical help seeking. Unfortunately, many participants, regardless of symptom and problem recognition, delayed seeking medical intervention. Participants waited anywhere between several days to over one year from the time of initial symptom discovery and/or recognition of a problem, to seeking medical attention. Precise quantification of time between symptom recognition and obtaining health care was not possible. I asked participants two questions regarding the amount of time that had passed: (a) "About how long ago did you first notice something was wrong?" and (b) "About how long would you say it took from the time you first noticed a problem to when you saw a medical provider for the problem?" The responses varied from exact time periods to vague recollections. Some participants had not known a problem existed until it was discovered by a health professional or were not able to remember when they first noticed the problem. A 61-year-old woman with tonsil cancer remarked "Like I said, I didn't know anything was wrong, but I got myself here for an appointment as soon as (doctor) told me

to. That was eight days ago.” On the other hand, one 52-year-old man with laryngeal cancer answered the second question by stating: “Looking back I think I knew all along that it wasn’t normal... I’d have to say that was right around Christmas, one, no, heck, two years ago, since [son] was home that year. And now here we are. Geez, that’s a long time, isn’t it?”

Few participants seemed to acknowledge the potential severity of their recognized health problem early in their experience. Frequently, participants used phrases such as, “It wasn’t really bothering me,” or “It seemed like such a little thing,” when reflecting on their initial perceptions of the problem.

**Initial responses to symptoms.** When participants were asked if they tried to do anything to make their problem better, the responses fell into four broad categories: (a) seeking information, (b) taking spiritual or religious action, (c) implementing personal health practices, and (d) seeking medical help. Some participants (n = 26, 63.4%) reported researching their diagnoses on the internet, in the library, or via social networks to help explain their condition. Others (n = 28, 68.2%) reported that they prayed, went to church, sought spiritual or religious counsel, or increased their spiritual activities in an effort to overcome or cope with the problem.

I’ve had a lot of problems in my life, and God always shows me the way. I would pray every day that he would give me the strength to live a good life and that I’d be okay, if I had my faith.

Another participant said, “I asked my wife to take it to her prayer circle, to ask for guidance on what I should do. It didn’t seem like something to cause a big fuss over. That way, I was doing something at least.”

In addition, some participants (n = 13, 31.7%) altered or introduced health practices like eating better, taking medications, or engaging in health behaviors such as practicing good oral hygiene.

I wasn't sick, but I didn't want to be sick either. My daughter kept telling me I needed to take better care of myself, so I made sure I ate better... I added more vegetables, smoked fewer cigarettes, and then I bought a fancy toothbrush.

Other participants took over the counter medications (n = 8, 19.5%) or home remedies (n = 6, 14.6%) in attempts to treat or cure the problem. One woman who believed she had burnt her mouth and might have an infection, took left over antibiotics from a prior urinary tract infection. When the problem didn't go away, she began using mouthwash, gargled with salt water, drank herbal teas, and attempted a homemade salve. When I asked her if any of those things worked, she indicated that the salve would have worked but she couldn't keep the affected spot in her mouth covered with the salve. She had tried soaking a small piece of bread with the salve and then placing the bread on the lesion, but found that she then gagged on the "slimy" bread. She commented, "I had been under a lot of stress at work and had been sick a lot. I thought I could give my immune system a jolt... that it would heal up. I mean, these things do happen."

Although the vast majority tried to handle their medical problems on their own, some participants promptly sought medical attention (n = 5, 12%). Participants reported seeking advice or treatment from their family physician and/or dentist. One participant even sought medical advice from a local veterinarian. Only one of the five participants in this group confirmed that his or her original encounter with a medical professional resulted in an immediate HNC diagnosis or referral. More commonly, these individuals



were sent home with medications used to treat other health problems. For example, one participant reported:

My dentist thought I had severe gingivitis and gave me mouthwash, a new toothbrush, and toothpaste. It didn't help, so I stopped going in for follow up visits. [A few months later,] I asked my doctor about it at a work physical and got referred here.

Another participant reported that a physician linked his symptoms, including persistent cough, a bad taste in his mouth and shoulder pain, to bronchitis and smoking. He switched to a "younger" physician who was out of his insurance network, who immediately referred him to an ENT who provided the subsequent referral to the UK ENT clinic. The time between his first doctor visit and the UK ENT visit was 9 months.

Participants who reported recognizing a health problem usually did so as a result of an abrupt discovery of some unusual growth that had been previously unknown. One participant who had believed he was in excellent health and had not experienced any symptoms reported:

One day I was watching TV and playing with my beard. I felt a little bump, like a hard pea just under my jaw. I thought it might be an ingrown hair, but my wife looked at it and said she thought it was deep under the skin. It didn't hurt. I kept playing with it and then one day I noticed it started to kinda tingle if I bothered at it, and it was getting bigger. That's when I decided to see our doctor about it.

In addition to actions and behaviors, participants also sought advice, information, or solace by discussing their problems with others. Twenty-nine participants (70%) reported that they talked to someone about their problem between the time they recognized symptoms and sought care. Among them, 17 (41%) reported that they spoke to a spouse, partner, or boyfriend/girlfriend. Eighteen (62%) spoke to a close friend or family member and three (15.7%) discussed it with a co-worker. Interestingly, three

people also reported that they “spoke” to someone on an internet blog or chat room while three others specifically identified their sponsors as people they spoke to about their health concerns. A sponsor is a person who provides support and or mentorship to someone overcoming addiction, specifically individuals participating in a 12-step recovery program like Alcoholics Anonymous. For study participants, sponsors were seen as confidants, role models, friends and advisors across many aspects of life, including health and treatment decisions. Participants explained that they discussed their health concerns with the sponsors because they viewed them as individuals who had witnessed or encountered others who had overcome adversity and had dealt with substance abuse related health conditions. One participant remarked:

I used to think he (sponsor) didn't know anything... but then I started to thinking about how many people he's seen live and die cause of this, uh, problem, or you know, addictions. There's people there that know what works and doesn't and will help you, they uh expect you to now, you know fall down and they help you up. I talk to [my sponsor] about everything in my life, 'cause everything is part of it.

One of the most interesting patterns that emerged during data collection was the exposure to and or knowledge of 12-step programs such as Alcoholics Anonymous (AA). Thirty-one participants (76% of the study population) either directly identified AA experience or invoked 12-step language during the interviews. Twelve-step programs, commonly referred to as twelve-step groups (TSGs) are autonomous, self-help, community based support groups for individuals who are addicted to substances (i.e., alcohol, cocaine, narcotics) or behaviors (i.e., gambling, sex, video games) (Gould, 1999). TSGs are the most prolific resource for addiction recovery in the United States. In fact, it is estimated that there are at least 18 million AA members in the United States

alone (Ashenberg Straussner & Byrne, 2009). These programs generally rest on three pillars: unity, in the form of fellowship and tradition; service, to the organization/fellowship; and recovery (*Alcoholics anonymous; the story of how many thousands of men and women have recovered from alcoholism*, 1947). Recovery is perhaps the most well-known aspect of 12-step programs and consists of “working” through the 12 steps (Table 4.3). Participation in a 12-step program is free, voluntary, anonymous, and independent of formal corporate, or organizational oversight (Minnick, 1997). While there is no formal recognition of a specific religious deity or body, TSGs are spiritual by design, encouraging participants to seek and rely upon a “higher power.” TSGs have been consistently shown to be an efficacious intervention for cessation and sobriety. The mechanism by which success is achieved has been linked to enhanced self-efficacy (Bogenschutz, Tonigan, & Miller, 2006), as well as social support and social networks (Laudet, Morgen, & White, 2006). A recent theory regarding AA and other TSGs is that the process of working the steps, as well as social support, facilitates the negotiation of grief and loss that accompany cessation and recovery from addiction (Streifel & Servaty-Seib, 2009).

During coding, I came to recognize that certain phrases were often repeated across the sample. Upon interviewing the twenty-first participant, I asked him to explain one such phrase that hadn't made sense to me; “I cleaned up my side of the street.” I had heard various renditions of this statement from several other participants. He then explained that this is an AA “slogan” that means you have to take responsibility for your mess and clean it up. He also gave me a copy of the Big Blue Book, which provides a detailed plan for living the AA way (*Alcoholics anonymous; the story of how many*

*thousands of men and women have recovered from alcoholism*, 1947). I was struck by the similarities between some of my codes and AA themes. The book was helpful in revisiting and recoding prior interview sessions in light of the AA meaning imbued in the phrases. In Table 4.3, I present examples of participant quotes reflecting 12-step program language, juxtaposed with the AA 12 steps.

Table 4.3 12 Steps of Alcoholics Anonymous and Related Participant Quotes

Description ( <i>Alcoholics anonymous; the story of how many thousands of men and women have recovered from alcoholism, 1947</i> )	Participant Quotes
We admitted we were powerless over alcohol—that our lives had become unmanageable.	“We [alcoholics] make ‘pour’ choices, it’s what we do.”
Came to believe that a Power greater than ourselves could restore us to sanity.	“Until I can accept that I’m sick, I can’t get better, I can’t recover.” “Find my own higher power. It’s within us all. It’s whatever you want it to be, anything that is greater than yourself.”
Made a decision to turn our will and our lives over to the care of God <i>as we understood Him</i> .	“Let God.” “God, as I understand him.” “Find my own higher power. It’s within us all. It’s whatever you want it to be, anything that is greater than yourself.”
Made a searching and fearless moral inventory of ourselves.	“Change your behavior to meet your goals, not the other way around.”
Admitted to God, to ourselves, and to another human being the exact nature of our wrongs.	“I got right with myself first, and then I got right with the man upstairs.”
We’re entirely ready to have God remove all these defects of character.	“You don’t have to take the elevator to hell, you can go up to the penthouse, or get off anytime you want.”
Humbly asked Him to remove our shortcomings.	“I want die with a clean conscience. I hit my knees everyday asking to become a better man.”
Made a list of all persons we had harmed, and became willing to make amends to them all.	“Sweep my side of the street.” “Change your behavior to meet your goals, not the other way around.”
Made direct amends to such people wherever possible, except when to do so would injure them or others.	“It’s real important to make good on the bad things I’ve done to my kin.” “Doing something good for her was doing something good for me.”
Continued to take personal inventory, and when we were wrong, promptly admitted it.	“I check myself all the time, everyday... you know when you screw up you have another opportunity to fix it...”
Sought through prayer and meditation to improve our conscious contact with God <i>as we understood Him</i> , praying only for knowledge of His will for us and the power to carry that out.	“I pray to the Creator for guidance and strength in getting through all this.”

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Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs.

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“...I’m more anxious, and now that I know it’s a disease, I feel a lot better about what I need to do to keep it under control, because *it’s a life problem.*”

**Barriers to seeking treatment.** The health literature has demonstrated that the act of medical help seeking can be influenced by patient beliefs (Rogers, 2010), level of health literacy (Ishikawa & Yano, 2008), socio-economic access to resources (Wiltshire, Roberts, Brown, & Sarto, 2009), geographic barriers, and personal choice (Bourne, 2010). As demonstrated in this study, patients may not experience or recognize symptoms associated with HNC. In addition, they may not immediately seek care, or if they do, they may not be correctly diagnosed. Likewise, questions about health care utilization and screening indicated that the study population had low health care service utilization. Participants were asked if they experienced any factors that made it difficult for them to see a primary care provider. Initial visits to any doctor or initial ENT visits were not distinguished in the interview. Only nine (21.9%) of the respondents did not perceive any barriers to seeing the doctor. The remaining 32 participants cited barriers that were coded and categorized into four primary categories: (a) work and family obligations, (b) financial concerns, (c) access to medical resources, and (d) infrastructure.

Eighteen of 32 (56.2%) participants reported that work or family obligations prevented them from scheduling an appointment (Table 4.4). Time away from work could result in lost wages, penalties, requirements to make up time, or a risk of termination. Three individuals reported that they were the primary care-giver for a spouse, child or grandchild, and that arranging alternate plans for their care was difficult, inconvenient or too costly.

Table 4.4 Participant Responses to Questions about Obstacles to Obtaining Treatment

Obstacle Type	Quotes from Participant Interviews
Occupational	“I have to work. I’d have to miss to keep an appointment. There aren’t any places I can go to that’s open when I’m off work.”
	“I have my own business and can’t just go off when I want to. I asked one of my employees to look after a job site for me so I could (come to this appointment). It took a while but it all worked out.”
	“Me. I didn’t want to leave ‘em high and dry at work, ‘cause we’re always so short. I love my job.”
	“I just kept putting it off because I have a million other things to do than try to get to the doctor and if I miss time at work, it all just piles up.”
Personal	“I don’t drive so I have to have my kids or (husband) bring me. I feel so bad asking...”
	“Oh goodness, was it ever hard to get here!”
	“I have six grand babies and I help look after all of them. It’s real hard for their families to find someone else so I try to get all my appointments when they’re in school, you know.”

Sixteen (50%) participants identified financial barriers. Fear and or uncertainty regarding medical benefits, costs and future resource use were considerations in seeking care. To illustrate, one man who suffered from an array of long term medical conditions and who was worried about his wife’s health, commented:

We got to spread around our benefits... double dip. She can’t work, and I have to get enough hours in or they’ll cut me. We share our Glucophage... and we gotta keep our spending below the, uh, you know, the limit or cap, whatever, or we gotta pay out of pocket... The doc, he is always trying to get us on more pills, more “therapies,” but as far as I can tell, we just need to keep on going... no... I don’t think we need all that stuff. What if I take something today and use it all up, what will we do later?

Similarly, another participant explained:

You're young, but let me tell you, someday you wake up old and your body doesn't work for you anymore. Save your money and stay healthy! We have a lot of health problems that we probably could have prevented outright, but more than not being able to do the things we love to do, I think the biggest thing that bothers me is always worrying about how to pay for tomorrow and what else tomorrow might bring. When you have that burden, not going to the doctor looks good, because then you can pretend that nothing else is going wrong and you can hold onto that change in your pocket a little while longer.

Fourteen (43.7%) participants discussed provider access problems related to finding, scheduling, or driving to a provider. Several stated that they waited weeks or months for an appointment, or did not know where to go or whom to see for their problems. In fact, one participant consulted with his veterinarian on two occasions because he claimed he was unable to coordinate his time off with the doctor's office "a few towns over." He said, "I would have had to spend a whole day, after it was all said and done, getting that [doctor's appointment] over with."

A significant number of participants resided in rural Appalachian counties. These locations are chronically underserved by the medical community, particularly with respect to medical specialists like dentists and ENT doctors who would be most likely to correctly identify cancer of the head and neck. If patients are willing and able to travel to the doctor, overcoming time management challenges imposed by work and family obligations may deter help seeking.

Infrastructure is the fourth category that encompasses participant barriers to getting to a primary care provider. For the most part, this category represents barriers to medical help seeking that arise from real or perceived challenges to accessing the medical system. Twenty-one respondents (51.2%) specifically listed problems they encountered while attempting to seek medical care at the University of Kentucky Medical Center.



One participant said, “We been here for hours, sittin’ and waitin’.” In the second interview the same participant discussed how waiting room times and long appointments were one reason he had been reluctant to comply with the scheduling of visits. “I just don’t see what takes em so long. If I get here five minutes late, I gotta wait for them. But if I show up on time, I gotta wait too. It’s just too much time wasted.”

It was not uncommon for study participants to complain at the outset of our interview about logistical frustrations while at their appointments. Navigating the city’s one-way streets, finding parking, paying for parking, finding the clinic, waiting, filling out forms, and producing records were common complaints. Six participants indicated a prior negative experience with the UK Medical Center or other urban medical institutions such as the Lexington VA Medical Center or other local hospitals. Current and past unpleasant experiences related to infrastructure were cited as barriers that prevented patients from making future visits, led them to find alternate providers, caused them to delay appointments, or made them feel like they had to make additional plans to accommodate appointments. It should be noted that experience with the ENT clinic medical staff and satisfaction with their care was overwhelmingly positive. However, several participants did refer to prior experiences (see Table 4.5) in which health related outcomes or interactions were less than desirable and served to reduce their trust in providers and or the speed at which the patient sought care.

