Curriculum Vitae

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Education

University of Maryland School of Nursing, Baltimore MD. Doctoral Candidate

University of North Carolina Chapel Hill, North Carolina. Certification in Qualitative Research. July 2008.

University of Pennsylvania School of Nursing, Philadelphia PA. Master of Science in Nursing. August 2003.

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Employment

Teaching Assistant, University of Maryland School of Nursing. August 2005 to December 2005.

Teaching Assistant. University of Pennsylvania School of Nursing. September 2003- December 2003.

Staff Nurse, Oncology Home Care. Newark, DE. March 2001 to September 2001.

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Clinical Experience

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Lectures, Presentations and Publications

Edmonds, M., & McGuire, D.B. (2012). Managing change: The process of caregiving for informal caregivers of head and neck cancer (HNC). Supportive Care in Cancer, 20 (Suppl 1), S267.

Informal Caregivers of Head and Neck Cancer Patients: A Grounded Theory Study. Poster presentation. Oncology Nursing Society 36th Annual Congress. April 2011. Boston, MA.

Edmonds, MF & McGuire, DB (2011). Informal caregivers of head and neck cancer patients. Oncology Nursing Forum 38(2). E174-E175.

Family Caregivers of Head and Neck Cancer Patients: What we know and where we are going. Presented at the GBMC and The Milton J. Dance, Jr. Head & Neck Center's 13th Annual Conference on Head and Neck Rehabilitation: Multidisciplinary Care Friday, October 22, 2010.

Edmonds, M. & McGuire, D. (2007). Treatment adherence in head and neck cancer patients undergoing radiation therapy: challenges for nurses. Journal of Radiology Nursing (26) 3. 87-92.

Patients' perceptions of the importance of treatment adherence in head and neck cancer. Poster presentation. Oncology Nursing Society 9th National Conference on Cancer Nursing Research. Hollywood, CA. February 2007.

Data Collection Techniques and Analysis of Existing Data. University of Maryland School of Nursing. Fall, 2005.

The Evolution of Cancer Care. University of Pennsylvania School of Nursing. Fall, 2004.

A Survey of Stress in Doctoral Students. 2nd Annual Poster Mock Session, Doctoral Student Organization and Pi Chapter of Sigma Theta Tau, University of Maryland School of Nursing. April 14, 2004.

Oral Complication of Cancer Therapies: Oral Mucositis. University of Pennsylvania School of Nursing, Spring 2004, Spring 2006.

Nutritional Challenges and Oral complications Related to Cancer Treatment. University of Pennsylvania School of Nursing. Spring, 2004.

The History of Cancer Care. University of Pennsylvania School of Nursing. Spring 2004

Professional and Academic Memberships and Honors

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Abstract

Managing Change: The Process of Caregiving for Informal Caregivers of Head and Neck Cancer Patients

Maura Fulham Edmonds, Doctor of Philosophy, 2013

Dissertation Directed by: Dr. Deborah B. McGuire, Professor, University of Maryland School of Nursing

Purpose: The goal of this study was to gain a better understanding of the process undertaken by the informal caregivers of head and neck cancer (HNC), with an eye toward theory development. Although the development of a theory was beyond the scope of this project, it was meant to be a first step toward understanding the important categories and concepts that are part of this process.

Methods: This study used grounded theory methods and was conducted at a large urban National Cancer Institute (NCI)-designated cancer center in the Mid-Atlantic region of the US. Constant comparative analysis and theoretical sampling were used to gather and analyze data from six caregivers of HNC patients. Audio-recorded and transcribed, de-identified raw data were analyzed using Atlas ti Software™.

Results: The caregiving process was described in terms that yielded a core category and two other categories. Subcategories were identified as well as dimensions of some of the subcategories. The core category was entitled Managing Change and the two other categories were entitled Types of Change and Strategies for Managing Change. Types of Change encompassed the subcategories of Changes in Life Patterns, Witnessing Physical Changes, Relationship Changes, and Increased Uncertainty. Strategies for Managing Change included the subcategories of Controlling Life Pattern Changes, Utilizing the

Quality of the Relationship, and Managing Stress. Key findings included the identification of many different types of change, variation in types and amounts of change over time, utilization of quality of the relationship between patient and caregiver as an important strategy for caregivers, and caregivers' use of a variety of strategies to manage change.

Conclusions: This study has attempted to broaden the understanding of the role of a caregiver of a patient with HNC using grounded theory methods. This work is the first step in developing a theory of caregiving related to this population which may also be applied to a broader population of caregivers.

Managing Change:
The Process of Caregiving for Informal Caregivers of Head and Neck Cancer Patients

by
Maura Fulham Edmonds

Dissertation submitted to the Faculty of the Graduate School of the
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Dedication

To my mother, Barbara McGoldrick Fulham, and my sister, Gerarda Marie Fulham. Your lives were a testament to what it is to be a caregiver, whether it be to children, the elderly, the underrepresented, the underserved, or the forgotten. It is your spirit that guides me in my work and in my life. For you, I am eternally grateful.

Table of Contents

List of Tables

Table   **Page**

CHAPTER I: INTRODUCTION

Statement of Problem

A multitude of challenges accompany a diagnosis of head and neck cancer (HNC). For the patient, these challenges can include paralyzing fear, physical and mental anguish, and uncertainty (Blood & Simpson, 1994; Mah & Johnson, 1993; Vickery, Latchford, Hewison, Bellew, & Feber, 2003). For an individual who assumes the role of informal caregiver, the diagnosis means entry into a new and frighteningly unfamiliar world. It introduces a new and complex role whose demands, if not met, can imperil the life of the person they seek to help and protect.

How someone prepares for the role of caregiver may be affected by many elements. The unique viewpoint of the caregiver, his or her relationship to the patient, and previous exposure to the caregiver role are all components of this process. It is this symphony of experiences and elements that affect a caregiver and the process that is experienced in assuming the caregiving role.

Background of the Problem

Every year in the United States, approximately 40,000 people are diagnosed with cancer of the head and neck (including the oral cavity, pharynx, paranasal sinuses, nasal cavity, larynx) as well as half a million people worldwide (Kim & Califano, 2004). In 2012, the American Cancer Society (ACS) estimates that there will be 40,250 new cases of oral and pharyngeal cancers and 12,360 new cases of laryngeal cancer (ACS, 2012). The incidence rate in men is approximately twice that of women, with men over 50 being at the highest risk (ACS, 2011). Additionally, African American men have the highest incidence and are considerably less likely to be diagnosed at an early stage. Five-year

survival rates for all stages combined are 61%; this decreases to a 50% survival rate at ten years (ACS, 2011). There is a distinct survival difference, based on race, with a 60% five-year survival in whites and a 36% five-year survival in African Americans (Settle, et al, 2009; Clarke & Dropkin, 2006). In addition to the poor long-term survival, the effect on the patient's quality of life and ability to function is profound (Bjordal.et al, 2001; Hammerlid et al., 2001). ACS estimated that cancers of the oral cavity and pharynx will be among the top ten leading sites of cancer cases in men in 2010, representing 3% of all newly diagnosed cancers (ACS, 2012).

Risk factors for this group of cancers include the use of tobacco and heavy alcohol intake (Goldenberg et al., 2004) as well as exposure to human papillomavirus (Argiris, Karamouzis, Raben, & Ferris, 2008; Chaturvedi, Engels, Anderson, & Gillison, 2008; National Comprehensive Cancer Network (NCCN), 2009). Although cancers of the head and neck represent a relatively small percentage of cancers overall (3%) (ACS, 2010), they present unique challenges to practitioners, patients, and informal caregivers. Treatment periods are long and may include multiple different types of interventions, each with its own list of possible sequelae, complications, and logistical challenges. In addition, the patients and their families face intense psychosocial, emotional, and physical alterations to their former lives brought on by both the disease and its treatment (Baghi et al., 2007; Blood, Simpson, Dineen, Kauffman, and Raimondi, 1994).

Diagnosis and Treatment

The term HNC refers to 11 different types of cancer, each affecting a specific area within the upper aerodigestive tract (Clarke & Dropkin, 2006). In each type, the goal of treatment is to eradicate the tumor while maintaining the greatest amount of organ

preservation and function. Regardless of the type or location of the tumor, there are three major treatment modalities used to address the disease: surgery, radiation therapy, and chemotherapy. Each of these treatment modalities have a specific side effect profile that must be managed. These modalities and their side effects are described below.

Surgery is commonly used in the treatment of many forms of HNC. The choice of whether or not to use a surgical intervention is based on a number of factors including tumor size, location, postoperative function, and the patient's cognitive ability (Quon et al., 2004). Comprehensive or selective neck dissection is used to either address clinical node disease or to prevent the spread of disease in cases when there is no evidence of regional nodal spread (NCCN, 2009).

Radiation therapy is used to destroy malignant cells while, ideally, avoiding healthy tissue. It can be delivered a number of different ways, including external beam radiation, intensity-modulated radiation therapy, and brachytherapy. (Ding, Newman, & Raben, 2005). External beam radiation is delivered over a period of five to seven weeks in fractions. This fractionization allows for the greatest possible dose with the least number of side effects. Intensity-modulated radiation therapy also employs an external beam but this beam is modulated to produce a more accurate and precise treatment field. This treatment allows for a higher dose of radiation to be delivered to the tumor with less damage to surrounding, healthy tissue (Hogue, 2007) and thus less toxicity and a decreased symptom profile (Hong, Tome, & Harari, 2005). Brachytherapy involves the use of a radiation source that is implanted into the body in order to deliver a prescribed dose of radiation to a specific area. This implantation can be permanent or temporary, and it delivers the radiation to the tumor and lessens the effect on surrounding tissues.

Brachytherapy can be used with either a curative or palliative intent and can be aimed at the primary tumor, regional disease, or metastases. It can be used before surgery to reduce the tumor bulk and preserve organ function, concurrently with chemotherapy, or after surgery, to eradicate any remaining cancer cells (Quon et al., 2004). This method of delivery is not used as frequently because of the emerging and successful use of combination radiation and chemotherapy (Quon et al., 2004). It is, however, still used primarily for cancers of the lip and oropharynx (NCCN, 2009).

The use of chemotherapy in these patients is most commonly employed as a radiosensitizer (Agarwala, Cano, Heron, Johnson, Meyers, Sandulache, Bahri, Ferris, Wang, & Argiris, 2007) in combination with radiation therapy. Both Carboplatin and Paclitaxel have been used with success either as single agents or in combination. Both are radiosensitizers and have been shown to offer survival benefits to patients with advanced, recurrent, and/or metastatic disease (Agarwala, et al. 2007)

Recent advances in the area of biological agents have produced more options for the treatment of these cancers (Licitra, Locati, &Bossi, 2006). Drugs which target the epidermal growth factor receptors are being studied in conjunction with traditional therapies in both phase I and Phase II trials (Mehra, Cohen, & Burtness, 2008). Of these, Cetuximab has shown promising results in improved locoregional control when used in combination with radiation therapy (24.4 months versus 14.9 with radiation alone) because it did not produce an increase in radiation- related mucositis (Licitra, Locati, & Bossi, 2006). This agent has also been used in conjunction with Cisplatin, showing an improved response rate (23% versus 9%) although it did not affect progression-free survival (Licitra, Locati, & Bossi, 2006).

Side Effects and their Management

In cancers of the head and neck, both the disease and its treatment can impede or destroy the patient's ability to speak, chew, swallow, and breathe. Sequelae can include facial disfigurement and difficulty communicating, which can be extremely stressful for patients, caregivers, and clinicians alike. Side effects of HNC and its treatments can also include the loss of speech and swallowing; xerostomia; mucositis and skin desquamation related to radiation exposure; physical disfigurement related to surgical interventions and the placement of a tracheostomy; emotional and psychosocial issues related to depression, anxiety (Clarke & Dropkin, 2006; Herranz & Gavilan, 1999); disfigurement, role change, altered body image, and financial and emotional burdens (Cady, 2002); and lack of support from family (Herranz et al, 1999, Ramirez et al, 2003).

With each individual treatment side effect, there are numerous activities that must be undertaken in order to prevent or treat the side effect as it arises during the treatment trajectory. As the treatment progresses and patients become more fatigued, the responsibility falls to the informal caregiver to manage and assist the patient on a day-to-day basis. These caregivers experience their own unique challenges as they learn and implement the caregiving role (Bagdi, et al., 2007). Specific side effects and their implications for care are briefly reviewed below.

Communication Difficulties

Changes in the ability to communicate are a distressing side effect for patients, and they can stem from multiple sources including physical, emotional, psychological, and cultural issues. The position of the tumor may interfere with the movement and agility of the tongue. It can also impair the vocal cords, causing hoarseness. Treatment

for these tumors can produce swelling and pain, which makes speaking difficult or impossible. Placement of a tracheostomy can also impede the ability to speak. The emotional and psychological impact of the diagnosis, treatment, and resulting facial disfigurement can affect the patient's willingness and ability to communicate effectively (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). These adverse sequelae can negatively influence relationships between patient and friends, family members, and professional caregivers. Cultural issues related to communication in this population are not well known but the need for culturally sensitive care is well documented (Tucker, Herman, Pedersen, Higley, Montrichand, & Ivery, 2003).

Dysphagia

Dysphagia is defined as difficulty swallowing, adversely affecting the patient's ability to eat. In HNC patients being treated with chemotherapy and radiation, this difficulty eating can persist even up to a year after the beginning of treatment (Rademaker, et al., 2003). Thus nutritional status can be compromised, and social interaction can be impeded by elimination of regular eating and food as a source of social interaction. Dysphagia can also result in the placement of a gastrostomy tube or intravenous port to supplement or replace oral intake, as these are often compromised during treatment (Wiggenraad, et al., 2007). These challenges require the preparation of special meals with attention to the texture and acid content of food and /or the care of a stomach tube or intravenous port to keep the tube or port patent and the skin around the insertion point in good condition. In addition, close monitoring of food intake is essential to ensure sufficient nutrition. Although the care of a port and its access would fall to a

medical professional, the remainder of these tasks is often managed by the patient and/ or his or her informal caregiver.

Xerostomia

Xerostomia is the perception of oral dryness; salivary gland hypofunction or dysfunction is caused by the irradiation of the salivary glands during radiation treatment. Xerostomia is not only uncomfortable, but it interferes with the ability to chew and swallow (Clarke & Dropkin, 2006). It changes the pH of the mouth and alters the thickness of the saliva from neutral pH with thin secretions to an acidic pH with thick, ropey secretions (Dirix, Nuyts & Van den Bogaert, 2006). It also puts the patient at higher risk for dental caries and infection (Brodsky, 2007; Seikaly, 2003; Scarpace, Brodzik, Mehdi, & Belgam, 2009). Patients with xerostomia must be encouraged to engage in very thorough oral hygiene and must constantly sip on liquids, use antibacterial mouth rinses, and use artificial saliva to help deal with the discomfort related to a very dry mouth (Brodsky, 2007; Scarpace, Brodzik, Mehdi, & Belgam, 2009). The need for assistance with these tasks varies from patient to patient and may become more intense as the treatment progresses and the patient becomes more fatigued.

Mucositis

Mucositis involves inflammation of the mucosa of the mouth and, commonly, the digestive tract (Clarke & Dropkin, 2006). The trajectory of this side effect ranges from inflammation to ulceration, causing extreme pain and increasing the risk of infection (Scully, Sonis, & Diz, 2006). Brown and colleagues report that the consequences of mucositis include difficulty eating/drinking (88%), weight loss (83%), depression (38%), difficulty talking (29%), sleep disturbances (25%), and hospitalization (13%) (Brown,

McGuire, Peterson, Beck, Dudly, & Mooney, 2009). Interventions for this condition involve the frequent use of mouth rinses and frequent mouth and oral care. Pain assessment and management are also vital. The development of mucositis can compromise the patient's ability to eat, which can lead to issues related to nutritional deficits (Brown, et al, 2009; Scully, Sonis, & Diz, 2006). Guidelines for the prevention and treatment of mucositis include regular assessment of oral pain; topical anesthetics; consistent assessment of the oral cavity; regular oral hygiene including brushing, flossing, rinses and moisturizers, and the use of more potent analgesics if needed for pain relief (Keefe et al., 2007). Because these interventions must be performed on a regular schedule to be effective, they can be very time-consuming, especially when they must be coordinated with meals, medications, and other caregiving tasks. Although patients are likely to engage in the personal care tasks, the coordination of these tasks may fall increasingly to the caregivers.

The Study of Caregiving

In 2006, The National Family Caregivers Association (NFCA) and Family Caregiver Alliance (FCA) reported that there were an estimated 28.8 million individuals who identified themselves as caregivers, providing more than 30 billion hours of care with an estimated value of $306 billion dollars a year (NFCA & FGA, 2006).

Historically, caregiving was done in the home. Whether by family members or skilled homecare nurses who came periodically to assist the family, care was centered at home (Reverby, 1998). With the advent of hospitals in the nineteenth century, medical care began to be moved out of the home. In recent years, changes in the healthcare system have meant that the responsibility for care has shifted once again to the home

(Lim & Zebrack, 2004). Patients who might have been admitted for lengthy hospital stays are now being discharged and sent home with complex medical needs that must then be managed by their family members, friends, or neighbors. Although the provision of care by family or informal caregivers is a phenomenon with a long history, its appearance in the literature is a relatively new occurrence.

The study of informal caregivers has its roots in pediatric and gerontology literature, primarily in the areas of dementia and Alzheimer's disease (Baronet, 1999; Kuhlman, Wilson, Hutchinson, & Wallhagan, 1991; Vitaliano, Young, & Russo, 1991). The focus of these early studies primarily was on the burden associated with caregiving, both objective and subjective. Over time, caregiving has been investigated in many different areas, one of which is oncology.

Care Needs in Cancer

In recent years, the shift from inpatient cancer care for all forms of cancer to more outpatient and home-based care has increased the complexity of care (Given, Given, & Kozachik, 2001). Family members are now expected to provide much more than emotional support. They are often involved in symptom management, medication administration, assistance with personal care, and the use and management of multiple technical instruments and tasks (Given, et al. 2001). These responsibilities can affect their quality of life (Kitrungrote et al., 2006) as well as their mood state and anxiety level (Miaskowski et al., 1997) because of the emotional, psychosocial, and physical challenges that accompany the diagnosis and treatment. Not surprisingly, these caregivers have many unmet needs, including finding time for themselves, managing emotional and physical stress, and balancing the responsibilities of work and family (National Alliance

9

for Caregiving (NAC) and American Association of Retired Persons (AARP), 2004). They also identify the need for information and the need for assistance when talking with healthcare professionals (NAC & AARP, 2004).

