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**The Dissertation Committee for Kimberly Crocker Crowther certifies that this is
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**Secondary Stress and Coping Experiences of Partners of
Persons with Oral Cancer: A Descriptive Study**

Committee:

Nonie Mendias, Ph.D., Chair

Alice Hill, Ph.D.

Yolanda Davila, Ph.D.

Ernestine Cuellar, Ph.D.

Mary Duffy, Ph.D.

Dean, Graduate School of Biomedical Sciences

**Secondary Stress and Coping Experiences of Partners of
Persons with Oral Cancer: A Descriptive Study**

by

Kimberly Crocker Crowther, MSN, APRN-BC, FNP

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Dedication

Dedicated to persons with oral cancer and their partners who stand beside them, give them space, and prop them up when needed

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Secondary Stress and Coping Experiences of Partners of Persons with Oral Cancer: A Descriptive Study

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The purpose of this study was to explore the existence of Secondary Traumatic Stress (STS) in caregivers of persons with oral cancer, describe the nature of the experience of STS and its relationship to other variables of interest, and generate substantive contributions to emerging theory. Congruent with the purpose of the research, the first aim of the study was to determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explained a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer. The second aim of the study was to determine the extent to which the selected demographic variables of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explained a caregiver's ability to cope as measured by the Coping Skills Test Abridged (CST-A). Self-identified caregivers of persons with oral cancer (n=86) participated in the study. The theoretical underpinning of the study was Constructivist Self-Development Theory (CSDT), a framework that viewed caregiving for persons with oral cancer through the lens of a traumatic experience. Because of the contemporary nature of this topic and concomitant dearth of existing nursing research regarding STS in caregivers of persons with oral cancer, the quantitative methodological approach of descriptive, correlational survey design was utilized. Study findings revealed that caregivers who reported increased CS and moderate Burnout were at risk for the development of STS symptoms as evidenced by increased CF. Younger caregivers with lower CS scores and higher Burnout and CF scores were more likely to have lower Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts. Conversely, older caregivers with higher CS, lower Burnout, and lower CF scores were more likely to have higher Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/Interpersonal scores on the

LSR than their counterparts. The addition of one open-ended question yielded abundant and rich subjective data that supported the findings and provided correlation and elaboration on the phenomena of CS, Burnout, and CF as well as a self-reported commentary on factors that positively and negatively impacted the caregiving experience of the person with oral cancer.

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CHAPTER ONE: INTRODUCTION

INTRODUCTION TO THE STUDY

The purpose of this chapter is to introduce the study, which explored the phenomena of Secondary Traumatic Stress (STS), quality of life, and coping experiences of caregivers of persons with oral cancer. A statement of the problem; background and significance of the problem; theoretical framework; description of the variables measured and relevant terms utilized; purpose and aims of the study; assumptions of the study; research questions; and research design and methods overview are presented in the chapter.

STATEMENT OF THE PROBLEM

According to the Surveillance Epidemiology and End Results of the National Cancer Institute (SEERS), it is estimated that 35,720 men and women (25,240 men and 10,480 women) were diagnosed with oral cancer in 2009. Of those diagnosed with oral cancer, 7,600 men and women combined are projected to die of the disease (Horner et al., 2009).

Cancer is truly a family affair; it affects every household member and wreaks havoc on the lives of individuals and the family unit as a whole when someone is diagnosed with and undergoes treatment for cancer. Additionally, a less tangible but more distressing cost of coping with the diagnosis and treatment of oral cancer is the profound impact the experience may have on patients' family members. Family members' lives may be impacted in areas such as overall health, psychological well-being, financial stability, day-to-day running of the home, personal relationships, and intimacy needs. The impact may be greatest on the primary caregiver, who is often the patient's spouse, partner, relative, or friend.

While many studies have documented the post-traumatic impact of a cancer diagnosis on the quality of life and well-being of the patient (Brewin et al., 1998; Kwekkeboom & Seng, 2002), fewer studies have detailed the impact of a diagnosis on

patients' caregivers (Ben-Zur, 2001; Carlson et al., 2000a; Ey et al., 1998). Moreover, even fewer studies reported on the experience of partners of patients with oral cancer partners (Drabe et al., 2008; Verdonck-de Leeuw et al., 2007; Vickery et al., 2002).

Although oral cancer may be an extremely stressful condition for caregivers, no specific research is known to exist that explores the experiences of caregivers of persons with oral cancer and their risk for the development of STS. Because of the paucity of research regarding STS experiences of caregivers of persons with oral cancer, information gleaned from this study will directly enhance nursing practice by raising awareness about the unique needs of caregivers of persons with oral cancer. Study findings will lead to recommendations for the provision of education and services to better meet the needs of caregivers of persons with oral cancer. Lastly, study findings may also contribute to the development of support programs needed to address the specific needs of caregivers of persons with oral cancer.

PURPOSE AND AIM OF THE STUDY

The purpose of this research was to explore the existence of STS in caregivers of persons with oral cancer, describe the nature of the experience of STS and its relationship to other variables of interest, and generate substantive contributions to emerging theory.

Congruent with the purpose of the research, the first aim of the study was to determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explained a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer. The second aim of the study was to determine the extent to which the selected demographic variables of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explained a caregiver's ability to cope as measured by the Coping Skills Test Abridged (CST-A).

The study identified and described types and strengths of relationships between scores on self-reports of STS symptoms, perceived quality of life, and stress-coping experiences among caregiving partners of persons diagnosed with oral cancers.

Biodemographic data were collected to describe the sample and facilitate the examination of relationships between the variables of interest and specific caregiver characteristics.

RESEARCH QUESTIONS

A descriptive correlational survey design was utilized to achieve the overall purpose and specific aims of this study and to answer the following research questions:

Research Question One (RQ1): Determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiver role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explain a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer.

RQ1: To what extent do the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's biopsychosocial well-being as measured by the LSR subscales in a sample of caregivers of persons with oral cancer?

RQ 1 was answered using Canonical Correlation analysis. Canonical Correlation is a technique that analyzes relationships between two sets of variables. This method maximized linear correlation between the variables, thus determining if a relationship existed between the independent and dependent variables.

Research Question Two (RQ2): Determine the extent to which the selected demographic variables of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's ability to cope as measured by the Coping Skills Test-Abridged (CST-A).

RQ2: To what extent do the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's biopsychosocial well-being as measured by the CST-A?

RQ 2 was answered via multiple regression analyses using forced entry of the predictors into the equation. An examination of the beta weights, T values, and statistical

significance indicated that no variable made a significant contribution to explaining this variance, despite the fact that the original amount of explained variances (17.8%) suggested that this was a significant amount of variance. The results were not found to be viable for use, but were analyzed and reported exclusively to provide an answer to the research question.

BACKGROUND AND SIGNIFICANCE OF THE STUDY

Cancer, a group of diseases characterized by the proliferation and spread of abnormal cells, is a major health problem and significant cause of death in the United States of America (U.S.). Americans are at-risk for developing a variety of cancers, and that risk increases as adults enter middle age and beyond. Many theories of cancer causation claim links between external factors (e.g., tobacco, chemicals, radiation, exposure to infectious organisms), internal factors (e.g., inherited mutations, hormones, immune conditions, metabolic mutations), and the body's response to uncontrolled proliferation of tumor cells.

It is estimated that 43% of cancer-related deaths can be attributed to tobacco use, unhealthy diet, alcohol consumption, inactive lifestyles, and infection. Persons living on a low income, minorities, and disadvantaged individuals are often at increased risk for exposure to environmental carcinogens and avoidable risk factors such as alcohol, tobacco, and infectious agents. In general, persons with fewer economic or social means have more limited access to health services and education and are less empowered to take the necessary steps to improve their own health (Petersen, 2009).

DEFINITION OF ORAL CANCER

Oral cancer, the focus of this study, is a category of head and neck cancer encompassing the mucosal surfaces of the upper aerodigestive tract and oral cavity including the subsites of the lip (excluding skin of the lip), tongue, salivary glands, gum, mouth, pharynx, oropharynx, and hypopharynx. Oral cancer contributes to the national and global cancer burden and accounts for approximately two percent of all cancers diagnosed annually in the U.S. (American Cancer Society, 2008).

Lifetime Risk and Incidence of Oral Cancer

Based on the most recent statistical data from 2004-2006, 1.02% of men and women are at a lifetime risk of developing oral cancer. The percentage can also be expressed as: 1 in 98 men and women will be diagnosed with cancer of the oral cavity and pharynx during their lifetime (Horner et al., 2009).

Between the years 1992 and 2001, oral and pharyngeal cancer ranked as the seventh most common cancer in men in the U.S., with an incidence rate of 16.7 cases per 100,000 (Clegg & Ward, 2004). During the same time period, oral cancer was the fourth most common cancer and ranked as the most common cause of death in African American men (Shiboski et al., 2005). The incidence rate for women during this time frame was less than one-third of the rate among men.

Incidence rates for oral cavity cancer are two to four times higher among men than women for all racial and ethnic groups except Filipinos, for whom occurrence rates are equal across genders. Among men, the highest rates are found in blacks, followed by non-Hispanic whites, Vietnamese, and native Hawaiians. Between 2001 and 2005, the incidence rate among African American men was 17 cases per 100,000. In women, the highest rates are in non-Hispanic whites, followed by blacks and Filipinos. Incidence rates for oral cancer increase with age in all groups except the oldest age groups of black men and women. The greatest increase in rates occurs between the 30 and 54 year old group and the 55 and 69 year old group.

From 2002-2006, the median age at diagnosis for cancer of the oral cavity and pharynx is 62 years of age. Approximately 0.6% of individuals are diagnosed under age 20; 2.4% between age 20 and 24; 6.8% between age 35 and 44; 20.9% between 45 and 54; 26.2% between 55 and 64; 21.3% between 65 and 74; 16.1% between 75 and 84 years; and 5.8% \geq 85 years of age (Horner et al, 2009).

Prevalence of Oral Cancer

Statistical data from January 2006 revealed that there were an estimated 244,473 living men and women who had a history of oral cancer or cancer of the pharynx at any

point prior to that date. The data included persons with active disease and those who had been declared cured (Horner et al., 2009).

Mortality Rates for Oral Cancer

Mortality rates for oral cancer are lower than the incidence rates, which may reflect reasonably high survival rates due to screening, early diagnosis, and advanced forms of treatment. From 2002-2006, the median age at death from oral cavity and pharyngeal cancer was 68 years of age. According to SEERS (Horner et al., 2009), approximately 0.2% of those affected died under age 20; 0.8% between 20 and 34; 3.4% between 35 and 44; 14.5% between 45 and 54; 23.6% between 55 and 64; 22.2% between 75 and 84; and 11.2% at ≥ 85 years of age. The age-adjusted mortality rate was 2.6 per 100,000 men and women who died of oral cancer in the United States between the years 2002 and 2006 (Horner et al., 2009).

Risk Factors for the Development of Oral Cancer

Historically, oral cancer predominantly affected males over the age of 50 years and those with lower socioeconomic status. Well-established risk factors for the development of oral cancer include tobacco use in the form of cigarettes, smoking pipes, and chewing (smokeless) tobacco. Chewing the betel nut, an uncommon practice in the U.S. but widespread throughout other parts of the developed world, is also a known cause. An increase in marijuana use in industrialized countries in the past 20-30 years may also play a role in an increased risk of developing tongue and tonsil cancer in younger adults (age < 45 years). The synergistic effect of alcohol consumption and cigarette smoking in older adults (age > 55 years) is the most well-known risk factor for the development of oral cancer.

Trends in Oral Cancer Rates

Over the past decade, the age at time of diagnosis with oral cancer has decreased by an average of five years in men and women. A growing body of research evidence suggests that the increased prevalence of human papilloma virus (HPV) in the adult oral

cavity over the past 30 years may be a contributing factor to the increasing occurrence of oral lesions in younger persons and in those without well-established risk factors (Terai et al., 1999).

Investigators in the U.S. and Europe have noted an alarming new trend of increased incidence rates of squamous cell carcinoma of the tongue, tonsil, and oropharynx in adults less than 45 years of age (Shiboski et al., 2005). The overwhelming majority of oral squamous cell carcinomas diagnosed in younger patients (age < 45) are HPV-positive. HPV-positive patients have fewer risk factors of alcohol and tobacco exposure compared to those patients who are older and diagnosed with HPV-negative oral carcinomas.

Specifically, most tonsillar cancers are HPV-positive. Persons at-risk for developing tonsillar cancer are those with a history of HPV-associated malignancy, women over the age of 50 years with a history of *in situ* and invasive cervical cancer, and husbands of women with *in situ* and invasive cervical cancer (Hemminki et al., 2001).

HIV-positive and immunosuppressed transplant patients are also at an increased risk for tonsillar and oropharyngeal cancer (Frisch et al., 2000). Moreover, patients with a condition known as Fanconi Anemia have a 500-700 fold increased risk of developing oral squamous cell carcinoma (Kutler et al., 2003).

As this decade has progressed, researchers (Rajkumar et al., 2003) have documented that individuals exposed to HPV are at increased risk for the development of oropharyngeal cancer. Further, a strong association between HPV-positive oral cancers and certain sexual behaviors in men and women has been determined. Risk factors include: (1) young age at first intercourse, (2) number of sexual partners, (3) history of genital warts, (4) history of performing oral sex, and (5) oral-anal contact.

Infection with certain strains of HPV, a DNA virus with an affinity for the squamous epithelia, has been specifically correlated with the development of squamous cell carcinomas of the head and neck region, including the oral cavity. There are over 120 different types of HPV strains varying from low- to high-risk. Low-risk strains of HPV (HPV-6 and -11) may cause benign hyper-proliferation of the epithelium, while higher risk strains (HPV-16, -18, -31, -33, and -35) have strong oncogenic association with cervical cancers (Fakhry & Gillison, 2006).

TREATMENT APPROACHES TO CURING CANCER

Most types of cancer are treated by singular or combination modalities such as surgery, radiation, chemotherapy, hormone therapy, and immunotherapy. Each year, an increasing number of advances in cancer treatment have raised survival hopes. While overall survival rates are increasing, prevalence rates remain stable for some cancer types and are increasing for others.

Some forms of cancer have been found to demonstrate resistance to treatment. In some instances, the treatment itself may cause permanent damage and disfigurement. Many cancer treatment modalities exert heavy physical, emotional, and financial burdens on patients and their families. Annually, billions of dollars are spent in the U.S. to achieve cure, treat complications from the disease and its treatment, and compensate for the loss of productivity due to lost work time (American Cancer Society, 2002).

Treatment Approaches to Curing Oral Cancer

Treatment modalities for oral cancer vary according to location, type, stage, and extent of metastatic activity. Standard approaches to effect cure include resection of the primary tumor; modified radical neck dissection with or without flap graft alone or followed by radiation; radiation alone; radiation and chemotherapy; or a combination of all three modalities.

Oral cancer is significantly harder to treat than some other forms of cancer due to the typically late stage at diagnosis coupled with the grueling process and side effects of surgery, radiation, or chemotherapy.

Many persons treated for oral cancer are subject to additional complications from the various treatment modalities. Among the complications are the risk of airway compromise necessitating a temporary or permanent tracheostomy, radiation sickness, immunosuppression, graft site infection, temporary or permanent loss of neurologic innervation of the neck, chewing and swallowing deficits, altered or absent speech, appearance-altering physical disfigurement, weight loss, poor nutrition, fatigue, nausea, oral cavity pain, and negative psychosocial effects.

Survival Rates for Oral Cancer by Ages, Race, Sex, and Staging at Diagnosis

Oral cancer, if detected early and while the disease remains localized, is a highly curable form of cancer, with a five-year relative survival rate of 82%. Unfortunately, approximately half of oral cancers are diagnosed when the disease has spread beyond the original tumor site. According to Horner et al. (2009), approximately 34% of oral and pharynx cancers are diagnosed when the cancer is confined to the primary site, 46% after the cancer has spread to regional lymph nodes or adjacent to the primary site, and 14% after the cancer has metastasized; staging data are unknown for the remaining 7%.

The overall five-year relative survival rate from 1998-2005 was 61.0%. Approximately 7,400 persons in the United States died from oral cancer in 2002 (American Cancer Society, 2002), and the five-year survival rate for all forms and stages of head and neck cancer combined was estimated at 25.5%-76.7% (Ribeiro, 2003).

The five-year relative survival rate is higher overall for younger adults aged 20-44 years with tongue (64%) and tonsil (63%) squamous cell carcinoma compared with adults over age 45, for whom survival rates are 51% and 43%, respectively. The five-year survival rate is highest for both age groups in those who have tonsillar cancer versus those who have oral cancer affecting another pharyngeal site (Ribeiro, 2003).

Five-year survival rates by race and sex were 62.4% for white men, 63.8% for white women, 38.2% for black men, and 53.2% for black women. Poorest outcomes have been consistently reported among African American males (Hoffman et al., 1998). To date, there remains a profound difference in survival rates between African American men and white men. Approximately 61% of white men survive more than 5 years but only 36% of African American males with oral cancer live that long (National Institutes of Health, 2008).

Currently, the five-year survival rate for early diagnosis with localized oral or pharynx cancer is 82.7%. Diagnosis often occurs after the cancer has already spread to nearby tissues or lymph nodes, reducing the five-year relative survival rate to 54.3%. Among younger adults (age 20-44 years), the number of cases of tongue cancer diagnosed at a local stage (48%) is similar to those cases diagnosed that had metastasized (46%). In older adults, more than one half of cases of tongue cancer had metastasized by the time of diagnosis. In the case of tonsillar cancer, the stage of disease at diagnosis is

similar for both younger (8%) and older adults (76%), with most tumors having metastasized to regional or distant sites at the time of diagnosis (Shiboski et al., 2005). Cases diagnosed when the cancer had spread to distant organs have a mere 31.8% five-year relative survival rate, and those with unstaged disease have a 53.4% five-year survival rate (Horner et al., 2009).

Effects of Oral Cancer Treatment on the Patient

A study examined the quality of life and fear of recurrence in 111 three-year disease-free survivors of head and neck cancer (Campbell et al., 2000). The study identified that cancer of the head and neck region can cause profound effects, including when the patient looked in the bathroom mirror each morning. Burdens identified as unique to living with oral cancer encompassed disfigurement of the face, distortion of speech, loss of taste and appetite, impairment of eating, oral dryness, and stiffness of neck tissues.

Campbell et al. (2000), in a one year longitudinal study, examined 41 patients who underwent radiation therapy with and without chemotherapy or surgery. The researchers found that head and neck cancer treatment was associated with a prevalence of depression in those receiving radiation and chemotherapy as well as continued self-reported psychological distress.

Functional deficits caused by chemoradiation, such as eating and weight changes that may or may not resolve, created further physical and psychosocial changes that impacted the survivor and caregiver, as sharing a meal often serves as a social bonding experience (Newman et al., 1998).