Table 4.5 Sample of Participant Responses on Past Negative Experiences with the Healthcare System

Theme	Quotes from Participant Interviews
Geographical/ecological barriers	<p>“This has to be the hardest place in the world to find a parking spot. I swear I’m late to every appointment, even when I come early. The garage is too expensive and too far, and I can’t make sense of the bus. The place they drop you is different than what I’m used to and then I can’t find my way here.”</p>
	<p>“How are we supposed to know to bring all these charts and lists? They ask for something new every time.”*</p>
	<p>“This place is a maze! You know like a rat in a maze.”</p>
Negative experiences	<p>“I tell you what, it makes me so mad when you get jerked around. You run over to one place because the place you came from says you’re going to be late and then you get over there and they have no clue who you are or what to do with you.”</p>
	<p>“I have always dreaded the hospital. I visited a friend of mine here last year... He messed his bed and they never even changed the sheets till his wife asked the nurse to help get him out of the bed so she could do it herself.”</p>
	<p>“The last time I was here, they gave me a medicine that I told them I was allergic to. I thought I was going to die.”</p>
	<p>“The doctors and nurses talked to my wife like she was a baby before her hip replacement. Then afterward, in recovery, I walked into her room and heard them talking about her... she has an old tattoo and they were making fun of it.”</p>
	<p>“The nurse took it [stool sample] and then left the specimen on my tray. They had to re-take another one later and that one never made it either... it disappeared, so I gave them like three samples then was released before the results came back”</p>
<p>“I left with some kind of... I guess, a yeah, [central] line infection. I was sick for months and had to have IV antibiotics. My daughter said it was preventable.”</p>	

\*Note. “Charts and lists” referred to medical records from another office and lists of medications taken by the patient.

## **Perceptions of Current Health**

Individuals receiving a cancer diagnosis must consider the consequences of both the disease and its treatment upon their broader life experience. After receiving their diagnoses, participants were asked how healthy they thought they were, what aspects of their condition caused them worry or what scared them, and what they hoped to gain from their provider and or treatment. Despite having very recently received a cancer diagnosis, in some cases with very poor prognosis, 18 individuals (43.9%) described their health as positive, stating “I’m doing fine,” or “I think my health is decent overall.” Others described their health using words including “excellent,” “good,” and “not bad.” A second group (n = 15, 36.5%) seemed unsure of their health status, commenting that they didn’t know, or stating “I guess I’ll be okay.” The last group (n = 8, 19.5%) reported more negative health statuses, represented by statements including “I suppose I’ll be lucky if I live past Christmas,” “Looks piss poor to me right now,” or “I’m about the sickest person I know.”

HNC treatment has the potential to result in significant physical and functional changes or loss. Previous studies have reported that patients fear facial disfigurement, vocal changes or loss, death, dependency on medical devices like feeding tubes, and becoming a burden to a family member (Smith, Pope, & Botha, 2005). At the time of the first interview, participants reported the most worrisome aspects of their condition (see Table 4.6). The frequencies and issues listed reflect a count of each type of worry identified by each participant. For example, one participant said that “I might not get better. This might be the best I’ll ever be, right now.” He also worried about his appearance, stating “those stomas... I’ve seen others with one. That scares me a little... I

don't want to look that way.” His responses are counted under functional decline or loss as well as under negative changes in appearance. Some issues were seen as worrisome because they required more effort from the patients. For example, one patient worried that her condition would require her to attend more medical appointments, take more medication, and pay more attention to her health. Other things were worrisome because they represented loss of life, income, time or independence. Of the 41 participants, three indicated that they could not say or did not know what was most worrisome.

Table 4.6 Categories of Issues Reported as Most Worrisome (N = 41)

Factor	Frequency (N)
Death	7
Pain/Suffering	26
Functional decline or loss	32
Relapse or new health concern	41
Addiction	5
Becoming a burden/loss of independence	25
Increased medical intervention	25
Negative changes in appearance, resources, or relationships	67
Treatment	12
Financial vulnerability	19

Participants also were asked what scared them. Interestingly, participants seemed to delineate fear from worry on the basis of future health threats. In other words, many of the “worrisome” factors were linked to things that they perceived as threatened by the lifestyle consequences of their condition, rather than the condition itself. For example, radiation and surgery would no doubt influence work and/or pay which was worrisome, but there was perceived potential for long-term financial recovery. In addition, worrisome events often were events or issues that held uncertainty. In the above example, radiation

and treatment may influence work and pay, but it was not a certainty. A person could survive treatment and return to a pre-diagnosis work status. On the other hand, future health threats like relapse, metastatic cancer, loss of function, and death can prevent social/instrumental recovery, which seemed to be the most feared attributes of having HNC. Fearful issues were frequently discussed as imminent or inevitable, rather than a potential possibility. One participant explained:

The thing that scares me the most is problems with being able to eat like I have in the past. We have dinner at our house every Sunday after church and anybody's welcome. It's usually the kids, you know. Food is good, it's what keeps a family together, shows people you love them. When times are hard it's the go to thing that keeps us connected. I really enjoy that time and I think that not knowing how all this will make me feel or keep, you know able to smell, taste, even eat, and be comfortable around food. I just want to be able to be a part of all of it... having cancer is bad because of what it takes away from you if you survive.

In another interview, a participant reminisced about her worst fears regarding her health status in general. When asked about her tonsil cancer she told me that she was dealing with her fear like she had dealt with other problems.

I sit myself down and write a letter to the higher power. Somehow putting the words on paper makes it more real. I write down all the things that scare me about whatever I'm worried about, so I can figure out how to overcome it, and the number one is always the same: being a burden because I can't take care on my own. It's not about if I'm going to live or not, but how I'm going to do it.

One might imagine, as I did, that hope associated with treatment would eradicate or at least allay significant worries and fears. When asked what participants hoped or wanted their doctor to do in order to help them, many (n = 17, 41.4%) simply replied that they wanted help "getting better," to "provide a cure" or "manage pain." An additional 13 participants (31.7%) said they didn't know or weren't sure what they wanted their

doctor to do. Only nine participants (21.9%) provided detailed responses outlining specific actions, treatments, or outcomes.

### **Planning and Time Orientation**

**Influences on the present.** Perceptions of time and planning were explored in the first session with questions about how participants thought about the future before their diagnoses, and how they perceived their future lives would change after their cancer diagnoses. Responses to the questions varied greatly both in scope and depth. Perhaps due to the immediacy of prognosis, many participants approached these questions with reserve, apathy or sadness. One man responded, after a brief silence, “Well, now, uh, I don’t really have much of a future, as I understand it.”

I asked participants what they were afraid they would not be able to do because of their condition. The most common responses centered on losing the ability to maintain or engage in social activities, such as not being able to talk to a grandchild on the phone, or not eating with family. Respondents specifically identified the social aspects of certain functions as the “problem” or aspect that they most feared. Losing the ability to speak altogether or to not be able to articulate, for example, was certainly a fearful prospect. However, what respondents most feared were the social consequences of that loss. As one participant described this:

Being alone. I have friends and family here, but my granddaughter [name removed] is the light in my life. I only get to see her maybe once or twice a year... we talk every day on the phone. If I can’t be there for her... you know, talk to her, I won’t be no good for her. Why would she keep calling, if I can’t talk back? She might not even recognize my voice, or maybe it will scare her. I try not to think about it.

Another participant feared that the possible physical side effects of treatment would affect her relationship with her husband.

He's always loved my smile, or at least he says so. I know the chances are small, but you know, there is always the risk. What if I come out of this not looking like me? Don't tell him I said this, but I'm afraid that he won't want me anymore... Well, maybe he'll keep me, but I want to look good for him.

The second category represents responses embodying fears related to interruption, loss, or alterations to occupational roles and responsibilities. Similar to the first category, fears focused on possible consequences of a primary condition-specific attribute. In this category, responses included: "I need to get back to work or I could lose everything;" "How am I going to be able to (do my work)?" and "I'm afraid that I might have to give up my job." Several participants expressed fear that they would no longer be able to adequately support a spouse, financially and/or functionally. In these cases, participants referred to "taking care of someone" as a job.

I won't be able look after [name removed], and I don't know who will do it or how it will get done if it's not, uh, me. Am I supposed to just sit around and try to get better, while she could [be] worse off?

Fears around functional loss also were quite prevalent. This third category included fears of not being able to perform physiological functions. In this regard, the origin of fear was proximal or immediate to the problem. Whereas, the first category of social fears demonstrated that a loss of speech, for example, may produce fears of being unable to communicate and maintain social ties, some responses in this category refer to a fear of the functional loss of speech itself. Participant comments that illustrate this include: "It scares me to death to think I could have to write down what I want to say, because I wouldn't be able to say it with my own voice;" and "It would be a sad day to

not be able to eat. You know, it's something we all take for granted... That would be the ultimate diet." Another participant said:

Chemo and all the other cancer stuff is really terrifying. I've had some kin get real sick with it and they couldn't do anything but lay there and die. I can't think of too many other worse ways to die. For me, the worst thing that I fear would be knowing I'm alive and watching, waiting to die and not being able to do anything useful.

The final category captures fears of substance use cessation, withdrawal, and/or consequences of behavior-based addictions. Many participants indicated long-term tobacco use, while others mentioned and/or freely discussed addictions or (mis)use of over the counter and prescription medication, illicit substances, alcohol, and/or addiction to gambling. Many participants (n = 17) feared they would no longer be able to manage or engage in these activities due to their cancer or its treatment. Some comments were very brief, such as: "If I have to be in the hospital long, I won't be able to smoke." One participant explained:

I've gave up heroin and alcohol long time ago but I've never been able to quit smoking. You know how many times I've tried... I can't even count, tried 'em all. It's really hard to sit here right now and not smoke. I think it's only been about an hour since my last one, but I've been after one since I put the last one out. I don't think I can stop, that's bad, scary, you know, um... I don't even know if I can get through this if I can't smoke. Like, uh, they want me to have some kind of scan that supposed to take a while. That's scary, makes me want to smoke even more, but they won't let me.

While substance use continued to be discussed and suggested throughout the interviews, the presence of behavior-based addictions such as gambling and eating were also identified. A 62-year-old man discussed how he spends \$50 each day playing bingo. He told me how his wife, family and job couldn't make him stop, and that "no 'condition' was going to get in my way!" When I asked him if he could explain, he went on to say:



That game, the people, all of it... especially when I win, make me happy. I'm not going to stop... Why?! For what? If I can't play, I don't want to be here anyway. It brings me, makes me feel good, happy... So, yeah, I'll say it...I'm damned afraid I won't be able to keep playing.

**Influences on the future.** The temporal frameworks in which fears were grounded are best described as immediate and/or short-term. For the most part, the fears that were reported likely would have been experienced in the days, weeks and months following the interview. In contrast, responses to the question, "What plans for your future have you changed because of your illness?" reflected longer time periods of several months to years. Before presenting the findings for this question, it should be noted that the timing of the first interview often eclipsed the opportunity for patients to consider or reflect on their long-term futures in the context of their new diagnoses and prognoses. It occurred to me that many patients might not have had the opportunity or wherewithal to really think beyond the emergent situation of becoming a cancer patient. Participants frequently commented that they couldn't answer the question, or didn't know.

Changes in plans related to housing, travel, and work/retirement, were the three primary areas that participants felt were likely to change in the future. Some participants talked about doing the things they had always wanted to do (e.g., buy a fancy car, go on a big vacation, build a new home, retire). More participants talked about not being able to do those same things, now that they had cancer. For example, one man commented: "We probably won't be able to, you know it wouldn't be a good idea, wouldn't make sense to buy our dream coach (motorhome) now;" and another stated: "I can't retire because I

need the medical benefits and extra income to put away for [name removed] when I'm gone." Similar statements were common.

### **Treatment Considerations**

The participants' thoughts and feelings about their health, including hopes, fears and plans illuminate important factors with the potential to influence treatment and medical decision-making. Responses related to determining a course of action and treatment reveal alignment with previously reported fears and goals. Participant responses fit into six categories of considerations related to making treatment decisions: quality of life, functional preservation, social consistency and cohesion, occupational (and thus financial) preservation, pain management, and recovery/cure.

**Overall treatment experience.** The second interview (Time 2) focused on the treatment experience and included questions about life experiences and factors that may shape that experience. Questions focused on overall experience, considerations, goals and priorities, resources needed and/or used, coping and emotional regulation, and perspectives on the past and future, specifically within the treatment context. I developed many of the initial questions to identify the information and/or goals that were used to frame decisions and the treatment-specific aspects that were most considered.

In one of the initial questions of the second interview, I asked participants to describe their overall treatment decision experiences. While the intent was to explore the actual decision-making process, often the discussion turned to participants' treatment experiences. During coding, the substance of the responses reflected that treatment decisions and experiences are often perceived as parallel, simultaneous and connected. In other words, once treatment had begun, the perception of the decisional experience was

influenced by the treatment experience. As such, the responses fit within the context of the illness experience.

In terms of overall decision experience, responses fell into three categories: positive (n = 11, 26.8%), negative (n = 15, 36.5%), and neutral (n = 15, 36.5%). It is interesting that five participants who reported a positive experience also described the decision as “difficult,” and “daunting,” commenting that it was “the hardest decision I’ve ever made,” and “I hope I never have to make another decision like that.” Their responses reveal that while the process may be “empowering,” or a means for achieving personal “growth and spiritual strength,” the act or execution can be hard.

*Positive experiences.* Four participants reminisced at length about how they had grown spiritually or emotionally as a result of their cancer and treatment. A 59-year-old male participant had believed he was in good health when he received his diagnosis. During the first interview he conveyed that he was very angry; angry that he had “obviously not taken good enough care of himself;” and angry because he felt that he “always, always followed good health practices.” He had also told me that he had felt “jealousy and hatred” for all the “well people” who didn’t “deserve their health” and were “ungrateful.” At the second interview the participant reported that his anger had passed and in fact, had evolved into a “clear knowing about why I am here and what I need to do.” He explained that having cancer had forced him to examine himself in the face of death and that through his ardent wishing for things to be different, he found that he “was able to see and knock down a lot of old barriers,” and live “with integrity.” He described integrity as having the ability to live honestly and wholly, which he believed was a “path to personal peace and truth.”

Another participant explained that a positive aspect of the decision-making experience was realizing that he could have control over his life and that he could be a stronger person through survival. He could choose to be “sick, wounded, or broken.” He explained, “I decided to be wounded, because wounds heal and the scars give you strength and they are kind of like your witness. Broken people can’t be made strong. It’s like a broken plate, you can glue it and not notice the break, but that plate will never be whole again, it will always be weak... I got through my treatment and got to spend another day above ground. Every day I’m here, I know I have the grit and gumption to keep on going... I didn’t know that before.”

*Negative experiences.* Among the negative responses, participants indicated despair and feelings of being overwhelmed by the experience. One participant commented that after receiving his diagnosis: “I felt so numb but so full of pain. Like parts of me were already dead and dying. I just didn’t know what to do.” In another interview, a family member of a patient told me that her husband (the patient) had described the experience as a flood where “we just didn’t have enough fingers between us to stop all the leaks in the dam... the fears and pain just kept spurting out faster and faster, until we were numb and floating on the flood.” Another talked about how helpful the ENT clinic staff and doctor had been at his visit:

At first I thought I’d be all right. I left here thinking I can get through it. They gave me information and told me I could call if I had questions. A few days later it hit me like a truck. Baffled, crazy thinking. Then, um, you, I needed more information about things I hadn’t thought about... life insurance, disability stuff the doc can’t help with. It’s more than one person can do on their own.

Yet another commented:

It was all-overwhelming. First you make, you know, take all these options, information and have to like, pick something. Then I started treatment and all these things, they (nurses/doctors) kept telling me about taking care of myself. You know, like, there's a visit here, a medication there, more treatment, therapy, risks. It was like trying to take a drink from a fire hose.

***Neutral experiences.*** Twelve of the 15 participants who reported neutral experiences also indicated (either in this question or later), that they had deferred their decisions, at least in part, to someone else. Neutral responses included statements including: "It was fine. Somebody had to do it;" "It was short and sweet. I just did what Dr. [name removed] had told me;" "I can't really say. I didn't spend a lot of time trying to figure it all out. It wasn't a big deal;" and "[Shrugs shoulder] I don't know, like you mean did it bother me? ... It was all okay."

In general, participants who revealed the most surprise, worry and/or fear in response to their diagnoses at Time 1 also reported the decision-making experience to be more negative or neutral. Furthermore, they reported less use of resources in evaluating treatment choices and often were unable to provide clear explanations of their selected treatments. These patterns suggest that patients who enter the illness experience unexpectedly and with a poor prognosis and/or with low health literacy could benefit from provider counseling or other support aids throughout their HNC experiences to promote coping, decision-making and positive treatment outcomes.

**Feelings of uncertainty and surprise.** "The only certainty I have had is knowing that everything is uncertain," remarked one participant. His reply underscores the general indeterminate context of being a cancer patient. Being a HNC patient, I would argue, frequently introduces a significant amount of uncertainty across the illness experience,

despite patient and provider attempts to identify and reduce risk, fear, and surprise. Consider, for example, that among the 41 patients in this study, no two people had the same sentinel complaint symptom, array of treatment choices, or outcome. The diversity of origin, treatment, scope, and personal experience is vast, and lends itself to emergent and evolving feelings of uncertainty regarding treatment and its outcomes.