Much attention has been given to the burdens and stress of the caregiving role. Although caregiver burden and role strain are believed to be important elements, more recent approaches focus on both the content and the dynamics present in the relationships between the caregiver and the care receiver (Schumacher, 1996). As the study of informal caregiving has evolved, the concept has broadened, encompassing more aspects of the role, extending beyond burden and stress (Schumacher, et al. 2000). These aspects include positive elements of the role as well as the identification of the core processes of the role of a caregiver.

The role of the informal caregiver for a patient with cancer is complex and fraught with challenges. It requires the caregiver to act as advocate, medication manager, nutritionist, and psychosocial supporter all while trying to adjust to the dramatic and difficult realities of watching a loved one cope with a life-threatening and life-altering disease while undergoing extremely toxic treatment. The literature reflects the complexities of the caregiving role, while also noting the challenges facing these caregivers as they attempt to develop into competent, confident practitioners of an art that is as old as humanity itself.

In 2000, Schumacher and colleagues developed a concept of family caregiving skill, which identified 63 indicators of family caregiving. These indicators were then organized into nine core caregiving processes: monitoring, interpreting, making decisions, taking action, making adjustments, accessing resources, providing hands-on

care, working together with the ill person, and negotiating the healthcare system. The authors defined family caregiving skill as the ability to engage effectively in these nine processes (Schumacher et al., 2000). This conceptualization represents a fuller, broader understanding of the many facets and influences present in the complex situation of caregiving. It presents the opportunity to address the question of how these many skills are acquired as the process of becoming a caregiver evolves. This concept encompasses not only information-based skills but those skills that are born of experience and the development of intuition. The limitations of this study, as identified by the authors, included a lack of sociocultural diversity in the sample. They also suggested that because the study looked at a narrow band of patients (only those receiving chemotherapy), the study should be replicated in other patient populations. No indication was given as to the types of cancer represented, but the choice to use only chemotherapy recipients would narrow the types of cancer represented in the study. Also, because cancer represents a collection of diseases each with its own challenges and treatment protocols, narrowing the sample to only chemotherapy shortchanged the understanding of the caregiving experience as it was experienced by those who received radiation and/or surgical interventions.

Glajchen (2004) reviewed many of the challenges facing family caregivers of patients with cancer, including the physical, social, spiritual, and psychological impact of caregiving on the caregiver's quality of life. Sequelae included the relentless physical demands of full-time caregiving and their impact on the caregiver's risk of morbidity and mortality and the increased incidence of depression, distress, and anxiety, coupled with the positive feelings and sense of satisfaction which comes from feeling they have

achieved something of great worth. Glajchen also addressed the high incidence of unmet needs in this population, which ranged from 60% to 90%. These unmet needs included assistance with personal adjustment to illness, psychosocial support, transportation, finances, homecare, and medical information. She also discussed of the importance of appropriate educational interventions for caregivers and stressed that caregivers need factual information from reliable sources. Once again, the author did not indicate the types of cancer these caregivers were dealing with or what kind of treatment plans were represented, vital pieces of information if we are to understand the caregiving process.

Gaugler and colleagues (2005) identified factors accounting for caregivers' stress in a sample of 233 family caregivers of cancer patients in active treatment in two separate, geographically diverse cancer centers. Using the Stress Process Model as a conceptual framework, the authors identified indicators, which increased perceived stress as well as some, which seemed to decrease the perception of stress. Data were collected using multiple scales, including an eight-item scale to measure socioemotional support of the caregiver by those around them, a seven-item scale to measure mood problems and caregiver's perception of patient's behaviors and feelings, and a seven-item subscale from Given's Caregiver Reaction Inventory to assess mastery/optimism. The researchers performed a multiple regression to analyze the data, adding initial correlations to determine the significance of the covariates to address issues related to sample size and statistical power. Indicators found to increase stress included shorter treatment times ($p < .05$), caring for a patient with brain cancer ($p < .05$), high amount of assistance with Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs) ($p < .05$), and being a younger, female caregiver ($p < .05$). Caregivers who perceived that

they had good family support reported less caregiver stress and those who reported a sense of mastery of the caregiver role were less likely to report distress (p < .05). In addition, the authors emphasized the need for more research aimed at understanding the impact of the cancer site on the caregiving experience and the need to understand how those with limited access to care and limited socioeconomic resources adjust to care demands. Although these authors mentioned caregiver support, they focused solely on stress, ignoring many other elements that influence how stress is perceived. For example, while mastery appeared to mitigate stress, it was unclear how this mastery is attained by the caregivers.

The issue of preparedness has only recently been identified in the literature as having a significant impact on family caregivers. Schumacher and colleagues (2007) studied mutuality (defined as relationship quality between caregiver and patient) and preparedness for the caregiving role and their relationship to family caregiver outcomes in a sample of 87 cancer patients, 21% of which were HNC patients. Preparedness for caregiving was defined as the caregiver's perceived readiness to provide care (Schumacher, Stewart, & Archbold, 2007). The study found that, even in the face of increased care demands, both mutuality and preparedness protected against perceived caregiving difficulty and mood disturbance. These results highlighted the idea that caregivers need to feel prepared in order to effectively perform the caregiving role without negative consequences. Although this study addressed the importance of preparedness, it stopped short of suggesting why preparedness was important and how this information impacted the caregiver's evolution into this new role.

In summary, the need for caregivers in all types of cancer is an accepted reality. For most individuals engaged in healthcare, formal training provides basic knowledge as well as a framework for information gathering. For informal caregivers, the path to knowledge and understanding is not so clear. To date, there is a dearth of information about caregivers of HNC patients and nothing in the literature describing the process informal caregivers go through to assume this role.

Care Needs in HNC

As demanding as care needs are for cancer in general, the demands on caregivers of head and neck patients face a plethora of uniquely challenging issues. Cancers involving the head and neck can have a devastating effect on a patient's ability to perform tasks which were previously taken for granted. The literature dealing with HNC outlines the many challenges and difficulties these patients face in the period of time from their diagnosis through their treatment and beyond (Ramirez et al., (2003), Cady, (2002), Clarke & Dropkin, (2006). What is lacking in the literature is an understanding of the process these caregivers go through to evolve into their new role. As the complexity of the disease and its treatment increases, so does the complexity and uniqueness of the caregiver role. Caregiving in other forms of cancer has been studied, as well as caregiving in cancer generally (Given et al, 2001, Kitrungrote & Cohen, 2006, Miaskowski et al., 1997, Scherbring, 2002), but rarely has caregiving been studied in the HNC population.

A Medline search produced four articles dealing with caregiving in relation to these types of cancer. Of these, one was a reflection of one man's experience over a six - year period as the friend of someone with oral cancer and was not a research article

(James, 1983). The other articles used a variety of methods to look, primarily, at caregiver strain and /or burden.

Mah and Johnson (1993) used a descriptive, exploratory, longitudinal design consisting of semi-structured interviews, observation, and chart review over a three - month period. They were interested in understanding the concerns of families in which one member has been diagnosed with HNC. Data were collected pre-, during, and post treatment. The sample consisted of four patient/caregiver dyads, three of whom completed the study and one of whom refused to be followed. Researchers included the data from this pair in the analysis because they were able to follow them through the rehabilitation period. Using constant comparative analysis, they identified five major areas of concern for these caregivers: care and its meaning, social relations, hospital experience, treatment, and future placement. No definition of these terms was provided and, other than frequency, no analysis was reported.

Blood and Simpson (1994) studied a sample of 75 spouses of laryngeal cancer patients to assess caregiver strain and burden using four self-report instruments. These instruments included the Caregiver Strain Index (CSI), the Burden Interview (BI), the Global Assessment of Recent Stress (GARS), and the short form of the Health Survey of Medical Outcome Study (HS-MOS). Although evidence toward reliability and validity is mentioned for all instruments, there is no indication whether or not they have ever been used in this population before or what population was used to develop them. Caregivers were divided into one of six subgroups based on time since diagnosis. The majority (81%) reported being in excellent health, as measured by the HS-MOS. Results included higher amounts of strain during the time periods closest to diagnosis and a significant

difference between subgroup 1 and all other subgroups (p<.006), a higher mean burden score in subgroups 1 and 2 as compared with other subgroups, and a significant difference between genders on the BI (p< .002). There was low significance reported between the two caregiver scales and the GARS, which the authors attributed to the possibility that the two scales measured different components of caregiver burden. It is also possible that the concepts of "strain" and "burden" were conceptualized differently and, therefore, were measuring two similar but not interchangeable concepts.

Baghi and colleagues (2007) assessed the demands on caregiving relatives of HNC patients using an anonymous self-report questionnaire. The sample included 78 relatives of previously treated HNC patients. The questionnaire measured quality of life and was considered by the researchers to be multi-dimensional, cancer specific, and relative based. There is no indication it was developed for the study and no information is given regarding evidence toward reliability or validity. Data were analyzed using both descriptive statistics and the non-parametric chi square test. Logistic regression was also used to test hypotheses, with the level of probability calculated at the .05. After noting the lack of studies related to family caregivers of HNC patients, the authors identified five demands on these caring relatives: 1) a desire to be informed about different therapeutic modalities (89.7%), 2) a need for more information about cancer as a disease (80.8%), 3) the necessity for simultaneous psychological care for patients (60.3%), 4) the necessity for simultaneous psychological care of caring cancer patients' relatives (43.6%), and 5) a desire to have contact with self-help groups (43.6%). The findings highlighted the perceived need for information often expressed by caregivers. The researchers concluded

that it was vital for healthcare providers to take the needs of caregivers into account and ensure that the needs were met (Baghi, et al., 2007).

At present, there is extensive literature documenting that the role of the informal caregiver is complex and challenging and that the needs of these caregivers must be taken into consideration. In HNC, a relatively bleak prognosis is combined with technically challenging care needs and difficult psychological and emotional issues affecting both patient and caregiver. As evidenced by the above examples, the focus has been primarily on the negative impact of the disease on the informal caregivers. What has not been addressed is how these individuals evolve into caregivers and what healthcare providers can do to address their needs in the most effective, efficient manner.

Purpose Statement

The goal of this study was to gain a better understanding of the process undertaken by the informal caregivers of HNC patients from the caregivers themselves, with an eye toward theory development. Although the development of a theory was beyond the scope of this project, it was meant to be a first step toward understanding the important categories and concepts that are part of this process. Knowledge of this process will improve the ability of nurses and other healthcare practitioners to better support and inform informal caregivers. In turn, caregivers will be able to provide a higher quality of care leading to fewer complications for the patient and a higher quality of life for the informal caregiver. The information gathered from this study can then be used to develop interventions tailored to this population, aimed at assessing their needs and concerns as they undergo the dynamic process of becoming caregivers.

CHAPTER II: CONCEPTUAL UNDERPINNINGS

Theoretical Framework

Symbolic interactionism was selected as an appropriate framework for this study because it focuses on the importance of an individual's perception and interpretation of the things around him or her and the meanings attached to these things. By understanding these things, researchers and clinicians can better interpret the process. Symbolic interactionism also provided the underpinnings of Grounded Theory, which was the guiding methodology for this study and is discussed in more detail below.

Symbolic interactionism is defined as a theoretical perspective that states that people construct selves, society, and reality through interaction. In this view, people create shared meanings through their interaction with others and these shared meanings define their reality (Blumer, 1969). Crotty described symbolic interactionism as the "meaningful matrix that guides one's life" (Crotty, 2003, p. 71). Symbolic interactionism places primary importance on an individual's perception and interpretation of the things around him or her and the meanings attached to these things. It is based on three major premises. The first is that human beings act toward things based on the meaning these things have for them. Secondly, the meaning of things comes from the social interaction a person has with peers. Lastly, the meaning of things is handled and modified through the interpretive process a person uses in dealing with the things that are encountered (Blumer, 1969).

In the history of symbolic interactionism, the most significant contributor was George Herbert Mead. Mead rejected behaviorism and Freudian thought primarily because of its focus on external stimuli and its view of the person as a victim of forces

around him or her over which there is no control. He identified the two "phases of the self" (Ritzer, 2008, p. 362) which he called the "I" and the "me." The "I" is the individual self and the "me" is the attitude of others. This schema shows the self as dependent on social interaction. Much of Mead's thinking was derived from the theory of pragmatism (Corbin &Strauss, 2008).

Pragmatism, the worldview from which symbolic interactionism was derived, stresses that reality is actively created as people act within and toward the world (Corbin & Strauss, 2008). People remember and base their knowledge on what has proved useful to them. They define the social and physical objects they encounter in the world according to their use for them. Lastly, pragmatism states that if people want to understand actors, they must base that understanding on what people actually do in the world (Ritzer, 2008). The three key points from pragmatism that inform symbolic interactionism are the interaction between actor and the world; the view of the actor and the world as dynamic, not static; and the importance attributed to the actor's ability to interpret the social world.

Six basic ideas, or root images, are central to symbolic interactionism. These root images are the significance of human groups or societies, social interaction, the nature of objects, viewing the human being as actor, human action, and the interconnection of the lines of action. Each is described briefly below.

The significance of human groups or societies states that these groups exist in action and must be seen in terms of action. Culture is derived from what people do (Blumer, 1969).

Society consists of individuals interacting with one another, and this social interaction is important in and of itself. These interactions form human conduct, rather than merely provide simply a backdrop for said conduct. The individual must fit his or her own line of activity into the activity of others. It is through these interactions that meaning is derived, and human group life develops shared meanings for these interactions, including shared meanings for gestures and significant symbols. Once these shared meanings, also called mutual role taking, are established, communication and symbolic interaction can occur. The process of taking on the role of informal caregiver involves the evolution into a new role and an alteration to the caregiver's previous identity. The ability to communicate and socialize can be severely altered in the care recipient, and this alternation can fundamentally change the dynamic between the caregiver and receiver. In the context of HNC, certain interactions will change, primarily those involving speech and the preparation and sharing of food.

The nature of objects is defined as anything that can be indicated or referred to. These common objects emerge and derive their meaning through a process of mutual indication, where members of the culture see objects as having the same meaning. The human group life process creates, affirms, transforms, and, sometimes, casts aside objects as the dynamic process of symbolic interactionism proceeds (Blumer, 1969). This refers to the process of mutual indication where members assign meaning to objects. In taking on the caregiving role, informal caregivers encounter and must incorporate many new objects into their world (e.g., tracheostomies, feeding tubes, medications) and assign a meaning to each of them. In addition, objects that have always been part of their world

may take on new meanings (items related to communication, eating) or be cast aside in this new role.

Viewing the human being as actor, symbolic interactionism states that each individual is seen as an object of his or her own actions. The self emerges from social interactions that allow others to help the self define itself. The human is an organism, which takes what it sees, objectifies it, and assigns that object a meaning that then directs action. It is an acting organism rather than just a responding one (Blumer, 1969). This tenet highlights the importance of understanding that the caregiver acts and prepares based not on how the environment acts on him or her but on how the environment is understood by the caregiver.

Human actions are constructed and guided by humans, and these actions are not just reactions to factors acting upon them. Each person must act in many, varied situations based on what he or she sees and how it is interpreted. This will determine the "projected map of action they map out" (Blumer, 1969, p. 15). In this view, it is the defining process of the actor that is important, not the factor initiating the action.

Lastly, it is important to acknowledge the importance of the interconnection of the lines of action within a culture because these interlinked lines of action make up the collective cultural world. A wide variety of people, all at different points on the continuum, engage in actions driven by a common set of meanings. These actions are affected by the circumstances within which they occur. These actions are also influenced by the background and previous experiences of the participants. The past experiences of the caregiver with the caregiving role, the relationship with the care recipient, and interactions with the healthcare system are all important in understanding the various

lines of action that are a key to understanding the experience. Below is an overview of the elements of symbolic interactionism and how they related to this study (See Table 1).

Methodology

Grounded theory methodology was chosen for this study for four primary reasons. First, it stresses the existence of multiple realities (Corbin & Strauss, 2008). Second, it views the researcher as part of the process and acknowledges the construction of these realities (Corbin & Strauss, 2008). Third, it addresses the importance of the sensitivity of the researcher and the value that past experience can have on the final product (Corbin & Strauss, 2008). Lastly, and most importantly, it is well suited to the study of processes (Oktay, 2012).

First described by Barney Glaser and Anselm Strauss in 1967, grounded theory methods began as a positivist approach to qualitative inquiry whose goal was to discover theories, which emerged from the study of basic social processes (Glaser & Strauss, 1967). Glaser and Strauss believed that the theory emerged from the data and that it was there waiting to be discovered. The researcher was to identify biases and maintain objectivity throughout the research process. No literature review was used to help avoid forcing the data in a particular direction. The end product was a core category around which all the other categories revolved. Strauss and Corbin's (1998) approach to grounded theory evolved away from the positivist approach. As Strauss refined his research, he and Juliet Corbin saw reality as a construction and believed that multiple perspectives led to multiple realities. Theory was something that was a co-construction produced by the researcher and participant, not something that was purely emergent.

Table 1. Relationship of Symbolic Interaction to Family Caregivers Study

Symbolic Interactionism (Blumer, 1969)	Proposed Study
Human Groups or Societies (pg 6) -Exist in action and must be seen in terms of action. -Culture derived from what people do.	-Looks at the culture of informal caregivers of HNC patients and how they develop into the role (culture is defined as the attitudes and behaviors characteristic of a particular social group or society) within the world of the caregiver and the patient.
Nature of Objects -An object is anything that can be indicated or referred to. -Out of the process of mutual indications, common objects emerge (objects that have the same meaning for a given set of people and are seen in the same manner by them) -People may live side by side yet be in different worlds. -World: designates the setting, the surroundings, and texture of things that confront them. -Human group life is the process in which objects are created, affirmed, transformed and, cast aside.	-Caregiver role may bring together people who might otherwise never encounter each other (different histories). They will then establish their own world within this environment. -Objects encountered here may include things that are completely foreign to any other "me" in their life.
The Human Being as Actor -Self as object -Object of their own action. -Self emerges from social interaction in which other people are defining a person to himself. -Form our objects of ourselves from process of role taking. -Must see oneself in the view of others. -Interaction with their self. -Human as an organism, which must deal with what it notes. Makes what it notes an object, gives it meaning and that meaning directs action. -An acting organism rather than just a responding organism.	-New self, caregiver role-taking process -Sense of success/ failure related to others reactions? -Practitioner attitudes? Family attitudes? -How does our reflection of them (and their efforts) impact the process? -How does this awareness affect how we attempt to intervene?