Another study, which assessed quality of life in head and neck cancer patients, identified that these patients had significant difficulties in the areas of physical functioning, role functioning, global quality of life, depression, appetite, and finances (Sherman et al., 2000).

A recent study by Hinerman et al. (2006) examined the rates of local-regional control, survival, and complications from treatment with postoperative continuous-course external beam radiation for squamous cell carcinomas of the larynx, hypopharynx, and oropharynx. All of the 295 study participants had undergone prior resection of the

primary tumor with or without a neck dissection. Study results indicated that there was regional control failure in 42 patients, and of those, 34 (81%) were detected within two years of surgery.

Hinerman et al. (2006) noted that five-year local-regional control rates according to site were: larynx, 85%; hypopharynx, 77%; and oropharynx, 83%. All 11 patients who underwent a supraglottic laryngectomy were local-regionally controlled. However, the study also documented that numerous mild to moderate (n=20) and severe (n=25) complications of radiation treatment occurred within the population as a result of treatment.

Finally, a study by Garavello et al. (2006) explored risk factors for distant metastases in head and neck squamous cell carcinoma and the incidence of distant metastases in this population. The study validated that the incidence of distant metastases occurred in about 9.2% of cases, within the first two years after initial treatment. Although squamous cell carcinoma typically remained localized to the primary site and regional lymph nodes, the risk for distant metastasis remained a clinical concern for health care providers and represented another potential source of extreme anxiety for patients and their family members and caregivers.

STRESS OF A CANCER DIAGNOSIS ON THE FAMILY UNIT

Nearly three decades ago, Mages and Mendelsohn (1981) identified a state of prolonged stress that ensued from discovery of cancer; the processes involved in diagnosis; any surgical intervention, medical treatment, and follow-up; and a constant fear of recurrence. Further, Mages and Mendelsohn posited that reaction of patients' family may have positively or negatively affected outcome. The studies outlined below focus on partners of persons with cancer.

In a study of stress among parents of seriously ill children, Santacroce (2003) found that uncertainty emerged as the single greatest source of psychosocial stress for the sample. Santacroce discussed the role of uncertainty as a harbinger of looming danger, and further purported that, over time, the human drive to find meaning in the experience of prolonged uncertainty would motivate parents to reframe their personal values, possibilities, and choices. For the parents, a serious illness in their child created a sudden

overwhelming event that destroyed the notion of the world as “taken for granted,” and induced feelings of helplessness.

AFFECTIVE RESPONSES IN PARTNERS OF PERSONS WITH CANCER

A study conducted by Oberst and James (1985) found that wives of cancer patients felt more distress, anger, frustration, and lack of support during the treatment process than before treatment began. Wives also reported feelings of personal vulnerability, inability to cope with daily hassles, generalized fatigue, and exacerbation of preexisting medical conditions as well as the development of new somatic complaints.

An exploratory study conducted by Carlson et al. (2001) examined partners’ understanding of the breast and prostate cancer experience. This study screened for mood disturbance in the patient as rated by patients and their partners as well as partner understanding, patient satisfaction, perception of the degree of difficulty of the cancer experience, and type of social support deemed important to the patient with prostate or breast cancer. Carlson et al. reported that partners of cancer patients understood the cancer experience quite well; however, partners were found to overestimate patients’ distress levels. In addition, study findings demonstrated that the more satisfied the patient was with social support and perceived empathy provided by the partner, the more likely patients were to have positive psychosocial adjustment scores.

Quality of the relationship between spouses has also been studied to gauge reactions and adjustments to a diagnosis of cancer in dyads. Carlson et al. (2000b) found that impact of a cancer diagnosis was reactionary in nature and that adjustment to the diagnosis involved the act of taking control and making changes to a new life situation. The study also found that having a wife with breast cancer had a negative impact on a husband’s job performance, work satisfaction, and work attendance, which, in turn, adversely affected his emotional adjustment. In addition, a husband’s dissatisfaction with his wife’s level of emotional support in the marriage was found to increase the husband’s sense of worry, tension, and feelings of unease.

A study by Walker (2002) examined partners’ experiences of living with a patient with lung cancer. The phenomenological approach used in that study generated the emergence of themes, which revealed the caregiving partners’ perceptions of changes in

their daily life responsibilities; coping mechanisms; frustration from role changes; worries about their spouse's condition and new symptoms; the inability to share feelings with their spouse; worry about their own health; and anxiety about the future.

Ben-Zur et al. (2001) determined that, over time, a cancer diagnosis took an immeasurable toll on the spouses, parents, siblings, and partners of cancer survivors. Ben-Zur et al. found that patients with breast cancer and their spouses suffered similar degrees of distress, with the patients themselves using more problem-focused coping strategies than their spouses, who often resorted to emotion-focused coping that included verbal venting and avoidance, which, in turn, contributed to distress and poor adjustment in the spouse with cancer.

A study by Fergus et al. (2002) on patients with prostate cancer revealed that individuals were keenly aware of the toll their illness had on their partners and took deliberate steps to minimize the impact. For some patients, the realization that emotional interdependency between themselves and their spouse caregivers affected stress and coping in both parties, leading patients to practice a form of "safeguarding" as a way to shield the caregiving spouse from additional worry.

THE EXPERIENCE OF BEING A CAREGIVER OF A PERSON WITH ORAL CANCER

Over the past decade, increasing emphasis has been placed on studying the stress responses and experiences of partners and significant others who provide care to persons with various types of cancer. The impact of oral cancer on the family unit, and on caregivers of persons with oral cancer in particular, has not been studied adequately. Historically, caregivers of persons with oral cancer have been a grossly understudied group.

Three studies explored the impact of oral cancer on quality of life and the incidence of psychological distress in patients with oral cancer and their partners (Drabe et al., 2008; Verdonck-de Leeuw et al., 2007; Vickery et al., 2002). The study conducted by Vickery et al. examined the impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. Verdonck-de Leeuw et al. conducted a study that investigated distress in spouses and patients after treatment for head and neck

cancer. Drabe et al. (2008) examined the psychiatric morbidity and quality of life in wives of men who had long-term head and neck cancer.

This author's study was relevant and timely because of the increased incidence of oral cancer worldwide, which meant that there exists exponentially more caregivers for persons with oral cancer than in prior decades. The dearth of documented data about the caregiver experience as a partner of a person with oral cancer was striking given the nature and scope of the problem. Further, none of the studies conducted on oral cancer caregivers attempted to correlate the cancer caregiving experience as a traumatic one that could have resulted in distressing symptoms as a result of their helping work. It is hoped that this study will be a useful addition to the sparse body of literature on this topic.

PHENOMENON OF INTEREST IN THE STUDY

Dr. Beth Hudnall Stamm, an expert and researcher in the joint fields of psychology and traumatology, explored the stress experiences of many different types of helpers. Stamm et al. defined a "helper" as a professional or a lay person who is secondarily exposed to trauma through involvement with a friend or family member experiencing stress or trauma (Figley, 1998; Stamm et al., 1998).

As a result of her research with helpers, Stamm et al. (1998) coined the term "Secondary Traumatic Stress" (STS) to refer to the phenomenon of traumatic exposure due to some kind of helping activity (either paid or voluntary) that places one in the path of another's traumatic material. Stamm et al.'s identification of STS in lay caregivers and explanation of the characteristics of STS helped to advance traumatic stress research by differentiating between phenomena related to the direct experience of stress (such as in post-traumatic stress disorder [PTSD]), and indirect or secondary traumatic stress an individual experiences because of exposure to trauma experienced by another person (Best et al., 2001; Libov et al., 2002; Manne et al., 2000).

Applicability of the Phenomenon of Interest to Caregivers of Persons with Oral Cancer

Receiving a diagnosis of oral cancer is generally considered a bad event and carries with it negative connotations. Experiencing a diagnosis of oral cancer meets the

criteria for a traumatic event as it is sudden and unexpected, exceeds a person's ability to meet its demands, and disrupts the individual's frame of reference and other central psychological needs and related schemas (McCann & Pearlman, 1990a).

STS among caregivers for persons with oral cancer was explored in this study to fill a gap in knowledge about the experience of these unique helpers and to ascertain the types of support they needed to promote their well-being while in a caregiving role. According to Stamm et al. (1998), helpers often do not have sufficient support to meet their personal needs for rest, family care, self-care, and professional development, and thus are at risk for compromised well-being. The physical, emotional, psychological, socioeconomic, interpersonal, and intimacy needs of caregivers for persons with oral cancer are underrepresented in the literature—this study aimed to highlight their plight.

STATEMENT OF THEORETICAL FRAMEWORK

A theoretical framework for understanding the oral cancer caregiving experience was sought to support the study. Extant literature provided a platform from which to promote the use of deductive reasoning as a tool for examining and analyzing the research questions in the context of the theory (Creswell, 1994).

Constructivist Self-Development Theory (CSDT) underpinned this study and formed its theoretical framework. CSDT, an interactive developmental theory common in trauma literature, focused on the interaction between person and environment. The theory blends developmental theory (Mahler et al., 1975), self-psychology (Kohut, 1977), social learning theory (Rotter, 1954), and cognitive theories (Mahoney & Lyddon, 1988).

In accordance with the tenets of CSDT, the “self” is the core of a person's individual identity and inner life. According to McCann and Pearlman (1990a), components of the self include basic capacities that maintain an inner sense of identity and self-esteem, ego resources that filter and add to interactions with the outside world, psychological needs that motivate behavior, and cognitive schemas.

A schema is a “lens” or imaginative window through which individual perceptions of the world are shaped and experiences interpreted. Janoff-Bulman (1992) posited that most people's fundamental assumption is that things that affect us are usually good and carry with them positive outcomes.

CSDT was a heuristic model that helped frame understanding of how individuals respond to a variety of traumatic situations including rape, sexual and physical abuse, war, violent crime, chronic illness, accidents, and other stressors (McCann & Pearlman, 1990a). The theory was used to understand the sum of the parts of the experience by exploring patterns and relationships among its smaller components.

This theory was applied to the STS experience of caregivers of persons with oral cancer in the current study. The researcher explored whether caregivers of persons with oral cancer could experience the impact of oral cancer as a traumatic event that shattered their fundamental assumptions about the world and caused psychological upheaval, requiring acquisition of skills to tailor individual perceptions to meet the new schema. The second prong of the study, supported by CSDT, examined if the stress of the trauma itself, as well as the stress of dealing with the demands of the situation, could exceed an individual caregiver's coping skills.

CSDT was utilized as a scaffolding theory that informed the researcher and could offer guidance to a trauma survivor (i.e., a caregiver of a person with oral cancer) to integrate the traumatic event into a new whole while maintaining an intact sense of self.

DESCRIPTION OF STUDY VARIABLES

Variables selected for inclusion in this study were found to have significance in describing the life experiences and states of well-being among caregivers of those who have experienced a traumatic event; this author posited that a diagnosis of oral cancer can be classified as such an event.

The variables below were operationally defined and measured in the study to provide an observable manifestation of the phenomena and to inform the author about the possible applicable theoretical constructs.

- **Demographic Factors:** characteristics of a study participant that are unique to that person. For this study, the demographics factors recorded were age, gender, marital status, stage of partner's cancer, and length of time in caregiving role.
- **Compassion Satisfaction:** pleasure derived from being able to do work well and from having helped another person.

- **Burnout:** a state of having feelings of hopelessness and difficulties in dealing with work or in doing a job effectively. Feelings may have reflected a perception that efforts make no difference, or that they were associated with a very high workload or a non-supportive work environment.
- **Compassion Fatigue/Secondary Traumatic Stress (STS):** work-related, secondary exposure to extremely stressful events. Involved exposure to another person's traumatic events. In this case, the traumatic event was diagnosis and treatment for oral cancer. STS involved a rapid onset of symptoms that included being afraid, difficulty sleeping, mental recreations of the upsetting event, or avoidance of things that reminded one of the event.
- **Quality of Life:** a person's self-described standard of living, which included health, social interaction, social satisfaction, and positive engagement within a self-identified family unit.
- **Life Status Review:** the state of a person's well-being in relation to activities of daily living.
- **Coping Skills:** the ability of a person to successfully contend with an unexpected and potentially stressful situation.

RELEVANT TERMS

The following terms were operationally defined and utilized in the study in order to achieve consistency and clarity.

- **Oral Cancer:** a category of head and neck cancer encompassing the mucosal surfaces of the upper aerodigestive tract and oral cavity, including the subsites of the lip (but excluding skin of the lip), tongue, salivary glands, gum, mouth, pharynx, oropharynx, and hypopharynx.
- **Person with Oral Cancer:** a person who is undergoing or has undergone treatment for head and neck cancer, encompassing the mucosal surfaces of the upper aerodigestive tract including the lip, tongue, oral cavity, pharynx, and larynx.
- **Caregiver of a Person with Oral Cancer:** any person, family member, or significant other who, by self-report, had an integral role in the life and

functioning of someone undergoing or who has undergone treatment for head and neck cancer, encompassing the mucosal surfaces of the upper aerodigestive tract including the lip, tongue, oral cavity, pharynx, and larynx.

ASSUMPTIONS OF THE STUDY

The following assumptions were relevant to this study:

1. The volunteer sample was comprised of caregivers of patients with oral cancer.
2. Responses received from study participants accurately reflected their personal experiences while caring for a person with oral cancer.
3. The caregiver participants in this study answered all of the demographic data and survey items openly and honestly.

OVERVIEW OF THE STUDY DESIGN AND METHODS

This study used a descriptive correlational design to identify, analyze, and describe relationships between specific caregiver characteristics (demographics) and survey data that included self-reports of the STS symptoms, perceived quality of life, and ability to cope as experienced by the sample.

Descriptive correlational analysis of survey and demographic data determined relationships between the variables identified in the study's research questions. Multiple regression and discriminant analysis was used to determine the predictive value of selected variables in anticipating and identifying the short-term and long-term support and coping needs of caregivers for persons with oral cancer.

The volunteer (non-random) sample for this study was recruited from August 2006 – March 2007 using flyers distributed at local support group meetings of the Support for Persons with Oral and Head and Neck Cancer (SPOHNC) group. Notices were also posted electronically at the password-protected online member support forum of the Oral Cancer Foundation (OCF). Group leaders also invited the investigator to introduce the study in-person and online via a letter of introduction. The IRB-approved recruitment materials are found in Appendix A. To reach as many self-selecting oral cancer caregivers as possible, a mailed survey approach was used as the major data collection strategy.

Inclusion criteria were: participants must be: a) 18 years of age and older, b) able to read and understand English, and c) the self-identified caregiver for a partner who has been diagnosed with oral cancer. The recruitment materials briefly described the study and specified how those interested in finding out more about the study could contact the researcher directly by e-mail or phone.

The researcher answered all potential participants' questions before asking if they wished to receive a packet of questionnaires. Callers were informed that a cover letter explaining the study would be enclosed with the mailed questionnaires, and that completing and returning the questionnaires would constitute their consent to participate. Those who wanted to receive the packet provided the researcher with a mailing address. Enclosed along with the cover letter and instruments was a self-addressed postage-paid envelope that subjects used to return the completed questionnaires. A detailed presentation of design and methods is provided in Chapter Three.

MEASUREMENT OF THE VARIABLES

Measurement of the variables of interest was accomplished by using subject self-reports and survey questionnaires that were distributed and returned by postal service. The following instruments and data collection strategies were utilized:

Socio- and Bio-Demographic Data (Appendix B)

Demographic data collected in this study were relevant to the constructs found in the literature in the following ways: being significant to the experiences of STS; dynamics of coping with serious illness; abilities to seek out, obtain, understand, and use resources; and the appraisals of life quality. Basic data collected from each subject included age, gender, income, living arrangements, relationship to the person with oral cancer, work status, marital status, elapsed time since the diagnosis of oral cancer, and computer literacy and usage. Self-reports of computer literacy and usage were necessary to identify relationships between available resources and choices caregivers make about using various resources.

Family/Significant Other Quality of Life (FamSoQOL) (Stamm, 2003): Compassion Satisfaction and Fatigue Subscales (Appendix C)

For purposes of this study, a self-identified caregiver for the person with oral cancer was recognized as the “helper,” “significant other,” or “partner.” The self-reported quality of the person’s life, i.e., how good or bad they felt about themselves, their partner, and what they are doing, was measured by the FamSoQOL. The FamSoQOL consisted of 30 items that asked subjects to describe how they felt while taking care of another person with a life-threatening illness. Items were screened for both positive and negative feelings and experiences, including compassion and fatigue that may occur during helping relationships. Subjects were asked to respond to the statements using numbers to indicate the frequency with which they experienced the feeling or thought in the past 30 days. The scale was: 0=Never, 1=Rarely, 2=A Few Times, 3=Somewhat Often, 4=Often, 5=Very Often.

The FamSoQOL was a recent adaptation for lay caregivers of a well-established and psychometrically sound measure known as the ProQOL (Stamm, 2002), which was originally designed to measure compassion satisfaction and fatigue in professional caregivers. This instrument addressed STS, Compassion Satisfaction & Fatigue, and Burnout using a 30-item survey that takes approximately 10 minutes for participants to complete. The ProQOL had been tested repeatedly to assess its psychometric properties; it performs well on the item-to-scale statistics due to increased specificity and reduced collinearity as well as stable internal consistency. The ProQOL is a robust tool with proven utility in measuring issues related to professional quality of life. It is this researcher’s belief that the FamSoQOL, which contained only minor adaptations of terminology tailored for use with lay caregivers, was a proper measure for this study.

Life Status Review (LSR) (Stamm & Rudolph, 1997) (Appendix D)

In this study, the caregiving partners provided self-reports using the Life Status Review (LSR) comparing how their lives were in the present compared to before the diagnosis of oral cancer. The areas the subjects were asked to appraise included housing, transportation, health and wellness, employment, financial status, and alcohol and substance use. The response sets allowed for positive, negative, and neutral appraisals

that ranged from “worse” to “great,” with “an issue,” “fine,” and “good” as additional choices.

The LSR also tracked life necessities and human interaction, examined support systems and stressors, and identified problem areas in the person’s biopsychosocial environment. The LSR was comprised of 30 items clustered into 8 subscales that represented a construct in either the personal (Alcohol/Substance Use), interpersonal (Self/Social/Interpersonal), or social (Employment/School) domains. The LSR tracked both good and poor outcomes and used a 5 point Likert type scale that spanned negative numbers, which represented a problem, and neutral to positive numbers, which represented good things that were happening. The self-report checklist of items took 5-10 minutes to complete (Stamm et al., 1998).

The LSR was used for four distinct study purposes: (a) identification of positive and negative stressors in an individual’s life; (b) identification of stressors that threatened an individual’s well-being or ability to continue in their current activities (Rudolph et al., 1996; Stamm, 1995); (c) development of a profile of an individual’s well-being across time; and (d) modeling of healthy attention to one’s life and identification of areas of strength that can be used as a transition to healing (Stamm et al., 1998).