Participants reported very few instances of being completely surprised or blindsided by aspects of treatment. Most discord between anticipated and real events or outcomes occurred early in the illness experience. It is noteworthy that misconceptions about personal health status, as well as logistical, procedural and administrative aspects of seeking and obtaining care were most often at the root of surprise and ill preparation. In fact, I believe that many study participants eagerly enrolled in my research because they saw it as an opportunity to vent their emergent anger and frustration. Many interviews began or ended with patients pointing out the warts of the health care system as they had experienced it, and strongly voicing complaints about waiting times, forms, parking, and health care costs. In this regard, there is much room for improvement that could improve the overall experience of both the patient and provider. If challenges and sources of patient dissatisfaction can be identified and improved or resolved, the patient would clearly benefit. For the provider, improved access to patients through better compliance and timeliness of appointments, may serve to create a better experience.

*Positive spiritual/emotional benefit.* Participant responses related to surprise and/or being ill-prepared for treatment fall broadly into three primary categories. First, from a positive perspective, 17 patients reported an altogether unanticipated spiritual/emotional benefit, or that a positive spiritual/emotional aspect was more

powerful than originally anticipated. Emotional/spiritual aspects included meaningful emotional or spiritual connections to themselves, others, or a higher power. Growth, compassion, forgiveness, grace and acceptance were terms frequently used to describe positive emotional aspects. One participant explained:

[I was] surprised that after so many years of holding back, I could, you know, give... let it all go. Recognize myself for who I am and then I could accept it all a lot better. I found that, it sounds funny... I can see beyond myself, like outside myself, because I've had to look, uh... inside of me. The real big gift from it all is that it's not problem solving, but I think, you know, uh, it's problem management... like, uh, gives you more things to pick from, and now the big problems are a lot less big. I never saw that comin'. I think I've grown a lot and I have a lot more respect for myself and everybody, too, I guess.

Another participant explained that he had gained emotional insight and grown spiritually as a result of his cancer diagnosis and subsequent illness experience. He explained that he had not anticipated, nor would he have believed previously the self-described shift in his own perspective on mortality and legacy.

Well, to be honest with ya, I hadn't really, you know personally, ever thought about what happens after you die. Getting cancer made me start, I started thinking, about what was next, I guess everybody looking at death would, and if I died how would people remember me. And I always wanted to be right with God, because I was always afraid of going to hell. Now, well, I don't really know if there is a heaven or what not, maybe not even a God, well, but I do know that I can change who I am today and how people will remember me in the, when I'm gone. I was always focused on life after death bit. It's all really hocus pocus. I'd have never thought a year ago that I'd say heaven and hell don't matter. But to me, what matters is right now! God's not here right now, I am, me and cancer are walking together. It's good for me. Who knew that I'd put aside God and believe in myself, become a better person, and embrace the death I want. It's so peaceful now and I know people will have better words to say about me and this world, not heaven, but this earth, will be better. I have a better, more fulfilled legacy now.

Many participants expressed a general ability to feel and/or share emotions in a more meaningful or positive way. Although negative feelings were frequently discussed,

positive emotions such as love, joy, happiness, and peacefulness were also expressed as unanticipated.

I didn't shed a single tear when my son died. My wife went through months of pain and loss when she was sick and I never flinched, but this brought me to my knees. At first I felt guilty for feeling sorry for myself. And then, I gave into it, shared my fears, shed my pain from all those years, and then realized no one was laughing at me. They were on their knees too. I never knew I was loved that much... Now we talk, cry, laugh together so much more. I'm sorry it took this long and this cancer to get me here.

A second positive unanticipated aspect of treatment was an increased importance of touch, particularly among the female participants. A total of eight people, six of whom were women, commented that physical touching and closeness had become powerful and important aspects of their care. One participant explained:

One day [my son] came to visit with me post-op. He was really choked up, so he just sat at on the edge of the bed, at my feet, and stroked the top of my foot. I asked him later why he did that, and he said because I had done it to him when he was sick as a kid. I remember feeling the stress and pain drain away when he did it, my whole body relaxed. I asked him to do it again when I was back home. It really calmed me down and made me feel so secure. I was telling my daughter-in-law and so she bought me a gift card for massage. I had had them before for my back, but now they are so much more healing to me. I think the power of touch is the best medicine. At least it has been for me.

Another woman described that her husband would often rub her shoulders in the morning before he would get up to get ready for work.

All the sudden, even after I was diagnosed, I just wanted to be close to him and I always wanted my shoulders rubbed. I know it's weird, but it got me out of bed every day and kept me going. I've never been the touchy feely sort, so it was a little surprising to me that I suddenly wanted it. Like, needed it.

***Physical changes.*** The other two categories of responses related to surprise have to do with negative aspects of treatment that were underestimated or unanticipated by the patient. The first, and perhaps most devastating is physical changes in appearance, voice,



or function. Although HNC patients generally receive a great deal of pre-operative and pretreatment counseling regarding potential physical side effects and changes, the full influences of such changes are difficult to comprehend. Thus, as was demonstrated in this study, surprise often has less to do with a lack of information or preparation, and more to do with a patient's psychological ability to cope with and or incorporate the changes.

I was very aware that I could have this [physical disfigurement], in fact, they pretty much told me I could count on it, so then it happened, and it just seemed so improbable. My wife told me that I kept acting like I was going to wake up and it would [be] gone... she told me to get over it and move on. I didn't expect it to be such a big deal for me. I wasn't really prepared for the little things I'd have to change to make things work like they did before. It's hard to change things when they are a part of who you are, or at least who you were.

One participant went into surgery thinking:

Here we go again, like when I had the bypass, pain, swelling, fluids. I thought I'd probably look the same. I completely didn't think about the long and short term. [The doctor] had told me that I'd look the same, but that there was always the chance for certain bad consequences, well, you know... anyway, I guess I thought I'd go in and come right out the same way, so when I woke up and my head was wrapped up and I didn't recognize myself, I was terrified, couldn't even recognize my own eyes and I thought the worst, and everything hurt so bad, and [I] was on all these machines. Oh... I just hadn't put it all together like that. Oh, the, and then I remember I couldn't move at first either, I didn't expect that at all.

*Altered time.* A third area of surprise regarding the treatment experience is altered time, which refers to changes in the perception of time. Specifically, perceptions of time at least during and shortly after treatment became slower, faster, shorter or longer. Participants said things such as: "Time just stood still and then it [time] was gone;" "Things just kept moving faster and faster and I couldn't keep up;" "I can't believe how fast it all happened;" "I didn't expect to feel like I was out of time. I still feel like I'm out

of time;” and “I didn’t think it would ever end. That surprised me because with my wife, it went by too fast.”

Others reported that they did not expect to feel as tired, embarrassed, lonely, or useless following treatment. The range and scope of responses exemplifies the physical, psychological, and spiritual aspects of treatment and care that can change the trajectory of a patient’s recovery. Preparing patients for treatment and providing resources and support before, during, and after treatment appeared to be misplaced, lacking, or insufficient.

### **Summary of Research Findings**

This chapter began with a demographic overview of the individuals who participated in this study. This all white, mostly male, older, rural population experienced cancer and treatment within the context of competing comorbid health conditions including tobacco and alcohol use and related health concerns. The relative isolation and poverty of the Appalachian communities in which many participants resided may have also been partly responsible for the frequently reported delays in initial help seeking and challenges in accessing resources that would facilitate seeking and obtaining medical care.

The second section of this chapter focused on how participants perceived their health, factors they believed contributed to their health, and aspects of the initial illness and treatment experience. While most participants perceived their health as average or fair and recognized lifelong behaviors such as smoking as detrimental to their current and future health, many underestimated or were altogether unaware of their risk for HNC. Initial or early symptoms of their cancer were often overlooked, ignored, or unrecognized

in the context of competing health concerns and/or daily obligations to family or work. Most participants had delayed medical help seeking and subsequently were diagnosed with late stage disease. Seeking information and spiritual or religious guidance, and implementing new personal health practices or seeking out medical care were strategies that participants employed in response to initial detection or symptoms. During the time between symptom recognition or discovery and obtaining health care, most participants (n = 29) sought information, advice, or counsel from other people, including significant others, co-workers or sponsors. The role of sponsors and TSGs like Alcoholics Anonymous was revealed as a significant support and or influence in the cancer experience and treatment for many participants. Specifically, the 12-step model appeared to be a useful one for negotiating change, fear, and uncertainty

Delving beyond the initial diagnosis, the third section of this chapter documented barriers to treatment as well as fears and perceptions. Interview findings suggested that a significant opportunity may exist for health promotion and health education, as participants frequently lacked knowledge and understanding regarding their disease and its treatment. In this regard, a lack of awareness of risk and severity may serve as a barrier in that patients may not recognize early symptoms as a significant health threat that warrants medical care. Additional barriers included work and family obligations that prevented timely help seeking, difficulty in obtaining and maintaining the resources needed to access and obtain health care, and challenges related to the infrastructure of rural living and the health care system. Additionally, the cancer treatment experience of participants was shaped by past interactions with the health care system. Distrust or

dislike of health care professionals stemming from previous health encounters may have kept participants from fully engaging with the health care system.

Treatment for HNC threatens functional ability, encroaching on normal daily activities and function. In addition, physical changes can impart consequences to aesthetics and mental health. Participants in this study most frequently cited negative changes in appearance, resources, or relationships as the most feared or worrisome aspect of treatment. Pain, suffering, and the development or exacerbation of other health concerns were also significant worries for study participants.

The chapter concluded with findings related to planning, aspects of time, and treatment considerations. In keeping with fears and worry regarding functional loss, most participants' present concerns focused on maintaining normalcy in social activities and other daily occupations. While participants managed their conditions day to day, they also worried that the future would be influenced by the development of other co-morbid conditions. Future time perspective also eroded between the first and second interviews, regardless of treatment outcomes and goals. In other words, as participants moved through the illness experience, they became less future oriented and perceived less future time.

The treatment experience was as varied as the participants in this study. Positive, negative, and neutral experiences were documented and shaped in part by past and present experiences, as well as by many smaller, acute decisions related to adapting to life with cancer. Uncertainty was a common element of the experience, as were spiritual and emotional growth, increased desire for touch or intimacy, and surprise regarding the depth and or scope of physical change related to treatment. A final element that many

participants reported was a shift or change in time perception. Making treatment decisions and undergoing treatment had the effect of increasing, halting, or slowing down the perception of passing time for many participants.

In the following chapters, I explore these findings more deeply, and introduce broad themes that reflect the nature of the treatment experience among the HNC participants in this study. I examine my findings against the original theoretical foundation of the study and suggest a model of the HNC treatment experience. The components of the model and its themes, as well as the findings presented in the previous chapter, are illustrated through four case studies. As with Ben, whose story was offered in the Prologue to this dissertation, the names of people and places have been assigned pseudonyms. “Cecil,” “Russ,” “Lou,” and “Glenda” each serve to exemplify the diversity of treatment experienced by the men and women who participated in this study. Their collective perspective and experience provides the context in which the model is grounded.

## Chapter 5. Patient Vignettes

The stories presented here illuminate the multi-faceted and complex journey faced by many older HNC patients. Shrouded in fear, facing competing demands, and drawing on lifelong experiences, older patients navigate the cancer experience within the larger context of living a “mostly lived” life (Kagan, 2009). It is in this setting that the cancer experience is imbued with manifold complexities related to the substantial social, physical and psychosocial heterogeneity reflected in the older population (Rowe & Kahn, 1987). Through the interviewing process, study participants described and explored the rich and ephemeral reality of living with a life threatening, potentially disabling and disfiguring disease. Four participants were selected for the vignettes based on their relative ability to reflect the range of characteristics and themes of the larger participant population. The narratives contextualize the study findings presented in the previous chapter while simultaneously articulating the broad themes that become the scaffold of the emergent model discussed in Chapter 6.

### **Vignette 1: Russ**

*Life is known only by those who have found a way to be comfortable with change and the unknown. Given the nature of life, there may be no security, but only adventure.*

*-Rachel Naomi Remen*

The tension in the clinic waiting room was electric. In the humid mugginess of a crowded waiting room, three prisoners dressed in orange jumpsuits, ankles and wrists shackled, stood against the wall behind an armed officer and a half-dozen civilians. I studied the crowd, seeking out the piercing green eyes and stone face of Russ and his wife Greta. Although I had only met the couple an hour before, it seemed to me that all

three of us were relieved to find one another and make our way out into the busy, generic halls of the Medical Center. Greta was still clutching the instructions, prescriptions, and orders for consultations and lab tests the nurse had given them before providing them with instructions to make their way to the dental school offices, “close by” on the medical campus. I dropped my materials at my workstation down the hall and hurried back to chaperone the couple across campus to the dental school. I frequently offered to walk patients from place to place on campus, sometimes even to their cars. Even those patients who declined to participate in the study almost always accepted such offers. While walking and waiting with patients, I learned a great deal about patience, courage, resilience and coping, and perhaps less about the treatment process and experience. Yet, it was often these experiences that helped me to make sense of the data and to comprehend the complexity of treatment decision making against the backdrop of an individual’s life. These were the rare moments when, unbound by my interview questions and the clinical environment with its proximity to diagnosis and treatment, I felt the profound weight of bearing witness to living an uncertain, unraveling future.

Russ’s future had just taken an abrupt and unexpected turn when earlier that morning, he had been told that he had laryngeal cancer. At the end of his appointment, he had been sent to the dental school to receive a consultation for a total tooth extraction. Russ had not wanted to stay. He said:

We aren’t going to any more dammed appointments today. We been here for hours, sittin’ and waitin’... we ain’t got nothing now that we didn’t have before. Ain’t neither of us had any supper. Greta’s sugar is gonna be bad. We’re goin’ home.

I had offered to walk them to the dental school and indicated that there was a cafeteria on the way. “Well what about our parking? We’ll get a ticket if we don’t leave soon,” said Russ, still searching for reasons to leave. Greta whispered, “Might as well stay. Day’s already half gone and we’re here already.” Once Russ had been ushered to an exam room, Greta asked about the tooth extraction. “I don’t understand,” she said. “All this time gone by and he’s never been hurt. He doesn’t look so bad off to me. I can’t figure why he’d have to lose his teeth.” I nodded, unsure how to respond. “Having his teeth removed will be better for him, so he doesn’t get an infection or have problems when he starts treatment. Just think of how nice his smile will be when he gets dentures,” I offered.

Greta’s placid face twitched momentarily into a brief smile. “I guess that’d be better than what he’s got now. You reckon he’ll be able to eat good with ‘em?”

“I imagine he will,” I said, readying myself to return to the clinic. We exchanged goodbyes and I turned to go, wondering if and when I would see them again.

Five months passed until my second meeting with Russ. Our previous encounter had left me fearful that I would not see him again. In the short time I had been recruiting patients, many people had appeared on the daily appointment log only to fail to show up. The missed appointments were often those that had been scheduled after the first consultation. Russ provided details about his last visit for me. He told me that he and Greta had left their home in Appalachian Kentucky and had driven 3 hours to Lexington. Upon arrival at the medical center, Russ said “I didn’t know where the hell to park, there is always some rule.” Once they found their way to the clinic they were told they’d have to wait because they had arrived 15 minutes late to the scheduled appointment. Russ and



Greta had expected a short consultation of no more than an hour. Instead, Russ had been sent for blood work and a dental consultation for a total extraction of his decaying teeth. He commented that his primary concern that day was not his own health or eminent treatment, but Greta's diabetes. She had not brought her medication and had refused to leave Russ so that she could buy herself lunch. By the time they returned home, they had been away for almost 12 hours.

For the second visit, Russ arrived at the hospital with his son, whose familiarity with the city and campus greatly reduced Russ's frustration and anxiety. The doctor seemed satisfied with the radiation progress, and Russ, despite being very sick, reported that he was feeling like himself again. During our second interview he told me:

I'm making time for getting better. I guess I got sick 'cause all the drinking and smoking. I don't want to have any more problems so I stopped all that. I feel real lucky that I don't have problems with my heart or lungs and I care to keep it that way. When this is all over, whole family is gonna go see the world. It's up to me to make that happen.

A few months later, toward the end of Russ's treatment I visited him in his hometown, at a Sunday church dinner. There, I found a man much different from the man I first met. His scarecrow-like arm waved at me in greeting. We began our conversation by discussing his medical status and post-treatment plans. He summed up his health by stating more as a fact than a question, "What do you think? Don't I look good?" Before I could reply, he pulled out a photo. I recognized the place as Natural Bridge State Park. In the photo, he and Greta were standing on a bridge of stone surrounded by a halo of magnificent autumn leaves. "You know I hadn't ever been there? Lived here all my life and never been! We saw cars there from all over the country," he exclaimed. "It was our first trip to test out the trailer. Next week, we leave for Pigeon Forge!"