Table 1. Continued

Symbolic Interactionism (Blumer, 1969)	**Proposed Study**
Human Action -Must construct and guide actions (not just react to factors playing on him). -Activity consists of meeting a flow of situations in which they must act, based on what they note, how they assess and interpret what they note, and what kind of projected map of action they map out. -Initiating factor not focus. Defining process of the actor is!	-Actions directed at processing of caregiver role. -The defining process for the caregiver. -How does their sense of "being ready" affect how they assess, interpret and ultimately, act? -We assume the cancer is the driver, not the individual!
Interconnection of the Lines of Action. -Joint action of the collective is an interlinkage of separate acts of the participants. -Diverse array of participants at different points in network engage in actions based on given set of meanings. -Network functions because people at different points do something and what they do is a result of how they define the situation in which they are called to act. -Importance of the background and previous actions of the participants.	-Diversity of caregivers (brought together by common issue) all at different points form a network, which creates a caregiving world. -Awareness that this is a culture functioning within another culture.

A further move toward a post-positivist approach to grounded theory is found in Kathy Charmaz's approach (2006), who sees realities as mental constructions. She sees the theory produced as "…an interpretive portrayal of the studied world, not an exact picture of it." (Charmaz, 2006, p. 10).

Grounded theory methodology seeks to understand processes by collecting and analyzing data with an eye toward the development of a theory that is grounded in that data. Using primarily interviews and observations, data are collected from participants in

a certain population. Although grounded theory shares many common elements with other qualitative methods, there are certain elements that are unique to and help define grounded theory methodology (Oktay, 2012). These elements include the use of theoretical sampling, constant comparative analysis, a technique called intensive memo writing, and the need for theoretical saturation. Each of these elements is directed at theory development and is described below.

Theoretical sampling is defined by Glaser and Strauss as "the process of data collection for generating theory whereby the analyst jointly collects, codes and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory" (Glaser & Strauss, 1967, p. 45). It is purposeful and is guided by theoretical criteria that are developed from the initial data collected. The sample size is never determined *a priori* (Hood, 2007). Theoretical sampling allows the researcher to find and collect data and help in the identification and delineation of categories which arise from the data. The goal is not to create a sample that is considered representative or statistically generalizable but to allow for the conceptual and theoretical development of grounded theory (Charmaz, 2006). Once initial sampling has provided enough data to reveal some emerging categories, theoretical sampling can begin. Sampling decisions are based on these and other emerging categories with the goal of further defining the categories and their dimensions. It is from these more refined categories that the theory will emerge.

From the very beginning of this sampling process, analysis of the data continues in a process called constant comparative analysis, which involves going back and forth through the existing data to constantly compare categories and dimensions to each other,

further saturate existing categories, and look for the emergence of new ones. Constant comparative analysis occurs throughout the research process, as opposed to the analysis generally seen in quantitative research, which is usually performed at the conclusion of the study. Constant comparative analysis is central to the development of grounded theory, taking the analysis to a more abstract, theoretical level. The technique also allows for a better understanding of the relationships between categories and, eventually, their relationship to the emerging theory (Charmaz, 2006).

Throughout the above-described activities of data collection and analysis, extensive memo writing is a crucial part of the process of developing grounded theory. Memos can take whatever form is most effective for the researcher, whether it be notes, narrative, etc. as long as these analytic notes are focused on the goal of further explaining and expanding categories. They provide the opportunity to begin the analysis from the very beginning of the research process. Memo writing also starts the researcher thinking about possible categories and comparisons which can lead to the development of the core categories, properties, and, ultimately, the theory.

Theoretical saturation is a concept that refers to gathering data until there do not appear to be any new theoretical insights to be gained and until no new properties of the core theoretical categories seem to be emerging. It does not refer to seeing the same pattern emerging repeatedly but rather to the various properties of these patterns (Glazer, 2001, Charmaz, 2006). The achievement of saturation can be somewhat controversial. There are those who would suggest that, depending on the size of the study, the claim of saturation may be called into question.

Given the size and scope of this study, it is unrealistic to claim complete saturation of all the identified categories. However, the data collected in this study have been sufficient to support the creation of a core category and to provide for the identification of two subcategories, described in Chapter 4 below. Because the relationships among these subcategories have been established, it can be said that the sampling for the study was sufficient to meet its purpose (Corbin & Strauss, 2008).

In summary, grounded theory was the logical place to start to learn about the process of preparing to become a caregiver. It allowed for the development of an understanding of this process and provided a vehicle to develop a theory about how the caregiver goes through this process and performs the caregiving role.

Theoretical sensitivity, as described by Corbin and Strauss (2008), increases as the researcher is exposed to the data. It is this sensitivity that allows the researcher to find the meanings within the data (Corbin & Strauss, 2008). This sensitivity is also developed from the researcher's past experiences (Oktay, 2012).

The researcher conducting this study has both personal and professional experience with this topic. As an informal caregiver first to two immediate family members diagnosed with supraglottic (head and neck) cancer, she spent seven years learning to care for and supporting these family members. Subsequently, as an adult oncology nurse practitioner, she gained experience working with and caring for many patients with HNC and their families. These experiences continue to inform her world view, which is uniquely balanced between these personal and professional experiences.

The following chapter provides a description of the grounded theory methods used to perform the study. It details the study setting, participants, data collection strategy, and data analysis.

CHAPTER III: STUDY METHODS

Using symbolic interactionism as a guide, this study used grounded theory methodology to better understand the process informal caregivers of HNC patients encounter to prepare and undertake the role of caregiver. Using observation and interviews, the study added to the existing knowledge base and increased understanding of informal caregivers of HNC patients.

Before the study began, approval was obtained from The School of Nursing Institutional Review Board (IRB), The Greenebaum Cancer Center Clinical Research Committee, and campus level Human Research Protection Office's Institutional Review Board (IRB) of The University of Maryland, Baltimore .The researcher completed HIPAA training (HIPAA 125 and HIPAA 201) and The University of Miami Collaborative IRB Training Initiative (CITI) 11 Basic Modules for Social Science and Behavioral Research.

Description of Setting

Participants in this study were identified through the HNC clinic at The Marlene and Stewart Greenebaum Cancer Center at The University of Maryland in Baltimore, Maryland. The Cancer Center is located within the medical center and provides multidisciplinary cancer care to a geographically and culturally diverse patient population. The head and neck clinic occurs weekly and is staffed by a medical oncologist, an RN, a patient care technician, and various medical fellows. Consultations with a nutritionist, social workers, and other members of the multidisciplinary team were available as needed. Ranked among the top 50 hospitals nationally, the Greenebaum

Cancer Center is one of 64 National Cancer Institute designated cancer centers in the United States (NCI, 2012). It has a nationally recognized head and neck oncology program.

Study Participants

In order to be a part of the study, participants must have acted as the primary caregiver to a patient who had a history of a cancer diagnosis of the head and neck or of the oropharynx or larynx for which the patient received either radiation therapy or a combination of radiation and chemotherapy. The participant must have been actively engaged in the patient's day-to-day care at the time of diagnosis and/or throughout treatment. The participant must also have been able to speak and understand English. Finally, the patient must have completed his or her course of treatment, and this treatment must have been for a new diagnosis and have been done with curative intent. Treatment must have been completed no more than five years prior to entrance in the study. Exclusion criteria included individuals who had not been active caregivers and individuals who were non-English speaking. In addition, the care recipient may not have been in active treatment at the time data were collected and may not have been in treatment for a second primary tumor or a recurrence of a previous tumor.

The sample consisted of six participants of various ages, genders, and ethnicities who met eligibility criteria and consented to participate in the study. They were assigned false names to protect their privacy and to reduce confusion when they are referred to in later chapters (See Table 2). In each case, the caregiver was the primary caregiver to the patient. For some, it was their first experience in the caregiver role. For others, it was not

Table 2. Participant Data

PARTICIPANT	Fred	Betty	Cheryl	Mary	Ida	Leon
AGE	67	51	41	47	59	65
GENDER	M	F	F	F	F	M
ETHNICITY	Anglo-American	Celtic-American	African-American	Anglo-American	Anglo-American	African-American
CURRENT MARITAL STATUS	Married	Divorced	Single	Married	Married	Married
RELATION-SHIP TO PATIENT	Spouse	Sister	Child	Spouse	Spouse	Cousin
# INTERVIEWS	3	3	1	3	2	2

their first time as a caregiver but the first time they had cared for someone who was ill

(meaning they had engaged in other types of caregiving such as spouse, mother, or child).

Description of Participants

Fred was a 67 year-old man who provided care for his wife during her treatment

for base of tongue cancer. He was retired from a job working for the Federal government.

His wife received surgery, chemotherapy, and radiation. During the treatment period,

they stayed at Hope Lodge, a facility near the cancer center run by the American Cancer

Society, to provide housing for patients and their families who live more than 40 miles

away.

Betty was a 51 year-old woman who cared for her brother who was treated for

advanced throat cancer. She was divorced and had no children. At the time of his

diagnosis, her brother was living alone in another state. He had been a long-haul truck

driver but was no longer working. He was also a recovering alcoholic. Because he lacked

31

the resources to care for himself, he moved in with Betty at the time he was diagnosed. As siblings, they were at opposite ends of a large family so had never spent much time living in the same house.

Cheryl was a 41 year-old woman who had acted as caregiver to her 72 year-old mother with throat cancer. She shared a house with her mother, three of her sisters, and her teenage daughter. She "takes in" children during the day. During the treatment period, she lived with her mother at Hope Lodge, leaving one of her sisters to care for her daughter and run the small in-home daycare. She provided complete, hands-on care to her mother throughout: bathing, dressing, feeding, trach care, and stomach tube care.

Mary was a 47 year-old woman caring for her husband of 23 years. They had been together since high school and have raised two children. Until recently, she was a stay at home mother and homemaker. Two days before her husband's diagnosis, she went back to work full-time as an elementary school teacher. Her youngest child was still at home and also participated in the care of her father.

Ida was a 59 year-old woman caring for her 67 year-old spouse. They had been together for ten years, had been married for seven years, and he had been sick for five years. It is the second marriage for both. Ida works full-time, using her days off to take her husband to his many doctors' appointments. During treatment, they stayed at Hope Lodge.

Leon was a 65 year-old man who is married with grown children. He and his wife were both retired. About two years ago, Leon's cousin moved in with them, leaving behind a dysfunctional home situation. The cousin had been living with his wife in North Carolina in a house without heat or running water. Not long after arriving, his cousin was

diagnosed with advanced throat cancer. His wife, according to Leon, was an alcoholic and they had two children, both of whom had issues in their lives which render them unable to help their father.

Sample size issues in qualitative research are different from those in quantitative research. In qualitative research, samples are generally smaller and the sample size is not determined in advance. The final number is determined by the achievement of theoretical saturation rather than a traditional power analysis for the purposes of generalizability of results. In this study, the final number of participants was determined by the availability of potential participants, the length of time it took for the categories to emerge, and the amount of time needed to determine the relationships between these categories. Previous studies using similar methodology have reported sample sizes ranging from 13 to 28 and generally included only one interview with each participant (Gysels & Higginson, 2009; Kennedy & Lloyd-Williams, 2008; Kwong & Mak, 2009). This study had fewer participants (n=6) but generated 14 transcripts from 14 interviews. It also included up to three interviews with each participant, thus increasing the richness of the results and providing the researcher with enough time to engage in the development of relevant codes and categories. Although some categories were developed, and some of the relationships between the categories described, limitations regarding time, availability and access to the caregivers did not allow for saturation.

Data Collection

Participants were recruited through personnel working in the head and neck clinic within the Cancer Center. The researcher gave copies of a pamphlet explaining the study to the staff of the head and neck clinic so that they could provide them to the caregivers

or patients if the caregivers were not present (See Appendix I). The researcher was also present to meet with potential participants and to answer any questions. In the cases where the caregivers were present, the researcher presented the flyer to the caregiver and, if he or she was interested, obtained the informed consent and HIPAA waiver and had them complete the Participant Data Form (See Appendix III). At that time, the first interview was scheduled. The participants were given the option of where and when they wanted to be interviewed. In all but one case, participants chose to do the interview by telephone. Remuneration for study participants who completed all three interviews consisted of a 25-dollar gift card given at the conclusion of the third interview.

The interview method used three different interview guides for each sequential interview that consisted of open-ended questions and prompts (See Appendices IV, V, and VI). The first interview guide comprised open-ended questions designed to elicit the participant's story. Subsequent guides were based on the data collected in the first interview (i.e., the guide for interview two was based on data from interview one and the guide for interview three was based on data from interviews one and two). These interviews were, with one exception, done by telephone. In general, the interviews were between one and two hours long and were collected over a nine-month period. Of the six participants, three completed all three interviews, two completed two interviews, and one completed one interview. Ultimately, 14 interviews from six participants were completed, recorded, transcribed, and analyzed.

Interviews were recorded using a digital voice recorder and subsequently transcribed into Microsoft Word documents using a secure, online transcription service. Files were uploaded by the researcher as mp3 files and returned to her in Word

documents. These data were then entered by the researcher into Atlas ti ™ data analysis software on a password-protected computer located in the researcher's office. Transcripts were proofread for accuracy by the researcher using the original audio recordings for reference. All identifying information (including names, references to the patient, and location where the treatment was received) was removed (de-identified). Both the tapes and transcripts were stored in a locked, fireproof safe in the office of the researcher.

Data Analysis and Subsequent Data Collection

Once collection began, the data from these interviews were coded using open coding to break down the data and identify themes within the data. Categories and dimensions were developed from these themes using axial coding. This type of coding provided direction for theoretical sampling, which was done based on type of relationship between the caregiver and the patient because it seemed to be an important element. Further analysis revealed that this relationship was not a key category, but uncovered and highlighted the importance of the quality of the relationship rather than the type of relationship.

The coding strategies that were used were not a linear process because they were employed as part of the constant comparative analytic approach. As noted earlier, this approach, by definition, moves back and forth through the data across cases and participants.

Throughout the period of data collection, extensive memo writing took place to help further understand the emerging categories. These memos created a paper trail of the researcher's thoughts on the analytic process as the categories were being developed.

They provided a way to move toward theory development by allowing the researcher to reach increasing levels of abstraction.

Data collection continued until the core category and subcategories were established and the connections between them were identified. Given the size and duration of this study, theoretical saturation was not a realistic expectation.

In the following section, the various criteria used to evaluate the quality of grounded theory studies are discussed.

Evaluation of Qualitative Research

As a family of methods, qualitative research has many approaches for evaluating the quality of the results of any given study. Each qualitative method has specific criteria directly related to both the fit of the method to the question and the way the method has been implemented. This section reviews the areas specific to grounded theory, as described by Charmaz (2006).

Charmaz (2006) outlines a series of questions to be asked of the research and the researcher in order to determine the quality of the research. These questions are divided into four areas: credibility, originality, resonance, and usefulness.

Credibility

Charmaz (2006) believes that to establish the credibility of the data it is important to ask questions aimed at the researcher's familiarity with the topic, the sufficiency of the data to support the claims of the research, the broadness of the observations, and whether the study can convince someone else to agree with the researcher's conclusions.

In the case of this study, the researcher had both personal and professional familiarity with the topic under study. The sufficiency of the data is indicated by the

emerging categories which were supported by the data collected, meaning that there were sufficient data to support the creation of a core category, the two other categories, and their subcategories and dimensions.

Originality

The question of originality asks whether the categories offer new insights, whether or not there is social or theoretical significance to this work and, lastly, how the work contributes to what is currently known (Charmaz, 2006).

This study has provided a new view of what the process of caregiving is for this population. Rather than focusing solely on the tasks required, it has shown that the process of caregiving is influenced by the changes the caregivers undergo in relation to both their caregiving tasks and the inherent life changes associated with the process.

Resonance

Charmaz (2006) talks about resonance as it refers to the quality of the categories, the identification of meanings, the link between the individuals studied and the larger world, and whether or not the developed theory makes sense to those in similar circumstances to those who were studied.

This study has attempted to provide a better understanding of what the role of caregiver is and what it means to the individuals who take on this role. It has also tried to gain a sense of what it is like for these individuals to go through the process of becoming a caregiver within the context of the larger society.

Usefulness

Usefulness asks if the analysis has produced something that can be used in everyday life. Also, it explores whether the work could inspire future research and how (or if) it contributes to knowledge (Charmaz, 2006).

This study has provided an insight into the world of the caregivers, identifying more clearly their needs and challenges. This knowledge can be the base from which further research can be developed which is tailored more effectively to meet their needs as they go through the caregiving process.

Having discussed methods for evaluating the quality of this study, it is important to address the issues of participant protection and the potential risks and/or benefits this study may have posed. The next section reviews these areas.

Human Subject Considerations

There is no reason to believe that any aspect of this study placed the participants at any undue risk. Asking them to describe their experience in learning and implementing the caregiving role may actually have helped them to come to a better understanding of their experience as a caregiver. As detailed previously, the study was approved by all appropriate institutional review committees and the researcher underwent required human subjects research training.

Potential risks related to participation in the study included an increase in the sense of burden related to caregiving and an increase in the participants' feelings of being unprepared for caregiving. None of these participants expressed any of these issues.

Potential benefits included the opportunity to express their opinions and reflections about their experience as caregivers and the knowledge they gained

throughout the process. The information they provided might be used to help future informal caregivers in situations similar to their own.

Summary

This chapter has provided a detailed description of the methods used in this study of informal caregivers, including the participants, and the interview and the data collection processes that took place over a nine-month period. It has explicated the various methods and criteria related to evaluating the quality of qualitative research in general and in grounded theory specifically. It also outlined the relevant ethical issues.

In the following chapter, the results of the study are presented. The text describes the participants and the process they underwent to take on the role of caregiver to a very unique population of patients. The core category is described, along with two other categories, their subcategories and the dimensions of some of these subcategories. Finally, the relationships between the subcategories and some of their dimensions are also described.

CHAPTER IV: MANAGING CHANGE

The Process of Caregiving for Family Caregivers of Patients

If there was one constant in the lives of the men and women who participated in this study, it was change. The changes came from many directions, both directly and indirectly related to the disease and its treatment. In this chapter, the caregivers describe in their own words the various types of change brought into their lives by the caregiving role and the process they went through to manage these changes. They describe the relentless nature of these changes brought on them by the diagnosis, the disease itself, and the treatment of the cancer. They speak of the journey through the phases of treatment and their battle to maintain their normalcy and to keep cancer from consuming their lives. These caregivers told of their attempts to manage as the changes continued to increase through the treatment phases.

In the process of conducting this study, it became clear that the experience of being a caregiver of a HNC patient was one fraught with many types of change. For some, the changes were minimal: manageable physical side effects, easily managed changes to the daily routine, and little or no strain on finances or existing relationships. For others, the experience affected every part of their lives: intense physical changes in the patient, changes in living arrangements, and formation of new roles and relationships.

Analysis of a total of 14 transcripts revealed a core category entitled Managing Change. Two other categories were also identified: Types of Change and Strategies for Managing Change. In addition to these categories, some subcategories and some of their

dimensions were identified. A dimension is defined as the "variation of a property of a concept or category" (Oktay, 2012; pg 150).