The LSR could also be used as a self-report or a clinical interview for single or longitudinal administration. The measure can be used for tracking patients and for helping providers evaluate their levels of Compassion Fatigue and Satisfaction. The LSR and its subscales have demonstrated consistent reliability, both originally and after re-test, across clinician and patient samples (Stamm et al., 1998). The LSR was proven to be a successful tool in the measurement of life status and it directly enhanced this study of caregivers’ day-to-day life.

Coping Skills Test-Abridged (CST-A) (Jarebek, 2001) (Appendix E)

The CST-A was utilized in this study to measure the self-reported coping strategies that caregivers use, how stressed they feel, and how they reacted to various life situations. The CST-A consisted of 10 items that asked the subject to rate the statement being made using a scale of almost never, rarely, sometimes, quite often, and most of the time. The tool took approximately 5 minutes to complete. The tool was found to be inefficient, lacking in psychometric soundness, and lacking in the ability to inform study

results. In retrospect, the tool was not a good choice for use and participants' coping was not an adequately measured variable in the study. This will be explained further in Chapter Four.

ORGANIZATION OF THE DISSERTATION

The remainder of this dissertation is organized into Chapters Two, Three, Four, and Five. Chapter Two presents a review of related literature on caregivers of persons with diverse types of cancer, focuses on oral cancer, describes the evolution of the term STS, and documents the application of CSDT as it relates to understanding the experience of STS in caregivers of persons with oral cancer. Chapter Three delineates the research design and methodology of this study. Instruments used to gather data, procedures followed, and selection of the study sample are described in the third chapter.

Results of data collection and statistical analysis are reported in Chapter Four. Chapter Five contains the conclusions, limitations of the study, recommendations of the study, and implications for further research. The dissertation concludes with a bibliography and several appendices following Chapter Five.

CHAPTER TWO: REVIEW OF THE LITERATURE

INTRODUCTION

The diagnosis of a life-threatening illness such as cancer is typically a highly stressful event for patients and their partners—it can lead to emotional, psychological, and physical stress for both patient and caregiver alike. A cancer diagnosis can also disrupt the family unit and lead to impaired quality of life and stress in caregivers who attempt to coordinate all aspects required to care for an ill partner and maintain a stable home life.

Thus, a cancer diagnosis inherently qualifies as a traumatic event. The word “trauma” comes from the Greek word meaning “injury” and is characterized by frustrated desires, helplessness of an individual to achieve those desires, and one’s situatedness in a relationship with another person.

When one considers cancer to be a complex, traumatic event that involves both the patient and caregiver, one must examine the connection between the two parties as well as the effect of the cancer diagnosis on the caregiving partner, who often bears much of the responsibility for the care of the ill partner and the day-to-day running of the home. Caring for an ill family member is a profound experience that may have lasting effects on the primary caregiver, who is often a spouse or partner. Caregiver stress is often compounded by fear that his or her loved one may die, and further complicated by concerns about illness or treatment effects such as recovery from surgery, radiation or chemotherapy treatments, presence of physical disabilities, psychological distress, behavioral changes, and the presence of chronic pain. The current study focused on the caregiving partner of a person with cancer (specifically, oral cancer) as the traumatized individual in the relationship.

ORGANIZATION OF CHAPTER TWO

This chapter traces the evolution of the terms Vicarious Trauma (VT), Compassion Fatigue (CF), and Secondary Traumatic Stress (STS). Further, this chapter differentiates between the concept of Burnout and STS as described in seminal literature.

This chapter also describes Constructivist Self-Development Theory (CSDT), the theoretical underpinning of the study, and its applicability to STS in caregivers. Additionally, this chapter explains the applicability of CSDT to caregivers of persons with oral cancer.

This chapter reviews literature that has explored the experience of cancer as a disease affecting both patient and partner. Studies are presented that have examined the phenomenon of being a caregiver of a person with cancer and influenced researchers' thinking about the positive and negative outcomes of the experience. Lastly, studies that have described the experience of living with a partner with oral cancer are discussed.

EVOLUTION OF THE TERM VICARIOUS TRAUMA

The concept of STS, the phenomenon explored in this study, evolved from almost two decades of scholarly work, predominantly in the field of psychology. Pioneers in a branch of psychology named traumatology studied distressing psychological effects on those who have experienced or witnessed trauma firsthand. Similar psychological effects were noted in those who experienced trauma secondhand, e.g., mental health workers, counselor, nurses, first responders—as in those who had experienced trauma firsthand. Hearing the story of another's trauma, as well as the nature and magnitude of the stressor, was found to be as psychologically distressing as exposure to the trauma itself.

Initially, the effects of secondary exposure focused on professional helpers such as psychologists, medical and nursing professionals, and first responders. Recently, however, effects on lay helpers such as caregivers and partners have been thoroughly examined, and these individuals have been identified as persons susceptible to the effects of secondary traumatic exposure.

An extensive review of the medical, psychological, sociological, and educational literature revealed that initially, three terms were used to refer to the negative impact on therapists working with traumatized individuals: Vicarious Traumatization (VT), Compassion Fatigue (CF), and Secondary Traumatic Stress (STS). A search of the PsycINFO Lit database revealed that the term VT made its debut in the literature in 1985 in a journal article explaining the vulnerability of children to trauma experienced by others (Terr, 1985).

Among the early researchers to study and expound on secondary exposure in helpers were McCann and Pearlman (1990a, 1990b), who applied the term VT to their work while further developing the concept, including recognizing its defining characteristics. VT referred to detrimental changes that occurred to a professional's view of oneself, others, and the world after working with and being exposed to a client's traumatic material. McCann and Pearlman viewed VT as a typical response to exposure (not anomalous), and one that may challenge the beliefs of the professional helper. They expressed concern that susceptible helpers might experience decreased efficiency, motivation, and reduced feelings of empathy toward others in their professional and personal lives. McCann and Pearlman connected the phenomenon to a disruption in personal schemas of the world, a theory that blossomed and became known as Constructivist Self Development Theory (CSDT).

Disrupted Schemas and the Association with VT

The concept of VT was found to be associated with the disruption of relevant world schema in five areas that represent the manifestation of psychological needs: safety, trust, esteem, intimacy, and control in one's life. Intrusion on and disruption of these needs caused changes in therapists that were believed to have intrusive and cumulative effects (McCann & Pearlman, 1990b).

Chronic disruption of schemas was believed to cause permanent psychological damage. Since the inception of the term VT, many articles, book chapters, and doctoral dissertations have addressed the phenomenon (Follette et al., 1994; Pearlman & MacJan, 1995; Wee & Myers, 2002; Young, 1999). Additionally, when authors Pearlman and Saakvitne (1995) published a text titled *Trauma and the Therapist*, they expressed their views on the concept of counter transference and VT as applied to psychotherapists working with incest survivors. Their work laid the groundwork to understanding the degree of secondary exposure that could occur during therapy sessions.

A seminal study applying the concept of VT was conducted by Schauben and Frazier (1995). The authors set out to examine counselors who worked with sexual violence survivors. Participants were comprised of members of a female psychologists' organization and a group of sexual violence counselors. Schauben and Frazier asserted

that long-term exposure to the traumatic experiences of victimized clients could result in disruption of the counselors' basic schemas about the world, such as the belief that the world is safe and that people can be trusted. Schauben and Frazier believed counselors were prone to developing symptoms of Post Traumatic Stress Disorder (PTSD) as a result of their helping work.

Finding from the study by Schauben and Frazier (1995) were pivotal. Participants with a higher percentage of sexual violence survivors in their caseloads (> 45% for psychologist and > 97% for sexual violence counselors) had more disrupted beliefs, including core beliefs about the goodness of people, increased PTSD symptoms, and more self-identified VT, than those with less survivors in their caseload. For the first time, the study established the existence of VT as a direct effect of vicarious exposure to traumatic material. Schauben and Frazier did not find a higher incidence, however, of depression, anxiety, or hostility in those working with survivors. Critically important, and at odds with past work by Sigmund Freud, the authors also found that the counselors' own history of victimization had no bearing on the development of VT in practice.

The final part of the Schauben and Frazier's (1995) study identified strategies that counselors used to cope with work-related stress. Strategies included active coping and problem solving, seeking emotional support from friends or relatives, seeking social support, and humor. Uncommon remedies were use of alcohol or drugs, denial, or behavioral disengagement. Schauben and Frazier's study made possible further development of the concept of VT and added a new lens, STS, through which researchers could view secondary traumatic exposure.

EVOLUTION OF THE TERM COMPASSION FATIGUE

Roots of the term of STS can be traced back to a description of a state of "traumatic contagion" that occurs when a professional caregiver is exposed to the traumatic material of the patients they are helping. Authors (Solomon et al., 1990; Way et al., 2007) posited that, much like a virus, trauma symptoms could be passed from one person to the next simply by contact. Figley's (1995) critical text *Compassion Fatigue: Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized* describes the phenomenon as it applied to professional helpers and first responders. He

coined the term “compassion fatigue,” which was well accepted in the psychological community and embraced as an adequate representation of the state of tiredness inherent in the helping process. Stamm (1995) expanded the meaning of STS with the publication of her text, *Secondary Traumatic Stress: Self-care Issues for Clinicians, Researchers, & Educators*.

TRANSITION FROM THE TERM COMPASSION FATIGUE TO SECONDARY TRAUMATIC STRESS

The term STS remained linked to the term “compassion fatigue” (CF) and was popularized by Figley (1995), who described it as a disorder afflicting those professionals helping persons with PTSD. The cluster of symptoms that Figley associated with STS was exhaustion, hyper vigilance, avoidance, and psychic numbing in helpers and family members of persons with PTSD. As the name indicates, CF’s essence is the belief that those in the helper role suffer from exhaustion due to their compassionate work. Figley posited that there is a fundamental and inherent cost to caring that causes professionals who listen to clients’ stories of fear, pain, and suffering to feel similar emotions of fear, pain, and suffering simply because they engaged in the act of caring.

Figley (1995) broadened his description of STS to encompass lay family member helpers. STS included the cognitive phenomenon of VT as well as distinct, subjective symptoms of PTSD that met the criteria for the disorder. The concept of STS was enhanced by Stamm (1999), who expounded on Figley’s description of a disorder among professional helpers that is identical to PTSD and occurs after a helper becomes exposed to the traumatic experiences of others. Stamm further enhanced the criteria for STS and noted that the precipitating experience of the helper can be of short duration, such as in the case of an emergency response team at the site of a natural disaster or terrorist act. During the past decade, there has been interest in applying the combined work of Figley and Stamm to contemporary research studies (Creamer & Liddle, 2005; Ortlepp & Friedman, 2002).

Some confusion has ensued about the similarities and differences between the terms VT, CF, and STS. In reality, the terms were often used interchangeably and continue to be cross-referenced. In an effort to promote clarity, the term VT refers to

psychotherapists and professional helpers (such as nurses and first responders) who are impacted by having worked with traumatized persons in the workplace. VT occurs when a single person is affected due to contact with other members (i.e. war, natural disasters, hostage taking). CF became a more general term that refers to any person who has experienced a state of suffering while serving in a helping capacity. STS, on the other hand, refers to the traumatic effect that ensues when a caregiver is secondarily exposed to the traumatic material of another person.

APPLICATION OF THE TERM SECONDARY TRAUMATIC STRESS TO THE CURRENT STUDY

The term STS was the most applicable for use in the current study to partners of persons with oral cancer because, by definition, it refers to family members and close contacts that experience suffering as a result of their loved one's trauma. Secondary trauma occurs when the traumatic stress of one person affects an entire system after appearing in the first member. This study sought to correlate symptoms of STS with the state of being a caregiver of a person diagnosed with oral cancer. For the purpose of this study, STS has been defined as the natural behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other, and the stress that occurs from helping or wanting to help a traumatized or suffering person (Figley, 1995).

CHARACTERISTICS OF SECONDARY TRAUMATIC STRESS

Figley (1995) established diagnostic criteria for STS. In his definition, a person vulnerable to secondary stress had experienced an event outside the range of usual human experiences that would be considered distressing; such an event constituted a serious threat to the traumatized person as well as a sudden destruction of the traumatized person's environment.

According to Figley (1995), persons with STS re-experience the traumatic event in the form of recollections and dreams of the event, sudden re-experiencing of the event, and reminders of the event. Acts of avoidance and numbing are evident, including efforts to avoid certain thoughts, feelings, activities, or situations; psychogenic amnesia; diminished interest in activities; detachment or estrangement from others; diminished

affect; and a sense of foreshortened future. Persons with STS also experience symptoms of persistent arousal such as difficulty in falling or staying asleep; irritability or outbursts of anger; difficulty concentrating; hypervigilance over the traumatized person; exaggerated startle response; and physiological reactivity to cues. All symptoms listed above are considered normal within the acute crisis period of one month, but may be categorized as STS if they persisted for a longer amount of time.

As stated by Figley (1995), the three operational components to the theoretical definition and diagnostic criteria for STS are as follows:

1. Having witnessed or been confronted by actual death or injury, or by a threat to the physical integrity of oneself or others;
2. Provocation by the stressor of responses of fear, horror, and helplessness; and
3. Direct or indirect exposure to an exceptional mental or physical stressor either brief or prolonged. (p. 53)

Analysis of the Concept of Burnout as It Is Differentiated from STS

Extensive research has been conducted on the concept of burnout as a possible component of STS. The term was first coined in relation to workplace stress by Freudenberg (1974) and explained further by Maslach (1976). Pines and Aronson (1988) later asserted that burnout is a state of physical, emotional, and mental exhaustion caused by long term involvement in emotionally demanding situations. Pines and Aronson developed a Burnout Measure to measure signs of physical and emotional exhaustion, which they characterized as feeling tired and rundown, depressed, hopeless, disillusioned, and resentful toward others.

Burnout, according to its literal definition, refers to “a point in time or in the missile trajectory when combustion of fuel in the rocket engine is terminated by other than programmed cutoff” (*Webster’s Dictionary*, 1988, p. 131). In short, a short circuit occurs in what had been a pre-planned process. The missile analogy is similar to the experience of burnout in professional and personal helping relationships. The colloquial use of the term now refers to problems encountered by workers in the workplace.

Kahill (1988) identified five categories of symptoms of burnout. These included physical (fatigue and physical depletion or exhaustion, sleep difficulties, headaches,

gastrointestinal disturbances, colds, and flu), emotional (irritability, anxiety, restlessness, depression, guilt, and a sense of helplessness), behavioral (aggression, callousness, pessimism, defensiveness, cynicism, and substance abuse), work-related symptoms (quitting, poor job performance, absenteeism, tardiness, misuse of breaks, and theft) and interpersonal symptoms (inability to concentrate, withdrawal from clients or coworkers, and dehumanization of clients).

While the concept of burnout, taken at face value, appears to be an identical variable to STS, most literature comparing the two concluded that they are separate and distinct phenomena and thus were considered as such in this study. Burnout is a gradual process that begins innocuously and becomes progressively worse as exposure to job strain heightens, idealism erodes, and a lack of achievement is perceived.

STS is entirely different from burnout in that the condition could emerge suddenly with a rapid onset of symptoms and a profound sense of confusion, helplessness, and perceived isolation from supporters. In the case of professional helpers, symptoms may lack a discernible cause and recovery may occur at a faster rate with support.

THEORETICAL UNDERPINNING OF THE STUDY: CONSTRUCTIVIST SELF-DEVELOPMENT THEORY

A theory is an imaginary string that ties concepts of a phenomenon together in an organized manner. The resulting structure provides a framework for connecting components of a phenomenon in a logical way that it easily understood and applied.

The theoretical underpinning of this study is Constructivist Self-Development Theory (CSDT). The theory of CSDT is borne from an offshoot of the psychology field, a subcategory of research and practice known as traumatology, which is defined as the study of and interaction with individuals who have been traumatized. CSDT was developed as a theoretical model that focused on the interactions between persons and situations, with an additional concentration on the positive and negative personal development that occur from exposure to a traumatic event.

This study utilized CSDT as the scaffold that framed the explanation of the phenomenon of STS in caregivers of persons with oral cancer. A discussion of the theory, its defining characteristics, and its core components will be presented in this chapter.

Further, a heuristic model that applies CSDT theory to caregivers of persons with oral cancer will be presented.

COMPONENTS OF CSDT

CSDT incorporates several theoretical frameworks, including trauma theory, self-development theory, and educational theory (via elements of constructivism). McCann and Pearlman (1990a) developed CSDT to be used as a new lens through which providers could view trauma survivors. The theory was developed while the authors were treating survivors of a variety of traumatic events including sexual assault, childhood abuse (both sexual and physical), war, domestic violence, crime, chronic illness, accidents, and other major stressors. The affinity of this theory to the major stressor of a cancer diagnosis in a partner lent itself well for use in this study. McCann and Pearlman collaborated on the formulation of the theory with colleagues at The Traumatic Stress Institute, a private mental health organization located in Windsor, CT, which provides specialized care to survivors of trauma. The result was the development of a heuristic model that integrated features of trauma with components of individual psychological development.

Since the inception of the theory in 1990, McCann and Pearlman's partnership disbanded and the theory has not been developed further. Despite the limited amount of available information, the core tenets of the theory remain solvent and applicable to this study.

DERIVATION OF CSDT FROM THE UNDERLYING CONCEPT OF CONSTRUCTIVISM

CSDT has its roots in the concept of constructivism, an idea originally attributed to philosopher Emmanuel Kant and later to Jane Piaget and others. More recent work in constructivist theory has been credited to Mahoney (1981) and Mahoney and Lyddon (1988).

The central premise of constructivist thinking is the belief that humans actively create their personal realities. These realities, in turn, comprise a representational model of the world. The reality becomes a "lens" through which one can view the world, enabling an individual to categorize experiences and assign meaning to them. The model also filters experiences and determines which of them will be experienced as realities.

The Self as the Center of the Being

The notion of “self” is a central component of CSDT. The self is the “driver” of the personality and the connector that unifies the body and mind as a single unit. Evolution of the self is a fluid process, of which the hallmark is individuation, demonstration of psychological development, and freedom of expression. In constructivist thinking, the self has the ability to be unique and act as no other self in existence. The self also has the capacity to organize (McCann & Pearlman, 1990a). Construction of self-knowledge, or learning to be a self, is a fundamental process by which humans progressively bolster knowledge about themselves into a coherent, integrated whole (Mahoney & Lyddon, 1988). McCann and Pearlman applied the above definition of “self” to CSDT and viewed the self as the psychological foundation of the individual.

McCann and Pearlman (1990a) linked development of the self to more generalized personality and developmental theories. They posited that development of the self occurs from infancy through adulthood and involves the assimilation and internalization of new information from a variety of sources. Over time, a child develops a sense of self and full individuation through interactions with his or her primary caregiver through relationships, and moves from dependency on others for self-esteem to the ability to provide internal validation of the self. Further, the child, over time, learns that his or her needs will be met, and gains exposure to social norms by pleasing his or her primary caretaker. The child then generalizes this information to society-at-large as he or she becomes increasingly independent while learning to choose meaningful intimate and interdependent relationships. Thus, the family of origin may be critical to the process of shaping a person’s view of himself, others, and the world.