## **Vignette 2: Glenda**

*I took a deep breath and listened to the old bray of my heart: I am, I am, I am.*

*~Sylvia Plath*

Glenda is a patient whom I fondly remember. She was one of the first women who enrolled in the study. She was eager to talk to me about her cancer, but also her life. She told me that four months before our first interview, she had undergone an emergency double bypass surgery on her heart. At her three month check-up (to obtain an early medical release so she could return to work), she asked her physician to look at a canker sore in her mouth. Unlike previous sores, this one “didn’t hurt, but didn’t heal” and seemed to be in an unusual place. She explained to me that she had only asked her physician about it because she thought she might be able to obtain a prescription medication to help it heal. The doctor immediately sent her to another physician in a nearby community who biopsied it, revealing that she had a stage III cancer of the tonsil. Her diagnosis was a complete surprise and eroded the fragile and tenuous belief that she could and would “get back to normal.”

I smoked a pack a day of cigarettes for 35 years... stopped 3 years ago. No, I hadn’t heard of this kind of cancer before. Now, when I, the bypass, I had to have the bypass, it was a surprise too, I didn’t have any symptoms... that I noticed, but I always figured I was fixin’ to have something happen on account of the smoking. My ex-husband smoked too. I quit when he left. If I was goin’ to live alone, I wanted to take care of myself better... I don’t know if I would have quit earlier if I’d known I could get this. It would be good for people to know though. My doctors and dentist never gave me, told me, anything about it.

Glenda’s hard features softened and her eyes filled with tears as we discussed her health. She said that she was most worried about her job and paying her bills. The

double bypass capped out her insurance coverage and she was paying a base fee of \$200/month for her medications.

“I bet I get 50 calls a day from creditors, so I don’t even answer my phone anymore,” she said. “If you try to call, leave a message so I can call you back.”

“Will your financial situation impact your treatment decision?” I asked.

At first I was so upset I just went home and cried, unplugged the phone and stayed in my room. After a few days, I said to myself, “Are you going to lay here and die, or do something?!” I couldn’t face my co-workers or my family. I was ashamed. I finally got myself fixed up and came to see Dr. A. They said I’d have to have surgery right away and I’d have to get my teeth all out. I didn’t know it would be that... except that, with cancer... I was prepared for radiation or chemo. ‘Cause it’s bad, I guess, I just do what they tell me. They [medical staff] all have been a blessing... no sugar coating. I got some counselling about the new bills through the hospital, so that helps. I don’t really have a choice... if I don’t do it, I’ll be dead.

Except for a crown of thick red hair poking out above bandages, I didn’t recognize the woman I had met just weeks before. She was in an intensive care recovery room, one day after surgical removal of the tumor. I donned the mandatory gloves, gown and mask before entering her room. The ventilator and other machines tapped out an empty and eerie cadence. She had told me that her family all lived “out in the hollers” and that her sister might come only if she could take the time off work. Her face reminded me of a swollen, rotten watermelon, and I wondered what new challenges she would face during her recovery. Her treatment choice had been life or death: follow through with surgery and 6 weeks of follow up radiation in London, KY, or go home, “put things in order and wait.”

Glenda was 65 years old and she told me how she had worked nearly every day of her life since her fourteenth birthday. In her youth she had harvested tobacco, processed

chickens, managed orders for a dairy farm, and worked as a waitress. In 1992, she “hit a lucky strike” and got a job at a distillery bottling bourbon. After 27 years of marriage, a devastating divorce had left her estranged from family and friends, living in a singlewide house trailer and without a car. She had lost her job because she was frequently unable to find transportation to work. She said, “Just when I felt I’d get a little ahead, I’d be down again, even worse.” After a brief period of unemployment that had further eroded any finances she had managed to retain, she got a job working on an assembly line for a large manufacturing company. The first time we met, she had talked about how much she wanted and needed to return to work. It was the fulcrum around which her entire universe turned. “What would a person do without a job, drawing [disability or unemployment] isn’t, well, I won’t do that.” Her treatment decisions had less to do with her health and the significant functional impairments treatment might impart, and more to do with determining the most expeditious route back to gainful work.

What I fear most is losing my job... I used all my sick leave and every other kind of leave with my heart. I just can’t keep up with my debt. I’ll spend the rest of my life working, anyhow [laughs sarcastically]. What do you think, do you see any other way around this? I just don’t know... I always bounce back somehow, but this time, I don’t know how I’ll do it alone.

In Glenda’s ICU room I could not help but wonder how and when she would move on and what her future would look like. Unlike Russ, who finished treatment surrounded by family and with great optimism for enjoying what life he had left, Glenda’s journey seemed doomed to loneliness and tiresome work in the face of crushing debt.

### **Vignette 3: Lou**

*I wear the chain I forged in life! I made it link by link and yard by yard! I gartered it on of my own free will and by my own free will, I wore it!*

*-Jacob Marley, in Charles Dickens' A Christmas Carol*

The first time I spoke to Lou, I had called him to introduce myself and ask if he would like to participate in the study, following a clinic appointment in which he received confirmation of his cancer diagnosis. He had asked me why I wanted to know about treatment decision making and cancer when there were much more “interesting things to know about someone.” My explanation was met with a chuckle and Lou said, “Why not? Sure, you can ask me anything you want.” Over two interviews and several other “off the record” conversations, Lou told me a great deal about his past. At first I struggled to interview him. I would ask a question, and often he would repeat it back to me and provide a seemingly unrelated answer. Many study participants had had very little to say, so I decided to sit back and let Lou “drive” as he once put it. He decided what we talked about during an interview and then he would call me a day or two later to answer a specific question that he had evaded. Most of our conversations were dominated by stories of his lifelong history of drug addiction beginning with his army enlistment. His drug use reached a peak one year after he was honorably discharged. “That was the darkest time,” stated Lou referring to his homecoming. “There was nothing here for me. I was as good as dead.” One year after his discharge, he was addicted to alcohol, tobacco, marijuana, and prescription pain medication.

At our first interview, I asked about his health during the first half of his life. He replied, “I think you mean the part of my life that I was living?” Confused, I attempted to

clarify. “If you split the time you’ve been alive, since your birth and now in half, how do those two parts compare?” His responded:

Well, I was born in 1950 so that would make the first half up to about 30 years old, right?... But, I got a second chance, kinda a re-birth in '96. So I guess the first half was pretty piss poor. [Viet]nam messed me up with my leg, you know. I got into drugs and a lot of bad stuff when I got back. I’ve damn near survived everything, you know? Since '96 things have gotten better. I still have issues but I got a handle on it.

When I asked about things had affected his health, such as the drugs and his combat injury, he described his recent diagnosis and cancer status as a mere “hiccup in life.” He saw it as a small and almost insignificant thing relative to his profound life experiences. That is not to say that he did not understand or appreciate the seriousness of his prognosis. Rather, his accumulated life experiences, in his words, had “tempered his emotional response.” He estimated that he had spent at least 10 years drunk, couch surfing, living in treatment facilities, “locked up,” or on the street. Much of that time evaded his memory. He also served two years in prison for theft and aggravated assault. Part of that sentence was served in a psychiatric hospital. He referred to these periods as “time out,” which can be understood as periods of time in which a person has greatly diminished control over his ability to participate fully in his own life or exert little, if any, personal agency.

“What things about your cancer scare you, or are there things you worry about?” I asked. When I originally asked this question, he responded by telling me about his combat experience in South Vietnam. He told me about using tobacco and marijuana to help combat fatigue, boredom, anxiety and fear. Lou explained that the first drug he had used was marijuana in army basic training. Shortly after being deployed into combat he

began using heroin and army-issued amphetamines in Vietnam. “Man, that chilled me out,” he stated.

I could stay focused forever... for the first time. I was one of those bad kids and I always was in trouble. I went 100 miles an hour and didn't know what I was doing. Today they'd give me that Ritalin stuff. In the jungle there was more dope than decent food.

When Lou called me two days later, he had an answer to my question about what things scared him. We met at the Starbucks located in the medical center.

I guess, you know, the pain meds scare me. Lots of people get on those things, man, y'know. They're killin' people for 'em too. I don't want 'em. You gotta pick the lesser of two evils... I got away from all that. I got my side of the street cleaned up. I can't take some stuff, 'cause they make me crazy. Not being able to smoke scares me, but... it would be real cool to stop smoking. I've tried a lot you know. Chantix helped but I can't get it anymore.

I asked, “Is there anything else that scares you, maybe about treatment?”

No ... just I'm real active with my [AA]. Like, I said, I've survived a lot of shit. Anyway, you know, some of us are like a family, we help each other. You've got to give away the gift if you want to keep it. A brother got, uh, I think... yeah, colon cancer a few years ago. He stopped coming to meetings and started drinking again. I think that's what killed him. I hate being tied up, out, you know.

Lou told me that he had been attending AA meetings since 1996. He claimed that his alcoholism had not only exacerbated or created health problems, but had been contributing to severe mood swings and periods of intense rage. In one story, he described passing out drunk on a busy city street. He attacked and thought he had killed a man who had attempted to pull him out of the roadway. In his drunken state, he had believed that the man was an enemy soldier trying to kill him while he slept. A VA social worker had been encouraging him to attend Alcoholics Anonymous meetings for years. After fearing he had killed someone, Lou finally “hit the bottom” and turned to AA for help. The role of the 12-step program in his life became apparent as our

conversations moved toward discussion of his future plans and mechanisms for coping with cancer.

Yeah, I worry. But I'm not going to waste time trying to fix things I can't control. In AA you learn how to make the 12-step process a working part of your life. It's up to the person to improve themselves. You can do that and be sick, have some diseases. I can heal. I can recover... cure, nah, recovery is better... it's my goal. I got to accept that I got this thing, that it might kill me, but so what... cancer is just part of it, I got work to do either way.

His enthusiastic and comprehensive explanation of the AA program and steps helped me to comprehend the meaning and understanding of subtle similarities in language and attitudes (see Table 4.3) frequently reflected in earlier interviews. During our second interview, Lou gave me a copy of the "Big Book," the bible of Alcoholics Anonymous. In reading it, I was struck by the similarities in language and perspective between the text and the participant data I had collected. After carefully reviewing previous interviews, I was confident that many of the emerging themes were grounded in the 12-step culture.

**Vignette 4: Cecil**

*See, I have set before you this day the choice; good and evil, the blessing and the curse, life and death. Therefore, choose Life!*

*-Deuteronomy 30:19*

Many of the participants in this study talked about their chronic fears regarding being able to provide emotionally and/or financially for themselves and their families. These fears often manifested while evaluating the economic aspects of treatment options. Cecil is one such patient. He lived about one hour away in a rural Kentucky town. He and his wife, Annabel, farmed 40 acres of farm land that had been in their family for four



generations. To make ends meet, Cecil had once worked three weeks on and three weeks off at a coal mine, and at the time of the study he was maintaining a job at a local poultry farm. Cecil's initial appointment was almost six months after he had first noticed a pea-size knot in the side of his neck. Even then, he had not made an appointment because he was not sure if he had enough cash to cover the visit. Once he made the appointment, he rescheduled twice due to changes in weather and work. He told me that he thought, "Why now?" when he received his diagnosis. Annabel "was finally getting back on her feet again and things were better. Matter of fact, you, I, I paid off the last of her medical bills just last week, and then bam, this." Annabel had just "come through" a long period of health problems. She had broken her hip and had it replaced. Cecil explained that she had been discharged too early "on account of her not having some sort of coverage" and that once she returned home she "got real sick." Cecil had sold some of their farm equipment to pay for a home health aide. During her illness, Cecil took on the cooking, cleaning, and other household chores in addition to picking up extra hours at the poultry farm. "Now that I'm sick, what is she going to do?" he asked me.

Before we formally started the first interview, Cecil had pulled a notecard from his pocket and asked if I could help him "understand what this stuff means." I took the card and read, "neoplasm, resection, margin, malignancy." These were common words for me, but despite their familiarity I felt inadequate as I explained what they meant. Surely, those terms would have a different meaning for Cecil. He also talked to me about radiation, specifically what it would feel like. This was something I had never thought about and recognized that my own understanding of this common cancer treatment strategy was purely clinical. Cecil offered that perhaps it would be warm and soft like

the feeling you get standing in a sunbeam. Radiation following surgery seemed to be the best option, according to his doctors, but he told me that he was worried about being able to keep working if it made him sick. He wondered if he could delay radiation treatment, at least until “I can get the hay cut and sold.”

Cecil, like Lou, was also active in AA. Over the past 12 years, Cecil had only missed four meetings. The first two had been seven years ago after a weeklong hospitalization due to complications related to a kidney stone, and the last two had been due to the side effects and timing of radiation treatments. While the radiation was expected to further remove the threat for recurrence of cancer, his full recovery required many more months of voice therapy, swallowing exercises, follow up testing, and possible reconstructive plastic surgery. “Well, I don’t know if I really need all that therapy. I have to come here for it, most of it anyway, it’s not worth it,” Cecil told me. “Annabel and I are getting along just fine now.”

Cecil had gone through a period after surgery where speech was very difficult. Post-therapy, it was still sometimes hard for me to understand what he was saying. He told me that during that time he and Annabel had started cutting and sorting coupons. Neighbors and people from their church saved and shared their weekly coupon circulars with them. Cecil and Annabel would sit in their kitchen, silently, but together and “spend some time doing little things that added up to a whole lot of difference,” explained Cecil. “It was something I could do to help out and I got to do it with [Annabel].”

**Summary.** The stories presented here illuminate the multi-faceted and complex journey faced by many older HNC patients. Shrouded in fear, facing competing demands, and drawing on lifelong experiences, older patients navigate numerous

decisions regarding treatment within the larger context of living a “mostly lived” life (Kagan, 2009). It is in this setting that the decision-making experience is imbued with manifold complexities related to the substantial social, physical and psychosocial heterogeneity reflected in the older population (Rowe & Khan, 1987). Through storytelling, study participants described and explored the rich and ephemeral reality of living with a life threatening, potentially disabling and disfiguring disease. Through the narratives, the lives and stories become permeable, offering clarity to the study findings presented in the previous chapter while simultaneously articulating the broad themes that become the scaffold of the emergent model discussed in Chapter 6. Among the many themes that emerged from the stories of study participants, were an array of participant similarities. Table 5.1 summarizes the most frequently observed characteristics and the conceptual theme for the study sample as a whole (n=41) and the four vignette case studies.

Table 5.1 Common Participant Characteristics and Themes

Characteristic or Theme	Sample				
	Frequency	Glenda	Russ	Lou	Cecil
12 step experience	31(76%)	X		X	X
Institutional experience	24(58%)	X		X	X
Extraction Industry Work	32(78%)	X	X	X	X
Labor and Manufacturing Work	29(71%)	X	X	X	X
Taking Time	25(61%)		X	X	X
Making Time	31(76%)	X	X	X	
Chained time/Time out	21(51%)	X	X	X	
Reconciliation	33(88%)	X	X	X	X
Hope	27(66%)	X	X	X	X
Self-Inventory	22(53%)	X	X	X	X
Reflection	35(85%)	X	X	X	X
Spirituality	21(51%)	X	X		X

## **Chapter 6. Toward a Conceptual Model**

### **Description and Application of the Model**

Figure 6.1 at the end of this chapter illustrates the cancer treatment experience among head and neck cancer patients. The following section describes the elements of the model and uses the experience of Cecil, from Vignette 4, to illustrate application of the model. The model begins with life before cancer, acknowledging the lives of participants prior to receiving their cancer diagnoses. Pre-cancer life provides the context in which the illness emerges and diagnosis is eventually obtained. Cecil, who was 63 at the time of diagnosis, was slightly older than the average study participant (58). Like many others ( $n = 28$ ), he had worked in labor intensive, low wage jobs for most of his life. He was also a lifelong smoker and had a history of drinking. He had begun attending AA meetings years before and said that he had relied heavily on them for social support when things were stressful in his life. One example of a stressful period was his wife's recent illness, which he indicated had stressed his time, finances, and emotional health. These are elements of Cecil's life before cancer. In his case, the financial stress deterred his initial help seeking and thus delayed his diagnosis. His life before cancer, in terms of his AA participation served to support him as he underwent treatment.

Decisional origination marks the beginning of the cancer illness experience and the initial introduction into decision-making regarding cancer management. Patients fall into one of three categories: unanticipated diagnosis, anticipated diagnosis, and sick role/emergent. Patients may not anticipate or suspect a serious illness threat such as cancer before they are diagnosed. Since the presence of illness is altogether unknown and unexpected, patients have not changed their behaviors or considered their health

status in response to a health threat. Other patients may have recognized symptoms or had other reasons to believe that they were ill. Patients who felt that something was wrong may have already begun to seek more information or treatment strategies to alleviate symptoms or improve overall health. Still others believe that a serious health threat such as cancer exists at the time of diagnosis. These patients have begun to take on the sick role.