The treatment received by the patient with HNC occurs across an eight-week period, with side effects continuing for up to a month after treatment is completed. The nature of this treatment means that the caregiving experience is constantly changing. These changes occur in many aspects of the lives of the caregivers and the patients. Managing Change emerged as the core category of this beginning level theory. This core category is illustrated below, in the words of one of the participants in this study. The two other categories of Types of Change and the Strategies for Managing Change are then discussed along with the subcategories and dimensions. For the sake of convenience, this information is presented according to the phases (e.g., diagnosis, treatment) of the HNC trajectory.

Pre-Diagnosis

Caregivers begin to experience change from the moment they realize that something is not normal. In some cases, it is a lump that cannot be explained, a change in function, or a symptom that was thought to be something benign (a sore throat or an earache) that turns out to be anything but. These moments are identified by the caregivers as the beginning of the changes.

Mary was the 47 year-old wife of a young man who was diagnosed with HNC. She had been a stay-at-home mom up until recently when she went back to work taking a full-time job as an elementary school teacher.

In the middle of last summer, Mary's otherwise healthy 47 year-old husband noticed a lump in his neck. At first, he ignored it but when it didn't go away and there were no other plausible reasons for its presences, he went to his family doctor:

> *My husband found like a lump on the left side of his neck, kinda like feeling almost like a lymph node. Like I thought it might have been a swollen gland or swollen lymph node in the summer – just this past summer. It wasn't going away, it wasn't getting better. He wasn't sick or anything like when you get swollen lymph nodes from an infection or cold or anything like that. So we started to think maybe something else was wrong so he made an appointment with the doctor – his family, you know, regular physician, and he didn't think much of it either, but thought it should be looked at.*

Mary describes the experience and conveys the introduction of uncertainty related to her husband's health. A needle biopsy done by the family doctor showed suspicious cells:

> *And they did a needle biopsy and that came back suspicious for cancer. So that was our first, 'oh this could be something else', but no confirmation so we were hopeful that maybe it was something else and not cancer since it wasn't something like positive for cancer cells.*

Mary tries to fight the uncertainty, hanging on to the hope that it isn't cancer. Further testing provided a more definitive diagnosis:

> *So then we went on and he had an ultrasound and needle biopsy at the same time and a PET scan and then it came back that they definitely thought it was some type of cancer. They were talking about surgery, radiation, chemotherapy. We weren't sure. That's when we decided to seek a second opinion just to – we have no experience with this, just to see if it's correct and that we didn't miss anything.*

Diagnosis

One of the most frightening moments is the moment when they first hear the word

cancer and realize that this is a new world. Especially for those whose loved one is young

and otherwise healthy, this is a moment of disbelief.

It was at this point that Mary and her husband came to the cancer center to have

the diagnosis confirmed and a plan of treatment was developed and executed:

> *He did an endoscopy and they did the PET scan and it definitely lit*
> *up at the site where the lump was and his left tonsil, which was Dr.*
> *[name] suspicion at the exam. He said I think this is coming from*
> *your left tonsil. Because the lump is like the secondary cancer,*
> *that's what they called it. So they had to find where the primary*
> *was and that was totally his suspicion, the left tonsil. So they did a*
> *tonsil biopsy first – that was like outpatient – and we waited for the*
> *results to come back and that did come back positive. And then we*
> *moved on to surgery to remove the lump and the left tonsil and*
> *then once that healed I think in a few weeks he started the chemo*
> *radiation treatments.*

When asked about the challenges she faces during this period she focused on the

fear and uncertainty:

> *Definitely in the early part just dealing with the diagnosis, that was*
> *scary. My husband was definitely afraid because you don't know*
> *exactly what it's going to mean. I mean they were starting to say*
> *how treatable they think it was and that this is what we're gonna*
> *do and we think we're gonna get all of it, but there's no guarantees*
> *with that. So I think dealing with that emotional part.*

As this phase ended, the caregivers came to terms with these realities and

prepared to manage the changes that were to come as treatment began. Like the previous

phase, the diagnosis phase presented changes in the amount of uncertainty because the

caregivers began to anticipate the treatment and the effects it would have on their loved one. In addition, they voiced the thought that the treatment may not be successful.

Early Treatment

The early days of treatment (which can include a surgical procedure and the beginning of concurrent chemotherapy and radiation therapy) were a time when the caregiver was in a whirlwind of doctors' appointments, radiation mapping, possible hospitalization of their loved one (if a surgical procedure was included), and a barrage of information about what was to come.

In Mary's case, the first hurdle was the period of time surrounding her husband's surgery:

> *And then surgery was quite difficult. He was in the hospital for five days. I had to take off work for that and you know, that was just stressful driving down to Maryland two or three times a day and kind of backing up the care because he was on pain medication and in a lot of pain and couldn't talk, had trouble eating. You really needed to be like the advocate for the patient.*

It is in this phase that the first physical changes appear. The patient begins to need physical care and the caregivers begin to witness changes in their loved one's appearance and physical function. Difficulty eating and speaking introduced changes in their ability to relate to one another. This phase also introduced the alteration of the physical and emotional aspects related to sharing a meal together.

Once healed from the surgery, Mary's husband began the eight-week chemotherapy and radiation therapy regime. This regime consisted of three rounds of chemotherapy given along with the eight weeks of radiation.

Late Treatment Period

From the third or fourth week of the eight-week treatment period, the snowball of side effects and physical changes began its rapid descent. Side effects were greatly increased, pain was increasing, the ability to swallow was diminished, and the patient became increasingly fatigued (both physically and mentally). With the treatment came the ever-changing challenges of caregiving:

> *Chemo and radiation is just very long. It starts out pretty okay, maybe even the first two weeks not that much symptom-wise and then it just – it just piles on, one thing after another. It keeps getting worse. It's hard to swallow and then it's hard to eat and you can eat no food. So we were making shakes and Ensure and we had to order this stuff called Benecal, which adds calories to everything you eat. Managing that was very challenging.*

As the treatment continued, the side effects of Mary's husband's treatment became more intense and more difficult to manage:

> *As the weeks went on it was very trying. There was pain, dryness, unable to eat and so many medications. The chemo, all the anti-nausea medicines, feeling nauseous, being sick*

The side effects seemed to take over the most important parts of life. One of the areas most profoundly affected was the patient's ability to eat:

> *I mean it affects so much of your daily life. If you can't taste food, if you can't – swallowing is difficult. That is a big impact on the enjoyment of life… This was like taste and food. It affected all day every day because you eat three meals a day or you snack or you like to go out, all those things were affected.*

Post-Treatment Period

As the symptoms related to the treatment began to finally subside, Mary and her husband began the slow crawl back to their pre-treatment lives.

And then the slow climb back too, the same way, just slowly starting to be able to maybe taste something or eat something he hadn't had before.

The amount of change experienced by the caregivers varied considerably. The variation was determined by the types of changes the caregivers encountered, the timing of the changes, and the availability of strategies to manage that change. In the pre-diagnosis and diagnosis phases, the changes were minimal and the participants were primarily managing uncertainty related to the diagnosis and the upcoming treatment. As the treatment progressed, the number of changes increased as did the intensity of the changes. By the late treatment phase, the amount of changes and their intensity meant that caregivers must use all their strategies in order to cope.

As illustrated above, change and its management are a constant in the lives of these caregivers. As this core category emerged, it became clear that there were two other categories related to Managing Change: Types of Change and Strategies for Managing Change. Each of these categories is described below

Types of Change

In this study, the caregivers often made reference to different types of change that occurred to them and their family member. These types emerged from the participants' description of the process they had gone through as caregivers. Each subtype is seen as a dimension of change.

The category of Types of Change includes subcategories of Changes to Life Patterns, Witnessing Physical Changes, Relationship Changes, and Increased Uncertainty.

Changes to Life Patterns

The introduction of cancer into a person's life alters many of the established patterns of daily routines and patterns of behavior. In the case of caregivers, the dimensions of this subcategory include change related to daily schedules, food preparation and feeding, and socialization.

Changes to Daily Schedule

From the diagnosis onward, the increased number of visits to doctors and treatments presented enormous changes for the caregivers. Balancing work schedules and childcare needs with extended hospital stays, chemotherapy appointments and daily radiation therapy often required changes in the established life patterns of the caregiver. For Ida, caring for her husband of seven years, and Mary, there were lost workdays or the need to use all days off to accommodate doctors' appointments:

> *Ida: It's the time that it takes; the time. It's very hard for me to…like I say if I don't take an extra day off I don't really get a day off. When I'm not at work or running to doctors visits.*
>
> *Mary: I just – look back now and I just can't believe that we did all that and survived all that, the job and dealing with the cancer. Those are huge changes that any – either one would be overwhelming in a person's life, but to do them both at the same time is pretty crazy. And there were days of being completely stressed out from work and dealing with the cancer and just collapsing at home kind of thing.*

The demands of caregiving meant they needed to eliminate other activities (hobbies, book clubs, etc.) focusing their lives solely on the caregiving role, thus altering a previously established life pattern.

> *Ida: I'll tell you the first…when he was going through the treatment, probably the first year I neglected my family. I have two children and four grandchildren and my mother and sisters,*

*and I didn't have time. I did what I had to do, I didn't have time...I
missed a year of them growing up and everything.*

*Mary: It completely takes over all aspects of that 'cause it's
priority one, it's front and center of every day of your life. Other
things that were important or you thought were important kind of
fall by the wayside.*

For Leon, the burden of traveling to daily treatments meant long hours of travel
every day:

*Leon: You know, you ride the way to Baltimore, 88 miles to get one
– to get treatment, and then you've got to go there… yeah, every
day… I went there every day.*

For those who were able to leave home there was Hope Lodge, a facility close to
the cancer center operated by the American Cancer Society to house patients and their
caregivers during treatment.

For Cheryl, leaving home and staying at Hope Lodge reduced her need for travel
but presented other challenges. For her, being away from home was a difficult life pattern
change:

*Being away from home because we stayed at the Hope Lodge
where she had her treatment. And we're pretty much family-
oriented around here so just being away from home was the
hardest for me. Being away from home. Even though we came
home on weekends, it's still just nothing just like home.*

In Betty's case, the housing needs of her brother meant that he would be moving
in with her. For a divorced woman with no children who was used to living alone, this
life pattern change was dramatic:

*So I'd been alone for two years, so to speak. And then he came in.
And so, yeah. Not having my space… Just the chaos because*

48

you've lost your pattern of life, you know, the pattern that you knew is not there. It's just a whole new unfamiliarity is there that wasn't there before.

Betty also described the effect these changes in life pattern have had on her mentally:

It's a disruption to your daily life, energy…and a disruption of your peace of mind…Is there anything I'm doing that I shouldn't be doing? Is there anything that I could be doing that I'm not doing?" There's just not that peace mind, that questioning all the time

Food Preparation and Feeding

Managing the life pattern changes related to food preparation and feeding was a major concern. Mary spent a great deal of energy trying to manage the rituals of mealtimes together as a family. As a result, she had the added task of preparing special meals or shakes for her husband while also preparing food for everyone else.

Sometimes it was difficult to do that; trying to make dinner, always having to make a shake for him right in the middle of trying to get dinner on the table.

Leon's cousin refused to eat a balanced diet and rarely if ever shared the family meal. Leon's wife would prepare the meal and the cousin's refusal to eat it was disruptive to the household:

…you do get real disgusted at that, that he won't eat any you cook – he only eats what he wants to eat and that's junk. And that makes you very – very upsetting just to see the struggle he went through with all the surgery and he's getting better and he just turns to eating junk. And it just – it's just a bad feeling to watch it. I want to say a lot of times, just shake my head like, wow, you're eating that

Ida spent hours and a great deal of money trying to manage her husband's diet, an attempt that ended in frustration.

> *When he first started healing and he could swallow, I probably bought 20 cookbooks and bought all kinds of food and tried this and tried that, and anything that was soft, this, that, and the other. My grocery bill was going out the roof and the food was going in the trash, because if he did eat, he only ate a teaspoonful of each thing.*

Socialization

One of the most difficult life pattern changes for these caregivers was the change to their social lives and the social times they spent with their family members. Food and the ability to eat are central to many social events and occasions. Whether it is a holiday meal or coffee with friends or preparing dinner together while you talk about your day, each of these was an important part of socialization. For these caregivers, the life pattern changes related to food were intense.

Ida talked of the loneliness of eating alone. Mary spoke of the shared ritual they no longer had and the sense of loss because she no longer can prepare the foods he used to enjoy.

> *Ida: It is very, very nerve wrecking, especially with the throat cancer, because there's lack of communication. It's a lonely caregiver situation, because they can't eat, they can't talk, they can't really…he still won't go anywhere even now… as a caregiver, it just wears you out; and like I say there's a lack of communication and whatever, because you can't sit down and eat a meal together, you can't sit down and talk together, it took me a long time to get used being able to eat with him in the same room because of him coughing up the phlegm all the time.*

> *Mary: The frustration of not being able to enjoy something we typically enjoyed, which was eating and drinking as well. That wasn't appealing, he didn't like that. That was kind of part of our thing and so that was sort of upsetting that that was gone… It was very frustrating. Because he couldn't enjoy the stuff I was making*

or if the kids weren't home then it was just me, then I'm like I barely even want to cook if it's just me; so then I would just make a grilled cheese or do something like that. So it was kind of a drag to not be able to enjoy that part, and not be able to do something for him that he always did enjoy."

Betty related the difficulty she faced in the life pattern changes related to being her brother's caregiver:

The disruption was mainly the responsibility of caring for him and the disruption of not having my free time, not having my free time, somebody in the house, not having people over because my brother's living in the living room, you know? There was definitely disruption in my social life… I mean I know that sounds kind of callous but I kind of want my life back because when you start taking care of somebody, I don't know, you feel like you've given your life away.

In each of the above cases, the ability (or lack thereof) to eat had a profound impact on both the physical and emotional lives of the caregivers. The need to feed their family member transcended the nutritional demands and impacted their ability and opportunity to engage in social activities. For some, it was primarily related to the preparation and planning of meals and for others, it consumed not just the meals but their social lives as well, leaving them with a sense of isolation.

Witnessing Physical Changes

Another subcategory of type of change for caregivers to manage was witnessing the physical change in the people they cared for. The patient's pain and fatigue were of great concern to the caregivers, as was watching them lose weight as the treatment progressed. Each of these physical changes provided challenges for the caregivers as they saw their loved ones suffer.

For Leon, the fatigue experienced by his cousin caused one of the most frightening episodes of his time as caregiver.

> *He was scheduled to go back to Baltimore for chemo, and he just couldn't make it to the bathroom and the bathroom was only two, three feet from his bedroom and he could barely make it. So I had to sleep in the basement to watch him in case he fell, and he did – did fall several times*

For Ida, the fatigue her husband experienced was also part of what she describes as "the worst day" of the caregiving experience.

> *He had not had over two or three minutes of sleep at one time for two weeks, because of the pain and phlegm that keeps building in your mouth. And like I say I had to stand at the sink and hold him up while he got a couple cans of food through the feeding tube. And he was just so miserable that we didn't know what to do. People just don't know, it took him I would say a good six months to a year before he could sleep over an hour at a time. Even how he doesn't sleep over probably two hours at a time*

As treatment progressed, the fatigue made it challenging even to get her husband across the cancer center, as he would stop to nap on benches along the way.

> *…Because he was so tired and so sleepy, 'cause he didn't get any sleep he was walking, he had had radiation and we have to walk all the way to the other end of the hospital. So I told him I said, "I'm going to stop and get a cookie and then get a cup of coffee. I'll meet your right there." And I go… I said he better be here, and he had sat down on one of those little benches on the way to radiation and fell asleep.*

Betty found watching the physical changes agonizing. She described her brother's appearance and it's "ugliness" using it as a metaphor for the whole experience:

> *It's almost like combat, you know? It's almost like – it's almost like combat. I'm, like, seeing a person being inflicted with pain. I see his skin burning, I see his waste going from him and, you know, as far as witnessing it, I mean, all I can say is I just kept thinking*

how ugly it all was The ugliness of watching someone in pain. And he was turning ugly and it was coming out. His skin was burned, he wasn't talking, he was having trouble hearing, he was having, you know, tinnitus. His legs were going numb. He was changing physically. All his teeth had been taken out. You know, I would, like, turn to him and talk and he would be – I don't know, his skin would hang in a certain way and he was getting these sores and just looked – it was just so ugly… I mean, as far as witnessing, I just kept thinking to myself at times this is so ugly. It's all so ugly.

Mary experienced how the treatment affected her husband's ability to taste and swallow and the frustration that came with trying to cope with these changes:

It was so much bigger than what someone would think of as like maybe he has a sore throat and he can't eat. Saliva production was down, it hurt to swallow, it hurt just to be, but swallowing was way worse. His taste buds were affected so foods that, even bland foods where you would think, "Oh well that would probably be okay," tasted terrible. Mashed potatoes tasted terrible, and I'm thinking before we started, "Oh he loves mashed potatoes; that will probably be something I'll make a lot; it'll be easy to swallow." But they tasted terrible to him, because of the taste bud situation, just changed and there's a reduction of sensitivity; but certainly he lost taste…and then when it came back it was weird, because we had a whole week where everything tasted salty. After treatment had ended, the taste buds I guess had started to sort of reawaken or revive; then that was weird. Even milk shakes were tasting salty; so we were trying to find a balance there. It was just very real, and of course you couldn't go out to eat; that was just practically impossible. Because he couldn't eat any foods at all for a long period of time; he was only drinking.

As the treatment progressed, Mary found it hard to watch her husband lose weight from his already lean frame:

It was difficult to watch him lose so much weight. I think he lost between 20 and 25 pounds. That was just unbelievable, because in that very short time to watch him lose that much weight.

For Ida, her challenge was her husband's refusal to try to swallow and the excessive amount of secretions he couldn't manage. She even found it hard to be in the same room with him when she ate.