DESCRIPTION OF ASPECTS OF THE SELF AND THEIR FUNCTIONS AS COMPONENTS OF CSDT

McCann and Pearlman (1990a) asserted the self comprises the following attributes:

- (1) Basic capacities whose function were to maintain an inner sense of identity and positive self-esteem (the ability to tolerate strong affect, to be alone without being lonely, calm oneself, and regulate self-loathing);
- (2) ego resources, which served to regulate and enhance one’s interactions with the world outside oneself

(intelligence, ability to introspect, willpower, initiative, ability to strive for personal growth, awareness of psychological needs, ability to take perspective, empathy, ability to foresee consequences, ability to establish mature relations with others, ability to establish boundaries, ability to make self-protective judgments) (3) psychological needs, which motivated behavior; and (4) cognitive schemas, which are the beliefs, assumptions, and expectations, both conscious and unconscious, through which individuals interpret their experience (frame of references, safety, trust/dependency, esteem, independence, power, & intimacy) and (4) development of cognitive schemas which organize experiences of self and the world (beliefs, assumptions, and expectations related to psychological needs). (pp. 16-17)

Self Capacities

Kohut (1977) believed that the self is comprised of four vital self-capacities. The first is one's ability to experience feelings of both pain and joy without disrupting his or her psychological stability. The second self-capacity is the ability to enjoy time alone without feeling empty or lonely. The third capacity is the ability to use self-soothing behaviors to calm oneself in the vent of emotional upset. The final, crucial, self-capacity is the ability of the person to accept constructive criticism and negative feedback without the risk of damage to one's self-esteem.

Ego Resources

McCann and Pearlman (1990a) posited that the self is comprised of ego resources that enable a person to interact with others in a positive manner. They contended that a psychologically intact person is intelligent and introspective; possesses willpower and initiative; strives for personal growth; meets his or her own psychological needs; is able to view self and others from more than one perspective; and manifests empathy when warranted. CSDT also identifies ego resources exclusive to trauma survivors that enable the person to be protected when facing future harm. Pertinent resources to trauma survivors are the ability to predict consequences, sustain meaningful relations with others, establish boundaries between self and others, and the ability to make self-protective judgments.

Psychological Needs

Psychological needs are individual in nature and differentiate one person from another. They drive behavior and formulation of interpersonal relationships. Some needs are readily apparent to an individual while others are inborn, genetic, or based on environmental factors.

McCann and Pearlman (1990a) identified the following needs as central to CSDT:

(1) Frame of reference: the need to develop a stable and coherent framework for understanding one's experience; (2) Safety: the need to feel safe and reasonably invulnerable to harm; (3) Trust/Dependency: the need to believe in the word, or promise of another and to depend upon others to meet one's needs, to a greater or lesser extent; (3) Esteem: the need to be valued by others, to have one's worth validated, and to value others; (4) Interdependence: the need to control one's own behavior and rewards; (5) Power: the need to direct or exert control over others; and (6) Intimacy: the need to feel connected to others, through individual relationships; the need to belong to a larger community. (p. 23)

Psychological needs vary over time and with exposure to new experiences but generally remain fairly consistent during adulthood. A psychologically stable adult is able to appraise situations, identify needs, and adjust needs in accordance with a particular situation. Exposure to trauma could disrupt an individual's ability to properly assess and meet his or her own needs in a personally and socially acceptable manner.

MAJOR ASSUMPTIONS OF CSDT

McCann and Pearlman (1990a) listed the following major assumptions of CSDT:

(1) Individuals construct their own realities; (2) The self is the seat of the individual's identity and inner life; (3) the self develops over the life span through internalization and accommodation; (4) the self comprises four interrelated aspects: self capacities allow for the development and maintenance of positive self-esteem, ego resources regulate interaction with others and the environment, psychological needs motivate behavior, and cognitive schemas are the manifestation of psychological needs; (5) traumatic experiences are encoded in the verbal and imagery systems of the memory; (6) trauma could disrupt any or all parts of the self, including capacities, resources, needs, and schemas; and (7) adaptation to trauma reflects the interaction between life experiences and the self. (p. 14)

A second major assumption of CSDT is that individuals develop schemas in critical psychological need areas that may be at an unconscious or pre-conscious level of

awareness to the individual. Schemas are derived from life experiences, are interpreted with social and cultural contexts, and are most closely aligned with basic human needs such as frame of reference, trust or dependency, independence, power, esteem, and intimacy. Having a meaningful frame of reference is the most pivotal psychological need and supersedes the other six psychological needs (McCann & Pearlman, 1990a).

CSDT utilizes the concept of schemas as a central tenet of the theory. McCann and Pearlman (1990a) adapted developmental and social cognition theories, of which the latter, derived from Piaget, embraced the construct of schemas. The term “schema” denotes a construct that, over an individual’s lifetime, relates to the development of structured actions formulated into patterns borne from experience. Schemas are cognitive manifestations of psychological needs representing beliefs, expectations, and assumptions about oneself and others. Schemas create a “lens” through which one may view the world and use to help a person organize and interpret data about their experiences. The hallmark of psychological stability is the ability to be realistic in one’s expectations and adjust oneself accordingly in response to situational shifts perceived as schematic changes.

McCann and Pearlman (1990a) determined the following belief to be the crux of CSDT:

Psychological development depends on the evolution of increasingly complex and differentiated psychological systems. We are interested here in three major psychological systems: (1) the self (or the individual’s sense of himself or herself as a knowing, sensing entity, complete with capacities to regulate self-esteem and ego resources to negotiate relationships with others); (2) psychological needs (which motivate behavior); and (3) cognitive schemas (or conceptual frameworks for organizing and interpreting experience). (p. 6)

Schemas represent a cumulative body of organized knowledge that accumulates within an individual and determines how events are appraised and coded for future use. The presence of schemas creates a workable way to appraise the world and assign meaning to positive and negative events. Schemas impact an individual’s view about the world and are directly correlated with the formation of psychological needs. Words used synonymously with schema in the literature are assumptions, beliefs, and expectations.

McCann and Pearlman (1990a) remained committed to the idea that systems evolve over the course of an individual’s lifespan, foster personal development and

promote assimilation of the context of the environment in which he or she exists, and that individuals internalize schemas to develop conceptual frameworks. Data from the surrounding environment are incorporated into existing schemas for the purpose of developing a structured model through which one may view life and experiences while progressing through predictable stages of growth and development. If the environment presents a challenging situation for which a person has no existing schema, that person's cognitive schema would be modified via a process known as "accommodation." New information, in turn, could be assimilated into the person's conceptual framework via encoding into memory,

Emotions and sensory perceptions associated with an experience are included in the cognitive coding of data. Data can be encoded as richly positive, resulting in personal growth, or as deeply negative, causing pain and avoidance of the memories. The experience of trauma could become encoded in a manner laden with negative emotional, cognitive, behavioral, and interpersonal response patterns, resulting in a stunted personal development (McCann & Pearlman, 1990a).

FRAME OF REFERENCE: A CRITICAL SCHEMA

Within CSDT, the schema "Frame of Reference" holds a superior place to all other psychological needs. The phrase refers to the perspective, meaning, and methods of interpreting experiences (schemas) that a person uses to interpret life events. In an interesting juxtaposition, over time the schemas become uniquely identified with an individual while also being generalized to diverse situations or contexts. Schemas may have positive or negative attributes. CSDT can be applied to the experience of trauma because schemas can be disrupted by disparate life events not in accordance with the existing psychological structure through which an individual perceives the event (McCann & Pearlman, 1990a).

Moreover, a new situation that cannot be categorized into an existing schema would warrant an accommodation to integrate the schema into the individual's reality. If this cannot be accomplished, or there is a major, catastrophic, or threatening stressor, the event may cause a psychological shock to the individual. An individual lacking psychological resources to process the event would interpret it as traumatic or

overwhelming. For this reason, it is more typical for individuals to seek out experiences that affirm their existing schemas, even if others may perceive such an act negatively. Seeking familiar schemas, even if they are not productive, can be perceived by the individual as less threatening and more manageable. Over time, persons with pervasive negative schemas may ignore positive information about themselves, which can result in reinforcement of the disruptive impact of a negative event.

CSDT AND THE TRAUMA SURVIVOR

CSDT became an interactive theory that was easily applicable to trauma survivors, in which the interaction between person and environment is consistent with similar beliefs in extant trauma literature. For clarity, McCann and Pearlman (1990a) designated specific criteria that characterized an experience as traumatic. These criteria were that the event must (1) be sudden, unexpected, and non-normative; (2) exceed the individual's perceived ability to meet its demands; and (3) disrupt the individual's frame of reference and other central psychological needs and related schemas. Thus, chronic, predictable life events are not considered traumatic.

The second part of McCann and Pearlman's (1990a) definition of trauma derived from the Transactional Model of Stress by Lazarus (1966). The inherent disconnect between the demands of a situation and an individual's perceived ability to meet the demands causes psychological stress. Of critical importance to the perceived magnitude of the stressor is the individual's subjective appraisal of the situation and perception of the stressor; thus, an individual's subjective sense that an experience is stressful becomes a credible diagnostic indicator. Further, McCann and Pearlman posited that recognizing differences among individuals is a tenet of CSDT. An experience that fits the criteria as traumatic for one person may not be so for another. In order to be perceived as traumatic, an experience must be viewed as a threat to one's subjective psychological core.

Due to the magnitude and complexity of the event, a traumatic experience temporarily disrupts existing schemas until new schema are borne from personal development and adaptation to the experience. In turn, the meaning of the traumatic event can be incorporated into existing schemas or form new schemas that represent a new reality base. Individual adaptation will result in healing from the traumatic event as well

as enhanced personal development, strengthening of self-capacities, balanced psychological needs, and incorporation of the traumatic event, of which all will allow an individual to progress toward experiencing pleasure and satisfaction in life (McCann & Pearlman, 1990a), Negative adaptation may result in permanent disruption of an individual's psychological schemas and permanently distorted psychological sequelae, including an inability to cope and adapt.

Exposure to a traumatic event and the ensuing disruption of schemas may result in the development of variable psychological response patterns reflective of the consequences of victimization. Most post-trauma reactions met the diagnostic criteria for PTSD, which was first defined in the *DSM-III* (American Psychological Association, 1980) and later revised in the *DSM-III-R* (American Psychological Association, 1994). Indeed, McCann et al. (1988) identified disturbances in five areas of psychological functioning resulting from rape, childhood sexual or physical abuse, domestic violence, crime, disasters, and the Vietnam War.

While the criteria for PTSD is controversial among some researchers, Breslau and Davis (as cited in McCann & Pearlman, 1990a) agree that the unique features of PTSD are the presence of a severe stressor and the re-experienced phenomena. Both the diagnostic criteria for PTSD and CSDT incorporate recognition of response patterns into the understanding of the trauma response. For the purposes of this study, assessment and measurement of response patterns or participants were embedded in the survey tools used in the study.

McCann and Pearlman (1990a) also studied the "person-situation interaction," which refers to the uniqueness of an individual's psychological development as it combines with the traumatic experience itself to ultimately affect adaptation to the event. McCann and Pearlman asserted that this dimension, although complex, allows for a more comprehensive assessment of an individual's adaptation to trauma because it fully encompasses "the full complement of the person" (p. 4).

Further, CSDT, with its focus on interaction between the person and the traumatic situation, empowered the survivor to become a "change agent" capable of creating his or her own reality after exposure to a traumatic event. Trauma survivors need to be assured of their individuality and not studied simply as a collection of persons with common

symptoms. In the current study, although a commonality of post-traumatic symptoms was discovered among caregivers of persons with oral cancer, the individual experience of each participant was honored as a freestanding phenomenon as well as a part of a larger whole.

CSDT AS IT CORRELATES TO SHATTERED ASSUMPTIONS AFTER EXPOSURE TO TRAUMA

Exposure to a traumatic event can cause a cataclysmic shattering of basic assumptions held by individuals regarding self and the world. Initial study on cognitive-experiential self-theory was conducted by Epstein (1985), who believed an individual's personality was based on interplay between the self and the world as constructed by that person. His theory was explicated further by Janoff-Bulman (1992) who focused specifically on three major assumptions that she believed to be disrupted by trauma, including belief in personal invulnerability, the perception of the world as meaningful, and the perception of the self as positive.

Janoff-Bulman (1992) expanded her theory to include individuals' beliefs that the world is fundamentally a good and benevolent place, the presence of meaningfulness in the world, and the belief in the worthiness of the self. She considered the aforementioned schemas to be of a higher order and relatively unshakeable in those who have not experienced a traumatic event. For those who have been traumatized, fundamental assumptions of the world are challenged, which may cause irreversible disruption of the individual at a core level.

Janoff-Bulman (1989), in a study using her World Assumptions Scale, determined that victims of trauma (as opposed to non-victims) perceived the world as lacking benevolence, believed that random acts accounted for poor outcomes, and viewed themselves in a less positive light. Conversely, Janoff-Bulman noted that in some cases, exposure to a traumatic event may have a positive effect on schema development by promoting reaffirmation of the goodness of the world while also assisting the individual to become more conscious of the limitations of core assumptions about self and one's place in the world. Descriptions of the common negative post-trauma response patterns are presented below.

POST-TRAUMA RESPONSE PATTERNS

Emotional Response Patterns

Common emotional response patterns after exposure to a traumatic event are fear, anxiety, depression, decreased self-esteem, identity problems, and anger. Originally, the emotional responses of guilt and shame were also identified as traumatic patterns but later removed from *DSM-III-R* due to lack of generalizability of the symptom. Nevertheless, subsequent clinical literature reviews associated the responses of guilt and shame with victims of rape (Burgess & Holmstrom, 1974), childhood sexual abuse (Gelinias, 1983; Herman, 1981), other crimes (Bard & Sangrey, 1986), and Vietnam combat (Glover, 1984, 1988; Shatan, 1974).

Cognitive Response Patterns

Survivors of trauma are prone to perceptual disturbances, intrusive thoughts, flashbacks about the event, and feelings of reliving the event. Some survivors also experience dissociation—an altered state of consciousness that blunts integration of experiences and affects memory and awareness. Other cognitive deficits noted in persons with PTSD are impaired verbal fluency, memory, and attention as well as a decline in intellectual functioning (Gil et al., 1990).

Biological Response Patterns

Physiological response patterns associated with PTSD are comprised, most notably, of physiological hyperarousal and somatic disturbances. Chronic anxiety among trauma survivors results in a state of increased autonomic nervous system arousal. Somatic disturbances range from actual injury of the autonomic nervous system to generalized somatic complaints. Overall, there tends to be an increase in the number of health problems seen in trauma survivors (McCann & Pearlman, 1990a).

Behavioral Response Patterns

Survivors of trauma may be prone to anger and antisocial behaviors, suffer from serious depression, exhibit suicidal tendencies, engage in substance overuse, and

demonstrate impaired social functioning inclusive of withdrawal and isolation (McCann & Pearlman, 1990a).

Interpersonal Response Patterns

Persons who experienced trauma have distinct difficulties in the area of interpersonal relationships. Sexual dysfunction is commonly seen among survivors of trauma, as is decreased trust, marital discord, and skewed familial relationships. Additionally, a survivor may revert back to a state of victimhood should re-victimization occur. A state of re-victimization could result in a higher incidence of anxiety and depression in survivors of multiple traumas. For extreme cases of victimization in early childhood, the victim may, in turn, become the victimizer later in life (McCann & Pearlman, 1990a).

CSDT AS A NEW LENS: VIEWING THE EXPERIENCE OF BEING A CAREGIVER OF A PERSON WITH ORAL CANCER AS A TRAUMATIC EVENT

McCann and Pearlman (1990a) proposed their theory as an alternative way to view the interaction between a person and the traumatic situation, with the major focus on the ways in which a person developed as a direct result of a traumatic situation. This concept was in direct opposition to older theories suggesting that persons affected by trauma may have preexisting pathology. CSDT can be used a new lens through which to interpret the cancer caregiving experience in general, and the oral cancer caregiving experience in particular.

For the purposes of this study, the experience of being a caregiver of a person diagnosed with oral cancer constituted the traumatic event; the caregiver is deemed the trauma survivor. CSDT has been applied to various types of trauma including physical, psychological, or sexual abuse; crime; natural disasters; war; and genocide. For the purposes of this study, diagnosis of a person with oral cancer, a life-threatening illness, and the secondary effects of the diagnosis and treatment on the caregiving partner were considered to be forms of trauma.

To contextualize the current study and apply CSDT to the oral cancer caregiver, the researcher conducted a thorough review of existing literature related to caregivers of

persons with various types of cancer, including oral cancer; these findings are reviewed below.

RELEVANCE OF A LITERATURE REVIEW TO THE CURRENT STUDY

This study explored the phenomenon of caregiver stress as it related to caregivers of persons with oral cancer. A careful and complete literature review is essential to a research study. To be thoroughly informed about how a current study compares to others in the literature, the researcher must review and evaluate extant literature on the topics of quality of life and caregiver stress in spouses and persons with a variety of different types of cancer.

An initial search of the medical, nursing psychology, and social work literature revealed a trend that had evolved since the 1950s in which cancer began to be viewed as a disease that affects the family unit and may be equally threatening to the patient and individual family members (Cassileth & Hamilton, 1979; Dyk & Sutherland, 1956; Olsen, 1970; Weisman & Worden, 1976) This trend was markedly different from historical beliefs that viewed the cancer patient's spouse as a inconsequential figure in the cancer process, despite well-established data describing the death of a spouse as a profoundly stressful life event.

As the paradigm of cancer as a condition affecting the family unit shifted, an evolution in researchers' thinking about the generalized experience of illness of partners of patients also occurred. A review of 45 years of generalized studies on the effects of various life-threatening and chronic illness on patients and their loved ones revealed early beliefs that spouses who are subject to the stress of their partner's illness may experience a decline in their own physical and mental health (Croog & Fitzgerald, 1978; Hinkeldey & Corrigan, 1988). Practical, day-to-day issues affecting spouses of cancer patients were also documented in the literature search results. Literature exists detailing the need for spouses of cancer patients to maintain the economic security of the home, assume more domestic responsibilities, provide emotional stability and care for children, and manage employment obligations.

Further literature searches led to the discovery of more recent studies exclusively addressing the effects of diagnosis and treatment on partners of cancer patients. The

search revealed that, over the past four decades, there has been increased emphasis placed on the experience of being a caregiver—typically a spouse or partner—of a person diagnosed with cancer. Over the past decade, studies have been increasingly specific and categorized according to type of cancer. Many recent studies focused on the partners of persons with breast or prostate cancer. A representative example of available studies is outlined in the section below. Commentary addressing the applicability of the studies to the current study is also provided.