Cecil's decisional origination was anticipated diagnosis. Having felt a growth under the skin of his neck, he had not made an appointment because of financial concerns. He waited for six months, monitoring the size and shape of the knot and also noting any other changes or symptoms. He explained to me that shortly after finding the bump he had sought out a co-worker who had had a problem with his lymph nodes. Cecil had asked him about the nodes and what they felt like, suspecting that perhaps his condition was similar.

Diagnosis and identification of treatment strategies often co-occur. Patients employ active, collaborative, or passive decision-making styles, sometimes shifting back and forth from one style to another. Active decisional preference involves deliberate, if not aggressive participation on the part of the patient to obtain information and resources in order to fully evaluate treatment strategies and outcomes. Patients who opt to make treatment decisions collaboratively with their health care providers reflect collaborative decisional preference. Finally, patients with passive decisional preference may accept the advice or instructions of their health care provider or a family member, without extended research or considering other options.

Cecil's decisional preference shifted after his initial treatment choice. Cecil had decided to follow "doctor's orders," and scheduled his surgery within days of his diagnosis. He had taken home several pieces of information regarding radiation, wound care, and swallowing therapy in order to know what to expect and how best to take care of himself. According to both Cecil and his wife, with whom I spoke after both interviews, they never deliberated over multiple treatment choices. Instead they followed the "best case scenario" expressed by their physician. After treatment, more decisions were to be made regarding follow up care. For example, he needed to decide whether to receive chemotherapy in Lexington or at a facility closer to his home. For these decisions, Cecil took a collaborative approach, talking through his options and identifying their advantages and disadvantages with his healthcare team, family and friends. Here again, Cecil's life before cancer was influential. He also included some of his AA peers in his decision-making process and said that his experience with his wife's recent illness made him realize how important it was to take his medications, follow instructions, and maintain a positive perspective.

Depending on the decisional preference or style, patients may arrive at a decision after several days, weeks, or months of personal deliberation, or may quickly agree to the preferred treatment strategy of the medical provider, as was the case with Cecil. From diagnosis to treatment decision, patients engage in an ongoing process that may include one or more activities including reconciliation, hoping, self-inventory, reflection, or spiritual practices. These activities are facilitated through the deliberate making and/or taking of time. These activities include reconciling the past, addressing the present, or preparing for the future. Cecil made time to keep a notebook in which he recorded his

thoughts, feelings, and questions. He explained that it helped him to “figure out what to do,” and to keep track of things. Cecil also made future plans to purchase an RV and to travel.

Finally, a patient arrives at a treatment decision that is then executed. This can include medical treatment, an alternative non-medical treatment like prayer or acupuncture, or doing nothing at all to alter or remove the cancer. If a patient decides to “do nothing” they may then move from treatment decision making to contemplation and/or management of the decisional outcome, such as attempting to manage symptoms. Patients who opt for medical treatment including surgery, chemotherapy, palliative care and/or hospice may deal with treatment outcomes before considering the overall decisional outcome.

By the time Cecil had completed surgery and radiation, he had begun re-thinking his previous perception that follow-up therapy probably would not be needed. He also admitted that he had wondered if he had made the “right” decision when he “saw how much it took out of [Annabel].” He explained that he had felt like a burden to his family and that he was not useful. “I knew I was getting better, the cancer, was getting better, but it took so long and it feels that everything else has to get worse,” Cecil explained about the side effects of radiation.

Regardless of flow from or between discreet sections of the model, patients ultimately move toward recovery and a “life after cancer.” Often recovery is reached through ongoing reconciliation, hoping, and elements of self-discovery, personal reflection, and spiritual growth that continues after treatment and may help to define the self and life after cancer. Cecil, for example remarked that he felt content in life after

treatment. He said that he had often wondered what life would have been like had he not ever had cancer. I asked him what, if anything, he had concluded. He responded, “I’ll tell you, I live a good life, and I’m thankful for it... If I, if it comes back, I know I’ll be okay. It will all be okay.”

The HNC treatment decision-making process is bound by the forward passage of time and the context of a patient’s life. Preferences and behaviors are continuously shaped by internal factors, such as a patient’s life history, overall health, age, income, personal autonomy, and beliefs. Likewise, external factors may impinge on the treatment process, such as when Cecil delayed seeking help. Access to medical services, for example, or even poor weather may deter seeking prompt medical help when symptoms are recognized. Similarly, insurance coverage may limit or expand treatment choices, such as when an insurance company denies coverage for an efficacious chemotherapy drug such as Cisplatin in preference for another.

As a whole, the model represents a linear movement from life before cancer to life after cancer. In this regard, the treatment decision-making event can be understood as a fragment of a much larger process or experience in which a person contemplates and negotiates self-preservation through multiple strategies, which may or may not include medical treatment.



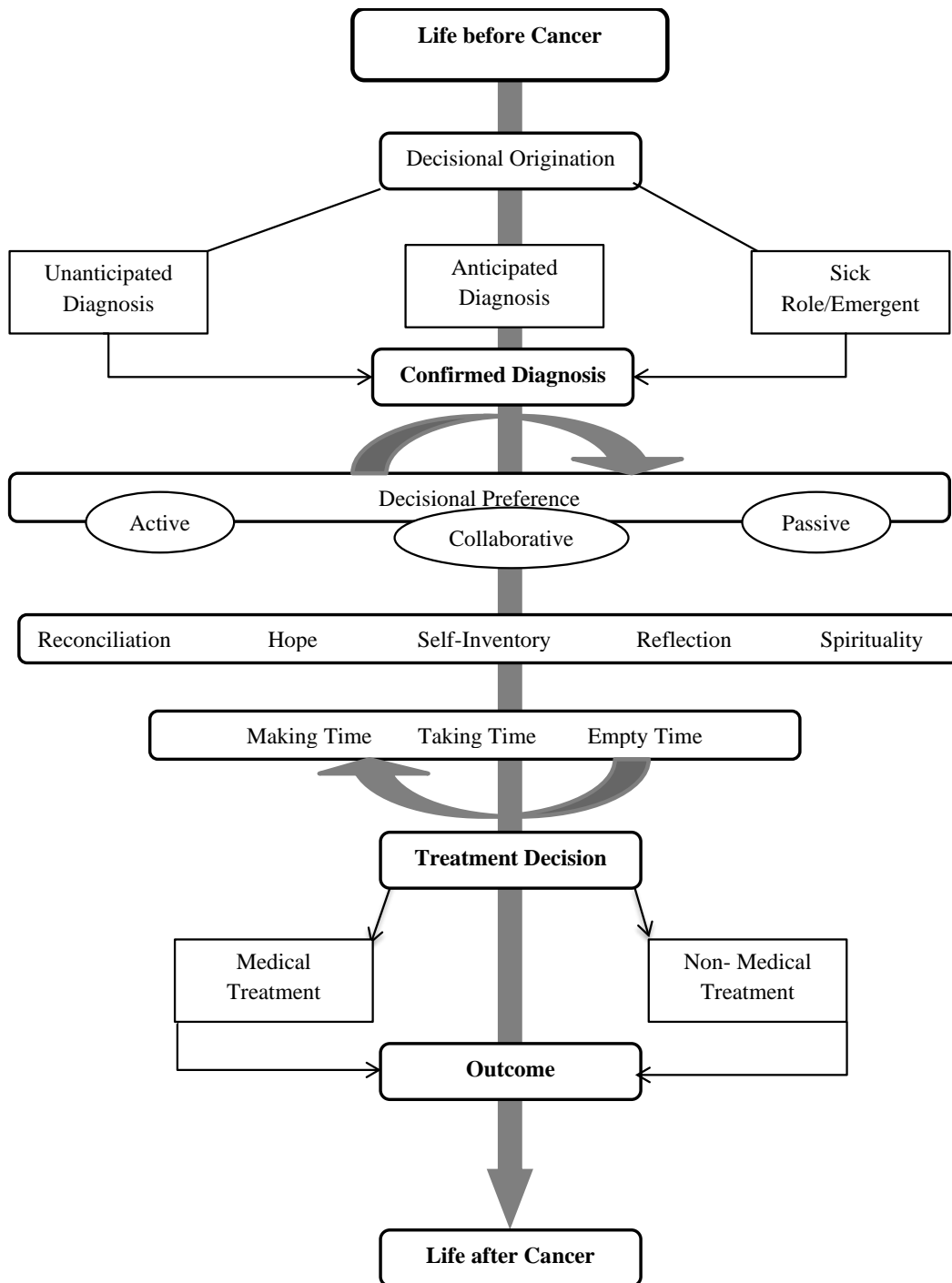


Figure 6.1 A model of cancer treatment experience for head and neck cancer patients.

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## **Chapter 7. Model Elaboration**

The model is representative of the process through which patients in this study came to decide on and manage a treatment strategy. A treatment strategy may include a single specific treatment, like surgery, or more typically, a set of actions and attitudes directed at cure or recovery. While the model is represented as a linear, stepwise process, patients may move forward and back again, skip from one point to another, or stay in one domain. The organizing framework of the model consists broadly of temporal frames, decisional origination, and recovery. Temporal frames include ways in which participants used or framed time periods that are: (a) from the past but influence the context of treatment decision-making; or (b) specific ways in which participants plan to use present and future time. Origination refers to the context in which the treatment decision-making experience began, which may influence all other aspects of the process. Recovery is an intellectual dynamic process that influences the participant's TDM experience through redefining a new sense of self within the context of "life after cancer."

The overall framework is sensitive to both internal and external factors. Internal factors include a participant's subjective reality, including thoughts, feelings, ideas, emotions, and goals. Additionally, collective (we) factors are also influential and may include shared meanings, expectations, and understandings between the participant and their care providers, loved ones, or other social contacts. External factors include space, systems, and structures/resources.

### **Temporal Frames**

In this study, the overall temporal orientation or context of the model preserves the past, present, and future framing of time periods across the life span. In addition,

three primary temporal categories were identified: *empty time*, *making time*, and *taking time*. *Empty time* includes *junk time*, *chained time*, and *time out*. *Junk time* is time that was perceived as wasted, unproductive or “lost” due to personal choices or consequences of personal choice, such as being incarcerated, “strung out,” or “lost in a haze of drugs, somewhere in the bottom of a bottle.” *Chained time* refers to time that was spent attached, bound, or obligated to someone or something, often entered into without choice, consent, or complete free will. Lou’s perception that he had to quit school and enter the military where 3 years of his life were orchestrated and monitored by his superior officers is one example of chained time. *Time out*, also described by Lou, refers to time periods that are typified by low personal agency and autonomy and that often have a specific beginning and end time.

*Making time* and *taking time* refer to ways in which time has or will be spent, generally for a specific purpose or intent. The second vignette features the story of Russ. His story illuminates *making time* as well as demonstrating other features of the patient experience.

Like Russ, many patients commented that they were *making time* to do something. In contrast, others often used the phrase *taking time*. At first, the choice of wording seemed inconsequential, but after a number of interviews, subtle differences appeared. In making time, individuals create time in their lives for specific tasks or activities that they believe will improve treatment, the treatment outcome, or some aspect of health. Making time reflects accountability and personal investment in the treatment process. Russ “made time to get better” by focusing on aspects of his life that he felt he could control, like making a point of taking his medications on time, keeping a diary, and

attending Bible school with his wife for the first time in over 20 years. Patients who make time for something build the time by reducing the hours, minutes, or days spent engaged in other activities or by piggybacking activities. Russ explained that he used to stay home and read the paper on Sunday mornings while his wife attended Bible school and church services. By attending Bible study with her, he was still able to read the paper in the morning, but also was able to go to church.

*Taking time*, on the other hand, is time that is used specifically for “giving back,” or doing something for others. One’s personal time, for example, a Sunday morning typically spent over coffee and a newspaper, might be sacrificed for volunteering at the food bank, being an AA sponsor, or offering to watch the grandchildren. The time is freely and intentionally “taken” from one’s personal time and used in a way that facilitates collaboration or social engagement, or creates a feeling of worth for the individual.

### **Decisional Origin**

Decisional origin refers to the time preceding the cancer diagnosis that is the basis for the emerging context of the treatment decision-making process. There are three origins. The first is unanticipated, where individuals enter treatment decision-making after receipt of an altogether unexpected or unanticipated HNC diagnosis. These patients are often the least prepared for the myriad treatment decisions and other life somatic considerations that must be balanced or altered as a result of their cancer. They also are frequently unable to correctly explain their diagnosis, prognosis, and or aspects of available treatments.

As illustrated in Chapter 6, Glenda seemed overwhelmed by the grief, fear, and sheer surprise of her diagnosis. Other patients expressed similar responses. “I just couldn’t believe it, I was absolutely dumbfounded. I’m sure I didn’t hear anything else,” commented a patient who also reported that he “went with the flow” and followed his doctor’s treatment advice because he “just couldn’t get past the diagnosis. Nothing made much sense.”

The second decisional origin, anticipated diagnosis, is found among patients who suspect or believe something is wrong prior to receiving their cancer diagnoses. In Vignette 1, Russ acknowledged that something was wrong and that medical care was warranted many months before seeing an ENT about the knot in his throat. Russ had a great deal more time than Glenda, for example, to ponder, cope, and adjust to the *idea* that something was wrong and would require care. Presumably, patients who believe something is wrong are also likely to believe that they will require treatment. Russ had gone so far as to begin “putting things in order,” and had been “paying more attention to health information and resources,” in anticipation of his new health status.

Patients with the third decisional origin, anticipated diagnosis, seek and obtain a diagnosis having already confirmed or perceived a significant health threat that would require medical intervention. In this situation, patients already believe they are sick, may have predicted a specific diagnosis, and have in many cases begun to assume a sick role and/or engage in specific health behaviors in response. Lou, the patient reflected in the third vignette, exemplifies this decisional set. Having been persistently and consistently immersed in his own health and substance abuse recovery, Lou seemed to have a high level of health literacy. He understood medical terminology, care plans, and the value of

healthy behavior. He also was well versed in the potential risks of long term substance abuse and other consequences of his lifestyle and activities. “It wasn’t any one thing in particular,” he explained. “I just knew something was off. I’ve seen a lot a people get sick, and I just thought ‘Hey, it’s my time.’ I’ve been a lucky SOB so far. Everybody’s afraid of the big C-word. It wasn’t so shocking.” Patients with this decisional origin generally have begun to investigate and assess possible treatment options or have given time and attention to accommodating a treatment strategy. Unlike Glenda, who unflinchingly went with her doctor’s advice and had very little time to prepare and think through the consequences of her treatment, Lou, who also went with his doctor’s advice, seemed to adapt and cope more easily. Whether or not this is a function of decisional origin or some other variable, like AA, remains unclear.

### **Reconciling Self: Blending the “Before” and “After” Cancer Self**

Throughout the cancer treatment experience, participants considered a vast array of factors including quality of life, occupation, social relationships, and cure. The sum of these smaller considerations is reflective of a larger “before cancer” sense of self or identity. In other words, study participants generally sought solutions that would minimize intrusion and interruption to their normal ways of life. In particular, those participants who reported feelings of despair, loss, and overwhelming uncertainty were also those who struggled to imagine their futures any differently. Over the course of her illness, Glenda remained intensely worried and pre-occupied with returning to work. She described her future much like her present. She had no future plans and revealed no future dreams or goals, other than to “get back to normal” and return to work.

Participants organized their lives around two distinct time periods: life before cancer and life after cancer. Life *before* cancer, as discussed above, is tied to a person's sense of who they are before formal confirmation of their cancer diagnosis and based on largely external roles and responsibilities. Likewise, treatment decisions were usually selected for their capacity to return patients to their normal lives efficiently and effectively. On the other hand, life *after* cancer can be understood as the manifestation of a new sense of self, even if the cancer or sick role remains present or threatening.

In this study, the crisis of a cancer diagnosis often invited a shift away from outward thinking and action, to forcing energy inward for the purposes of internal assessment and attention to self. The overall process may serve to shift goals and actions toward those that are emotional, spiritual, and/or mindful, thereby reducing the anxiety that unfolds from the immediacy of coping with cancer. While many patients experience physical somatic weakening, the mind, the spirit, and the self can grow, enabling forgiveness, acceptance, and joy. For example, one female participant conveyed how she had "purged" her home of clothing and other "meaningless icons of the past" while completing her treatment. She said that afterwards she had felt the acceptance and joy of being truly free for the first time in her life.

This is not to say that study participants were not concerned for their physical health or the functional limitations that treatment might impart. However, for some patients, inward reflection may be a means of self-development that supports external goals and buffers threats of loss. Participants reconciled a past and present sense of self in four primary ways: reconciliation, moral/self-inventory, reflection, and spirituality.