> *You can't sit down and eat a meal together, you can't sit down and talk together, it took me a long time to get used being able to eat with him in the same room because of him coughing up the phlegm all the time.*

Reflecting on her experience, Mary described the rollercoaster that was the treatment experience:

> *In the beginning of treatment I think we were very much, "Let's get going. Let's get this started. The sooner we start the sooner we finish. We're ready; we're ready to handle it."*
>
> *And that goes for a couple of weeks and then the grind, and the reduction of saliva and taste and ability to eat, and then you kind of get a handle on that; then symptoms escalate. It's the chemo stuff and the radiation is so cumulative so it just kind of keeps getting worse, worse. Even the last day of treatment, the weeks after that were some of the worse times.*
>
> *And looking for a light at the end of the tunnel and really feeling like are we going to see it soon or not, because it was getting to be really a drag, really long. And then there's that slow, "I think I'm hungry for this." Or, "Oh my God I think I can taste that." Or not feeling like you want to throw up; that's a triumph right there, those kinds of things.*

Cheryl missed the mother who was always in the kitchen but now can't get off the couch:

> *You know, because – like growing up we would call our house the Kool-Aid house. You know, we would call our house the Kool-Aid house. My mom had everybody. Kids in the block. There were cookouts in the backyard. And every holiday, you know, my mom would cook for everybody. And just to see her just, like, not able to get up and just wash her face in the morning. It's hard for me to see her that way because, like I said, she's a very independent woman. It was hard for me to see her that way .*

The physical changes to the patients ranged from fatigue to disfigurement to losing the ability to taste and swallow. From the earliest days of treatment when the physical changes were minor to the later days when these changes became dramatic and life altering, the caregivers contended with these changes as they attempted to carry out their roles.

Relationship Changes

Some caregivers experienced changes to their relationships with the patient. For some the new role involved a change to an existing relationship and for others it involved creating new ones altogether.

For Leon and Betty, their roles as caregivers involved the establishment of new relationships. Because of this, they experienced the most change among those caregivers in the study. Leon took on the care of his cousin, taking a distant relationship and evolving into a full-time hands-on caregiver. For Betty, her relationship with her oldest brother also changed from a distant one to a daily hands-on caregiver. In both cases, the patient moved in with the caregiver, establishing new relationships for all involved.

Betty said:

> *We kind of have to switch roles. I mean all of a sudden I'm taking care of my older brother? That's -- that was a change; that was a big difference. So I mean at first he just -- you know, he wasn't listening to me, so to speak, and it was a little -- the relationship was a little more combative than what it had been before, of course.*

Cheryl and Ida experienced a drastic change in an existing relationship. For Cheryl, there was a close, longstanding mother-daughter relationship but the mother's illness caused a role shift in which the daughter became the caregiver. Cheryl described

her mother before her illness as always cooking and taking care of her and her four sisters as well as the surrounding neighbors. During the illness, she could no longer fill this role and became completely dependent on Cheryl for everything.

For Ida, her husband's illness and treatment permanently changed their relationship as man and wife:

> *It's like we don't want a real good connection; it's like we do, but we don't, because he likes to take care of me. There's never anyone anywhere do anything you know; and real companionship… as far as sexual, that's gone… We have a nice compassionate relationship, but there's no sexual relationship. We're both probably more withdrawn, and that's probably a little bit of depression on both of our parts. And the less you do together and the less you're involved with the community and your family, I guess the less you have to talk about.*

Ida and her husband no longer have the intimacy of a married couple. The role of caregiver had all but replaced the role of wife.

Mary cared for her husband of 20+ years using the same patterns that had sustained them before he was sick.

> *When this came…yeah I would probably say it pretty much stayed the same. I mean that's just kind of the stuff that I do. I feed people and I take care of them when they're sick and I'm just that sort of nurturing type person; and it was what I did full-time when you stay home and take care of the kids. So yeah I would say that did not change that much; just on a bigger scale and a more important factor. This just wasn't, "Are you eating your vegetables?" This was, "You've got to have enough calories or they're going to put you on a feeding tube." Or, "You're going to be in the hospital." You know something like that; it's just a bigger risk or a bigger deal. But I don't feel like the relationship changed much, or my behavior changed much; that's pretty much the way I am anyway. Nag and boss; I'm very bossy. I did…that wasn't hard for me to tell him what to do with that; that's what I do sort of.*

Mary's role was not drastically different from before her husband's diagnosis. She was responsible for the care and feeding of her family but now the stakes were higher.

For each of the caregivers, change was a constant. For some, the changes were wholesale. For others, the change involved a reassignment of their existing roles. For those whose preexisting role was able to absorb the new responsibilities of a new type of caregiving, change existed but not to the degree that it did for those who had greatly altered or no previous relationships.

Increased Uncertainty

From the earliest moments of the pre-diagnosis phase and throughout the treatment and post-treatment phases, the caregivers experienced uncertainty as to what the future will hold. The increase in uncertainty began at the first sign of change, (i.e., pre-diagnosis) and continued throughout the caregiving process. The uncertainty was constant but came from many sources. Primarily, the caregivers expressed uncertainty related to the disease and the possibility of a cure and the treatment and what the experience would hold.

Mary talked about the treatment period and the sense of never knowing when or if they would be done with the cancer experience:

> *...as the weeks went on it was very trying. There was pain, dryness, unable to eat and so many medications. The chemo, all the anti-nausea medicines, feeling nauseous, being sick - those kinds of things I think really started to weigh on his mental state. Feeling down, feeling depressed, feeling like when is this ever gonna be over and if it is over, this treatment part, what is that gonna mean? Are we done, are we not done, you don't know.*

Ida talked about the value of not knowing what was coming and how it could

have affected the choices they made:

> *I think you're better off not knowing. Because I'll tell you as miserable as he was towards the end of the treatment had he known what to expect if he had really known how it was going to be and what to expect I really don't think he would have gone through with it. There were days when we both could have just got on the floor and cried as miserable as he was, and wondered if it really was going to be worth it.*

Fred also expressed uncertainty as to the outcome and whether the process had

been worth it in the end:

> *Well, you could see the effects of the treatment. And you're, you know, you've got in the back of your mind that this may or may not work. So you're saying, yeah, we're going to go through this. And it's so bad, and you don't even know if after you get over it, if it's done any good or not. Because you've got some of those people that you've talked to that have gone through some of these treatments, and it didn't work. So you're thinking that well, you know, this is, this is an excessive amount of strain on her. And, you know, you don't even know if it's going to work.*

Mary, too, was uncertain as to what the experience would be like and how she

would cope:

> *So then when I look back, I'm just like, "Oh, my God, all that - all the stuff plus the stress of concern, of, you know, is this gonna work and how sick is he gonna get and how bad is the side effects and the treatments gonna be?" 'Cause those things were all very - different people respond different ways, so you didn't really know how that was gonna be, but yeah, it was crazy.*

Ida reiterated the feeling of never knowing what was to come:

> *Because you never know what tomorrow's going to bring. You know you just live on pins and needles all the time.*

Betty also expressed lingering uncertainty as to the physical aspects of providing care, pointing out that caregivers often lacked the experience required to develop the instinct to know when something was not right:

> *Well, of course, not knowing. Not being a trained healthcare professional at all. What is serious? What is not? You know, take your temperature. Take your temperature. Um, is it supposed to look like that? Are you supposed to feel like this? Oh, my gosh. You just threw up. Should we go to the hospital? That was the thing. When do I go to the emergency room or not?*

In addition to the sense of uncertainty related to the physical aspects of the treatment and the chances of success, other caregivers, primarily those who had not had an existing relationship with the patient, experienced uncertainty related to their understanding of the patient. Betty expressed concern about her lack of insight related to her brother and his emotional needs:

> *Even mentally, I kept thinking I don't even know if I'm saying the right thing to him. You know, does he need tough love? Does he need – you know, he seemed to be the kind of person that I didn't – you know, if I felt like he needed a pep talk – he's not gentle person, really. Kind of a rough guy.*

She also talked about her lack of confidence and her concern as to the patient's reaction:

> *I don't know. There's just so – there's just that - that confidence level that I'm not sure I'm doing this right. You're thinking of the patient's frustration level and making them comfortable, what is gonna be the reaction. Is - you know, is it gonna be a waste of time?*

In each instance, the caregivers described the various sources of uncertainty related to the role of caregiver and the treatment experience. For some, the uncertainty is

solely related to the treatment and the disease. For others, the uncertainty extends to their lack of insight into the patient and the patient's emotional needs.

Strategies for Managing Change

The second other category discovered in this study involved the strategies used by these caregivers to manage change.

These men and women used a variety of strategies to manage the many types of change introduced into their lives by this new role of caregiver. These strategies included the subcategories of controlling life pattern changes, utilizing the quality of relationship, and managing stress.

Controlling Life Pattern Changes

This subcategory strategy could best be described as "keeping it normal." As part of their role, caregivers had to manage the life pattern changes introduced by the disease and its treatment. For some, this strategy is an attempt to manage control over the disease and treatment-related changes and protect their shared life. For others, the control issues occur between the caregiver and the patient as they try to determine who will be the driving force in the relationship. Two dimensions of this subcategory were identified:

Control Over Treatment-Related Changes

For Mary, her ability to control her husband's care was nothing but an extension of the dynamic that had previously existed in their 23-year marriage. She maintained control over the areas she had always been responsible for: keeping everyone feed, healthy, and on track. The difference for her was that the stakes were higher. Her primary need was to control the impact that the cancer was having on the normal patterns of her life:

I guess I just felt like I didn't want our whole lives to be about cancer or [patient] being sick or that kind of thing.

Mary tried to keep things as close to normal as she could:

So we tried to maintain as much normalcy as we can so that the cancer wasn't completely running our lives. So we still had to have Christmas, it still had to be decorated. I think that's what [Patient] wanted also was just to sort of keep as much of the same stuff that we normally do as possible. So, we continued to eat meals together, even though he wasn't really eating.

Control Within the Relationship

Fred took a somewhat passive approach to control. He felt that giving his wife control over the treatment experience, including the choice of where to be treated and what treatments to consider, would be better for her. As he described her personality and her approach to seeking information, it was clear that he had cast himself as a supporting player. Even through the treatment period and their days living at Hope Lodge, he actively bent to her will to avoid unnecessary conflict and stress. These choices reflect a previously established pattern of interaction between Fred and his wife:

You try and help her and do all this stuff as much as possible, but you know, you kind of get, if she's in a bad mood, you just give her as much room as you can… But I just figured well, it's her decisions and I will go along with it and since there weren't very many stress points i.e. because of the job etc. situation, it just made it easier.

Although, at times, I wasn't much of a teammate. I was just rolling over and saying, okay, we'll do this. You know, what you want to do. Team I figure, we're pushing the same, well, we're going to the same goal. Just that the, I guess I wasn't in an aggressive mode. So, but that's not something you want to really do.

Ida also gave control to her husband as much for his benefit as her own:

[Patient] and I have a pretty good relationship as far as talking about the treatments and this and that and the other. I basically let

him call the shots because if [patient] was hateful and contrary to me, I probably could have never made it through this.

Leon battled with his cousin constantly over the basic activities of daily living, attempting control with limited success. His cousin was resentful of Leon's intrusion, but Leon felt it was his job as caregiver:

> *Well, that was kind of – for instance, he needed a cane to walk with, 'cause he just got kind of clumsy when he started taking chemo. But he really didn't want a cane. He didn't want you to open a door for him. At first it was kind of difficult, because he didn't want you to help him do a lot of things. He didn't want me to monitor him going back and forth to the bathroom, even though he fell several times… In fact, one time he fell and he would not let us help him get up. He crawled four feet to get back to the bedroom, rather than let me help him. So it was kind of difficult at times… Same thing with, you know, food. We'd fix food and he wouldn't eat it. So that became another problem, because my wife didn't like the idea she had to fix food and he wouldn't eat it, so we kind of changed that around. I just fixed it, rather than have her keep saying something about it. I just fixed his food.*

Utilizing the Quality of the Relationship

At the beginning of this study, the researcher's intuition was that the type of relationship (i.e., husband, wife, cousin, sister) would prove to be an important factor of the model of caregiving. As the study progressed, however, it became clear that the part of the relationship that was most important was not the type but the quality. For the purposes of this discussion, "quality" is defined as a familiarity and closeness between the caregiver and the patient and the caregiver and the caregiving role. This familiarity and closeness of the relationship appeared to confer an advantage to those who had it and acted as a stumbling block for those who did not.

Throughout the treatment phases, Mary's household continued on in its established pattern. The solid foundation she had established over 20+ years was able to absorb the changes wrought by the disease and its treatment. The high relationship quality between Mary and her husband provided her with a built-in strength and framework within which to act as a caregiver:

> *A lot of people you got to make it through college or early part of working or raising kids, money; all the things that come along that are tough on relationships. When you make it through those different phases it far strengthens our relationship. So when something like this came along, I think we felt like, okay, here's what we gotta do. We gotta do these things. And it was not a fall apart situation or a bland situation, which I know that these that come along and illness and cancer would be one of them, really present a challenge for people… I think we relied on the strengths we already had built from so many years and through so many phases.*

For Mary, caring for her husband during treatment (and starting a full-time job on the day he was diagnosed) was simply an extension of her role as wife, supporting him just as she always had during their 20+ years of marriage. Now she had to support him through this difficult time:

> *Any kind of sickness or illness, there's a lot of unpleasant parts to it. That's just the way it is. You're the person who's the caregiver, and you have to deal with those things and clean up and move on, make it nice and, of course, make the person not feel – it's not their fault, it isn't like they did this on purpose. You have to put them at ease, make them feel comfortable again.*

Fred was a husband and father who cared for his wife of 39 years. He also felt that the experience of being a caregiver hadn't changed his 39-year relationship with his wife. He described the benefits of knowing each other well and how this valuable insight affected his approach to being a caregiver:

> *After all this time, it's hard to – I think we've gotten pretty used to each other and can anticipate what's going to cause a problem and what isn't going to cause a problem. I just kind of took the position that well, if she was irritable or something, it wasn't really her, it was the fact that she is under a lot of stress from the treatments, from the fact that somebody told you look, you have cancer…if you have made it that long, you have kind of figured out everybody's irritation points etc. So if something comes up you either realize that they are doing this on purpose or they are not and let's not make a deal about it. You get to know each other, needless to say, pretty well so you know what may irritate and what may not irritate. And unless you were looking for a fight or something, you kind of stay away from the bad areas.*

Betty was a single woman caring for her previously estranged brother. Caring for her brother caused her great anxiety and uncertainty as to how to appropriately provide his care:

> *Am I gonna make him angry? You know, is [patient] going to be angry because I made him go to the emergency room, wait and they said go home... just worried that - that I would do something detrimental to him, or not help him the correct way. Even mentally, I kept thinking I don't even know if I'm saying the right thing to him… just that uncertainty, not knowing and not feeling peace.*

As illustrated above, high relationship quality appears to provide these caregivers with a higher level of confidence in their ability to take on this role. The in-depth understanding of the needs, likes and dislikes, and temperament of the person being cared for is an important advantage for those who have it. For those who don't, the process of becoming a caregiver presents greater changes in both the type and amount of change experienced.

Managing Stress

Managing stress was a constant challenge for all of the participants in this study. The primary dimensions of managing stress were getting away and allowing support.

Getting Away

This strategy was employed by each of the participants in differing ways. For some, it was a physical act: going for a walk, going shopping, or going to the gym. For others, it was a mental removal: crafting, reading, watching football, or going to work. Betty talks about the importance of physically removing herself from the caregiving situation:

> *Just to get away from the environment, because when you're here, you're just - you know, I'm always thinking of what else can I do. You get away and there's none of that. You know, there's none of that…you can be completely removed and completely out of the situation. I mean, it's much better.*

For Ida and Mary, work was an outlet and a way to get away from their roles as caregivers:

> *Mary: Work was actually, I guess in some ways an outlet as well as a stress because when I was at school it was hard to think about the cancer and things because that job is so demanding. I have 25 kids in my class who all needed me and so in some ways that was a relief from the cancer… I did sorta have that outlet and that not thinking about cancer for some hours of the day because my job is so demanding and kind of all consuming. Sometimes I think that was a good thing for me 'cause I was not able to be completely swept up in cancer 24/7 'cause I had other things I had to do if I was gonna do this job.*

> *Ida: Some days it's exhausting and I would rather not go, but other times it was an outlet to get out of here. Especially with going in the office and learning a new job - while I was there I didn't have to think about it because I was busy concentrating on new things and learning a new job…sometimes work is just a release to get*

away from it. I mean I was glad to go back to work when I went. I stayed home with him three months through the liver transplant and almost three months for the cancer treatment, so by the time I went back, I was ready to go back.

Fred found that taking regular walks would help relieve tension and help him get through the day. Also, getting out and doing errands helped pass the time:

> *What I would, what would give me some help is taking these walks I would take. And that would, with treatments were until, I'm trying to think. Until eleven o'clock. I would, I would go out and head on back to the two stadiums down there. And the reason I headed down there is you could actually walk without having to stop at every stop light…So I would go down there and do four or five laps around the stadium every day. And that kind of, you know, get some of the tension away from me. If, I can't, I wouldn't say there was any tension. But for me, it just, you know, I like to get a little bit of exercise all the time…And that seemed to set me up for the rest of the day… just even getting away. Maybe take a drive out to Wal-Mart and pick up some, my wife is on Boost and stuff. But you know, my wife was sleeping most of the time. She took naps in the afternoon before dinner. And that would be something else to do.*

Mary also found that she could remove herself mentally to help deal with the fear she felt about her husband's diagnosis:

> *I felt like I sort of had to kind of remove myself from being frightened about the whole cancer diagnosis and what that could mean. I just couldn't get - I couldn't get caught up in that. I had to do the work. I had to concentrate on those things so I felt like I could not get lost in the oh my God, my husband has cancer. What am I gonna do or what's gonna happen down the road… I felt like I had to concentrate on the now. We need to deal with this right now and not get too caught up in the other stuff. And not get too emotional. Like I found when I told friends… diagnosis and we'd maybe start to tell people, I felt like I was so - like almost removed from it. Everyone was so shocked and I just felt like it was just not so shocking any more. I guess I was so used to it or whatever, but I couldn't get caught up in the tears and all that emotional. My mother cried when I told her, but I never did. I just felt like there was no time for that. I had stuff that I had to do to take care of this*

and get through this as best we can. That's what I have to put my energy in. I guess I couldn't go the other way. I guess that's maybe just the way I am.

Ida talked about the importance of making time for herself:

Tomorrow is my day. I'm just going to sit around and craft and do whatever I want. Tomorrow is my day, because Thursday is another day to take tests in Baltimore. And that's the only way I can work it. Every day is spaced out into someone else's day, and once in awhile I take one for myself. It's the only way I can do it. If you don't, you go crazy.

In each case, getting away physically or mentally, or both, was an important strategy for managing change for these caregivers.

Betty stated that:

There's that uncertainty: uncertainty that he's going to die, uncertainty of if he's going to die, is it going to get worse, is it going to get better?

Allowing Support

As caregivers, these individuals had many offers of supports from family, friends, fellow caregivers, and co-workers for emotional support and help fulfilling care tasks.