EFFECTS OF SPOUSAL CANCER ON CAREGIVERS

Affective reactions of spouses of cancer patients were addressed in early studies from a variety of perspectives. One early study by Dyk and Sutherland (1956) posited that spouses of cancer patients may have resented the time and energy required to care for their partners. Wortman and Dunkel-Schetter (1979) stated that mutilating cancer surgery or physical deterioration caused by the disease and treatment side effects might have caused feelings of disgust in spouses toward their partners. Moreover, their study suggested a spousal tendency to blame the victims for the situation and treat them poorly as a consequence. Simonton (1984) described spousal feeling of helplessness when partners were diagnosed with cancer, and posited that a prolonged state of spousal “over helping” may cause the spouse to become resentful of the ill partner.

Attention to the psychosocial effects of cancer on the spouse became more noticeable in the 1980s and continued through today (Keitel et al., 1986; Oberst & James, 1985). Keitel et al. (1990a) examined the incidence of psychological distress (anxiety and depression) and coping skills in spouses and cancer patients before and after surgical intervention. Keitel et al. (1990b) observed that spouses remained distressed post-surgery whereas patients actually became less distressed in the post-operative period. Lindholm et al. (2002) found that significant others were conflicted between focusing on their own suffering and the desire to alleviate their partners’ suffering.

Oberst and James (1985) interviewed 40 spouses and patients with gastrointestinal, bladder, and genital cancer. Surprisingly, they found that the preoperative level of anxiety was higher in spouses than in patients themselves. The difference in anxiety levels persisted six months after the patient was discharged from the

hospital. The researchers noted that partners had anxiety but also felt increased vulnerability and an inability to cope with daily stressors. Additionally, the spouses experienced feelings of anger and guilt. Most notable was that the spouses suffered from physical symptoms such as diffuse aches and pains, fatigue, indigestion, and worsening of existing disease states than existed prior to their spouses' diagnoses. In earlier studies, Northouse (1988) and Given (1992) found similar problems in partners.

Glasdam et al. (1996) explored the incidence of anxiety and depression in spouses of cancer patients. The premise of their study was that a diagnosis of cancer is an event that impacts an entire family. Glasdam et al. (1996) interviewed 120 spouses of patients treated at a hospital-based oncology clinic in Denmark and administered The Hospital Anxiety and Depression Scale and an additional 51 item questionnaire. A response rate of 83% was achieved. Eighteen percent of respondents had scores consistent with the "anxiety" dimension whereas 6% were consistent with the "depression" dimension of the scale. There were no variations according to sex, age, patient diagnosis, treatment, and performance status. Glasdam et al. (1996) discovered that many of the spouses who identified as having anxiety or depression also had physical symptoms or latent anger that they had not discussed with their ill partners. The authors concluded that members of the health care team needed to be vigilant in their search for signals of problems in spouses, as spouses did not appear to ask for assistance readily.

Many studies have been published on the impact of partners' experiences living with women with breast cancer. Lindholm et al. (2002) inquired about the experience of being a significant other of a woman with breast cancer. This qualitative phenomenological case study utilized an interview format with 17 women and 16 significant others from four different cultures in Sweden and Finland. Analysis of recurrent themes revealed that significant others experienced deep and frequently unresolved suffering. Significant others often felt they were captive in an uncertain situation, and thus were rendered powerless. The study by Lindholm et al. (2002) helped inform interpretation of the responses to the qualitative open-ended survey question asking participants to describe what the experience of caring for a person diagnosed with oral cancer has been like for them.

Coristine et al. (2003) conducted a three-year longitudinal study of patients with advanced breast cancer (n=88) at two tertiary care centers in Ontario, Canada. The study examined home-based health care services and health-related quality of life of patients. Patients identified a caregiver who was invited to take part in the study. The study encompassed a palliative care component, as some patients were in the terminal phase of illness. At the three and six month intervals after the death of some patients in the larger study, a total of five focus groups—comprised of bereaved spouse caregivers and non-spouse caregivers (close friends or relatives)—were held. Participants (n=30) were eligible for inclusion in the study following the death of the patient who had participated in the larger study. Caregivers shared their experiences related to the terminal care stages of life for their loved one. The qualitative methodological process of content analysis was used to identify themes.

Prevalent themes that emerged from the focus groups conducted by Coristine et al. (2003) included: (1) assuming the care giving role; (2) contextualizing caregiving for the patient with advanced breast cancer; (3) the care tasks implemented over time; (4) understanding and managing the patient's medical needs; (5) medical management during the terminal stages; and (6) emotions and their consequences on the patient-caregiver relationship. From these themes, the authors deduced that working spouse caregivers had to manage their job, family responsibilities, and childcare but did not consider household management to be a tremendous burden. Caregivers often received support from their employers; the no-spouse caregivers had more roles to balance because they lived in separate residences and had their own families and jobs to manage. Non-spousal caregivers were not extended the same courtesy and time off by employers. Non-spouse caregivers also took on the role of primary caregiver and were often a daughter, sister, niece, or friend. Time conflicts ensued for all caregivers when patients reached a stage that required assistance with activities of daily living and mobility.

Coristine et al. (2003) discovered that spousal caregivers often viewed themselves as co-decision makers whereas the non-spouse caregivers saw their role as a patient advocate. Both groups of caregivers commented that the caregiving role evolved over time and in response to the deterioration of their loved ones. Both sets of caregivers reported maintaining feelings of optimism while the patient was capable of functioning.

Interestingly, both groups reported that total dependency on the patient's part provoked less anxiety for the caregiver because there was no safety risk to the patient to try to maintain a functional status and risk injury. Incontinence greatly affected caregivers as they found it humiliating and invasive to manage the problem. The palliative phase of care was manageable for most caregivers with the exception of two individuals, who reached their limit of providing care at home. Coristine et al. noted that almost every caregiver reported surprise that their patient entered the terminal phase and died. Although all of the caregivers were aware of the seriousness of the situation, they were unaware that death was imminent. Many caregivers expected to have more time with the patient before death; they felt exhausted and experienced serious health problems themselves as the terminal phase progressed.

Vanderwerker et al. (2005) studied the prevalence of psychiatric disorders and mental health service use among caregivers of patients with advanced forms of cancer, an area that had previously received little attention. The study sample was comprised of 200 caregivers of patients with various cancers of the gastrointestinal tract and lungs. Caregivers were predominantly female, middle-aged, white, educated at a high school level or higher, and spouses of the patients. Mean time in the caregiving role was 11 months. Spouses were interviewed using the Structured Clinical Interview format from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (American Psychological Association, 1994). Thirteen percent of the caregivers met the criteria for psychiatric disorder, such as major depressive disorder, panic disorder, post-traumatic stress disorder, and generalized anxiety disorder.

Braun et al. (2007) investigated the incidence of psychological distress among advanced cancer patients and their spousal caregivers. The researchers were also interested in examining the effects of caregiver burden, attachment orientation, and marital satisfaction on symptoms of depression in the spouses. Braun et al. (2007) recruited 101 participants who were spouses of patients with advanced gastrointestinal or lung cancer; these patients had participated in a broader longitudinal study on the will to live and desire for hastened death among metastatic cancer patients. The study took place in the outpatient clinic of a hospital in Toronto, Canada. Participant eligibility criteria were: primary caregiver for a patient with Stage III or IV lung cancer or Stage IV

gastrointestinal cancer; married or in a common-law relationship; and able to speak and read English. The Beck Depression Inventory-II (BDI-II), the Caregiving Burden Scale, the Experiences in Close Relationships Scale, and the ENRICH Marital Satisfaction Scale were administered. Braun et al. reported that 38.9% of the caregivers experienced symptoms of depression as measured by the Beck Inventory, compared with only 23% of ill spouses. Hierarchical regressions were used to predict caregivers' depression, spousal caregivers' age, and patients' cancer localization as well as subjective caregiver burden, attachment, and marital satisfaction.

EFFECTS OF CANCER ON SPOUSAL RELATIONSHIPS

Impaired communication between cancer patients and spouses has been correlated to decreased intimacy and sexual satisfaction. Schain (1980) and Baider and Sarell (1984) reported decreased sexual satisfaction in cancer patients. Baider and Sarell also reported that a cancer diagnosis may lead to increased tension and decreased cohesion in marriage. Lindholm et al. (2002), in discussing a state of interdependence that evolved between a significant other and cancer patient, described the situation as co-existence in shared suffering. The authors identified a vicious circle in which there existed mutual protection between the two partners; this protection, in turn, worsened the suffering of the significant other. The state of shared suffering between partner and patient had the ironic effect of bringing relief to the significant other.

Sanders et al. (2006) studied ten couples surviving prostate cancer and examined long-term challenges in their relationships, their concerns about the disease, and their intimacy needs following treatment. Data were collected in three 30 minute, structured focus groups. Couples were asked to describe their experiences together, then individually, in concurrent male and female break-out groups. Discussion in both groups centered on relationship and intimacy needs; the process of diagnosis and treatment of prostate cancer; the experience of being a couple dealing with prostate cancer; helpful, harmful, and surprising aspects of the experience; current needs as a couple; and advice they might have for other couples.

Sanders et al. (2006) concluded that men and women responded differently to the experience of surviving prostate cancer. Women were more likely to feel their role had

changed from being protected and cared for to being the emotional caretaker. Women believed they needed to learn as much as possible about prostate cancer while trying not to become distressed by the situation. Women perceived that men did not communicate or take care of themselves by getting tested, attending check-ups (for fear of receiving bad news), or noting physical changes in their bodies. Women also reported that sex was “different” since treatment and that they felt unattractive, unwanted, and perceived a lack of romance in their intimate lives coupled with frustration over the lack of available sexual information. Women also experienced a lack of sexual spontaneity due to the planning involved in order to have sex. On a positive note, women were relieved that their partners were alive and had less urinary problems post-treatment.

Men who participated in the study conducted by Sanders et al. (2006) attributed the hormones they took on a daily basis to causing “chemical castration.” Many were surprised and pleased to find that they were able to have some form of sexual response. They were equally happy that the incontinence problems that they feared treatment would cause were less severe than anticipated. Similarly, they reported feeling less pain and fewer overall side effects despite lingering physical weakness and a lack of endurance and stamina post-treatment. The most pressing issue for the men was their perception of being less self-sufficient and the need to depend on their partners or hired helps to complete tasks they used to do easily. The men complained of miscommunication with their female partners and feeling as though they were talking about “different things.” Of note, a positive finding of the study was that men credited their wives for having offered necessary support during the experience.

The most recent study on partners of patients with prostate cancer was completed by Fletcher et al. (2008), which examined the prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. Fletcher et al. recruited a sample of 60 female caregivers whose husbands were scheduled to begin radiation therapy; the caregivers were screened for the presence and severity of anxiety, depression, pain, sleep disturbance, and fatigue. Self-report questionnaires were administered that measured demographic characteristics, symptoms, functional status, and quality of life.

Fletcher et al. (2008) reported that 12.2% of the women in their study had clinical levels of depression, 40.7% had anxiety, 15.0% experienced pain, 36.7% experienced sleep disturbance, 33.3% had morning fatigue, and 30% felt evening fatigue. Older caregivers with lower levels of anxiety but higher levels of depression, morning fatigue, and pain as well as more problematic functional statuses ($R^2=38.7\%$). Younger caregivers with more education; who were working; and who had higher levels of depression, morning fatigue, sleep disturbance, and lower levels of evening fatigue reported lower quality of life scores ($R^2=70.1\%$).

Fletcher et al.'s study (2008) highlighted a significant correlation between anxiety and depression and recommended that additional research be conducted because the occurrence of anxiety and depression is associated with morbidity in caregivers. Fletcher et al. also noted that the presence of depression had the greatest impact on the female caregiver's functional status. The high incidence ($> 30\%$) of anxiety, sleep disturbance, and fatigue was also worrisome. Fletcher et al. (2008) suggested that oncology clinicians should better recognize symptoms in caregivers, explore how symptoms may change over time in relation to the patient's disease trajectory, and be aware of the potential direct impact that symptoms may have on the caregiver and of indirect impacts on the partner in need of their care.

Lewis et al. (2008) studied predictors of depressed mood in spouses of women with breast cancer. They hypothesized that if the spouses of women with breast cancer were depressed, this could have negative effects on spouses' and patients' functioning and impede marital communication. Lewis et al. (2008) focused on examining why some spouses became depressed during the first few months of diagnosis and treatment while others did not. The purpose of Lewis et al.'s (2008) study was to utilize a predictive model to of spouses' depressed mood and to evaluate how well that model could discern between "normal" and clinically depressed spouses. The study was part of a larger clinical trial of couples managing newly diagnosed non-metastatic breast cancer. Participants ($n=206$ spouses and $n=206$ wives) were recruited from 70 sites in two Pacific Northwest states. To be eligible, a women needed to be diagnosed with non-metastatic breast cancer (stage 0, I, IIA, or IIB) or *in situ* disease within the last eight months;

married or partnered in an intimate relationship of 6 months or longer with a man; and able to read, speak, and write English.

Lewis et al. (2008) collected data using standardized questionnaires completed by participants. Spousal patients and their wives were screened for symptoms of depression within the prior week using a 20 item self-report scale created by the Center of Epidemiological Studies. Scores could range from 0 – 60 on the scale, with a score of 16 or higher used as an indicator of clinical depression. Quality of the marital relationship was measured by the Spanier Dyadic Adjustment Scale (DAS), which is a 32 item self-report scale that contains subscales relating to dyadic satisfaction, cohesion, consensus, and affectional expression. Content and manner of couples' communication with each other about breast cancer was measured using the 5-item Interpersonal Disconnection From the Wife About Breast Cancer Scale. The Demands of Illness Inventory was used to assess concerns for the wife's well-being, diminished social activities, altered sexual activity, job-related concerns, and feeling excluded by the medical team. Subscales of the Cancer Self-Efficacy Scales (CASE), known as Confidence to Manage Breast Cancer and Confidence to Emotionally Support the Wife About Cancer, were used to assess the husband's level of confidence to manage breast cancer. Lastly, Illness-Related Uncertainty was measured using a subscale of the Coherence Scale, which measures spouses' expectations that the situation will work out, that future events can be predicted, and that life is ordered.

Unsurprisingly, Lewis et al. (2008) found that middle-class, well-educated spouses in long-term, child-rearing relationships were depressed by the threat of their wife dying to cancer. Older, less educated spouses were at highest risk for depression and to be unable to frame the cancer experience as less than maximally threatening. Spouses also felt uncertainty in their personal and work life. Medical or treatment variables did not predict depression to the same degree as the spouse's view of breast cancer and the associated threat to their wives' lives. Early stage diagnosis of cancer did not assuage the spouses' level of fear and concern, which, in turn, impeded their job performance and caused anxiety about the future. Lewis et al. (2008) discovered a new "forgiveness" factor that enabled spouses to excuse behavior in their wives (e.g., depressed mood, diminished sexual activity, altered social life) that spouses may have found more

important had their wives been recently diagnosed with cancer. The shift was attributed to an all-consuming fear in the spouse of losing his wife to breast cancer. Lewis et al. (2008) concluded that their screening tool correctly classified 89.2% of spouses' depressed mood, but that it was more successful in classifying those spouses that were not depressed (98.2%) than those who were (51.3%).

Kadmon et al. (2008) examined the social, marital and sexual adjustment of Israeli men whose wives were diagnosed with breast cancer. The purpose of the study was to explore the psychosocial adjustment of Israeli men whose wives were diagnosed with breast cancer. A convenience sample of 50 Israeli men whose wives had been diagnosed with breast cancer was recruited from an urban tertiary medical center. The mean age of participants was 53.8 years and all participants spoke and read Hebrew. Participants filled out a demographic questionnaire as well as one about their wives' health, the Psychosocial Adjustment to Illness Scale, which measures adjustment to serious disease, and the Locke Wallace Marital Adjustment Scale, which measures marital and sexual adjustment. The husbands also completed a Social Support Questionnaire to measure the level of social support they were receiving from their wives. One-fifth of participants reported stress and concerns over their wives' health, and half of the participants reporting feelings of financial strain. A total of 75% of participants noted a change in their relationship and reduced communication between family members. All participants felt that they received adequate treatment within the health care system, but felt that being offered additional information would have been helpful.

CAREGIVER NEEDS AND COPING STRATEGIES

Simonton (1984) described caregiver attempts to fulfill all of the spouse's needs in order to combat the feelings of helplessness related to the cancer diagnosis. Stevenson (1984) suggested that spouses could be greatly assisted, and thus their anxiety reduced, by being offered strategies to deal with daily caregiver problems, such as the challenge of maintaining nutrition in cancer patients or coping with side-effects experienced from cancer treatment. A subsequent study by Keitel (1986) examined the effect that providing updated medical information and detailed instructions to spouses may have in decreasing

caregiver stress. He determined that providing additional information empowered spouses to cope more constructively. In addition to minimizing affective symptoms, providing information about the disease process and treatment was quickly identified in cancer care research as a source of empowerment for patients and their spouses.

Gladsam et al. (1996) discovered that spouses of cancer patients seldom discussed physical symptoms or feelings of anger. Very few spouses sought professional support, rather they tried to “muddle through” alone. Gladsam et al. (1996) concluded that spouses often do not ask for assistance outright, and that providers should be alert for subtle clues indicating the need for assistance.

Lindholm et al. (2002) concluded that members of the medical and nursing professions could alleviate the suffering of both patients and partners by holding case-oriented meetings with them. The authors posited that professional caregiver support would improve the deepest degree of suffering on both an individual level and on a collective, relationship-level.

Coristine et al. (2003) found that caregivers of cancer patients reported high levels of anxiety, which they managed by becoming withdrawn, controlling, or in need of constant companionship. Caregivers found that dealing with their anxiety was more challenging than the physical care of the patient. The authors posited that their findings support the hypothesis that caregiving for a patient with advanced cancer became more difficult as the disease progressed, and that caregivers ultimately became emotionally and physically spent due to emotional strain and the demands of terminal care. Recommendations from the study included having the health care system provide assistance to caregivers while they actively cared for the patient prior to patient’s death and to provide emotional support after the patient’s death.

A study of the prevalence of psychiatric disorders and mental health service use among 200 caregivers of patients with advanced forms of cancer (Vanderwerker et al., 2005) reported that, whereas 13% of the caregivers met the criteria for psychiatric disorder, only 25% of the caregivers had sought mental health treatment since their partner’s diagnosis. Vanderwerker et al. (2005) recommended that caregivers of cancer patients be viewed as a vulnerable population in need of screening for mental health

disorders, and that they be referred to available mental health services if positive diagnostic findings were found.