**Reconciliation.** The formal confirmation of a significant health threat requires a person to find a way to manage the new status or reconcile the difficulties and challenges that the condition imposes. A person can ignore the information and associated problems (denial); accept it and “move on” (acceptance); and/or attempt to assimilate it into their lives (integration). Decisional origin, discussed above, may influence how quickly, easily, and willingly a person begins to adjust and cope.

Those who deny their cancer ignore it, often desperately trying to escape the realities of the disease by minimizing its effects and attempting to maintain the status quo. Cecil, described in Vignette 4, had noticed a knot in his neck and ignored it for several months, hoping it would go away on its own. After he scheduled an appointment and learned of his cancer, he reported that he had tried to keep himself busy and not think about it. Another participant said, “I could feel that it was getting worse and starting to make it harder to eat. I just didn’t want to eat anything, so I made myself eat more. I ate all the time, just to prove I could.”

Others, like Glenda, are so overwhelmed that they retreat from life, huddling under the covers and wishing away their fears. But then, as one participant said, “It [cancer] is like the big monster in your bedroom. You feel it watching you. It rips the covers off and drags you kicking and screaming... and then you wake up.” Participants “wake up” to their cancer and *accept* that they will have to learn to live with the monster in the closet. They let go, and accept that they can only move forward, that their lives are no longer what they used to be, and that they themselves are changed. They integrate their diagnosis and its meaning into their lives, recreating a new normal or new life after cancer. Russ had traded in his retirement plans for a new RV and had found “new



appreciation for every day I've got above ground and with my family." Glenda came to accept her diagnosis, found a way to manage her fears about finances, her job, and her health, and eventually returned to work. The last time I spoke to her, she said

It is a sad day when you realize you gotta take all these pills to keep going. My God, how I hated that. You know it even hurts trying to swallow all those pills... Those pills are my friends now. They remind me every day that I am one of the lucky ones. They are my clock... I run my life by them.

I received card a few months later telling me that she had left her job for a new position. She was working for a health promotion program leading tobacco cessation courses and also volunteering for a bankruptcy support group. She had sold her trailer and moved in with a long-time friend who had recently lost her husband. "It's nice to be needed and wanted, and I can do something good for someone else," she said.

There is no doubt that the participants in this study experienced fear and grief at the time of diagnosis. Kubler-Ross (1969) studied the responses of terminally ill patients. She suggested five distinct phases or stages through which patients pass as they accept their own death. These stages include: (a) denial, (b) anger, (c) emotional feelings such as resentment and frustration, (d) bargaining and sadness, and finally, (e) acceptance and preparation for death. While most ( $n = 36$ ) participants clearly indicated that they had experienced some of these stages, it was not a universal experience. The most commonly identified stage was emotional feelings of resentment, frustration, and guilt ( $n = 30$ ), particularly around smoking or drinking habits. For example, one participant commented that she felt that it was her fault that she "got cancer" and she felt guilty for not having listened when her loved ones had tried to convince her to stop smoking. Another

participant said that he was frustrated at first because he felt that everyone else around him was “happy and healthy” and he had “always taken good care of myself.”

Few participants (n = 3) openly discussed or mentioned bargaining, or pleading for more time, although five participants talked about making promises to themselves or someone else if and when they recovered. “I just kept telling myself that if I made it though I would make myself a better person and apply myself more,” said one participant.

Another difference between the study population and Kubler Ross’ stages of grief is that some participants seemed to accept their fate and prepare for death without experiencing the other stages. I remember one participant who at the first interview looked me in the eye and calmly stated, “I’m going to die.” He described how he had suspected, or “had a feeling” that something was wrong despite not having any recognizable symptoms, several months before he was diagnosed. Three months before experiencing a tingling, numbing sensation in his face and neck, he had “put the house in order,” reviewed his will and provided instructions to his lawyer on how his death should be handled. Delays between symptom recognition and receipt of a diagnosis may have eclipsed the number of participants who were still in early stages at the time of the first interview.

Hope is a tool that can be used to integrate cancer into a patient’s life and self-image. In this study, as well as in AA and other 12-step programs, such as Narcotics Anonymous, and Co-AA, hope is a principle that allows a person to believe that a condition (i.e., alcoholism or cancer) is not more powerful and all-encompassing than a higher power. A higher power may be God, but may also be the self, or an intrinsic

power like the mind. Hope redistributes the focus away from disease and toward self, building personal agency and confidence in one's ability to reach an obtainable goal. Hope allows patients to believe and to maintain the motivation required to seek and pursue their goals. Having hope facilitates reconciliation and integration of self, because it requires that the person participate in finding creative ways to reach happiness, contentment, or satisfaction. One participant talked at length about the power of hope in overcoming cancer. He stated, "Hope is the only medicine. Without it, everything else is just a pat on the back. I have to hang on to hope, you know, open my heart to it, and then I can become grateful." Another participant, Glenda, whose story was presented in Vignette 2, explained that hope helped her to "focus on something else. Those bills were one part, the cancer, another, always wondering what was going to be next. But hope gets me past all that, to the bigger picture." During the second interview, Glenda remarked:

I hoped, and hoped, you know... I figured that since the moment I came into this world I had been breathing, one sweet breath after another. It is the only thing that we all have with us from the beginning to the end, so I kept hoping and being thankful for each and every breath – even when I couldn't breathe on my own, you know, on that machine. And hope got me through, breath by breath... because it is bigger than me. I realized that if I could do that one small thing, I could do another thing.

**Self-inventory.** Self-inventory is a deeply personal process of examining one's thoughts, ideas, values, goals, and actions. In this study, participants (n = 23) often carried out inventories while contemplating their death and how they would be remembered. To that end, participants often sought out old friends and foes and actively engaged in solidifying old relationships and creating new, meaningful relationships through making and taking time. Old grudges were forgiven and differences reconciled through forgiveness by making and taking time to explore the original problem and

“make things right.” Melvin was a 70-year-old retired truck driver who had a notorious reputation for making enemies. In fact, his wife explained that they had moved six different times because Melvin had disagreements with the neighbors. In addition, his relationships with family members including his brother and five children were tenuous at best. I met Melvin and his wife five days after he had been diagnosed with stage III laryngeal cancer. At that time, he had not shared his diagnosis and prognosis with his family. He told me that he didn’t need anyone’s sympathy and that he could take care of himself. Melvin had left his initial appointment with little hope for cure or remission. He said “My number came up. They tell you all those numbers. They might as well not waste my time and just tell me I’m gonna die.” When I saw Melvin again two months later, his prognosis was much the same. “I just take things a day at a time, cause, well, it might be the last,” he told me. His outlook on life, however, was much improved.

I took some time and tracked down a lot of people... old friends, lovers, people I hadn’t done good by. I needed to say I was sorry, to give them the freedom. I wanted them to know that it wasn’t them that was so bad or ugly.

Among the last people Melvin contacted to make amends were his children.

I did it because I wanted them to know I loved them and that I was sorry, that I was proud, that I was wrong. I never told them those things. I was afraid that they would not want me after all this time and all the pain I caused them. But they all did. I learned that I’m a good person that did bad things, and they all forgave me. Can you believe?

In another act of reconciliation, Melvin sold part of his pocket knife collection and sent a check for several hundred dollars to a family whose property he had vandalized many years before. One of his last acts of kindness was to donate money and his personal time (if he survived and was able) to a camp for special needs children. His granddaughter, whom he never met, had attended the camp in previous years before her

death, 8 months before. Melvin told me this in confidence, asking me to not tell his wife or daughter of his generous gift. He said it gave him a greater joy than he had ever known and that he learned that he was stronger than he thought and also a good person.

Self-inventory reinforces long held beliefs that participants internalize as part of who they are. On the other hand, it may also create an opportunity to gracefully abandon attitudes and behaviors that create or perpetuate barriers, anxiety, stress, or conflict. One of the female participants shared with me that she was very fearful of looking “ugly” after treatment. Evelyn was an attractive woman who had been diligent in maintaining her physical appearance. Her clothes, hair, nails, and makeup were impressive. In discussing her fears with me during our first interview, she told me that she never leaves the house without putting on her makeup. When I met her for our second interview, I was surprised at her appearance, not because of any physical deformations or changes, but because she looked like a different woman. Still dressed in nice clothes, her hair was short and the color had begun to grow out, leaving half her head white and the other brown. Her face, free of all but minimal makeup, glowed. Her long and graceful hands, once adorned with gold jewelry and nail polish, were now naked. I thought she was beautiful and told her so. She explained that after her surgery, she had become obsessed with her physical appearance, she shopped nearly every day but found nothing she liked. She explained that she had “felt more and more hideous, like an old dead plant that no one would throw out.” Then one day she had gone to meet a male friend and decided to wear one of her wigs; it was long and blond and had always made her feel sexy, smart, and powerful.

I remember walking into the restaurant, people stopped and stared at me and I thought, “Wow, I can still do this.” When Dan arrived he looked at me with this look of horror and instead of saying hello, he asked me, “What the hell is on your head?” That is when I realized that the wig had started to come off and had worked its way into a ball really. It was a mess. Dan was as vain as I was and, I guess, couldn’t bear to be seen with the likes of me. I went home and cried. I was so humiliated.

Evelyn spent the next few days cloistered in her home. She emptied her clothes, shoes, purses, furs, and makeup into the middle of her living room. She told me:

Looking at that giant heap, I realized that I had made a life I didn’t really want and the clothes and all that stuff had been my way of trying to control everything all the time. I wanted to be the center of attention as long as they didn’t get to close. I always wondered why I was alone and now it’s no big mystery. I’ve made some friends and I enjoy all the things I never noticed or made time for until now. It’s been good for me.

One of the great joys I had as the researcher in this study was listening to the stories that participants frequently shared. These stories extended beyond the interview content and spanned many decades of the person’s life. In some cases, participants told me during the second interview that they had “thought a lot” about the previous conversation or interview and then shared new information or revised what they had told me previously. The act of story-telling, particularly during times of crisis or personal trauma, is not uncommon. Gerontologist Robert Butler introduced the concept of “life review” in his seminal article first published in 1963. Butler saw the act of reminiscing as natural, universal, and potentially transforming (Butler, 1963). Looking back over time and examining one’s present from the perspective of the past frames the present self and instills personal integrity, purpose, and meaning. Having someone to share stories and reminisce with seemed to be important to many participants as they moved through their illnesses and came to understand themselves within the context of having cancer.

**Reflection.** While self-inventory is generally a retrospective and static assessment of one's self, reflection is a continuous "checking in" to monitor progress toward goals. Goals, in this regard, are "ways of being" that the patient has identified as positive, meaningful and useful in reconciling their before and after cancer self-image. Reflection keeps people on track toward "making better choices," "living a better life," and "feel[ing] better about things."

Cecil recognized early that there were certain things he wanted to do with whatever time he had left. He told me that he "made time" to get better by being more active through walking, going to church, learning about his medications and making sure he took them correctly. He did these things with intention, believing that they were intrinsically good and would be helpful to his recovery. He also made a list of things he wanted to do and kept a sort of notebook where he wrote down his goals and what things would have to happen to get him there. For example, Cecil and his family had not traveled much and he decided he wanted to drive across America and see as many states as he could. He educated himself about the different types of campers, trailers, and RV's and learned about campsites and fees. Cecil had told me that one reason he hadn't done this before was that he always felt afraid to spend the money. In preparing and planning for their first trip to a local state park, he had had to remind himself that it was okay to spend the money. He also recorded his feelings in his notebook and spent time thinking about why he felt so anxious about spending money for "non-necessary items." Lou also alluded to previous times in his life when he had engaged in self-inventory activities as part of his involvement in AA. As recovering addicts, both Lou and Cecil applied AA strategies to contemplate ideas, thoughts and feelings and to make decisions.

Reconciliation and self-inventory seem to lead up to a treatment decision. Participants struggle with cancer and self through setting up the context for future events, including treatment (reconciliation), and assessing their strengths, weakness, and goals (self-inventory). Reflection picks up where inventory stops, and assists patients in adjusting their lives and selves to the constantly evolving illness experience which includes treatment.

**Spirituality.** Spirituality grows out of hope and self-assessment, and grounds the sense of self internally, thus enabling patients to transcend their disease. For example, John, a gentleman in his early fifties, was devastated to learn of his diagnosis. He was very active and reported that he was very healthy and strong. During the course of his treatment, he participated in a cancer support group where he met others who openly shared their fears and triumphs. It was at one of these meetings where he met a soldier who had survived the loss of his leg only to be diagnosed with testicular cancer 3 years later. John admired the soldier because he was so “brave... confident and always humble,” characteristics that John came to believe he lacked in himself despite his physical strength and self-proclaimed success at hunting, fishing, and playing sports. The soldier offered to teach the support group members how to meditate and do guided imagery to help cope with their cancer. John agreed. During our second interview, John told me that he had first imagined himself as an eagle with a broken wing, unable to fly, belittled, vulnerable, and outraged. Eventually, after many months of imagery and meditation on the source of this initial image, John developed a new image of himself. It was a phoenix, the mythical bird that rises from the ashes to begin a new life. With this



image of himself, John explained to me that he had found the freedom to love life as it comes, to love himself and to be respectful of the “blessings of life.”

Everybody suffers something in their life, but I learned a lesson, and everybody can have joy and happiness. I think it was all worth it to find that. Suffering can bring us new life, at least for me it did.

Many participants in this study discussed aspects of spirituality that helped them to cope with their cancer and its treatment. Being mindful of one’s own strengths while also being humble was a particularly common spiritual component. Participants prayed, meditated, and “looked inside” of themselves, for answers and guidance and encouragement. Glenda had felt alone and that she could only depend upon herself. She reminded herself daily that she was strong and that she could survive. She said that she realized this after running into an old friend that she had not seen in several years. She had told her about her divorce, heart disease and surgery, and the cancer. Her friend had responded by telling her she was a warrior and the bravest woman she knew. “I tucked that away in my heart, nurtured it, and made it my rock,” she told me.

Another way in which participants nourished their spirituality was by “doing for others.” Like Melvin, people created opportunities to help others, such as taking time to be available to help a friend or family member; or volunteering time or resources to some cause. Of particular interest was the number of participants ( $n = 27$ ) who intentionally sought ways to interact and assist others with similar problems. Unlike with breast and colon cancer, there are very few HNC support groups, and even fewer for specific cancers such as laryngeal. Twelve participants shared their stories with other substance users at cessation programs or 12-step programs. Eight reported that they had found and offered help in online blogs and chat rooms specific to their type of cancer. “I just

wanted to share my story because when I got sick, I didn't know anything or anyone who had had it, and when I found someone it made me feel like I wasn't the only person with this," remarked one participant. Others attended grief and cancer related workshops or groups, contributing their own "gifts" of knowledge or service.

### **Summary**

The older adults who shared their stories for this dissertation relied greatly on past experience as a source of knowledge, support, and guidance. The consequences of cancer were negotiated through the iterative embodied learning of goals and preferences shaped by decades of daily living and the awareness of self over time. Both the old self and the treatment decision are diminished by the immediacy of many smaller daily trials that challenge coping and adaptation. Patients negotiate equilibrium of self and execute treatment decisions by shifting their focus inward and (re)defining a new "after cancer" self.

## Chapter 8. Discussion

The experience of cancer treatment among 41 individuals with HNC was explored in this qualitative study. The process of reconciling self, which includes the themes of reconciliation, hope, self-inventory, reflection, healing, and spirituality emerged among study participants. In addition, the importance of past life events as well as decisional origin were factors that influenced treatment decision making and shaped the cancer treatment experience (see Figure 6.1).

Findings from this qualitative study enhance the scope of research knowledge by providing insight into treatment experience among a distinct patient population and within the broader context of the person's life. This final chapter endeavors to provide a concise discussion of the study's findings, limitations, implications, and future directions.

Qualitative data from this study led to the development of a model that reflects the experience of cancer treatment among a mostly rural, older population of HNC patients. Rather than following a distinct set of stages to make a treatment decision, study participants exhibited a process of creating a "life after cancer" in which they negotiated and adapted to living as cancer patients and survivors. Certain demographic and socio-cultural patterns were found, including a high prevalence of blue-collar occupational roles, and life experiences that often included low personal agency and autonomy. These patterns are believed to influence personal thoughts, feelings, and emotions over the life course and influence the cancer experience.

The processes of reconciliation, hope, self-inventory, and reflection were used to help overcome obstacles and fears throughout the cancer treatment experience, and resemble means of coping with cancer as identified in previous studies. The role of

temporal frames, including past and present as well as empty time, making time and taking time, reflect the distinct ways in which participants organized time and perceived how time had been or will be used. These frames may be developed from the shared socio-cultural patterns that were specific to this population. In addition, identification and elaboration of these specific temporal aspects of the cancer treatment experience are novel contributions to the literature.