For Cheryl, caring for her mother during treatment meant leaving home and living at Hope Lodge. It also meant taking on total care of her mother (i.e., bathing dressing, and feeding). She had the support of her immediate family to help her through the caregiving experience:

Primarily my family. We didn't really need to use any outside resources 'cause like I say I had four sisters and we had – our offspring are mainly grown. So with my family we could just balance everything out. We didn't really have – we didn't use any outside resources besides the Hope Lodge to stay in Baltimore

67

For Ida, the treatment period just extended her role as caregiver, having cared for her husband during a liver transplant five years earlier. She and her husband have known each other for ten years, have been married for seven, and he has been sick for five. By the end, she saw her role not as wife but as caregiver. The core of what had once been an intimate relationship had been replaced to a full-time support role centered on his physical medical needs. It was not until the treatment was over and he regained a little bit of independence that she finally sought support from other family members, a fact she now regrets:

> *When he was going through the treatment, probably the first year I neglected my family. I have two children and four grandchildren and my mother and sisters, and I didn't have time. I did what I had to do, I didn't have time.*

Her support came from family, friends, and neighbors (a previously established support network):

> *Well his sisters are very supportive to me and I have a sister that you know as far as moral support, you know …. And like I say his one sister if I need a break, she's in Florida right now, but when she comes back if I need a break and she… a check or something like that she will take him and give me a break. And I can talk to her; I probably talk to her about everything more than I do anyone else.*

In allowing support for herself and her family, Mary was surrounded by close friends who would provide her with both practical and social support. She found, however, that, at times, she needed to limit it:

> *My really close friends called probably a couple times a week, and people stopping in, dropping off meals was nice to sorta catch up and a chance to thank people for all their help and stuff like that… We had such good support with our friends on meals and my friends always called me each week like, "What's your week like?*

Which days do you want them?" Or, you know, "Are you sick of people coming to your house with meals and you don't want anybody to come?" It was very flexible and not – I know other people who've gone through that 'cause we've had several people in our neighborhood deal with cancer, and we make the meals, and it can be a burden in itself. You got all these people coming over and then you gotta get the dishes back to them and people keep making food.

Mary also had friends who encouraged her to get out and socialize and family members whom she allowed to support her. They provided her with an outlet and a sounding board:

And everybody was, "Just try to come, even if it's for an hour. Don't worry if you didn't read the book." Just to sort of get with my girlfriends, have a glass of wine. Little bits of that, not a lot, but I guess I maybe didn't need a lot because I was that was my role all the time anyway so it wasn't a big stretch for me to do that. Being with the kids, the kids were really supportive, and helpful. Listening maybe about my day or something like that where I didn't really want to burden [patient] with that kind of stuff, "You won't believe what they did to me today." You know, but the kids, my daughter really wants to be a teacher so I'd feel like that was probably a good thing to have her there; a little sounding board to listen to just my stuff, my problems. And co-workers were very supportive with that kind of stuff.

The use of these strategies varied across participants. They were used by all but with varying degrees of success. That success appeared to be related to the access to various resources. For example, Fred, who was retired, was financially stable, had plenty of time to devote to the task, and had the benefit of a long, close relationship, managed the changes with little stress. Betty, on the other hand, expressed significant amounts of stress throughout the caregiving experience. She worked full-time, had a mortgage to pay, was used to living alone, and had no longstanding close understanding of her brother. For Mary, who worked full-time and had two children, the changes were

significant but her stress level was manageable. In each example, the resource that seemed to have the most impact was that of relationship quality. The utilization of relationship quality impacted not only the amount of change these caregivers experienced but how they managed to "keep it normal" and how well they managed stress. The categories of Types of Change and Strategies For Managing Change are interrelated. These interrelationships will be explored in the following chapter.

Conclusion

This chapter described the core category of Managing Change. The types of change and the amount of change were related to the phases of the treatment. The types of change were identified as were the strategies used to manage them.

In reacting to the changes in their life patterns (witnessing physical change, dealing with relationship changes, and increasing uncertainty), caregivers attempted to maintain normalcy, utilize the quality of their existing relationship with the patient, and manage the stress of caregiving by allowing support from others and getting away from the caregiving role both mentally and physically. This approach was easier for those who had a longstanding, close relationship with the patient. The utilization of this resource made it easier for them to manage these life changes.

The next chapter begins with a summary of the study findings followed by a discussion of the findings as they relate to previous studies. The rest of the chapter is a discussion of the limitations of the study design and the implications of the findings for theory development, policy, research, and practice.

CHAPTER V: DISCUSSION

Introduction

The goal of this study was to gain a better understanding of the process undertaken by the informal caregivers of HNC patients from the caregivers themselves, with an eye toward theory development. Analysis of the data produced a core category of Managing Change. Two other categories included Types of Change and Strategies for Managing Change. The subcategories of Types of Change included changes in life patterns (including dimensions of daily schedule changes, food preparation and feeding, and socialization), witnessing physical changes, relationship changes, and increased uncertainty. Strategies for Managing Change included controlling life pattern changes, utilizing the quality of the relationship, and managing stress (including dimensions of getting away and allowing support). Although the development of a theory was beyond the scope of this study, the study was a first step toward defining and beginning to understand these important categories. Thus, the aim of this study was to work toward building a theory of caregiving from the perspective of caregivers.

Knowledge of the caregiving process will improve the ability of nurses and other healthcare practitioners to better support and inform informal caregivers. This knowledge, in turn, should allow caregivers to provide a higher quality of care leading to fewer complications for the patient and enhanced quality of life for the informal caregiver (Schumacher, 2000). The information gathered from this study has the potential to be used to develop interventions tailored to this population, aimed at assessing their needs and concerns across the phases of diagnosis and treatment as they undergo the dynamic process of becoming caregivers.

Participants in this study included six family caregivers of HNC patients. In all cases, the patients had finished treatment and had no evidence of disease at the time the data were collected. Each participant took part in between one and three interviews, based on their availability. With the exception of one interview, all interviews were conducted by telephone at a time determined by the participant. A total of 14 transcripts were analyzed using Constant Comparative Analysis, revealing a core category entitled Managing Change, two subcategories entitled Types of Change and Strategies for Managing Change, and their respective subcategories and dimensions.

Theoretical Foundations

The theoretical foundation of this study was symbolic interactionism. This theory is based in the idea that people behave based on how they interpret the world around them. This interpretation helps them to understand our world and helps to give meaning to the people and things within it.

A number of other theories have been applied to the study of family caregiving in cancer patients, including stress theory and adaptation theory. This section provides a brief overview of the more common theories found in the literature as well as a discussion of how the emerging theory of Managing Change supports or expands on this existing work. The purpose of this comparison is to illustrate both the commonalities between the findings in this study and previous work and to illustrate how this study has added to our understanding of the caregiving role for this population.

Stress Theory

Stress is a concept mentioned regularly in the existing research related to family caregivers of HNC patients. Mah and Johnson (1993) used Lazarus and Folkman's theory

of stress and coping in their study looking at the concerns of family members of HNC patients. This transactional theory of stress describes it as the individual's appraisal of a stressor and his or her ability to cope with the stressor. The appraisal occurs in two phases (primary and secondary) that can occur simultaneously. Primary appraisal is concerned with the meaning that the individual places on the stressor as it relates to his or her own safety and well-being. The secondary appraisal is concerned with the implications of the stressor and whether the individual feels resources are available to deal with it.

If change is viewed as a stressor, then it can be said that there are some similarities between this previously developed theory and the theory that began to emerge in this research. In this study, it appears that the quality of the relationship between the caregiver and the patient may influence the meaning of the change in their lives (primary appraisal) and whether or not they feel they can handle it (secondary appraisal). The emerging theory stops short of asking how caregivers then attempt to manage those stressors and what impact the meaning has on those choices.

The emerging theory of Managing Change helps to extend our understanding of both the meaning of these various types of change to the caregivers as well as the implications of the changes on their lives. By further exploring what the stressors are and how the caregivers respond to them, we have a clearer understanding of the actual process and its consequences. In addition, by studying the strategies employed by these caregivers, it can be seen which resources are most important to them and how the availability of these resources affects the caregivers' perception of their role.

Adaptation Theory

Another theory that fits well with the emerging theory of Managing Change is Patterson's Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1989). This theory is a middle-range theory used widely in the nursing literature. It conceptualizes adaptation as the outcome the family's ability to deal with stressors. In the pre-crisis period, the stressor is impacted by existing resources and the perception of the stressor. The stressor is defined as "a life event or transition that produces or has the potential of producing change in the family social system" (McCubbin & Patterson, 1983b). Existing resources are considered to be the family's use of both community and familial resources. The perception of the stressor is the meaning the family assigns to the crisis. The crisis is defined as the family's inability to maintain stability in the situation. The post-crisis period centers on coping with the pileup that is the effect of managing changes and stressors over time and is affected by new and existing resources and the family's perception of the whole situation. The model takes place across time.

In comparing this theory to the emerging theory of Managing Change, there are certain similarities to the theory being developed in this study. The idea of change as being the source of stress is present in both, with the latter providing more specific areas of change. The strategies used to manage change are also alluded to in both, with the primary difference between the two being the inclusion of the importance of the utilization of relationship quality on Managing Change. One might also question the applicability of FAAR to a crisis that takes place over an extended period of time, i.e., the eight-week treatment period of treatment.

Discussion of Key Findings

This study was the first step in developing a theory, grounded in data, which explains the process caregivers of HNC patients go through to manage the changes introduced into their lives by the patient's diagnosis and subsequent treatment. The emerging theory, termed Managing Change, is composed of a core category (Managing Change) as well as two other categories (Types of Change and Strategies for Managing Change) described in the previous chapter. Each of these other categories has a number of subcategories, some with dimensions as previously discussed. They reflect the process caregiving that occurred and help to illuminate this process as it exists for the participants in this study. Like studies before it (Blood & Simpson, 1994; Mah & Johnson, 1993), this study identified that the process undertaken by these caregivers occurred across the phases of treatment. Mah (1993) described three phases including pre-treatment, treatment, and rehabilitation. Blood (1994) described six subgroups each defined by time from diagnosis ranging from two months to four years. In both cases, their findings support the observation that the period of time surrounding treatment is stressful for the caregivers. Unlike previous work, this study provides insight into the unique changes associated with caregiving and the strategies the caregivers used to manage them. In each case, the caregivers faced changes to their lives and the lives of their family members. Described below are four key findings from the study, which are discussed in light of previous research.

Change Came in Many Different Types

The changes introduced into the caregivers' lives came from many sources, including sources beyond the treatment itself. Changes to the health, appearance, and

function of the patient were also accompanied by changes in living arrangements, financial status, social interactions, and relationships.

A previous study of similar caregivers identified social interactions (Mah & Johnson, 1993) as an important area of concern for these caregivers. The authors indicated this concern was related to changes in family roles and responsibilities and the effect these changes had on interpersonal relationships with family and friends. Mah and Johnson's (1993) results are consistent with the study presented here but did not address any of the other changes identified by the participants in this study. The primary reason for these differences may be the fundamental differences in the samples and the treatment they received. In Mah's study, the sample comprised both caregivers and patients. In addition, the treatment received by Mah's sample was surgical only so the time periods described are pre-treatment (pre-hospitalization), treatment (hospitalization), and post-treatment (rehabilitation)**.** In addition, all of the participants were elderly and thus the caregivers had their own health issues, which often resulted in the patient needing to be placed in a rehabilitation facility after treatment. These differences could explain why none of the other types of change identified in this study were noted in Mah's study. The treatment period was spent in the hospital not at home so many of the life pattern changes would have been obscured by this change. Also, the need to place the patient in a rehabilitation facility may have interfered with participants' ability to feel any return to a degree of normalcy. In short, the participants in Mah's study had a profoundly different treatment experience than the ones described in this study. That said, identification of the importance of social interaction in both studies suggests that changes related to the

caregivers' need for social interaction transcended the clinical experience and had an important impact on this population of caregivers.

Changes in life patterns included changes to daily schedules (disrupted by treatment demands), housing needs (impacted by the need to either leave home or introduce a new person into the home), and food preparation (to accommodate the needs of both the family and the patient). Of the sources of change identified in this study, the disruption caused by the patient's eating difficulties was one of the most dramatic. It affected not only their ability to take part in the family meal but also their ability to engage in many areas of social interaction.

It has long been accepted that feeding is a large part of caregiving. Locher and colleagues (2010) conducted a study of the impact of the disruption of meal preparation and consumption in a population of older cancer patients. They concluded that this disruption caused great distress to both the patient and the caregivers, and this distress is consistent with the findings in this study. The frustration, confusion, and, at times, helplessness, expressed by the participants regarding the need to maintain the patient's weight and keep food intake up were present in many of those interviewed. Although Locher's study population included but was not composed entirely of HNC patients and caregivers, the findings resonated with this study. It is possible that Locher's results, although compelling, were affected by the mixed population of cancer patients and caregivers interviewed. In addition to the challenges presented by other cancers and their treatment-related nausea, lack of appetite, and other symptoms, the caregivers in this study also had to navigate through dysphagia, xerostomia, and excessive mucus production, so the burden presented by feeding and nutrition was even greater.

The Types and Amounts of Change Varied over Time

In two of the three previous studies of this population, the temporal aspect of caregiving was addressed. Mah and Johnson (1993) identified three phases (pre-treatment, treatment, and rehabilitation). Blood et al. (1994) identified six subgroups, dividing caregivers based on time from diagnosis (two to six months, seven to 12 months, 13-18 months, 19-24 months, 25-36 months, and 38-48 months). In this study, the treatment phases were determined by the participants and represented their interpretation of five distinct phases. It is not clear in either of the previous studies how the researchers came up with the time phases/subgroups. It is important to note that they found the highest amount of strain and burden in the first subgroup, which covered two to six months after diagnosis. This subgroup coincides most closely with the time period of the current study, supporting the idea that this time period is an extremely challenging one.

Utilizing the Quality of the Relationship Between Patient and Caregiver was an Important Strategy for Caregivers

Caregivers who had an established relationship before the illness tended to express less stress regarding changes related to the caregiver role. The definition of an established relationship is one in which the caregiver and the patient had a well-developed understanding of one another. The caregivers who had experience living with the patient benefited from their years together and their shared life experiences. In contrast, caregivers who did not have an established relationship or who had to alter a previous relationship tended to express more stress related to the changes. Schumacher et al. (2007), in a study of a mixed group of cancer caregivers, defined the quality of the relationship between caregiver and patient as mutuality. They found that a high-quality

78

relationship and sense of preparedness reduced the caregivers' perceptions of caregiving difficulty, even when they were faced with increased care demands. The caregivers who had this high mutuality expressed less strain regarding their ability to care for the patient. This finding is consistent with the findings of the study reported here. Participants who were caring for a family member with whom they had an established relationship were less likely to use language expressing stress and frustration than those caring for a more distant relative or one with whom they did not have an existing relationship. There could be a number of explanations as to why this appears to be the case. Based on the participants' descriptions, it seems that having an established relationship provided them with an existing template on which to base their caregiving role. In taking on this new role, they were able to use tried and true strategies to guide their choices. For those who did not have a strong, established relationship, they had to find their way through this new situation while also trying to build a new relationship with the patient that allowed them to do the work of caregiving. Establishing this relationship meant extra work and none of the sense of security that comes with knowing someone well when the need to make decisions arises.

Caregivers used a Variety of Strategies to Manage Change

Throughout the caregiver experience, caregivers used strategies to help them manage the changes they faced and, thus, they reduced the level of stress introduced into their lives by the caregiver role. Managing stress by allowing support and being able to get away from the role both mentally and physically were important strategies for these caregivers. Although previous researchers addressed sources of support (Baghi, 2007), they did not describe how, when, and why the caregivers sought support. As this study

has shown, caregivers not only sought support from many sources, but they also had to manage the support provided to them. Assistance from family, friends, and coworkers can require a great deal of management, and many caregivers find that sorting through all that help is a task unto itself. Some rejected the help as one more thing to deal with, while others assigned a family member to act as a filter to avoid having to answer phone calls and coordinate the support offered (e.g., meals, respite care). In addition to allowing the support provided to them, they were constantly providing support to the patient and trying to balance their needs with the patient's needs, all in an ever-changing landscape.

Allowing control was a strategy applied to many aspects of the caregiver role in this study. Caregivers had to negotiate with the patient over caregiving activities, with other family members over various role changes, and even with the cancer itself. For some, the greatest challenge was working with the patient to determine how much control the caregiver could have over the caregiving tasks. For others it was a question of how much control they would give to cancer to take over their lives.

Relationships Between the Other Categories

Types of Change and Strategies Used to Manage Change have many interrelations. How a participant used the strategies was often related to which types of change they were experiencing as well as which strategies were available to them.

Controlling Life Pattern Changes (a subcategory of Strategies Used to Manage Change) was made more difficult with an increased number of Changes in Life Patterns (a subcategory of Types of Change). When all three dimensions of Changes in Life Patterns were experienced (daily schedule, food prep/feeding, and socialization), controlling life pattern changes was challenging. For example, adjusting to the caregiving

role was more difficult for Betty than it was for Mary because the introduction of the new role of caregiver caused her to experience more changes in her existing life pattern, whereas Mary was able to subsume the role into her existing life pattern. Of the two dimensions identified for Controlling Life Pattern Changes (Controlling Treatment-Related Change and Control within the Relationship), the former seemed to be most related to Changes in Life Patterns. The subcategory Relationship Changes of the category Types of Change also made controlling life pattern changes more difficult. The use of Utilizing Relationship Quality (a subcategory of Controlling Life Changes) was not an effective strategy for those who had Relationship Changes, nor was it an available strategy for those without high-quality relationships. Betty did not have this high relationship quality established with her brother so this strategy was not available to her. Mary, on the other hand, had a well-established, high-quality relationship with her husband and this was a very important strategy for her.

Another type of relationship occurred within a single other category. For example, the strategy used by the caregiver was often determined by the availability of a certain strategy. Utilizing the Quality of the Relationship was only available to those caregivers who had high-quality relationships established with the patient. Allowing Support was a strategy that some caregivers were able to use while others lacked either the ability to use it or were not allowed by the patient to use it. Ida was not able to use this strategy because the patient refused to allow visitors. Getting Away was also a strategy that some caregivers embraced while others felt it was not an option for them. Ida was not able to use this strategy until long after treatment had ended. Initially, she felt too guilty to leave her husband and so her own mindset kept her from using this strategy.

The identification of these interrelationships both within categories and between categories provides the basis for the emerging theory of Managing Change. Further research could help to not only develop more dimensions of the existing subcategories but also provide additional evidence of these and other interrelated categories, subcategories, and dimensions.

Limitations

In this section, the limitations of the study and its design are discussed, including characteristics of the sample, the setting in which the data were collected, use of the telephone to collect the data, the researcher's ability to use the components of grounded theory, access to participants, and timing of data collection within the treatment experience.