A study of prostate cancer survivors and their spouses conducted by Sanders et al. (2006) suggested that additional information about managing the experience of dealing with prostate cancer as a couple may be highly beneficial. The researchers also suggested connecting cancer patients and spouses with other couples who were in similar situations at the time of diagnosis and treatment. Participants reported needing to talk with couples who were long-term survivors of prostate cancer living with side-effects of treatment. Women preferred the idea of attending support groups with other female partners, whereas men stated a written guidebook would have been helpful. Both men and women stated that personalized coaching from a health care team member would have made their experience easier. Sanders et al. (2006) stressed the need for health care providers to foster communication in couples, provide detailed treatment information, and have nurses available to offer affirmation and work with couples on their intimacy and sexual needs.

Lewis et al. (2008) recommended treatment measures to assist depressed spouses of women with early breast cancer. These measures include behavioral management, counseling, or a combination of the two methods to assist depressed spouses in the acquisition of skills to cope with the impact of their wives' cancer on everyday life.

Similarly, Kadmon et al. (2008) suggested that husbands of women with breast cancer attempt to manage stressors in many areas, and that they could benefit from offers of information and support by members of the health care team even if they do not ask directly for assistance. The authors also recommend that ongoing staff education take place so health care professionals recognize and respond to the "unspoken needs" of men whose wives have breast cancer.

QUALITY OF LIFE IN PATIENTS WITH CANCER AND THEIR CAREGIVERS

Northouse et al. (2002) examined quality of life in women with recurrent breast cancer and their family members. Northouse et al. noted that there were very few studies focused on the needs of patients and partners in the recurrent phase of cancer. Her study assessed patients and family members' quality of life within one month after recurrence and the effects of multiple factors on quality-of-life scores. Patient-family member dyads

(N=189) were selected for participation in the study. A stress appraisal model was used to assist with selection of personal factors, social or family factors, illness-related factors, appraisal factors, and quality of life. Quality of life was measured using a cancer-specific scale. Results of the study revealed that cancer patients experienced impairment in physical, functional, and emotional well-being, whereas their family members predominantly reported impairment of emotional well-being. Northouse et al.'s (2002) study most closely resembled the information sought in the current study, with the exception that hers dealt with dyads experiencing recurrence of cancer, of which the current study encompasses but is not restrictive.

Northouse et al. (2002) asserted that attempts to increase self efficacy, social support, and family hardiness positively impacted quality of life for the dyads; conversely, distress over symptoms, concerns, hopelessness, and negative views of their partner's illness or the caregiving role exhibited negative effects. Northouse et al. (2002) concluded that women with recurrent breast cancer needed programs to help them preserve their quality of life in the face of severe illness. Additionally, it was recommended that family members be included in the programs to decrease the negative effects of their partner's recurrence on their mental health as well as to empower them to continue in the role of caregiver. This study measured perceived quality of life by asking participants to rate their overall satisfaction with life using a subjective rating on the percentile scale (from -100% – +100%) of the Life Status Review tool.

Galbraith et al. (2005) studied the quality of life, health status, and marital satisfaction of a convenience sample of prostate cancer survivors (192 enrolled; 137 completed) and their female partners (126 enrolled; 104 completed) at intervals from 2.5 – 5.5 years after treatment for prostate cancer at a tertiary care non-profit medical center in the southwestern United States. Mean age for patients and partners was 70 years and 66 years, respectively. Over 85% of subjects were Caucasian, and many had some college education. Participants received separate questionnaires on an annual basis, with female partners enrolled in the study 3.5 years after their partners completed treatment. Participants were surveyed about their health-related quality of life, post-treatment symptoms, and degree of marital satisfaction using the Quality-of-Life Index, Medical Outcomes Study General Health Survey, Southwest Oncology Group Prostate Treatment-

Specific Symptoms Measure, and the Dyadic Adjustment Scale. Men's health-related quality of life, general health, and vitality decreased; they displayed increased urinary and sexual dysfunction symptoms post-treatment; and they were very worried about their sexual difficulties but reticent to seek treatment.

Galbraith et al. (2005) reported that couples' health-related quality of life and marital satisfaction were associated more closely with each other than with health status. Interestingly, the authors did not thoroughly explicate the specific findings relative to the partners, limiting discussion of findings to the patients themselves. Galbraith et al. (2005) suggested that, regardless of type of treatment for prostate cancer, patients experienced a decline in health-related quality of life and general health post-treatment, with those in the "watchful waiting" group having the poorest outcome. Galbraith et al. (2005) concluded that couples' health-related quality of life and marital satisfaction are linked without a discrete association to health status indicators. The researchers recommended that nurses assess health-related quality of life and sexual functioning in prostate cancer survivors and their partners. This study was inconclusive and did not add to this author's understanding of the phenomenon.

A study conducted by Wagner et al. (2006) explored quality of life of husbands with breast cancer. A comparative analysis compared quality of life of husbands of women with breast cancer (n=79) to that of husbands of healthy wives (n=79) in Indiana using the Medical Outcomes Study (MOS) tool. Wagner et al. (2006) also screened for any associations between quality of life, social support, and coping. The authors reported that husbands of women with breast cancer scored lower than healthy participants on subscales of general health, vitality, and the role of emotional and mental health. Interestingly, this study found no difference between groups on the subscales pertaining to physical functioning, bodily pain, or social functioning subscales. Moreover, there was no correlation proven between the husband's degree of quality of life and the stage of their wife's disease and time since diagnosis. Wagner et al. (2006) concluded that perception of higher quality of life in husbands of breast cancer patients correlated with lower caregiver burden on the Illness Impact Form, lower use of emotion-focused coping on the Ways of Coping Questionnaire, and reports of higher social support on the

Interpersonal Evaluation list. Implications for practice underscored the need to support husbands of women with breast cancer.

A comprehensive study on living with prostate cancer was completed by Northouse et al. (2007). Similar to earlier studies Northouse et al. (1989a, 1989b) conducted on quality of life in husbands of women with breast cancer, Northouse et al. (2007) explored quality of life in 263 men with prostate cancer and their spouses along the illness trajectory who had been recruited from three cancer centers in the Midwest. Northouse et al. included an appraisal of illness, symptoms, resources to handle illness, and risk for emotional distress and diminished quality of life during three distinct phases of illness—those who were newly diagnosed, those with a biochemical recurrence, and those with advanced cancer. The study was part of a larger randomized clinical trial that assessed the effect of a family intervention on the quality of life of men with prostate cancer and their spouses; this study was one of the first to compare patients' and spouses' appraisal of prostate cancer and differences across phases of illness. Initial treatment for the disease was either a prostatectomy or external beam radiation. Those patients with biochemical recurrence had completed treatment and showed post-treatment elevation of PSA levels, but no clinical evidence of disease. Patients were undergoing either treatment or surveillance. Patients with advanced disease had documented metastatic disease or progression of the primary disease. Criteria for patient participant selection were age 30 or above, life expectancy of 12 months or more, presence of a spouse or live-in partner, and residence within 75 miles of the cancer center. Patients with a second primary cancer diagnosis were excluded from the study. Spouses or partners were eligible to participate if they were over age 21 and identified themselves as the patient's primary caregiver. Baseline data were collected on the health of patients and their spouses or partners prior the start of the study. Approximately 67% of the patients had co-morbidities, such as heart disease, hypertension, and arthritis. Spouses complained of back pain and arthritis.

Northouse et al. (2007) assessed quality of life separately in patients and spouses or partners using the 39 item Functional Assessment of Cancer Therapy (FACT), which measured quality of life domains including physical, social or family, functional, overall, and prostate-specific well-being. Patients and spouses measured the extent to which they experienced 16 physical symptoms using the Symptom Scale of the Omega Screening

Questionnaire. Specific prostate symptoms were measured using the 50 item Expanded Prostate Cancer Index Composite (EPIC) that assesses urinary, bowel, sexual, and hormonal symptoms. A spousal version of the tool was given to partners to assess the degree to which they were impacted by their partner's urinary, bowel, sexual, or hormonal symptoms. Appraisal variables of illness/caregiving, the patients' degree of threat associated with illness, and the spouses' perceptions of problems resulting from caregiving were measured using a 27 item Appraisal of Illness and Caregiving Scales. Uncertainty and hopelessness were measured using the 28 item Mishel Uncertainty in Illness Scale and the Beck Hopelessness Scale. Confidence in managing the effects of cancer was measured using the Lewis Cancer Self-Efficacy Scale. Illness-related communication between partners was measured using the Lewis Mutuality and Interpersonal Sensitivity Scale and Social Support was measured with the Personal Resource Questionnaire.

Northouse et al. (2007) reported that patients with advanced cancer were found to have lower physical quality of life but higher emotional quality of life than their spouses. No difference was found in physical or emotional quality of life between members of the dyads in the newly diagnosed or biochemical recurrence phases of illness. Dyads with biochemical recurrence and advanced cancer were found to have a more negative appraisal of illness, caregiving, and uncertainty as well as increased feelings of hopelessness compared with dyads recently diagnosed with cancer. Spouses or partners experienced more uncertainty about the illness than patients. Regarding resource variables, dyads newly diagnosed with cancer rated higher on self-efficacy than those with biochemical recurrence or advanced cancer. Dyads experiencing biochemical recurrence reported less communication about the illness than newly diagnosed or advanced dyads.

Significant findings related to role effects in the Northouse et al. (2007) study included patients who perceived more self-efficacy and more moral support than their spouses or partners. Patients with advanced disease suffered from more general physical symptoms than newly diagnosed dyads, and all groups of patients experienced more physical distress overall than their spouses or partners. Dyads in the advanced state of cancer were at higher risk for emotional distress than the newly diagnosed and those with

biochemical recurrence. Lastly, the researchers found that the type of treatment had a significant effect on social well-being. Patients who had a prostatectomy and spouses of these patients had a lower level of social well-being than patients and their partners treated solely with radiation therapy.

Northouse et al. (2007) concluded that the psychosocial experience of a couple experiencing prostate cancer was affected more profoundly by phase of illness than whether a participant was the patient or spouse in the dyad. The authors posited that similarities between patients and spouses outweighed the differences and were affected by illness. Finding indicated that psychosocial interventions should be focused on both patients and spouses, and that programs of care should be tailored in accordance with phase of illness.

This section has provided a comprehensive review of studies related to caregivers, spouses, and partners of persons with a variety of cancers and related findings describing the caregiving experience and its effects on quality of life in partners. Findings of many of the studies reviewed support this author's assertion that a diagnosis of cancer affects the family unit as a whole and the partner of the patient in particular. Participants in several studies reviewed noted the difficulties they had maintaining stability at home and in their finances while being a caregiver for their partner. Further, negative affective responses in caregivers were identified, including perceived stress, decreased quality of life, depression, anxiety, and lack of self-confidence. Many patient-partner dyads experienced impaired communication and decreased intimacy while others noted that marital status and perceived quality of life were directly associated with health-related quality of the life. The studies in this section supported the need to add to the existing body of literature examining caregiver stress. The current study is unique in that it considers being a caregiver of a person with cancer as a traumatic experience to which characteristics of trauma responses and trauma theory can be applied. The subsequent section in this chapter summarizes the few available studies that related directly to partners of persons with oral cancer.

REVIEW OF LITERATURE RELEVANT TO PATIENTS AND PARTNERS WITH ORAL CANCER

A thorough search of the medical, nursing, psychological, and social work literature was conducted using keywords and phrases such as “oral cancer,” “impact of oral cancer,” and “partners of patients with oral cancer.” Oral cancer is often treated with surgery and results in stigma associated with visible disfigurement of the head and neck region. Unique effects of oral cancer treatment regimens on patients, such as soreness and dryness of mouth, disfigurement, swallowing difficulties, and problems in eating or drinking may lead to physical and social limitations including altered self-perception and social isolation. A multitude of medical studies exist that explored risk factors, diagnosis, treatment effects, and risk of recurrence of oral cancer

Nonetheless, very few available studies examined the experience of being a caregiver of a person with oral cancer. Scant data exist that compare oral cancer caregivers with other populations of cancer caregivers. There is a dearth of information on the experience of being a partner of a person with oral cancer and the degree of impairment or psychological distress. Over the past several years, merely four studies explored the impact of oral cancer on quality of life and the incidence of psychological distress in patients with oral cancer (Katz et al., 2003; Mathieson et al., 1996; Morton, 2003; Vickery et al., 2002). The lack of data on the topic of caregivers of oral cancer patients supports the need for further research. Of the four studies located, three were germane to the current study. This section will report on the three seminal studies that have been published on the experience of being a partner of a person with oral cancer. The current study will add credence to the limited body of knowledge on this topic.

Studies Involving Partners of Persons with Oral Cancer that Correlated to the Terms “Oral Cancer,” “Person with Oral Cancer,” and “Caregiver of a Person with Oral Cancer”

The studies in this section referenced the terms “oral cancer,” “person with oral cancer,” and “caregiver of a person with oral cancer.” In addition, the following studies addressed similar variables measured in the current study including demographic factors, quality of life, and coping skills. The variables of CS, Burnout, and CF/STS were not

directly assessed in the studies below and appear to be unique to this study. One study, which examined psychological distress in partners of patients with oral cancer, was the most closely correlated with the current study

A study conducted by Vickery et al. (2002) examined the impact of head and neck cancer and facial disfigurement on quality of life of patients and their partners. A sample of 28 surgery and radiotherapy/brachytherapy/chemoradiation patients and 25 partners of the patients was compared with 23 radiotherapy/brachytherapy patients and 19 partners. Participants in the Vickery et al. (2002) study were recruited from outpatient appointments at three clinics in England. All patients had cancer of the oral cavity limited to Stage 1-3, with 1-3 nodes involved and no metastasis. Patients were 6-18 months post-treatment and had no signs of recurrence. The mean age of patients and partners was 57 and 54 years, respectively. Patients and partners were grouped according to the type of treatment the patient received. All participants were screened for anxiety, depression, psychosocial adaptation to illness, dyadic adjustment, and degree of surgical disfigurement and dysfunction using validated scales. The authors noted that partners reported more distress than the patients on some scales. They also discovered that, while head and neck patients themselves do not necessarily experience poor quality of life, there was a more significant impact on partners.

Vickery et al. (2002) found that anxiety and depression scores for both patient groups were within normal range but that the median score for anxiety in both partner groups was classified as borderline for meeting the clinical case criteria for a diagnosis of anxiety or depression. This finding was attributed to the impact of diagnosis and treatment on the partner. No difference in degree of psychological distress was found between patient and partner groups. All patients and partners classified their relationships as “average.” Patients who underwent surgery were not found to be severely impaired in terms of disfigurement or dysfunction; the response of partners to disfigurement was not measured. No differences were found between the two patient groups in scales relating to physical status, role, emotional, cognitive and social functioning, global health status, or decrease in sexual activity. The researchers concluded that head and neck patients and their partners were not predisposed to psychological difficulties and lower quality of life.

Verdonck-de Leeuw et al. (2007) conducted a study, published in *The Laryngoscope*, which investigated distress in spouses and patients after treatment for head and neck cancer. The study consisted of 41 patient-spousal pairs who had undergone curative treatment for head and neck cancer and were visiting an outpatient clinical in the Netherlands for follow-up examinations. The mean age of the patient group was 61 years while that of the spousal group was 58 years. Participants completed a Dutch language version of the Hospital Anxiety and Depression Scale (HADS). The scale was originally geared for use with medically ill persons and had been widely used with head and neck cancer patients. Health status of patients and spouses was measured using separate scales. Patients and caregivers were also assessed for coping styles, and patients were tested for level of functional and social impairment.

In Verdonck-de Leeuw et al.'s (2007) study, caregiving burden was measured using an instrument (Caregiving Reaction Assessment) designed to assess positive and negative reactions to caregiving among partners. Similar to the tool used in this author's study, subscales of the instrument measured the impact of caregiving in disrupted schedule (5 items), financial problems (3 items), lack of family support (5 items), health problems (4 items), and the impact of care giving on the caregiver's self-esteem (7 items).

Verdonck-de Leeuw et al. (2007) reported that clinical levels of psychological distress were found in 20% of spouses and 27% of patients. The HADS score was significantly related to the subscale of vitality and passive coping style of the spouses. No significant relationship was found between distress in spouses and functional and social impairment of the patient as rated by the patient. The researchers also discovered that spouses of patients with a feeding tube had a higher score on the anxiety and depression scale. Further, Verdonck-de Leeuw et al. (2007) reported that caregiver burden in spouses was varied: spouses reported disrupted schedule from caregiving (31%), financial problems resulting from caring (26%), lack of family support (11%), health problems (31%), and positive self-esteem (32%) as a result of caring.

Verdonck-de Leeuw et al. (2007) concluded that the presence of a spouse may be a positive independent predictor of recurrence and survival. Moreover, spousal presence may be a protective factor for health-related quality of life for patients after cancer

treatment, as patients and spouses with poorer health status experienced more distress. However, a passive coping style coupled with pessimism or worry was associated with a poor overall health-related quality of life in patients and spouses. Speech and swallowing problems contributed to distress in patients. Distress in spouses was increased with the presence of a feeding tube in patients. No other functional or social impairment as reported by patients was noted as related to distress in spouses. The most pertinent finding, comparatively assessed in the current study, was that disruption of the daily life schedule was associated with distress in spouses.

Perhaps the most informative study was conducted by Drabe et al. (2008), which examined the psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. Drabe et al. (2008) studied the impact of head and neck cancer on quality of life and the prevalence of psychiatric disorders in wives of patients with long-term head and neck cancer. A sample of physically healthy female spouses was invited to participate to explore the potential effect of gender on the outcome of quality of life and psychological distress. The researchers hypothesized that wives would be highly distressed and demonstrate a high prevalence of psychiatric disorders due to the duration of their partners' disease and the life-threatening nature of their diagnoses. The authors also anticipated that wives would report a lower quality of life and quality of partnership compared to spouses of persons without head and neck cancer. Moreover, it was predicted that wives with a higher level of distress would show lower levels of quality of life and quality of partnership.

In the Drabe et al. (2008) study, a total of 31 patients and their female partners being treated at a hospital in Zurich, Switzerland filled out questionnaires and attended a psychiatric interview at the hospital. The mean age of patients was 58.2 years and the mean time since cancer diagnosis was 3.7 years. Treatment modalities were mixed between surgery only; surgery and radiotherapy; surgery, radiation, and chemotherapy; and a combination of radiation and chemotherapy without surgery. Mean age of spouses was 55.3 years with one to five children, the majority had completed apprenticeship training, and most worked full- or part-time.

The Hospital Anxiety and Depression Scale (HADS) was used to assess levels of psychological distress. Subjective quality of life also measured using the World Health

Organization Quality of Life assessment instrument (WHO-QOL-BREF), which measured four quality of life domains—physical health, psychological health, social relationships, and environment. The Dyadic Adjustment Scale was used to assess the quality of dyadic relationship between patients and spouses. Lastly, the Mini International Neuropsychiatric Interview (MINI) was used to screen for Axis I diagnoses that fit the DSM-IV criteria (Drabe et al., 2008).