In regard to theory, SST suggests that the emotional goals and coping styles of older adults are linked to the erosion of future time perspective that accompanies advanced chronological age (Lockenhoff & Carstensen, 2004). As a result, older individuals are less future-oriented, create more emotionally-based goals, and have fewer, but more significant social relationships. While similar trends were confirmed within the study population, the data suggest that age is not the primary variable. In fact, the average age of study participants was relatively low (58), diminishing the possibility that perceived time left to live by virtue of chronological age was responsible for shifts in goals and action.

According to the SRM, there are five domains of illness representation: identity, timeline, consequences, control, and cause. Each domain is comprised of multiple variables originating from a complex, dynamic social system in which societal norms are continually evolving. Individual appraisals of disease experiences and social and cultural factors contribute to the illness representation (Cameron & Leventhal, 2003; Leventhal & Cameron, 1987; Leventhal et al., 1998). In this study, such a relationship appears to be present. Social and cultural factors related to common occupations, organizational affiliation, and perhaps rural health beliefs may have influenced the identified themes of

reconciliation, hope, self-inventory, and reflection. The evolution and importance of spirituality reflected in the study population may also be related to these factors.

Participants prayed and engaged in other spiritual and/or religious activities to cope with their conditions. Similar to other studies of cancer coping, study participants also coped by utilizing various forms of social support. Additionally, similarities to the literature in regard to positive personal growth were observed. For example, several participants (n = 9) identified positive aspects of treatment decision-making, such as realizing that they could have or maintain control over their life and that they had the power to overcome fears and treatment related consequences.

### **Study Limitations**

One of the most challenging aspects of executing this study was identifying and securing interviews with participants. I had originally anticipated that I would be able to identify and contact potential participants while they were at the ENT clinic. I quickly realized that the nature of the clinical setting often impaired communication and provided a variety of logistical barriers that frequently made simultaneous recruitment, enrolment and interviewing inappropriate. Specifically, the ENT clinic is not a large space, and exam rooms were often in high demand. This left little time to conduct a full interview, as rooms had to be cleaned and other patients were always waiting. Although I was a welcome guest in the ENT clinic, my presence sometimes took up space in the often-congested physician and nurse stations. As a result, I relied on frequent clinic check-ins rather than continuous occupation. I also used adjacent spaces outside of the ENT clinic to interview. I interviewed some patients within days of receiving their diagnoses, while others were interviewed minutes or hours later. I had also planned to conduct the second

interview after treatment had been completed. The timing of multiple patient appointments, treatment compliance, and patient health status sometimes required that the second interview be conducted while the patient was still in treatment (n = 5) or had prematurely ended or suspended treatment (n = 3). Two patients who were identified as potential participants were lost to follow up and thus not included in the study. It is unclear if these patients were somehow significantly different than those who were enrolled.

The study sample is not reflective of the larger HNC population. In particular, African Americans and individuals from higher education and income levels are underrepresented. While this considerably limits the generalizability of the findings, the unique homogeneity of the study population enabled examination and identification of previously unrecognized phenomena.

The similarities among study participants raise questions regarding the influence of certain factors such as co-morbidity, and life experiences on the cancer treatment experience and health behavior in general. For example, the majority of the sample lived in rural counties of Kentucky (n = 36), many of which are designated as Appalachian (n = 34). Poverty, health beliefs, and other socio-cultural factors also may have contributed to the perceptions and experiences that shaped the context of cancer help seeking and treatment decision-making. For example, participants sought medical help from non-traditional sources like the local veterinarian, and used non-traditional approaches to treatment including the use of homemade salves and tinctures. For some participants, these strategies may have helped to avoid or minimize the costs of medical treatment, but may have also been viewed as acceptable and efficacious treatment strategies.

Additionally, some patients may have delayed help seeking due to cancer beliefs and health behaviors that have been documented in Appalachia.

Another limitation of this study is that while the study sample was relatively large, the overwhelming majority of study data came from 16 participants who shared their present and past life experiences broadly and deeply. In contrast, the remaining 25 participants provided relatively short commentary. It should be noted that the timing and topic might have prevented some participants from engaging more fully in the interviews. To illustrate, one participant had been reluctant to enroll, but did so after his wife convinced him that it would be good for him. From my perspective he seemed upset following his appointment and sat very quietly in the waiting room while his wife checked him out. I enrolled him into the study and scheduled the interview later that week when he'd be on the medical campus for another appointment. At the interview, he rarely looked at me while he twirled his wedding ring around his finger. After the third question, he replied "I'm not sure I can help you. I don't have anything to tell you... I'm still figuring things out you, know. I'm sorry." During the second interview his mood seemed to be better. Although he seemed genuinely interested in the interview, his answers were still short and vague. For example, when I asked him about how he made his treatment decision, he shrugged, chuckled and said, "I mean,... you know, well, I prayed about it a lot."

The coding of study data relied, to some degree, upon my subjective interpretation of the data. The use of NVivo or other qualitative data analysis software may have reduced the potential for subjectivity and or bias in the study outcomes.

## **Implications and Future Directions**

Cancer treatment is a complex, deeply personal process. Modern medical technology and science have elevated the skill and technique of medical providers as well as the possible treatment options for a wide range of conditions and diseases. Our ever-growing ability to prevent, identify and treat disease has increased the complexity of cancer experience in many ways. Negotiating cancer requires decisions with both short- and long-term consequences, sometimes spanning many years of life left to live. Implications for daily living, functional ability and disability, mental health, and personal resources are contemplated against aspects of treatment such as pharmacological maintenance, prognosis, side effects, coordination of medical provider teams, insurance and medical regulations, and judgment of quality and quantity of life.

The majority of participants in this study experienced treatment decision-making as negative or neutral. Of those who had neutral experiences, many had little time to contemplate a choice, or felt that the only choice was to undergo the treatment recommended by their physicians. The degree to which physicians and other providers are able to personalize treatment choices and provide meaningful information, particularly when working with abbreviated timelines, is one area for future research.

Patient and provider communication is another area of research. Participants reported that they often had questions but did not know whom to ask or where to obtain the information. In some cases, the information that was provided was unclear or confusing. This may be further complicated by the age, mental health status, and or level of health literacy of the patient. Further research with a more diverse and older population is recommended in order to facilitate our understanding of the older cancer



patient's perspective, values and goals related to the decisions they make and their experience of the cancer.

The number of participants who lacked understanding and knowledge regarding HNC as a disease and its relationship to tobacco and alcohol strongly suggests that patients could benefit from health education and health promotion. Few participants reported that they were aware of their risk, and even fewer had been screened for oral cancer as well as other types of cancer. The high rate of comorbidity within the population may provide an opportunity for earlier intervention and health education as they seek and obtain care for other health conditions. Additionally, many participants had sought help for substance abuse cessation in the past. These services could be used as an opportunity to educate people who are at a great risk for cancer of the head and neck. As much as 68.9% of the study population reported that they were surprised to learn they had cancer and most had not recognized early symptoms as threatening which may lead to delayed diagnosis and poor prognosis. This finding reinforces the need to provide health education that is specific to this family of cancers.

Early recognition and help seeking could reduce the severity of disease and thereby extend the range of treatment options while potentially minimizing negative or less favorable treatment outcomes. HNC patients often delay help seeking, sometimes waiting until symptoms interfere with daily functioning. These characteristics are salient to goal setting and treatment, in that HNC patients may perceive the value of treatment options from a functional, rather than curative perspective. A patient, for example, may opt for a less aggressive treatment based on the goal of being able to preserve voice function over prolonging life without voice. The recommendation of more in-depth and

focused assessment of patient goals and perspectives throughout the cancer experience enables less stressful and more satisfying patient decision making and strengthens the ability of the provider to work collaboratively to support the patient.

Patients often discussed wanting to go home to “let their cancer take its course” amid the comfortable and familiar environment of family and friends. Many patients, who felt that the distinctive and considerable social, emotional, physical, and economic consequences of medical treatment would significantly diminish their ability to enjoy an attenuated post-treatment life preferred this option. Participants expressed a wish to die in the comfort of home, where they had many attachments and a strong sense of belonging. Second, patients felt unable to discuss “no treatment” as an appropriate option with their medical providers. Likewise, those patients who did discuss it, or simply elected not to engage in medical treatment, reported that they felt unsupported by their physicians and less empowered to make personal health decisions. From a clinical perspective, recognizing and acknowledging “doing nothing” as a treatment choice may enable the patient-provider relationship by facilitating open communication, rapport, and trust.

Finally, it should be noted that many patients continue substance use after diagnosis and throughout treatment. In this study, a number of patients indicated that they were smokers or drinkers and that their addictions would be or had been a factor in their treatment experience. Services for cancer patients, particularly those with HNC, should include a formal means of identifying, addressing and supporting patients with co-occurring addictions to tobacco, alcohol, and/or other substances. This is particularly important for rural patients who often do not have access to such services. The significant lack of such programs in rural areas undermines clinical management of disease and fails

to support patients through the treatment experience. HNC patients frequently present with late stage disease and demonstrate a history of tobacco and alcohol use, substance addiction, and mental health problems such as depression that may negatively impact treatment compliance and efficacy. The development and implementation of clinically based cessation and addiction services would provide an immense opportunity for the management of addiction-related health problems. Furthermore, such clinical programs may provide much needed counseling and social support networks to support patients and their families in their recovery.

### **Conclusion**

Forty one men and women were recruited from the Ear Nose and Throat Clinic at the University of Kentucky, in Lexington KY. They each participated in two personal interviews. After coding the interview transcripts, rich insights about the treatment experience of head and neck cancer patients emerged. In sum, the study population was largely rural, underinsured, and of low educational and socioeconomic status. In addition, many patients had long-term histories of tobacco use and or other substances such as alcohol as well as associated medical conditions. Although many patients had smoking related diseases as well as other comorbidities, few had been screened for oral cancers and many did not know of their risk for HNC. Often patients waited for long periods of time to seek medical care, after discovering an abnormality due to fear, lack of resources, or because they perceived it to be of low risk. Overall treatment experience seemed to be linked to the patient's perception of their condition immediately before diagnosis. For example, patients perceived or suspected something was wrong (suspected); were completely unaware that a problem existed (unanticipated); or believed

that they had a serious medical condition like cancer (sick role/emergent). Patients that had suspected or believed they had a problem prior to diagnosis often reported more positive or neutral initial responses to treatment than those who had not known anything was wrong.

The third aim sought to develop a model of HNC treatment experience, thus reflecting the broad, lived journey of HNC patients. Elements of the model include the various strategies that patients used to cope with and navigate through their cancer to recovery, or a life after cancer. Participants employed one or more strategy and sometimes repeated or continuously engaged in various strategies. Reconciliation is the act of reconciling past actions or events. For example, seeking out someone from the past and apologizing, repaying an old debt, or doing something in attempt to relieve regret. Hope and or hoping were a strategy that aided participants in integrating cancer into their life. Through hope, a person can focus on something other than the cancer, thereby reducing fears, alleviating feelings of anxiety and hopelessness, and immerse themselves in creative pursuits toward being happy, content, and or satisfied with life. Another tool that was used to alleviate fear and also to cope with death and dying was self-inventory. This process brings to the focus thoughts, feelings, beliefs, goals, and attitudes that the person has experienced in the past and present. Identifying one's strengths and weaknesses often led to or paralleled reconciliation. Similarly, some participants also engaged in personal reflection. They intentionally thought about their present thoughts and emotions and attempted to find "triggers" that helped them feel safe and or happy and to avoid negative feelings. The last strategy, identified in the data and reflected in the model is spirituality. Often growing out of hope and self-assessment,

participants often described spiritual growth or the expanding ability to establish a strong sense of self, external to their clinical disease and its treatment. For some, spirituality meant doing for others, or leaving a legacy for future generations, that transcended material items. The role of temporal frames, including past and present as well as empty time, making time and taking time, are also included in the model. These temporal aspects of the experience reflect the distinct ways in which participants organized time and perceived how time had been or will be used.

The second aim of this study was to explore how elements of time and age influence coping and the cancer treatment experience. Within this study, patients exhibited significant decreases in their perception of future time, between interview 1 and 2, regardless of prognosis or satisfaction with treatment. One aspect that did seem to be significant, but requires further investigation, is the role of twelve step programs like Alcoholics Anonymous and patient perceptions of time. How is AA culture and philosophy used or applied to health problems other than addiction? Do aspects of AA, like performing self-inventory and reconciling past actions, bleed into other areas of life? Do long term twelve step participants have better coping skills and or differences in future time perspective, when compared to non-twelve step populations? Answering these questions and others like them, have the potential to enhance understanding and treatment for patients aging with life threatening disease and comorbid addiction.

Finally, the last aim sought to propose strategies or tools that could be applied by health providers and patients to improve the cancer treatment experience, and related outcomes. Participants in this study evaluated treatment choices and cancer care in regard to ability to maintain preservation of self and to find ways to integrate old and new

self-images. As such, the type of information presented to HNC patients should be helpful in identifying not only biomedical aspects of treatment, but also the influence on aspects of normal daily living. Treatment options should include curative and non-curative approaches and focus on positive aspects of care and treatment. Additionally, patient preferences and goals around quality of life rather than quantity of life should be acknowledged.

My dissertation journey began with meeting Ben, the Alaskan native with oral cancer. I wanted to understand how he and patients like him, made decisions about their care and to explore and document the emotional, psychological, and physical aspects of the cancer treatment experience. Although my journey changed course more than once, I have learned above all else, that for those living with head and neck cancer, the disease invades not only the body, but lives; the daily activity and meaning of life. While cancer treatment remains largely corporal, patients in this study demonstrate that treatment is experienced and navigated through many personal domains and that specific strategies are employed to “get to the other side of cancer.” Understanding salient aspects of the cancer treatment experience, both clinically and otherwise, builds the bridge between medical treatment and patient care. The clinical diagnosis, while omnipresent and paramount for clinicians, may fade for patients and their families who face their disease in the midst of competing demands and advancing age, all within the context of past life experience and perceptions of future time.

## **Appendix A: Abbreviations/Acronyms**

### **Abbreviations/Acronyms**

HNC: Head and neck cancer

HNSCC: Head and neck squamous carcinoma

SCC: Squamous cell carcinoma

QOL: quality of life

EGFR: Epidermal growth factor receptor

CAT: Computer Axial Tomography

MRI: Magnetic resonance imaging

NDM: Naturalistic decision making

SST: Socio-emotional selectivity theory

SRM: Self-Regulatory Model

SCT: Social Cognitive Theory

ENT: Ear Nose and Throat

UK: University of Kentucky

FTP: Future Time Perspective

DCPS: Degner's Control Preference Scale

UW-BQOL: University of Washington Brief Quality of Life scale

GT: Grounded theory

COPD: Chronic obstructive pulmonary disease

TDM: Treatment Decision Making

## Appendix B: Interview Guide 1

*Interviewer: I'd like to start off today by talking to you about some general information about your present condition and your health. Please feel free to share as much as you would like.*

**Start Time:** \_\_\_\_\_

### Overall Health Questions:

1. How would you describe your health over the first half of your life?
2. How has your overall health been during the most recent few years of your life?
3. Thinking back over your life, what things have you done that may have contributed to your current overall health?

*Prompts: work environment, tobacco, exercise, diet, financial resources, and access?*

4. Do you have regular (yearly) cancer screenings? elaborate
5. Have you ever been screened for oral cancer? elaborate
6. Do you have regular (yearly) dental exams? elaborate

### Head and Neck Cancer-Specific Questions:

#### Illness Representation

1. Tell me about coming here today? What about your health made you seek medical care here at the ear, nose and throat clinic?  
*Prompts: were you having symptoms? What were they?*
2. Have your symptoms caused you any problems, maybe at work, with your friends or family, or getting things done?
3. About how long ago did you first notice that something may be wrong?
4. How did you first discover that something was wrong?  
*Prompts: self-exam, changes over time, medical exam...*



5. What did you think was going on?
6. Did you do anything at that time to try to make it better?  
*Prompts: seek information, talk to others, self-medicate, change any behaviors (smoke), seek medical care.*
7. Did you talk to anyone at that time, or in the time between then and now, about the problem? Who?
8. About how long would you say it took from the time you first noticed a problem to when you saw a medical provider for the problem?
9. Was there anything that made it hard to get the doctor?
10. Looking back to the time between when you first noticed the problem and now, would you have done anything differently? Is there anything you wish would have been different for you?
11. What do you think you could have done to prevent this from happening?
12. How surprised are you that you've developed this condition? Are there other things that you expected to get? Why?
13. If someone asked you a month ago, or before you had your diagnosis, what head and neck cancer was, what would you have told them?

### **Perceptions of Current Health**

1. Overall, how healthy do you think you are?
2. In your opinion, what is the most worrisome part of having your condition?  
*Prompt: do you worry about cure, disfigurement, loss of function*
3. What things scare you or do you worry about, regarding your condition?
4. What do you hope or want the doctors to be able to do to help you?