Characteristics of the Sample

The sample used for this study was collected using both purposeful sampling and, at the end, theoretical sampling. The use of theoretical sampling was limited due to the availability of caregivers representing diverse types of relationships and due to time constraints. This limitation could have affected the outcome of the study and the development of the model by not allowing the study to complete the theory creation. Given more time and more sites, access to caregivers would have been greater and allowed for more diversity in the sample – perhaps interviewing more male caregivers, more single women, and individuals whose relationships were different than those seen in this sample. This would have allowed for a greater opportunity to fully develop the theory. Further sampling could have allowed for the identification of other types of change, more strategies for how change is managed, and new dimensions of the existing

categories and subcategories, all of which would have enriched the emerging theory. Some of the identified subcategories and dimensions may have approached theoretical saturation, because they recurred across caregivers, while others are based solely on one participant. Had more time and resources been available, a larger sample could have resulted in reaching theoretical saturation for the existing categories as well as the newly discovered ones and helped illucidate interrelationships among categories and subcategories. A larger sample would have enabled more focused theoretical sampling, for example, the inclusion of couples who had been married for a long period of time but did not have a high-quality relationship.

Setting

The setting of the study may also have affected the outcome of the study. The center in which the study was performed is a University-affiliated NCI-designated cancer center that provides care well above that of a community cancer center. If the study had been done in a cancer center with fewer resources and less patient support, the findings may have been altered. It is easy to speculate that these resources decreased the burden and stress on the caregivers, causing either fewer types of change or more resources with which to deal with change.

Access to Participants

Access to the participants was a complicated affair. Because data collection occurred after the completion of treatment, the caregivers were not always physically in the clinic. Because patients had recently finished treatment, caregivers were reticent to commit to returning to the clinic multiple times. In addition, to get the information regarding the study to the caregivers, the researcher relied on having the patient deliver it

to his or her caregiver. Of the 32 flyers distributed to patients, only one caregiver

contacted the researcher to ask about participation. There could be a number of reasons

for this result. First, it could have been that patients didn't see this study as a priority and

were distracted by their own issues. Second, patients may have acted as a filter, thus

putting them in the position of controlling whether or not their caregiver had the

opportunity to participate. In the cases of those caregivers who were present in the clinic

with their patient, all but one enrolled.

This limitation also affected the ability of the researcher to complete all three

interviews with all participants enrolled. During data collection, it became clear that with

each successive interview, the participants were more likely to open up and share more

details of their caregiving experience. The inability to access the participants more than

once in some cases may have affected the richness of the data collected and the

subsequent categories which emerged.

Use of the Telephone for Data Collection

The use of the telephone to collect data was a choice made to accommodate the

wishes and the schedules of the participants. Phone interviews do not allow the researcher

to see the person being interviewed, thus the researcher cannot observe the nonverbal

elements of the interaction and the caregiver's environment and loses these data. If the

interviews were done in person, the researcher would have been able to observe the

participant and have a better sense of how he or she was reacting to the questions and

what, if any, of the subjects discussed were sensitive. Although telephone interviews

have their limits, the researcher was able to establish a rapport, especially with those

participants who participated in more than one interview. In some ways, the anonymity

provided by the lack of face–to-face contact allowed a certain freedom to speak more frankly.

Had the interviews been done in person in the caregivers' environment, it is possible that other types of change might have been observed and could then have been incorporated into the theory. Also, it is possible that other strategies could have been observed and added to those already discovered.

Timing of Data Collection

All data were collected after patients had completed their treatment, a time period ranging from one month to two years. This timing was chosen to allow caregivers time to reflect back on their experience with whatever insights they might have developed. The downside of this choice might have been that the caregivers were not able to fully recall their experiences throughout the treatment experience. In addition, as mentioned previously, all of the patients whose caregivers were involved in the study were free of disease at the time of the interview. Including caregivers whose patients had had a recurrence of disease may have given a broader picture of the entire spectrum of the caregiving experience. Ideally, the researcher would have followed the caregivers from the beginning of the caregiving experience through treatment and beyond. Also, caregivers whose family member had a negative outcome could have been included. These steps would ensure a fuller picture and the creation of a more well-developed theory with additional categories and strategies.

The Researcher's Ability to Use the Components of Grounded Theory

As noted by the preceding list of limitations, the ability to use the components of grounded theory in this study was limited by a number of factors. The access to

participants was limited by their not being in the clinic with any regularity, which limited

the number of caregivers that could be recruited in both the purposeful sampling stage

and the theoretical sampling phase. Additional approaches to participant recruitment

could also have led to a more diverse sample and increased the likelihood that theoretical

sampling could have been successfully employed. Additional types of recruitment could

have included approaching caregivers who were in the clinic for caregiver support groups

as well as attempting to recruit at multiple sites. The ability to reach theoretical

saturation on all categories was also affected by this limitation. Given the many

dimensions identified, it is probable that subcategories such as increased uncertainty and

managing stress had more dimensions than are presented here. Further interviews with

more caregivers could expand these dimensions, providing better insight into the

subcategory itself. More time and greater access to caregivers could have allowed for

theoretical saturation of all categories and to have complete saturation of the core

category. Caregivers with more types of uncertainty and fewer resources (and therefore

less ability to use the described strategies) could help to further develop the theory.

Trustworthiness

Charmaz (2006) outlined a series of questions to be asked of the research and the

researcher in order to determine the quality of the research. These questions are divided

into four areas: credibility, originality, resonance, and usefulness.

Credibility

In the case of this study, the researcher had both personal and professional

familiarity with the topic under study. As a nurse working in oncology, she observed and

participated in the care of many HNC patients as well as assisting their family members

in learning the various caregiving tasks. As a family caregiver, the researcher spent ten years caring for two family members with head and neck cancer. These experiences provided her with a view of the experience from both sides and allowed for an understanding of the challenges facing both the family caregivers and the nurses trying to care for the patient and educate the caregivers. She experienced the frustrations as well as the triumphs that came with each role. In interviewing the participants in this study, many of those frustrations (e.g., how to keep them fed, controlling disease and treatment-related changes) resonated with the researcher. However, the researcher had a high-quality relationship with both of the family members for whom she cared and so she experienced fewer types of change (no relationship changes, for example).

The sufficiency of the data is indicated by the emerging categories which were supported by the data collected. What this means is that interviews produced enough information to support the creation of a core category, two other categories, subcategories, and dimensions of some of the subcategories, however, as previously discussed, additional data would have improved theoretical saturation and development of the emerging theory.

Originality

This study has provided a new view of what the process of caregiving is for this population. Rather than focusing solely on the tasks required, it has shown that the process of caregiving is influenced by the changes the caregivers undergo in relation to both their caregiving tasks and the inherent life changes associated with the process of caregiving. No other research to date that this researcher has seen has focused on caregiving as managing change.

Resonance

This study has attempted to provide a better understanding of what the role of caregiver is and what it means to the individuals who take on this role. It has also tried to gain a sense of what it is like for these individuals to go through the process of becoming a caregiver within the context of the larger society.

Early results of the study, including the core category and the other two categories, were shared in a poster at the Oncology Nursing Annual Society Congress in Boston, Massachusetts in the spring of 2011. Feedback from nurses attending the Congress indicated that the core and other two categories resonated with the nurses and the feedback was very positive. In addition, informal member checking was attempted during the third interview with several participants, demonstrating resonance of the categories with these participants.

Usefulness

This study has provided an insight into the world of the caregivers, identifying more clearly their needs and challenges. This knowledge can be the base from which further research can be developed which is tailored more effectively to meet their needs as the go through the caregiving process.

Experience of Doing the Study

The experience of doing this study was greatly influenced by both the investigator's personal and professional experiences. As a nurse and an advanced practice nurse, she was able to witness the grueling nature of this treatment and observe how challenging it could be on families. Personally, she had experienced the role of caregiver for two family members who were diagnosed with, treated for, and subsequently died of

head and neck cancer. In conducting the study, she was struck by how, over the 13 years since she had participated in her family's care, the treatment and its side effects had improved enormously. The question then became, "why are caregivers still reporting they feel unprepared to undertake the role?" In the end, it proved to be about much more than the physical aspects of care.

Conducting this study was a fascinating and, at times, frustrating experience. From the very beginning, the researcher was struck by the amazing ability of some of the participants to manage what seemed to be an unmanageable situation and simply keep moving. Although the researcher had had personal experience with this type of caregiving (as discussed previously), it had been more than 14 years since her most recent experience as a family caregiver to this population and nearly 9 years since she cared for them as a nurse. Although there were some findings that resonated with her during the study (as previously described), the vast changes in the way treatment is delivered and advances in symptom management over that time have created a very different caregiver experience. Caregivers are now able to focus on more than just the basic, caregiving skills required and look at all aspects of their lives as they relate to the role of caregiver.

When attempting to enroll participants, the researcher never considered how difficult it would be to get to the caregivers. She was struck by the various reactions she got from the patients when she explained the study and asked them to deliver the information to their caregiver. In most cases, the request was met with a nod and even some enthusiasm. In other cases, it was met with a suspect glare, as to say "who wants to know." Needless to say, using the patients to get to the caregivers was problematic at best

in this study but as noted earlier, a prospective approach would probably be better and at least mitigate this issue.

Once enrolled, the participants were very willing to talk. The researcher found that, for those who were interviewed more than once, the first interview tended to be somewhat reserved in nature. Subsequent interviews, however, tended to be more open and, often less charitable toward the person for whom they were caring. The longer they talked, the more frustration and, at times, anger were heard.

At the beginning of the study (before data collection and analysis), the researcher's assumption was that the greatest challenges for these caregivers would come from the treatment-related tasks. This assumption was grounded in both her personal experience as a nurse and as a family member caring for someone at home. At the time the researcher was caring for her family members, she was not yet a nurse. She had very close relationships with both her mother and sister and had no memory of having to negotiate control over who was in charge. She did remember the caregiving tasks as being onerous, but not until late in their illnesses when both had enrolled in hospice. Perhaps that is where that assumption came from. Unlike the participants in this study, both of the researcher's family members died as a result of their illness and perhaps that is why her recollection does not concur with what this study has found. The issue of control as described in the dimensions of one of the strategies does resonate with the researcher's experience which supports the idea that further work on this theory may reveal not only differences between those with positive and negative outcomes, but similarities as well.

In the end, it was, as the researcher has already written, the changes coming not only from the treatment itself but from all the corners of their lives. These changes be they changes to their daily schedules, activities related to food preparation feeding and socializing, changes in their relationships, or the increased sense of uncertainty they experienced all combined to challenge the caregivers' ability to manage change and support the theory that caregiving is about just that- managing change.

Implications

Theory Development and Research

This study represents the first step in the development of a theory of Managing Change. It has identified important types of change affecting the caregivers of HNC patients and illustrated some of the strategies they used to manage these changes. The implications for further development are based on the need to develop this theory further by expanding and saturating the existing categories, subcategories and dimensions. With further study, it is possible that new categories could emerge.

The category of Managing Change needs to be more fully expanded and saturated to provide a theory that is broadly applicable to other populations. Previous research in a broader group of caregivers has indicated that quality of the relationship between the caregiver and the patient has an impact on the caregiving experience (Schumacher, 2009). The research reported in this study has added to our understanding how the relationship quality affects the stress of caregivers. It has given insight as to how they attempt to manage the stress brought on the changes and indicated that a high-quality relationship provides an important resource for managing stress. Further research

needs to focus on the impact of relationship quality on this experience and continue to investigate how the strategy of utilization of relationship quality related to caregiving.

Future research in this area needs to expand on the emerging theory developed in this study. To do this, a longitudinal study, following caregivers from diagnosis through the treatment and the post-treatment periods, should include those whose outcomes were different from the participants studied here. This approach will allow for a better idea of the process of caregiving than this retrospective study can provide.

Further study to explore the findings described here is needed to continue to expand and enrich these findings. Additional studies to explore these categories and the relationships between them, their subcategories, and their dimensions are needed to continue to develop this emerging theory of caregiving. It is also possible that additional research could uncover additional categories not identified here.

Additional options for further research include testing this model using quantitative methods and a further investigation of the sources of change and strategies used by caregivers to manage it in this population.

Clinical Practice

The implications of the findings of this study for nursing practice include assessing caregivers throughout the treatment experience to determine the amount and types of change they are experiencing in order to provide appropriate levels of support at the appropriate time, assessing for support needs, and making appropriate referrals within the multidisciplinary team. They must also assess the caregiver's access to resources to support them throughout the caregiving process, always keeping in mind the dynamic nature of the treatment and the caregiver's experience.

The importance of understanding the caregivers' needs across the phases of treatment is an important piece of providing appropriate support. Nurses need to have this understanding in order to plan appropriate interventions that meet the caregivers' needs in each phase. Interventions aimed at the diagnosis and early treatment would be composed of helping the caregivers deal with and process the uncertainty and life pattern changes that come with these periods as well as preparing them in a meaningful way for what is to come. Late-treatment interventions would build on this foundation and include support for managing the physical changes in the patient as these changes become more dramatic.

Assessing the relationship between the caregiver and the patient is another important implication of this study for nurses. From their first contact, nurses need to determine the quality of this relationship, monitor the relationship, and provide appropriate support throughout the caregiving experience. In addition, nurses must be aware of the overall amount of change the caregivers are experiencing in order to provide appropriate support to the caregivers.

Building on their knowledge and experience, nurses in site-specific specialty areas can contribute to the development of site-specific caregiver teaching material for this population. This content could include offering strategies to caregivers to help them through the process, providing resources in both the clinic and the community to help support them in using the strategies presented.

Conclusion

This study has attempted to broaden the understanding of the role of a caregiver of a patient with HNC using grounded theory methods. This work is the first step in developing a theory of caregiving related to this population which may also be applied to

93

a broader population of caregivers. This study has identified a core category of Managing Change. Two additional categories, Types of Change and Strategies Used to Manage Change, were also described. Within these two additional categories, subcategories were identified, as well as some dimensions of these subcategories. For Types of Change, the subcategories included Changes in Life Patterns (with three dimensions including Daily Schedules, Food Preparation and Feeding, and Socialization), Witnessing Physical Changes, Relationship Changes, and Increasing Uncertainty (with its three dimensions of Uncertainty Related to Diagnosis and Treatment, Uncertainty About The Future, and Uncertainty Within The Relationship). The category of Strategies for Managing Change included the subcategories of Controlling Life Pattern Changes (with its two dimensions Controlling Treatment-Related Changes and Control Within the Relationship), Utilizing the Quality of the Relationship, and Managing Stress (with its two dimensions Allowing Support and Getting Away). Relationships among these categories as well as some of their subcategories and their dimensions were also identified. The identification of these relationships forms a preliminary basis for future theory development and research whose implications can impact future practice that better supports caregivers and will ultimately improve patient care.

**UNIVERSITY OF MARYLAND
SCHOOL OF NURSING**

Participants Wanted for a Research Study

Studying Informal caregivers of Head and Neck Cancer Patients.

Purpose of the Study: To gain a better understanding of the experiences of family and informal caregivers who care for patients who have been treated for cancers of the head or neck (including cancers of the mouth, tongue, larynx, pharynx, etc.)

Sample: 30 to 50 caregivers who have been the primary provider of care for their friend or family member who has been treated for one of the cancers mentioned above.

Study Methods: The patient must have completed their treatment within the last 5 years. Each participating caregiver will be asked to complete three (3) interviews. The time, place and length of the interviews will be determined by the caregiver participant and will be scheduled at their convenience.

Study Period: Study will begin in Spring 2010 and conclude by Spring 2011.

Please contact me to volunteer for the study or to ask further questions!

**Maura Fulham Edmonds RN, MSN, CRNP
Phone: 302-482-8535
Email: medmo001@umaryland.edu**

Protocol Title: Informal caregivers of Head and Neck Cancer Patients

Study No.: *HP-00044325*

Principal Investigator: *Dr. Deborah McGuire, RN, Ph.D, F.A.A.N.*
                         Professor and Director,
                         Oncology Graduate Program Director,
                         Developing Center of Excellence in Palliative Care Research
                         University of Maryland School of Nursing
                         Full Member, Program in Oncology, University of Maryland
                         Marlene and Stewart Greenebaum Cancer Center
                         655 West Lombard Street, 325B
                         Baltimore, MD 21201, USA
                         tel: 410-706-8351
                         fax: 410-706-0344

- This is a research study. Participation in it is completely voluntary and you may withdraw from the study at any time. You are not required to take part in this study. If you have any questions please ask co-investigator Maura Edmonds. She can be reached at 302-482-8535.

PURPOSE OF STUDY
- The purpose of this study is to gain a better understanding of what it is like to be an informal caregiver to a person with cancer of the head and neck.
- You qualify to take part in the study because you have been identified as caregiver to a patient who has had head and neck cancer and has received treatment to cure it..
- There will be approximately 30 participants in this study.

PROCEDURES
- This study consists of a combination of observation and interviews. The observation will take place anonymously at the Helen Graham Cancer Center in Newark, Delaware. The interviews will take place at a time and place most convenient to the participant.
- Each participant will complete a series of three interviews. Each interview will be approximately one hour long.
- The interviews will be tape recorded to make sure that the interviewer gets all of your comments and information.
- By signing this consent form, you are agreeing to participate in this research study. Once you have read the form you may ask any questions you have about the study. The researcher will then ask you to tell them your understanding of the study and what you have been asked to do.

POTENTIAL RISKS/DISCOMFORTS:
- There is no reason to believe that there are any potential physical risks or discomforts related to this study.
- Potential psychological or emotional risk is possible but unlikely. In the event that this occurs, the participant will be directed to the appropriate member of the care team.
- Risk of the potential for the loss/breach of confidentiality will be minimized by storing data in a secure location such as a locked office and locked cabinet. Electronic data will be password-protected

POTENTIAL BENEFITS

You will not benefit directly from your participation in this study. However, you will be given the opportunity to tell your story and share your insights. This information will be used to develop interventions that will help others who are in a situation similar to yours.

ALTERNATIVES TO PARTICIPATION

This is not a treatment study. Your alternative is to not take part. If you choose not to take part, your healthcare at University of Maryland, Baltimore will not be affected.

COSTS TO PARTICIPANTS

It will not cost you anything to take part in this study.

PAYMENT TO PARTICIPANTS

- A gift card worth $25 dollars will be given to each participant has completed all three interviews.

CONFIDENTIALITY
- All information collected will be kept confidential. Tapes and transcripts of the interviews will be cleared of any identifying information and will be kept in a secured, locked area accessible only by the researchers. Electronic files created from these documents will be stored on a password- protected computer. Study records will be considered confidential, and your name will not be used in reports or publications.