The results of the study by Drabe et al. (2008) were unanticipated. The MINI revealed that 38.7% (12 wives) were diagnosed with one or more Axis I diagnoses including substance-related disorders, social phobia, generalized anxiety disorder, hypomania, dysthymia, and major depression. Four wives had mood disorders, two showed symptoms of major depression, one had dysthymia, one has social phobia coupled with generalized anxiety disorder, and one had hypomania.

But perhaps the most revealing finding in the Drabe et al. (2008) study was that 22.6% of the wives reported having agoraphobia, which is also an Axis I diagnosis. All of the wives reported the onset or increase in their anxiety symptoms, especially agoraphobia, at the time their partner was diagnosed with cancer. Wives with an anxiety disorder, in turn, were found to have higher levels of depression than those without an anxiety disorder. The researchers stated that the range of scores on the HADS could be interpreted in various ways. While the wives reported more Axis I symptoms than the general population, those without anxiety disorders had higher quality of life and dyadic satisfaction scores compared to the non-cancer wives. Wives with anxiety disorders had a significantly lower quality of life, especially in the physical domain ($t=3.44$, $df=29$, $p<0.01$). The authors found no correlation between the wives' quality of life, psychological distress, and the time since their husband's diagnosis.

Drabe et al. (2008) described their findings as critical to treatment planning because recognition of mental health issues that affect wives had bearing on the amount of support they were able to offer to their husbands. The study revealed that agoraphobia was the most common anxiety disorder noted among wives of patients who underwent head and neck cancer treatment, and the severity of symptoms increased over time. The researchers posited that symptoms of agoraphobia may be a manifestation of the wives' unconscious fear of losing the diseased partner, which, in turn, leads to a stronger

attachment or dependency in the relationship and could prompt marital conflict. Drabe et al. (2008) further theorized that fear of leaving the house alone was a specific symptom to head and neck patients and their partners due to the physical dysfunction and facial disfigurement their partners may experience after surgery. They noted that there may be limited generalizability to partners of head and neck cancer patients because only females were studied. The researchers suggest replicating the study with female patients and their male partners. Drabe et al. (2008) concluded their discussion by recommending their findings be applied while counseling patients and their wives. They suggested that surgeons and general practitioners be aware of the possible acute and chronic effects of caring for a spouse with head and neck cancer. Treatment modalities could include educating oral cancer patients and their spouses as well as offering social support.

Studies reviewed in this section provided a glimpse into the impact of caring for a person with oral cancer. The impact of disfigurement due to treatment was found to negatively impact patients and their partners (Vickery et al., 2002) Wives of persons with oral cancer were found to have increased levels of anxiety and depression when their partner had a feeding tube in place (Verdonck-de Leeuw et al., 2007). Moreover, the most informative study (Drabe et al., 2008) revealed that wives of men with oral cancer have increased psychiatric morbidity including affective disorders, mood disorders, and a surprising tendency to develop agoraphobia.

None of the studies conducted on oral cancer caregivers attempted to correlate the cancer caregiving experience with the development of symptoms of STS. The absence of information on the experience of caring for partner with oral cancer, coupled with the unique view that it can be likened to a traumatic experience, supported the need for the current study.

CONCLUSION

Chapter Two traced the evolution of the term STS, explained its application to those who have been traumatized, and differentiated it from the concept of burnout. The chapter also introduced the theory that underpinned the study, CSST, and connected this theory to the experience of being a caregiver of a person with various types of cancer, including oral cancer. The critical assertion presented in the chapter was that caring for a

person with cancer could be viewed as a traumatic experience. The state of the science relative to the literature on cancer caregivers in general, and oral cancer caregivers in particular, was discussed. Chapter Three will discuss the methodology used to conduct the study.

CHAPTER THREE: METHODOLOGY

INTRODUCTION

This chapter identifies the research design, describes the sampling method and access, identifies the study setting, and presents ethical considerations relevant to working with human subjects. Measurement methods and internal consistency of the study instruments are described in detail. Limitations and assumptions of the study are discussed. Lastly, data analysis procedures are presented.

IDENTIFICATION OF THE RESEARCH DESIGN

A survey design provides a quantitative or numeric description of a portion of a population by using the data collection process of asking people questions (Fowler, 1988). A descriptive, correlational survey design was used for this study. This nonexperimental approach allowed for studying of variables not amenable to manipulation (Polit & Beck, 2010).

Descriptive research methodology was used to identify and describe the phenomenon of the experience of STS in caregivers of persons with oral cancer. Selection of this method allowed the researcher to collect data without introducing a treatment or intervention (Polit & Beck, 2010). Ideally, study findings can be generalized beyond the sample population and will describe a characteristic or experience common to the greater population (Creswell, 1994).

DESCRIPTION OF THE SAMPLING METHOD AND ACCESS

Sample Size

The study consisted of a sample of 86 participants. In order to use Canonical Correlation as a means of data analysis, the number of cases needed for analysis is dependent on the reliability of the variables. To comply with Tabachnick and Fidell's (2000) recommendation of a .80 reliability level, 10 cases are needed per predictor

variable. The predictor set in this study consisted of a case to predictor ratio that met the minimal requirement for Canonical Correlation analysis.

Sample Population

A volunteer, self-selected (non-random) sample of 86 community-dwelling caregivers of persons with oral cancer was recruited from a population of members of the Oral Cancer Foundation (OCF) and the Support for Persons with Oral Head and Neck Cancer (SPOHNC) organization during August 2006 – March 2007. Terms relevant to the sample population included:

- **Oral Cancer:** a category of head and neck cancer encompassing the mucosal surfaces of the upper aerodigestive tract and oral cavity, including the subsites of the lip (but excluding skin of the lip), tongue, salivary glands, gum, mouth, pharynx, oropharynx, and hypopharynx.
- **Person with Oral Cancer:** a person who is undergoing or has undergone treatment for head and neck cancer, encompassing the mucosal surfaces of the upper aerodigestive tract, including the lip, tongue, oral cavity, pharynx, and larynx.
- **Caregiver of a Person with Oral Cancer:** any person, family member, or significant other who, by self-report, had an integral role in the life and functioning of someone undergoing or who has undergone treatment for head and neck cancer, encompassing the mucosal surfaces of the upper aerodigestive tract including the lip, tongue, oral cavity, pharynx, and larynx.

Inclusion Criteria

Inclusion criteria for subject participation included: participant age of 18 years or older, ability to read and understand English, and self-identification as a caregiver of a partner diagnosed with oral cancer.

Exclusion Criteria

Exclusion criteria for subject participation included: participant age of less than 18 years, inability to read and understand English, and lack of self-identification as a caregiver of a partner diagnosed with oral cancer.

OCF Subject Recruitment

Participants were recruited from OCF using an IRB-approved recruitment message posted on the home page of the OCF website located at www.oralcancer.org (see Appendix G: Flyer for Posting). Once permission was given by Mr. Brian Hill, OCF founder, a message was posted on the OCF home page. The flyer described the study and specified how those interested in receiving more information or participating in the study could contact the researcher directly by e-mail or phone. A link was provided to the researcher's private email.

SPOHNC Subject Recruitment

The researcher visited two SPOHNC meetings held at Massachusetts General Hospital in Boston, Massachusetts and discussed the study with members after receiving permission to do so from Ms. Valerie Hope Goldstein, the leader of the Boston SPOHNC chapter (see Appendix G: Script for Face-to-Face Recruitment). Flyers with information about the study and instructions on how to contact the researcher directly were distributed at meetings in which the researcher announced the study. The flyer described the study and specified how those interested in receiving more information or participating in the study could contact the researcher directly by e-mail or phone. The researcher distributed business cards to the members with her contact information printed on them.

Additionally, the researcher obtained permission from Ms. Nancy Leopold, the founder of SPOHNC, to access the master list of SPOHNC chapters across the nation. The researcher was given access to the list of regional SPOHNC support group leaders across the nation. The researcher contacted each regional leader via email to describe the study and requested that interested leaders respond to the message. SPOHNC group leaders who responded to the researcher and indicated they would ask their regional chapter members to participate in the study were sent an adequate number of survey

packets according to their active membership list. The packets contained the survey flyer, cover letter, study instruments, and self-addressed stamped envelopes to return the study materials to the researcher. Regional support group leaders distributed the flyers and described the study. The leaders informed chapter members that study materials were available for those who wished to participate. No specific training was provided to the regional support group leaders. Those interested in participating obtained a packet of study materials after the meeting. Regional leaders also specified how those interested in receiving more information or participating in the study could contact the researcher directly by email or phone. Leaders also distributed business cards to the members with the researcher's contact information printed on them.

IDENTIFICATION OF THE SETTING

The researcher sent study materials via first class US postal service mail to individual participants and SPOHNC national chapter leaders for distribution. The materials described the study and contained the survey instruments. Participants completed the surveys in the setting of their choice.

PRESENTATION OF ETHICAL CONSIDERATIONS

Permission to conduct this study was obtained via the University of Texas Medical Branch (UTMB) Committee for the Protection of Human Subjects Internal Review Board (IRB). Participants received a cover letter with the questionnaire packet explaining the purpose of the study and stating that participation was voluntary; consent was indicated by a participant's return of the answered questionnaire to the principal investigator. Participants were informed that even though they received a survey packet, they were not obligated to complete the surveys or return them to the investigator.

Anonymity was assured in the cover letter, which stated that no names or addresses were placed on the packets. Surveys were coded anonymously for the purpose of tracking the number of replies without identifying individual respondents. Respondents were requested not to place their names, addresses, or any other identifying data on the returned survey packet. Participants were assured that their names would not be recorded if they spoke with the investigator by phone. Participants were provided with

self-addressed stamped envelopes for return mailing of the completed survey packets. Return envelopes were destroyed by the principal investigator to ensure anonymity. All surveys and demographic data sheets returned to the researcher were kept in a locked cabinet in her home.

DESCRIPTION OF DATA COLLECTION PROCESS

Participants who contacted the investigator via email or phone received an immediate response that answered their questions. Those who stated they wanted to receive the packet provided the investigator with the address where it should be sent. Enclosed in the packet were the cover letter (see Appendix F: Cover Letter), directions, and study instruments including the Socio-and-Bio-Demographic data sheet, Family/Significant Other Quality of Life Scale (FamSoQOL), Life Status Review (LSR) and Coping-Skills Test-Abridged (CST-A). Also enclosed was a self-addressed postage-paid envelope for participants to use to return the completed questionnaires to the researcher. Participants were asked to complete the study instruments and to return them to the investigator at their convenience. Reminder postcards asking participants to return the survey packet if they had not already done so and thanking them again for their inclusion in the study were sent to all individuals within two to four weeks after they received the study packet.

DESCRIPTION OF MEASUREMENT METHODS

This study utilized three measurement tools and a demographic data sheet. The first tool was the Family/Significant Other Quality of Life Scale (FamSoQOL) (Stamm, 2003). The second tool was the Life Status Review (LSR) (Stamm & Rudolph, 1997). The third tool was the Coping Skills Test–Abridged-Revised (CST-A) (Jerabek, 2001).

Demographic Data Sheet

Demographic data was collected in the first part of the questionnaire along with data specific to the caregiver's experience with oral cancer (Appendix B: Demographic Data). In order to fully indicate the date scope, **Demographic Data** was renamed as a variable known as **Demographic Factors**, which referred to a study participant's unique

characteristics. For the purpose of this study, demographics factors recorded were age, gender, marital status, stage of partner's cancer, and length of time in caregiving role. Demographic data collected to categorize as factors included gender, date of birth, ethnicity, marital status, educational degrees attained, weekly number of hours worked outside the home, and type of employment. Participants were asked to categorize their relationship with the person they cared for, provide type and staging of the oral cancer of the person cared for, state treatment status (active treatment or follow-up care), report presence or absence of remission, state if the cancer had recurred since original diagnosis, and list the amount of time that had passed after initial diagnosis until recurrence (if applicable). Participants were also asked to provide data about the initial type of oral cancer treatment the person they cared for had received and the duration of treatment from start to finish.

Participants were asked how long they had been in a caregiving role, the setting in which the person they cared for received treatment for oral cancer, and how often they accompanied the person they cared for to a medical appointment or treatment. Participants were asked to specify if they were members of OCF or SPOHNC, how often they visited the OCF website (if applicable), how many years of experience they had using a computer, whether they considered the OCF website to be a source of support (if applicable), how often they attended SPOHNC support group meetings (if applicable), whether they considered SPOHNC to be a source of support (if applicable), and what they concerned them most regarding the person they cared for who had been diagnosed with oral cancer.

Addition of an Open-Ended Question

One open-ended question was included in the demographic data section in order to allow participants the opportunity to share their experiences in their own words. The question asked participants to describe what the experience of caring for a person diagnosed with oral cancer had been like for them. Participants were not required to answer this question.

THE FAMILY/SIGNIFICANT OTHER QUALITY OF LIFE SCALE (FAMSOQOL)

The FamSoQOL was derived from a tool titled The Professional Quality of Life Scale (ProQOL), an updated version of the Compassion Fatigue Self Test (CFST) originally created by Figley (1995). At the time, there were multiple versions of the CFST used to assess Compassion Fatigue (CF) and Secondary Traumatic Stress (STS) (Figley, 1995; Figley & Stamm, 1996).

Due to psychometric problems involving the subscales of the tool, the CSF was revised, and the third revision was re-named the ProQOL after market testing revealed that a more positive focus on quality of life rather than the negative effect of CF was more conducive to supporting positive system change and to ameliorating negative effects of caregiving (Stamm, 2003).

The revised version of the ProQOL rectified earlier difficulties separating the concepts of burnout and secondary trauma and facilitated completion by shortening the test from 66 to 30 items. Data were clustered from separate studies and aggregated by participant group (e.g., therapists, teachers, nurses, humanitarian aid workers). Data were not analyzed to obtain information about the sex of the participants or for male-female differences, as prior studies did not reveal psychometric differences on any of the subscales. The revised version of the ProQOL was tested on over 1,000 participants in multiple studies; items deemed most theoretically salient were retained for continued use. The revised tool contained bolstered subscales with 10 items each—7 items from the previous CSF version and 3 new items that were designed to strengthen the theory of the subscale. New items were developed after the authors performed a comprehensive review of the literature on the concept of burnout and the theory relating to the concept of compassion satisfaction. A further revision of the ProQOL was introduced for use with lay helpers and lay caregivers. This scale was named the FamSoQOL and was identical in its description, items, and psychometric properties to the revised ProQOL (Stamm, 2003).

The nomenclature of the FamSoQOL scale supported its applicability for use by researchers studying lay caregivers. After extensive consultation between the investigator and Dr. Beth Hudnall Stamm, a member of the researcher's doctoral committee and author of the FamSoQOL, the scale was deemed the most appropriate tool to gather data in this study and permission was granted by the Dr. Stamm for the researcher to use the

tool with caregivers of persons with oral cancer. The researcher had agreed to share study findings and psychometric data with Dr. Stamm with the intent of adding to the normative data base of information about the efficacy of the FamSoQOL as an instrument used with lay caregivers.

The FamSoQOL (Appendix F) commences with a description of the tool that explained to the helper that caring for someone with a serious or life threatening condition placed them in direct contact with that person's life threatening experience. The tool introduces participants to the idea that compassion for a person they were helping or had helped had both positive and negative aspects. Participants then answer thirty questions characterizing their current situation and rate the frequency of occurrence of those characteristics within the prior 30 day period. Participants are asked to write the number they select for each question on the line next to the item. A Likert-type scale is included, with responses ranging from "Never" to "Very Often."

DESCRIPTION OF SUBSCALES OF THE FAMSOQOL

The FamSoQOL contains three subscales: Compassion Satisfaction (CS), Burnout, and Compassion Fatigue (CF)/Secondary Traumatic Stress (STS). The subscale of CS refers to pleasure derived from being able to do work well and from having helped another person. The subscale of Burnout involves the state of having feelings of hopelessness and difficulties in dealing with work or doing a job effectively. Negative feelings typically have a gradual onset. Lastly, the subscale of CF/STS relates to work-related, secondary exposure to extremely stressful events that involve exposure to another person's traumatic events. Symptoms of STS are usually rapid in onset and associated with a particular event. STS symptoms, as measured by the subscale, including being afraid, difficulty sleeping, having images of the upsetting event appear into a person's mind, and avoiding things that remind the person of the event (Stamm, 2003). In this study, the traumatic event was defined as being a caregiver of a person diagnosed with oral cancer.

Operational variables associated with the FamSoQOL are as follows:

- **Compassion Satisfaction:** pleasure derived from being able to do work well and from having helped another person.

- **Burnout:** a state of having feelings of hopelessness and difficulties in dealing with work or in doing a job effectively. Feelings may have reflected a perception that efforts make no difference, or that they were associated with a very high workload or a non-supportive work environment.
- **Compassion Fatigue (CF)/Secondary Traumatic Stress (STS):** work-related, secondary exposure to extremely stressful events, including exposure to another person's traumatic events. In this case, the traumatic event was defined as diagnosis and treatment for oral cancer. STS involved a rapid onset of symptoms that included being afraid, difficulty sleeping, mental recreations of the upsetting event, or avoidance of things that reminded one of the event.
- **Quality of Life:** a person's self-described standard of living, which included health, social interaction, social satisfaction, and positive engagement within a self-identified family unit.

Scoring of the FamSoQOL

The FamSoQOL is a 30-item instrument intended to be a self-scoring measure. Participants must have responded to all items to ensure proper scoring. The tool contains 3 bolstered subscales of Compassion Satisfaction (CS), Burnout, and Compassion Fatigue (CF). The 3 subscales do not yield a composite score. Each score stands alone psychometrically and cannot be combined with other scores (Stamm, 2003).

Scores are reversed on 5 items (1, 14, 15, 17, and 29), while an answer of 0 is never reversed as its value remained null. The participant is instructed to put an "X" by the 10 items that form the Compassion Satisfaction Scale (3, 6, 12, 16, 18, 20, 22, 24, 27, and 30). A check is placed by the 10 items on the Burnout Scale (1, 4, 8, 10, 15, 17, 19, 21, 26, and 29). A circle is placed around the 10 items on the Trauma/Compassion Fatigue Scale (2, 5, 7, 9, 11, 13, 14, 23, 25, and 28) (Stamm, 2003).

Participants could have been instructed to add the numbers written for each set of items and compare them with the theoretical scores for the scale, which could be provided as a handout. This step was not undertaken in the current study as the investigator scored the instrument.

Scoring of the CS Subscale

The average theoretical score on the CS scale was 37 (SD 7, alpha scale reliability 0.87). About 25% of people scored higher than 42 and about 25% of people scored below 33. A higher score on the subscale of CS represented a greater satisfaction related to a person's ability to be an effective caregiver in a job or caregiving role. The subscale's author (Stamm, 2003) recommended that persons who scored in the higher range be told that they probably derive a good deal of satisfaction from their position while those falling in a range below 33 may have experienced problems with their job as a helper.