### **Planning and Time Orientation Questions:**

*Interviewer: I'm interested in how you have thought about your future over your lifetime. For the next few questions, I'd like you to think back over your life.*

1. Thinking back several years, before you had this illness, how did you think about your future?
2. Are there things that are important to you, that you are afraid you might not be able to do now, because of your condition? elaborate
3. What plans for your future have you changed because of your illness?
4. What are the most important things to you in considering treatment for your condition?
5. People often have different needs for information and resources to help them make decisions about their care. At this time, what things do you think would help you make a decision about treating your condition?
6. When you were younger, (for example, when you were 25) how long did you expect to live?  
*For example, some people only expect to live to be in their 60's while others may plan to live to be 100.*
7. Has this changed? Why?
8. If someone you know develops a condition like yours in the future, what advice would you give them?

**Emotional Regulation and Coping:**

1. Is there anything you do or have done to try to cope with the symptoms of your condition? Need for a prompt to allow the participant to tell you what they did to cope with symptoms.

**Conclusion:**

*Is there anything that we haven't already talked about, that you'd like to add, or anything you'd like to clarify?*

*O.K. We are almost done for today. I just have a few more short questions that ask about time, your preference for making decisions and then a brief socio-demographic questionnaire. I'm going to read you 10 questions. Using this card (hand out card with answer options) please tell me which number best indicates your agreement with the statement.*

### Future Time Perspective Scale

1. Many opportunities await me in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

2. I expect that I will set many new goals in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

3. My future is filled with possibilities.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

4. Most of my life lies ahead of me.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

5. My future seems infinite to me.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

6. I could do anything I want in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

7. There is plenty of time left in my life to make new plans.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

8. I have the sense that time is running out.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

9. There are only limited possibilities in my future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

10. As I get older, I begin to experience time as limited.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

Hand out list of 5 statements from Degner's Control Preference Scale

Please review each statement and tell me which one statement best describes your preferred approach to making a decision about your treatment.

### Degner's Control Preference Scale

<i>I prefer to:</i>	<b>Check one</b>
<i>Make the final selection about which treatment I will receive</i>	
<i>Make the final selection after seriously considering my doctor's opinion</i>	
<i>Have my doctor and I share responsibility for deciding what treatment is best</i>	
<i>Have my doctor make the final decision but consider my opinion</i>	
<i>Leave all decisions regarding treatment to my doctor</i>	

Finally, I'd like to ask you about basic information about yourself.

### Sociodemographic Questionnaire

1. Would you say that your health in general is excellent, very good, good, fair, or poor?
  - a. Excellent
  - b. Very Good
  - c. Good
  - d. Fair
  - e. Poor
  - f. Don't Know
  
2. What is your current marital status?
  - a. Married/Partnered
  - b. Separated
  - c. Divorced
  - d. Windowed
  - e. Never Married
  - f. Other (please specify)\_\_\_\_\_
  
3. How many children have you ever had or adopted? \_\_\_\_\_
  
4. How many people, including yourself, live in your household? \_\_\_\_\_

5. What is the highest grade or year of school you completed?

**Grades of School**

**College**

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 graduate school

6. How would you describe your current financial status?

I have more than I need to live well

I have just about enough to get by

I sometimes struggle to make ends meet

7. What type of health insurance do you currently have? Check all that apply

Private Insurance     Company Sponsored Insurance     Medicare

Medicaid     None     Other (Please specify) \_\_\_\_\_

8. When is your birth date? Day:                  Month:                  Year:

9. What county do you live in? \_\_\_\_\_

10. How would you describe your race/ethnicity?

a. White

b. Black

c. Latino

d. American Indian

e. Asian

f. Other (specify): \_\_\_\_\_

*I look forward to meeting with you again. When we meet again, I'll be asking you about how you made your treatment choice.*

*Thank You*

**End Time:** \_\_\_\_\_

**Interviewer Observations:**

1. Respondent Sex:            M.    F

2. Were others present during the interview?

3. Did the presence of others influence the respondent's answers?

          A lot            some            very little            not at all            NA

4. Respondent's interest in the interview was:

5. Any problems with comprehension of questions:

6. Location of interview:

Notes:

## Appendix C: Interview Guide 2

*Interviewer: Thank you for meeting with me again. Today I'd like to talk with you about your health and your treatment, since we last met.*

**Start Time:** \_\_\_\_\_

1. We last met on \_\_\_\_\_ . How have things been going for you since then?
2. Have you started treatment yet? When?

### Decision-making

3. I'd like to ask you about making your decision. What was that experience like?
4. Can you tell me how you made your decision about your treatment? What options were you considering? Elaborate.
5. How did you first find out about these options?  
*Prompt: doctor, found information on their own...*
6. So what treatment did you decide on?
7. Can you tell me more about the treatment, what does/did it involve?
8. What about this treatment, appealed to you over the others?
9. Before you started the treatment, what did you expect or hope the outcome to be?
10. Did you have to change your treatment at any time?
11. Did your doctors and family support or agree with your decision?
12. How much time did you take to make your decision? Would you say....  
a. Hours      b. Days      c. Weeks      d. Month      e. More than a month
13. Who did you talk to about your decision? What did you talk about?



**Information and Resources:**

14. Did you use any other information or resources in making your decision? What were they?
15. Did you feel like your physician supported your decision? What role did your physician play in making your decision?
16. What were the most important factors in making your decision?
17. Can you tell me more about why \_\_\_\_\_? \_\_\_\_\_(from above) was so important to you?
18. What was the most difficult part about making your decision?
19. Is there anything you or anyone else could have done to help you make your decision?

**Time Perspective:**

20. Now that you've gone through (or begun) treatment, do you see your future differently? Are there things that you plan to do now that you didn't plan on doing before?
21. In contrast, do you think there are things that you had planned to do before you developed your condition that you don't think you can do now?
22. Looking back to the time between when you first noticed the problem and now, would you have done anything differently? Is there anything you wish would have been different for you?
23. If someone you know develops a condition like yours in the future, what advice would you give them? \*

**Emotional Regulation and Coping**

24. How have you been dealing with your condition emotionally?\*
25. Is there anything you do or have done to try to cope with the symptoms of your condition? \*

**Treatment Experience:**

25. What about your treatment experience did you not expect or feel prepared for?

**Conclusion:**

26. O.K. We are almost done with the interview. Is there anything at all that you've thought about, that we haven't already discussed, that you'd like to tell me?

*If there's nothing more you'd like to add, I just have a few more short questions.*

*I'm going to read you 10 questions. Using this card (hand out card with answer options) please tell me which number best indicates your agreement with the statement.*

**Future Time Perspective Scale**

1. Many opportunities await me in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

2. I expect that I will set many new goals in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

3. My future is filled with possibilities.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

4. Most of my life lies ahead of me.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

5. My future seems infinite to me.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

6. I could do anything I want in the future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

7. There is plenty of time left in my life to make new plans.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

8. I have the sense that time is running out.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

9. There are only limited possibilities in my future.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

10. As I get older, I begin to experience time as limited.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

*If you had to make a decision about a medical treatment in the future, which one statement best describes the approach you would most prefer. (Hand them the card for Degner's Control Preference Scale).*

**Degner's Control Preference Scale**

<i>I prefer to:</i>	<b>Check one</b>
<i>1. Make the final selection about which treatment I will receive</i>	
<i>2. Make the final selection after seriously considering my doctor's opinion</i>	
<i>3. Have my doctor and I share responsibility for deciding what treatment is best</i>	
<i>4. Have my doctor make the final decision but consider my opinion</i>	
<i>5. Leave all decisions regarding treatment to my doctor</i>	

## University of Washington Quality of Life Questionnaire (UW-QOL)

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This questionnaire asks about your health and quality of life **over the past seven days**. Please answer all of 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 I 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, mostly 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 solids.

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 foods 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.

11. **Mood.** (Check one box:  )

- My mood is excellent and unaffected by my cancer.
- My mood is generally good and only occasionally affected by my cancer.
- I am neither in a good mood nor depressed about my cancer.
- I am somewhat depressed about my cancer.
- I am extremely depressed about my cancer.

12. **Anxiety.** (Check one box:  )

- I am not anxious about my cancer.
- I am a little anxious about my cancer.
- I am anxious about my cancer.
- I am very anxious about my cancer.

---

Which issues have been the most important to you during the past 7 days?

**Check  up to 3 boxes.**

- |                                     |                                     |                                  |
|-------------------------------------|-------------------------------------|----------------------------------|
| <input type="checkbox"/> Pain       | <input type="checkbox"/> Swallowing | <input type="checkbox"/> Taste   |
| <input type="checkbox"/> Appearance | <input type="checkbox"/> Chewing    | <input type="checkbox"/> Saliva  |
| <input type="checkbox"/> Activity   | <input type="checkbox"/> Speech     | <input type="checkbox"/> Mood    |
| <input type="checkbox"/> Recreation | <input type="checkbox"/> Shoulder   | <input type="checkbox"/> Anxiety |

### 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** during the past 7 days has been: (check one box:  )

- 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
- 

Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions (you may attach additional sheets if needed).

*Thank you.*

**End Time:** \_\_\_\_\_

**Interviewer Observations:**

Were others present during the interview?

Did the presence of others influence the respondent's answers?

Respondent's interest in the interview was:

Any problems with comprehension of questions:

Location of interview:

Notes:



## **Appendix D: Informed Consent Form**

### Consent to Participate in a Research Study

#### **WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?**

You are being invited to take part in a research study about treatment decision making. You are being invited to take part in this research study because you have recently sought medical treatment for a type of head and neck cancer. If you volunteer to take part in this study, you will be one of about 50 people to do so.

#### **WHO IS DOING THE STUDY?**

The person in charge of this study is Heather Wallace, of University of Kentucky, Department of Gerontology. She is being guided in this research by Graham Rowles. There may be other people on the research team assisting at different times during the study.

#### **WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this study is to learn about how people with head and neck cancers make decisions about their treatment. This study is intended to identify reasons why people select different treatments. This information can help health professionals design decision aids and patient information that can help head and neck cancer patients in the future, to make satisfying and knowledgeable treatment decisions.

By doing this study, we hope to learn what things, like treatment information or personal issues are most important to patients in making their decisions about treatment.

#### **ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?**

Participation in this study is voluntary and you should not participate in this study if you are under the age of 18 or if you are not interested in participating.

#### **WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?**

The research procedures will be conducted at the *UK Medical Center*. You will need to come to the Ear, Nose and Throat Clinic located on the 3<sup>rd</sup> floor of the Medical Center. This is the same location where you have your clinic visits. Each interview will take approximately 60-90 minutes and can be completed while at your clinic visit. The total amount of time you will be asked to volunteer for this study is 180 minutes over the next 3 to 6 months.

#### **WHAT WILL YOU BE ASKED TO DO?**

Your participation in this study will consist of participation in two in depth interviews about your experience with head and neck cancer and your treatment decision. The interviews will be scheduled to correspond with your regular Ear, Nose, and Throat, clinic visits or at another time that is convenient for you. If you are unable to have an

interview while at your clinic visit, you may complete the interview over the telephone. During the first interview, you will be asked about your thoughts and opinions about head and neck cancer, and questions about yourself like your age, education, your health, and perceptions of time. During the second interview, you will be asked about the decision you made about treatment, including how you made a decision, your expectations about treatment, and perception about your future.

**WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

To the best of our knowledge, your participation in this study does not involve any serious risk of harm to you. Your participation in this research does not involve any known risks to your physical health. There is a small possibility that you may feel some mild discomfort answering some of the study questions as some of the questions will ask you to think about your past, your future, and your experience with head and neck cancer. You can choose not to answer any questions in the interview and you can also choose to stop participating in the interview completely at any time simply by informing the interviewer that you no longer wish to participate.

**WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?**

There is no guarantee that you will get any benefit from taking part in this study. Your willingness to take part, however, may, in the future, help health care professionals better understand treatment decision making among others who have your condition.

**DO YOU HAVE TO TAKE PART IN THE STUDY?**

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide not to take part in this study, your decision will have no effect on the quality of medical care you receive.

**IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?**

If you do not want to be in the study, there are no other choices except not to take part in the study.

**WHAT WILL IT COST YOU TO PARTICIPATE?**

There are no costs to you to participate in this study.

**WHO WILL SEE THE INFORMATION THAT YOU GIVE?**

We will keep private all research records that identify you to the extent allowed by law. Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.

**CAN YOUR TAKING PART IN THE STUDY END EARLY?**

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

**WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?**

In recognition of the value of your time, you will receive \$30.00 for each interview.

**WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?**

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Heather Wallace, at 859-277-9915. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428. We will give you a signed copy of this consent form to take with you.

**WHAT IF NEW INFORMATION IS LEARNED DURING THE STUDY THAT MIGHT AFFECT MY DECISION TO PARTICIPATE?**

If the researcher learns of new information in regards to this study, and it might change your willingness to stay in this study, the information will be provided to you. You may be asked to sign a new informed consent form if the information is provided to you after you have joined the study.

\_\_\_\_\_  
Signature of person agreeing to take part in the study

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of person agreeing to take part in the study

\_\_\_\_\_  
Name of [authorized] person obtaining informed consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

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## Vita

**Born:** January 6, 1978, Indianapolis Indiana

### EDUCATION

- 2004 - 2012            University of Kentucky, Lexington  
  PhD, Gerontology
- 1996 - 2000            Indiana University-Purdue University, Indianapolis  
  B.A., Sociology with High Distinction/Honors  
  Minor: Anthropology

### PROFESSIONAL POSITIONS HELD

- 2012 - Present            Assistant Professor of Nursing, Grand Valley State University,  
  Grand Rapids, MI.
- 2011- 2012            Visiting Assistant Professor of Nursing, Grand Valley State  
  University, Grand Rapids, MI.
- 2009 - 2011            Assistant Professor of Public Health, University of Lethbridge,  
  Lethbridge Alberta CA.
- 2009 - 2011            President Elect, Alberta Public Health Association. Alberta,  
  Canada
- 2006 - 2010            National Institute of Health, Rural Cancer Control and Prevention  
  Pre-Doctoral Trainee and Fellow. Advisors: Dr. Mark Dignan and  
  Dr. Nancy Schoenberg, University of Kentucky.
- 2006 - 2007            Healthscape. Personal Health Coach, Health Educator. Lexington,  
  KY.
- 2005 - 2006            Registrat. Clinical Research Associate/Computer Assisted  
  Telephone Interviewing Call Center Supervisor. Lexington, KY.
- 2004 - 2006            Kentucky Aging Research and Information Service (KARIS),  
  Research Challenge Fellow. University of Kentucky, Lexington.
- 2002 - 2004            Eli Lilly & Co., Global Clinical Data Management, Clinical Data  
  Management Coordinator (CDMC), Neuroscience Therapeutic  
  Area, Zyprexa Global Clinical Phase III Studies. Indianapolis, IN.
- 2002                    Volt Technical Services, Assignment: Eli Lilly & Co., Global  
  Clinical Data Management, Clinical Data Management  
  Coordinator, Neuroscience Program Phase I-II studies.  
  Indianapolis, IN.
- 2001 - 2002            Richard L Roudebush Veterans Medical Center, HBPC National  
  Program of Excellence, Research Health Science Specialist, Rural  
  tele-medicine and homecare program. Indianapolis, IN.
- 1998 - 1999            Saint Vincent Hospital, Transitional Care Unit, Team Care  
  Specialist, CNA. Indianapolis, IN.
- 1996 - 1998            Saint Vincent New Hope, Home Health Aid. Indianapolis, IN.

## **PROFESSIONAL PUBLICATIONS**

Renter, H.M. (2011). Perspectives on the Intersection of Cancer and Older Age.  
*Gerontologist*, 51(1), 135-137.

Wallace, H.M. (2010). Rural Head and Neck Cancer Patients: New Clinical Perspectives.  
*Canadian Journal of Nursing Research* 42(1).

## **SCHOLASTIC AND PROFESSIONAL HONORS**

2010	Creating Age Inclusive Communities: Community and Social Development for the City of Lethbridge. . \$15,000.00
2007	Behavioral Sciences Pilot Grant Awardee, Title of Project: Determinants of Head and Neck Cancer Decision Making among Rural Appalachian Patients. \$1,448.00
2005	National Cancer Institute, Rural Cancer Control and Prevention Training Award Scholarship
2003	Outstanding Achiever Award: Eli Lilly & Co.
2003	Certificate of Excellence: Eli Lilly & Co.
2002	Outstanding Achiever Award: Eli Lilly and Company
April 2002	Margaret Epp Weber Provider of Choice Award: Department of Veterans Affairs
Fall 2000	IUPUI School of Liberal Arts Award for Outstanding Service
Fall 2000	IUPUI: Outstanding Female Student Leader Nominee

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