The data from the study may be published. However, you will not be identified by name. People designated from the institutions where the study is being conducted and people from the sponsor will be allowed to inspect sections of your medical and research records related to the study. Everyone using study information will work to keep your personal information confidential Your personal information will not be given out unless required by law.

RIGHT TO WITHDRAW
- Your participation in this study is voluntary. You do not have to take part in this research. You are free to withdraw your consent at anytime. Refusal to take part or to stop taking part in the study will involve no penalty or loss of benefits to which you are

otherwise entitled. If you decide to stop taking part, if you have questions, concerns, or complaints, or if you need to report a medical injury related to the research, please contact the co-investigator Maura Edmonds at 302-482-8535.

- There are no adverse consequences (physical, social, economic, legal, or psychological) if you decide to withdraw from this research.

UNIVERSITY STATEMENT CONCERNING RESEARCH RISKS

The University is committed to providing participants in its research all rights due them under State and federal law. You give up none of your legal rights by signing this consent form or by participating in the research project. Please call the Institutional Review Board (IRB) if you have questions about your rights as a research participant.

The research described in this consent form has been classified as minimal risk by the IRB of the University of Maryland, Baltimore (UMB). The IRB is a group of scientists, physicians, experts, and other persons. The IRB's membership includes persons who are not affiliated with UMB and persons who do not conduct research projects. The IRB's decision that the research is minimal risk does not mean that the research is risk-free. You are assuming risks of injury as a result of research participation, as discussed in the consent form.

If you are harmed as a result of the negligence of a researcher, you can make a claim for compensation. If you have questions, concerns, complaints, or believe you have been harmed through participation in this research study as a result of researcher negligence, you can contact members of the IRB or the staff of the Human Research Protections Office (HRPO) to ask questions, discuss problems or concerns, obtain information, or offer input about your rights as a research participant. The contact information for the IRB and the HRPO is:

University of Maryland School of Medicine
Human Research Protections Office
BioPark I
800 W. Baltimore Street, Suite 100
Baltimore, MD 21201
410-706-5037

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

If you agree to participate in this study, please sign your name below.

_____
Participant's Signature

Date:_____

_____
Investigator or Designee Obtaining Consent
Signature

Date:_____

_____
Witness*

Date:_____

Appendix C: Guide for Interview 1

Question	Probe (Questions based on Stress Process Model)
Looking back at your experiences caring for your (family member/friend), tell me what it was like for you.	**Context:** **-History of illness** **-History of caregiving experience** **-Living arrangements**
What have the challenges been in providing care?	**Transitions:** **-Difficult events** **-Expectation of the experience** **-What has changed** **-Reaction to changes** **-Coping**
What have you found to be most stressful as the caregiver?	**Primary Stressors:** **-Stress related to illness.** **-Burdens?** **-Loss of relationships?** **-Lack of support from healthcare professionals?** **-What help have you received from healthcare professionals?** **Secondary Stressors:** **-Issues related to other roles.** **-Physical and emotional ability to cope.** **-Do you have the knowledge you need?** **-Perception of the role.** **-Easiest hardest parts.**
What resources have been most important to you?	**Resources:** **-Family/social support.** **-Did you have the information you needed to cope with the role?** **-How has it impacted your financial situation?** **-Opportunities for personal growth.** **-Other opportunities?**
What do you see as the outcome of this experience for you?	**Outcomes:** **-How did you deal with the physical/emotional symptoms?** **-How would you describe your quality of life?** **-What new perspectives have you gained?** **-What have you learned?**

Appendix D: Guide for Interview 2

1. Based on what we talked about last time, I had a few questions I wanted to ask and a few areas I thought we might focus on today.

(Areas of interest derived from interview #1 will be explored):

Appendix E: Guide for Interview 3

1. Today, I would like to go over with you what you have told me in our previous meetings. I want to be sure that I am hearing you correctly and that what I am hearing correctly reflects your thoughts.

(Will review findings from previous interviews.)

2. Is there anything else you wanted to tell me?

3. Does what I have said today accurately reflect your experience?

Appendix F: Basic Demographic Information Form

Date:_____ Time:_____

<u>PARTICIPANT DATA FORM</u>

Interview Location:

_____ Home(1)
_____ Clinic(2)
_____ Other(3)
    <u>If Other</u> please write in the space provided

_____

ABOUT YOU:

1. Age at last birthday: _____ Years

2. Gender: Male (1)   Female (2)   (Circle one)

3. Ethnic Background: (Check one)
    _____ Alaskan Native (1)
    _____ American Indian (2)
    _____ Anglo-American (3)
    _____ Asian (4)
    _____ Black or Afro-American (5)
    _____ Hispanic (6)
    _____ Native Hawaiian or Other Pacific Islander (7)
    _____ More Than One Race (8)
    _____ Other (9)
        <u>If Other</u> please explain in the space
    provided_____

4. Current Marital Status: (Check one)

    _____Single (1)
    _____Married (2)
    _____ Partnered (3)
    _____Divorced (4)
    _____Separated (5)
    _____Widowed (6)

5. Relationship to Patient (Check one)

    _____ Spouse(1)
    _____ Child (2)
    _____ Partner (3)

_____ Friend (4)
_____ Neighbor (5)
_____ Other (6)
If Other, explain in pace
provided_____

ABOUT THE PATIENT:

1. Age at last birthday: _____ Years

2. Gender: Male (1)   Female (2)   (Circle one)

3. Ethnic Background: (Check one)
_____ Alaskan Native (1)
_____ American Indian (2)
_____ Anglo-American (3)
_____ Asian (4)
_____ Black or Afro-American (5)
_____ Hispanic (6)
_____ Native Hawaiian or Other Pacific Islander (7)
_____ More Than One Race (8)
_____ Other (9)
If Other please explain in the space
provided_____

4. Current Marital Status: (Check one)

_____Single (1)
_____Married (2)
_____ Partnered (3)
_____Divorced (4)
_____Separated (5)
_____Widowed (6)

5. Patient's cancer Diagnosis: _____

6. Patient's Cancer Treatment (Check all that apply)

_____ Surgery(1)
_____ Radiation Therapy (2)
_____ Chemotherapy (3)

Appendix G: Researcher Certification

CERTIFICATE IN
QUALITATIVE RESEARCH

Qualitative
Research

This is to certify that

Maura Edmonds

has completed:

Qualitative Analysis I: Empirical / Analytical Methods
Qualitative Analysis II: Phenomenological & Narrative/Discourse Methods
Institute in Qualitative Research: Synthesizing Qualitative Research Findings
Institute in Qualitative Research: Mixed Methods Research

and has, therefore, fulfilled all the requirements set forth by the Continuing Education Department at the
University of North Carolina at Chapel Hill School of Nursing

This certificate was issued on July 18, 2008.

Margarete Sandelowski, PhD, RN, FAAN
Cary C. Boshamer Professor
University of North Carolina at Chapel Hill
School of Nursing

Pamela R. Jenkins, RN, MSN, EdD
Director, Continuing Education Department
University of North Carolina at Chapel Hill
School of Nursing

References

American Cancer Society. (2009). Cancer Facts and Figures 2009. Atlanta: American Cancer Society.

Argawala, S., Cano, E., Heron, DE. Johnson, J., Myers, E., Sandulache, V., Bahri, S., Ferris, R., Wang, Y, & Argiris, A. (2007). Long-term outcomes with concurrent carboplatin, paclitaxel and radiation therapy for locally advanced, inoperable head and neck cancer. Annals of Oncology, 18, 1224-1229.

Baghi, M., Wagenblast, J., Hambeck, M., Radeloff, A., Gstoettner, W., Scherzed, A., Spaenzed, B., Yuan, J., Hornung, S., Stebhardt, K. & Knecht, R. (2007). Demands on caring relatives of head and neck cancer patients. The Laryngoscope, 117, 712-716.

Baronet, A. (1999). Factors associated with caregiver burden in mental illness: a critical review of the research literature. Clinical Psychology Review 19(7). 819-841.

Bjordal, K., Ahlner-Elmqvist,M., Hammerlid, E., Boysen, M., Evenson, J., Biorklund, A., Jannert, M., Westin, T., & Kaasa, S. (2001). A prospective study of quality of life in head and neck cancer patients. part II: longitudinal data. The Laryngoscope, 111, 1440-1452.

Blood, G. & Simpson, K. (1994). Spouses of individuals with laryngeal cancer: caregiver burden and strain. Journal of Communication Disorders 27; 19-35.

Blumer, H. (1969). Symbolic Interactionism: Perspective and Method. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Brosky, M. (2007). The role of saliva in oral health: strategies for the prevention and management of xerostomia. Journal of Supportive Oncology 5(5); 215-225.

Brown, C., McGuire, D., Peterson, D., Beck, S.,Dudley, W., & Mooney, K. (2009). The experience of a sore mouth and associated symptoms in patients with cancer receiving outpatient chemotherapy. Cancer Nursing, 32(4); 259-270.

Cady, J. (2002). Laryngectomy: beyond loss of voice- caring for the whole patient. Clinical Journal of Oncology Nursing, 6(6), 1-5.

Charmaz, K (2006). Constructing Grounded Theory: A practical guide through qualitative analysis. London, England. Sage Publications.

Clarke, L. & Dropkin, MJ. (2006). Site Specific Cancer Series: Head and neck cancer. Pittsburgh: Oncology Nursing Society.

Corbin, J. & Strauss, A. (2008). Basics of Qualitative Research (3rd ed.). Los Angeles, CA. Sage Publications

Crotty, M. (1998). The Foundations of Social Research: Meaning and perspective in the research process. London, England: Sage Publications.

Ding, M., Newman, F., & Raben, D. (2005). New radiation therapy techniques for the treatment of head and neck cancer. Otolaryngologic Clinics of North America, 38, 371-395.

Dirix, P., Nuyts, S., & Van der Bogaert, W. (2006). Radiation-induced xerostomia in patients with head and neck cancer; a literature review. Cancer 107; 2525-2534.

Emerson, R, Fretz, R, & Shaw, L. (1995) Writing Ethnographic Fieldnotes. University of Chicago Press. Chicago, IL.

Gaugler, J., Hanna, N., Linder, J., Given, C., Tolbert, V., Kataria, R., & Regine, W. (2005). Cancer caregiving and subjective stress: a multi-site, multi-dimensional analysis. Psycho-Oncology, 14, 771-785.

Glajchen, M. (2004). The emerging role and needs of family caregivers in cancer care. The Journal of Supportive Oncology, 2(2), 145-155.

Glaser, B. & Strauss, A. (1967). The Discovery of Grounded Theory: Strategies for qualitative research. New Brunswick, USA. Aldine Transaction.

Goldenberg, D., Lee, J., Koch, W., Kim, M., Trink, B.,Sidransky, D., & Moon, C. (2004). Habitual risk factors for head and neck cancer. Otolaryngology- Head and Neck Surgery, 131, 986-993.

Gysel, M. & Higginson, I. (2009). Health care and cancer screening experience of chinese immigrants in New York City: a qualitative study. Palliative and Supportive Care. 7(2); 153-62.

Hammerlid, E., Bjordal, K., Ahlner-Elmqvist, M., Boysen, M., Evensen, J., Biorklund, A., Jannert, M., Kaasa, S., Sullivan, M., & Westin, T. (2001). A prospective study of quality of life in head and neck cancer patients. part I: at diagnosis. The Laryngescope, 111, 669-680.

Heaton, P. (1999). The gaze and visibility of the carer. A foucauldian analysis of the discourse of informal care. Sociology of Health and Illness. (21)6; 759-777.

Herranz, J. & Gavilan, J. (1999). Psychosocial adjustment after laryngeal cancer surgery. Annals of Otorhinolaryngology, 108, 990-997.

Hong, T., Tome,W., & Harari, P. (2005). Intensity-modulated radiation therapy in the management of head and neck cancer. Current Opinions in Oncology, 17, 231-235.

Given, B., Given, C., & Kozachik, S. (2001). Family support in advanced cancer. CA: A Cancer Journal for Clinicians, 51, 213-231.

James, G. (1983). Caring for the cancer patient: a friend's perspective. Ear, Nose, and Throat Journal 62; 75-82.

Kitrungrote, L. C., M. (2006). Quality of life of family caregivers of patients with cancer: a literature review. Oncology Nursing Forum, 33(3), 625-632.

Kennedy, V. & Lloyd-Williams, M. (2008). Information and communication when a parent has advanced cancer. Journal of Affective Disorders. 114; 149-155.

Kuhlman, G., Wilson, H., Hutchinson, S, & Wallhagan, M. (1991). Alzheimer's disease and family caregiving: critical synthesis of the literature and research agenda. Nursing Research 40(6), 331-337.

Kwong, K. & Mak, A. (2009). Health care and cancer screening experience of chinese immigrants in New York City: a qualitative study. Social Work in Health Care. 48(3); 321-47.

Licitra, L., Locati, L., & Bossi, P. (2006). Biological agents in head and neck cancer. Annals of Oncology, 17 (Supplement 10), x45-x48.

Lincoln, Y. & Guba, E. (1985).Naturalistic Inquiry. Sage Publications. Newbury Park, CA.

Mah, M. & Johnston, C. (1993). Concerns of families in which one member has head and neck cancer. Cancer Nursing. 16(5); 382-387.

May, J., Ellis-Hill, C., & Payne, S. (2001). Gate-keeping and legitimization: how informal carers relationship with healthcare workers is revealed in their everyday interaction. Journal of Advanced Nursing, (36)3; 364-375.

Miaskowski, C., Kragness, L., Dibble, S., & Wallhagen, M. (1997). Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. Journal of pain and symptom management, 13(3), 138-147.

Mehra, R., Cohen, R., & Burtness, B. (2008). The role of cetuximab for the treatment of squamous cell carcinoma of the head and neck. Clinical Advances in Hematology and Oncology 6(10). 742-750.

Morris, S. & Thomas, C. (2001). The carer's place in the cancer situation: where does the carer stand in the medical setting? European Journal of Cancer Care, 10; 87-95.

Morris, S. & Thomac, C. (2002). The need to know: informal carers and information. European Journal of Cancer Care, 11, 183-187.

National Family Caregivers Association & Family Caregiver Alliance (2006). Prevalence,Hours and Economic Value of Family Caregiving, Updated State-by-State Analysis of 2004 National Estimates by Peter S. Arno, PhD. Kensington, MD: NFCA & San Francisco, CA; FCA

Oktay, J. S. (2012). Grounded Theory. Pocket guides to social work research methods. New York, NY. Oxford University Press.

Padgett, D. (2008). Qualitative Methods in Social Work Research (2nd ed.). Los Angeles, CA. Sage Publications.

Pearlin, L., Mullan, J., Semple, S. & Skaff, M. (1990). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. The Gerontologist (30); 583-594.

Quon, H., Hershock, D., Feldman, M., Sewell, D., & Weber, R. (2004). Cancer of the Head and Neck. In M. Abeloff, Armitage, J., Niederhuber, J., Kastan, M., & McKenna, WG. (Ed.), Clinical Oncology. Philadelphia: Elsevier.

Rademaker, A., Vonesh, E., Logemann, J., Pauloski, B.,Liu, D., Lazarus, C.,Newman, L., May, A., MacCracken, E. Gaziano, J., & Stachowiak, L. (2003). Eating ability in head and neck cancer patients after treatment with chemoradiation: a 12-month follow-up study accounting for dropout. Head and Neck, 25, 1034-1041.

Ramirez, M., Ferriol, E., Domenech, Llaas, C., Suarez-Varela, M., & Martinez, R. (2003). Psychosocial adjustment in patients surgically treated for laryngeal cancer. Otolaryngology- Head and Neck Surgery, 129, 92-97.

Rose, K. (1999). A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. Journal of Clinical Nursing. (8); 81-88.

Scarpace, S., Brodzik, F., Mehdi, S., & Belgam, R. (2009). Treatment of head and neck cancers: issues for clinical pharmacists. Pharmacotherapy 29(5); 578-592.

Scherbring, M. (2002). Effect of caregiver perception of preparedness on burden in an oncology population. Oncology Nursing Forum, 29(6), E70-E76.

Schumacher, K. (1995). Family caregiver role acquisition: role-making through situated interaction. Scholarly Inquiry for Nursing Practice. 9(3); 211-229.

Schumacher, K. (1996). Reconceptualizing family caregiving: family-based illness care during chemotherapy. Research in Nursing & Health, 19, 261-271.

Schumacher, K., Stewart, B., Archbold, P., Dodd,M., & Dibble, S. (2000). Family caregiving skill: development of the concept. Research in Nursing & Health, 23, 191-203.

Schumacher, K., Beidler, S., Beeber, A., & Gambino, P. (2006). A transactional model of cancer family caregiving skill. Advances in Nursing Science. 29(3), 271-286.

Schumacher, K., Stewart, B., & Archbold, P. (2007). Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. Nursing Research 56(6). 425-433.

Scully, C., Sonis, S. & Diz, PD. (2006). Mucosal disease series: oral mucositis. Oral Disease 12, 229-241.

Seikaly, H. (2003). Xerostomia prevention after head and neck cancer treatment. Archives of Otolaryngology- Head and Neck Surgery, 129(2), 250-251.

Settle, K., Posner, M., Schumaker, L., Tan, M., Suntharalingam,M., Goloubeva, O., Strome, S.,Haddad, R., Patel, S.,Cambell, E., Sarlis, N., Lorch, J., & Cullen, K. (2009). Racial survival disparitiy in head and neck cancer results from low prevalence of human papillomavirus infection in black oropharyngeal cancer patients. Cancer Prevention Research, 2(9); 776-781.

Strauss, A. & Corbin, J. (1998). Basics of Qualitative Research: Techniques and procedures for developing grounded theory. Thousand Oaks, CA. Sage Publications.

Thomas, C., Morris, S., & Harman, J. (2002). Companions through cancer: the care given by informal carers in cancer context. Social Science & Medicine, 54, 529-544.

Tucker, C., Herman, K., Pederson, T., Higley, B., Montrichard, M., & Ivery, P. (2003). Cultural sensitivity in physician-patient relationships: perspectives of an ethically diverse sample of low-income primary care patients. Medical care, 41(7), 859-870.

Vickery, L., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. Head and Neck, 25, 289-296.

Vitaliano, P. Young, H., & Russo, J. (1991). Burden: a review of measures used among caregivers of individuals with dementia. The Gerontologist 31(1); 67-75.

Wiggenraad, R., Flierman, L., Goossens, A., Brand, R., Verschuur, HP, Croll, GA., Moser, LEC, & Vriesenddorp, R. (2007). Prophylactic gastrostomy placement and early tube feeding may limit loss of weight during chemoradiotherapy for advanced head and neck cancer, a preliminary study. Clinical Otolaryngology, 32, 384-390.