Scoring of the Burnout Subscale

The average theoretical score on the burnout scale was 22 (SD 6.0; alpha reliability 0.72). About 25% of people scored above 27 and about 25% of people scored below 18. A score below 18 likely reflected positive feelings about a participant's ability to be effective in his or her work. A participant who scored above 27 may need to be advised that he or she may want to reflect on what aspects of work make that person feel ineffective in the position. A high score may have reflected a participant's mood such as having a bad day or needing to have some time off. A persistent high score, or one that is reflective of other worries, has been noted as a cause for concern (Stamm, 2003).

Scoring of the Compassion Fatigue (CF)/Secondary Trauma (STS) Subscale

The average theoretical score on the CF/STS subscale was 13 (SD 6; alpha scale reliability 0.80). About 25% of people scored below 8 and about 25% of people scored above 17. The subscale's author recommends that a participant who scored above 17 be advised that he or she may want to take some time to think about aspects of his or her helping work that were frightening, or consider if there was some other reason for the elevated score. Higher scores did not necessarily indicate that a problem existed. Rather, the scores were an indication that a person may want to examine how he or she felt about his or her work environment (Stamm, 2003).

Internal Consistency of the FamSoQOL

Quantitative analysis of the original revised ProQOL was conducted by the researcher using Cronbach's alpha, item-to-scale analyses, common factor analyses, and multigroup factorial invariance (Stamm, 2003). The scales on the ProQOL measured different constructs with a known reduction in collinearity between CF and Burnout. CS had a 5% shared variance with Burnout and a 2% shared variance with Compassion Satisfaction/Trauma. The shared variance between Burnout and Compassion Fatigue/Trauma is higher and most likely reflects the distress common in both conditions (21%). Items deemed to have met high item-to-scale criteria and those that best represented the theoretical construct of the subscales were retained (Stamm, 2003).

Internal consistency reliabilities using Cronbach's Alpha were completed for the FamSoQOL and its 3 subscales. Psychometric properties of the revised, shorter version of the FamSoQOL were Compassion Satisfaction alpha = .87, Burnout alpha = .72 and Compassion Fatigue alpha = .80. These scores represent enhanced reliability over the longer form. Using a Spearman Brown formula, it was determined that reliability of the original tool was .82, compared with reliability of .69 on the shortened scale. The revised measure had proven improvement of the item-to-scale statistics due to increased specificity and reduced collinearity. The addition of new items was projected to reduce known collinearity between the subscales of Compassion Fatigue and Burnout. The standard errors of the measure were small and the test typically has less error interferences, which improved the measurable effect size. Owing to the small sample size of this study, this point is particularly relevant to data analysis. The ProQOL and FamSoQOL contained three subscales entitled Compassion satisfaction (CS), Burnout, and Compassion Fatigue (CF). Construct validity had been established in multiple peer-reviewed articles (Stamm, 1999, 2003).

This study also tested internal consistency reliabilities of the FamSoQOL and its three subscales using Cronbach's Alpha. The coefficient alphas for the study instruments were found to be reliable, and 11 were over the .70 level (Polit et al., 2001).

THE LIFE STATUS REVIEW SCALE

The Life Status Review (LSR) (Stamm & Rudolph, 1997) was created based on the theoretical premise that biopsychosocial consequences occur after exposure to trauma. This phenomenon had been observed and documented in both victims of trauma and in those who provided care to victims (Figley, 1995; Pearlman & Saakvitne, 1995; Stamm, 1995). The origin of the LSR was the Life Satisfaction Scale (LSS) (Kopina, 1996). The LSR was similar to the LSS but became a broader measure inclusive of addressing feelings, perceptions, and activities. The LSR was an instrument designed to assess an individual's biopsychosocial well being. Consequences of traumatic stress can be profound and negatively affect an individual's interpersonal and intrapersonal systems. Routine activities of daily living (ADLs) were included in the systems referenced above. Systems not working well can increase negative symptoms and the perception of individual vulnerability.

The authors of the LSR (Stamm & Rudolph, 1997) posited that it was important to monitor daily living for populations with chronic post-traumatic stress. Pearlman (1995) stated that these effects may manifest as STS and initially appear as difficulty managing routine daily tasks. An individual whose life becomes increasingly involved around his or her reality of the experience of trauma may be more vulnerable to positive and negative changes in his or her biopsychosocial systems.

The LSR enables caregivers to track patients' well-being with regard to ADLs. The LSR gauges items patients attended to daily, identifies potential problem areas, and recognizes things that are going well (Stamm, 1996; Stamm & Rudolph, 1997). Additionally, the LSR identifies positive and negative stressors in an individual's life, identifies those stressors that would threaten an individual's well being or ability to continue in current activities, develops a profile of an individual's well-being across time, and models health attention to one's life by identifying areas of strengths that could be used as a gateway to healing (Rudolph et al., 1996; Stamm, 1995; Stamm & Rudolph, 1997). The LSR was deemed appropriate for use in this study after direct consultation with a co-author of the tool, Dr. Beth Hudnall Stamm, who felt that the patient version of the LSR was equally appropriate for use with lay caregivers of persons with oral cancer. This study utilized the LSR as a one-time measure of the status of caregivers of persons

with oral cancer. The researcher has agreed to share study findings and psychometric data with Dr. Stamm to contribute to the normative database regarding the efficacy of the LSR instrument. The variable **Life Status Review** was operationally defined as the state of a person's well-being in relation to activities of daily living.

Specifically, the LSR (Appendix G) reviews 30 areas divided into 8 subscales. Each subscale represents a construct that from domains of a person's existence including personal (i.e., Alcohol/Substance Use), interpersonal (i.e., Self/Social/Interpersonal), or social (i.e., Employment/School). A unique aspect of the LSR is its ability to track both good and bad outcomes. Participants fill out a self-report checklist that takes 5-10 minutes to complete (Stamm & Rudolph, 1997).

Scoring of the LSR

The LSR is scored on a 5-point Likert-type scale spanning negative numbers, which represent a problem, and neutral to positive numbers, which represent good things that are happening to the participant. The scale ranges from -2 (a problem that required intervention such as a lost job, arrest, or divorce) to -1 (a potential problem that bears watching such as worrying about children or dealing with rumors at work) to 0 (characterized as an ordinary neutral state that was neither good nor bad) to +1 (something good has happened such as having received a raise at work or a friend coming to visit) to +2 (something absolutely great has happened, a longstanding problem has been resolved, a new job was offered, or the person got married). The ratings -2 and +2 are generally assigned when there is a strong effect attached to the item while the ratings -1 and +1 represent some effect but not as much as ± 2 (Stamm & Rudolph, 1997).

Internal Consistency of the LSR

The LSR was tested in two large studies and presented in poster format by the study's authors. Initial data were gathered from a patient sample of 217 Vietnam Veterans with PTSD who were participating in the Veteran's Administration (VA) Cooperative Studies and the VA National Center for PTSD group treatment, which was a multi-site psychotherapy clinical trial (Friedman et al., 1999). Reliability data for the

clinician's sample were derived from two studies including an unpublished study of debriefers in South Africa (n=145) (Stamm et al., 1998) and an unpublished study of crisis workers in Canada (n=30) (Stamm et al., 1998).

The LSR was administered to patients in a structural interview format. It was used on a monthly basis as part of case management to monitor the well being of participants. Any item reported to be a "problem" was considered a warning sign for impending crises. LSR results were entered into a database. Data on clinicians were compiled from a secondary analysis of three other studies that had used the LSR as a self-report instrument to measure life issues that would pre-dispose the provider to develop STS. Data from South Africa were collected from trained debriefers who were employees of the banking industry, while the Canadian sample was collected from staff at a rape crisis center (Stamm & Rudolph, 1997).

Testing and test re-testing on the LSR revealed reliability of the instrument initially and after test re-test procedures. Reliability was found to be consistent across both patient and clinician samples. The patient LSR data (n=217) showed an overall alpha of .93 (M=0.6, SD 7). The clinician LSR data (n=175) showed an alpha of .84 (M=0.5, SD 7). Both scaled ranged from -2 to +2. The alpha reliabilities of the subscales ranged from 0.67 – 0.96. Distribution data for the total scale and the subscales were provided courtesy of the co-author (see Table 3.1). The interscale correlation ranged from 0.14 – 0.70 with all but 3 values less than $r=.45$ (Stamm & Rudolph, 1997).

The subscale of Legal/Criminal was highly correlated with Alcohol/Substance because of the legal and criminal implications of using illegal substances ($r = 0.70$). Legal problems that resulted from substance overused were determined to be an artifact in the sample due to an overrepresentation of substance users in a PTSD group. The Employment/School subscale correlated with the Financial subscale ($r = 0.57$) and was attributed to the fact that about half of this sample was not working and had financial difficulties. The Health/Wellness subscale was moderately correlated with the Medical subscale ($r = 0.53$), yet data analysis revealed a discernable difference between health maintenance and prevention and remediation of medical conditions (shared variance = 28%) (Stamm & Rudolph, 1997).

Overall, the LSR and its 8 subscales had proven reliability as a measure used to track patients and to help providers evaluate their levels of CF and CS. The authors, at the time of psychometric testing, stated that psychometric properties would be further enhanced through the collection of additional data to assess the construct validity and ensure robustness of factor analysis. The authors also recommend collecting longitudinal data from providers. The authors (Stamm & Rudolph, 1997) concluded that the LSR was a useful tool to measure individuals' perceptions of their life statuses.

This study assessed internal consistency reliabilities of the LSR and its 8 subscales using Cronbach's' Alpha. The coefficient alphas for the study instruments were found to be as follows: Medical Status, .69, Health/Wellness, .85, Financial Situation .73, Housing/Transportation .93, Employment/School, .82, Legal/Criminal .92, Alcohol/Substance Abuse, .93, and Self/Social/Interpersonal .77. All subscales were found to be reliable, with the exception of Medical Status (.69). Findings are presented in Table 3.1 (following page).

COPING SKILLS TEST–ABRIDGED-REVISED (CST-A)

The Coping Skills Abridged, revised version (CST-A) (Jerabek, 2001) is a 10 item test used to assess how well one reacts to stress (Appendix H). The tool was utilized in this study after the researcher purchased a license for use from Queendom (www.queendom.com), a company owned by the author of the CST-A, Dr. Ilona Jerabek. The CST-A asks participants to evaluate their current level of coping by rating statements such as: (1) I get easily discouraged; (2) When the situation changes, I adjust my plans; (3) When I am stressed, my mind goes blank; (4) I know where to find the information I need; (5) I trust my judgment; (6) I accept my mistakes as a learning opportunity; (7) When something I wanted doesn't work out, I get rapidly back on my feet; (8) When a situation requires a change in plans or strategy, I feel confused or anxious; (9) When I fail, I am devastated for a long time; and (10) I am able to apply what I have learned in a new situation. A 5-point Likert-type scale is included with responses ranging from "Almost Never" to "Most of the Time." Participants are asked to mark one box to the right of every one of the 10 statements that best represent the degree to which the statement applied to them (Jerabek, 2001). For the purpose of this study, the variable

Table 3.1: Cronbach's Alpha Internal Consistency and Reliability Coefficients of Study Instruments (N = 86)

Instrument	Number of Items	Standardized Alpha
<u>Family/Significant Other Quality of Life Instrument (FamSoQOL)</u>		
Compassion Satisfaction	10	.90
Burnout	10	.78
Compassion Fatigue	10	.82
<u>Life Status Review (LSR)</u>		
LSR Medical Status	3	.71
LSR Health/Wellness	3	.85
LSR Financial Situation	3	.71
LSR Housing/Transportation	4	.93
LSR Employment/School	3	.83
LSR Legal/Criminal	4	.94
LSR Alcohol/Substance Use	3	.93
LSR Self/Social/Interpersonal	6	.80
*Coping Skills Test-Abridged	10	.68

* Coping Skills Test-Abridged: Dropped from analysis due to error rate of 32%

named **Coping Skills** referred to the ability of a person to successfully contend with an unexpected and potentially stressful situation.

Scoring of the CST-A

Upon purchasing the license to use the CST-A, the researcher received the tool electronically but the appropriate instructions for and interpretation of the scoring were missing. The investigator contacted Queendom (www.queendom.com) and was informed by a company representative that scoring could only be performed by the author's (Jerabek, 2001) team and all study data would need to be submitted to them. The

researcher would have no input in the analysis of the data or the interpretation of the findings. The researcher was uncomfortable releasing study data to an outside party and did not feel that doing so was in keeping with information participants had been given about data security procedures. Additionally, there was a substantial cost for the scoring. The researcher conferred with a member of her doctoral committee who was well-versed in quantitative methods and statistical analyses. Her recommendation was not to pursue this avenue as the CST-A was lacking in psychometric stability as described in the subsequent section of this chapter.

Internal Consistency of the CST-A

A message regarding credibility posted on the Queendom website stated that all tests on the website are scientifically validated by statistical analysis led by the author of the tool (Jerabek, 2001). The CST-A was tested on a sample of 16,383 persons. No description was provided as to the characteristics of the test sample. Distribution statistics on the 10 item scale revealed an overall mean score of 67.1 with a standard deviation of 16.6. Cronbach's Alpha was performed on the 10 item scale and revealed a score of 0.84 and a standard deviation of 16.59. Standard error of measurement was 6.63. Each item was tested individually (Jerabek, 2001).

This study also assessed the internal reliability of the CST-A and found disparate data from those that the author reported (Jerabek, 2001). Cronbach's Alpha was performed on the 10 item scale and revealed a theoretical score of 0.84 (SD, 16.59). The theoretical standard error of measurement was 6.63. Cronbach's Alpha for this sample was found to be 0.62 with a standardized item alpha of 0.68. Findings are presented in Table 3.1 (see above). Due to low reliability, the instrument was dropped from further analysis in this study.

DATA ANALYSIS

In this descriptive correlational survey design study, caregivers of persons with oral cancer completed the study surveys, including the FamSoQOL, LSR, and the CST-A as well as the Demographic data sheet. Participants in this study were not given a copy of the theoretical scoring sheet for any of the study instruments.

For the purposes of data analysis, the researcher entered the data into SPSS version 14.0 (Norusis, 2006) for scoring, statistical analysis, and comparison of results to the published theoretical scoring for the instruments. Means, standard deviations, and frequencies were performed on all study variables. Data were examined for systematic missing data, marked skewness, and outliers. Internal consistencies and reliabilities of all study measures were computed using Cronbach's Alpha. Pearson Product Moment Correlational Matrix of all study variables was computed and examined for multicollinearity. Canonical Correlation analysis was used to answer Research Question 1 (RQ1). Multiple regression analysis was used to answer Research Question 2 (RQ2). The predictor ratio was slightly lower than what is needed for multiple regression analysis; thus, caution will be exercised in interpreting the multiple regression results related to RQ 2. Findings of the data analyses will be presented in Chapter Four.

CONCLUSION

Chapter Three presented an overview of the research design, subject recruitment procedures, sampling method and access, study setting, and ethical considerations relevant to working with human subjects. Measurement methods and data about the internal consistency of each study instrument were provided. Limitations and assumptions of the study were discussed. Data analysis procedures were reviewed. All measurement tools, with the exception of the CST-A, were judged to have sufficient internal consistency for use in further analyses. Psychometric analysis of the CST-A using Cronbach's Alpha yielded a result of <0.70 and an error rate of 32%. Thus, the CST-A was deemed a poor tool for use in this study and was dropped from further analysis in the study. Chapter Four will present the sample characteristics, psychometric estimates for the sample, analysis of findings, and applicability of the findings to answering the research questions.

CHAPTER FOUR: RESULTS

INTRODUCTION

Chapter four will present the results of the study including sample characteristics, psychometric estimates for the sample, analysis and results for each research question, and a description of themes that emerged as a result of participants' answers to the additional open-ended qualitative question included in the study.

This study had one purpose and two aims. The purpose of the study was to explore the existence of STS in caregivers of persons with oral cancer, describe the nature of the experience of STS, and examine the relationships of STS to other variables of interest. The aims of the study were a) to determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explained a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer; and b) to determine the extent to which the selected demographic variables of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, stage of partner's cancer, CS, and CF explained a caregiver's ability to cope as measured by the Coping Skills Test-Abridged (CST-A).

Research Question 1 (RQ1) was answered using Canonical Correlation analysis. Extensive efforts were made to answer Research Question 2 (RQ2) using multiple regression analysis. However, due to the lack of reliability (0.69) of the Coping Skills Tool Abridged Version (CST-A), further analysis was precluded and RQ2 could not be answered satisfactorily.

SAMPLE CHARACTERISTICS

Demographic Characteristics of Caregivers of Persons with Oral Cancer

A volunteer sample of 86 caregivers of persons with oral cancer was recruited from the SPOHNC organization local meetings and the OCF website. The sample was predominantly white (95.3%), female (84.9%), and married (76.7%). The age of

participants ranged from 26 to 81 years, with an average age of 54.7 ± 11.7 years. The majority of respondents (53.6%) had college degrees or graduate degrees. Almost 35% of participants were either homemakers or retired. In 77% of cases, the caregiver was a spouse or partner of a person with oral cancer. Table 4.1 reports these results in detail.

Table 4.1: Demographic Characteristics of Caregivers of Persons with Oral Cancer (N = 86)

Variable	Value	Frequency	Percent
Demographics			
Age		54.7	11.7
Months in Caregiver Role		2.8	1.7
Gender	1=Male	13	37.3
	2=Female	73	62.7
Race	1=White, non-Hispanic	82	95.3
	2=Black, non-Hispanic	2	2.3
	3=Hispanic	0	0
	4=American Indian	0	0
	5=Alaskan Native	0	0
	6=Asian or Pacific Islander	2	2.3
Marital Status	1=Single, never married	4	4.7
	2=Married	66	76.7
	3=Divorced	6	7.0
	4=Widowed	5	5.8
	5=Other	5	5.8
Highest Degree Obtained	1=Elementary	1	1.2
	2=High School Graduate	15	17.4
	3=Some College/Tech Training	18	20.9
	4=College Graduate	26	30.2
	5=Masters	20	23.3
	6=Doctoral	5	5.8
Number of Hours Worked per Week	0=0 Hours	30	34.9
	1=8-16 Hours	3	3.5
	2=17-24 Hours	6	7.0
	3=25-32 Hours	7	8.1
	4=33-40 Hours	23	26.7
	5=40+ Hours	16	18.6
Relationship to Partner	1= Spouse	66	76.7
	2=Unmarried Partner	0	0
	3=Living Together	7	8.1
	4=Relative	9	10.5
	5=Friend	3	3.5
	6=Significant Other	1	1.2
	7=All Others	13	15.8

Psychometric Estimates for the Sample

The study consisted of a sample of 86 participants. To comply with the recommendation of Tabachnick and Fidell (2000), the case-to-variable ratio of 10 cases per predictor was used, which met the requirement to undertake Canonical Correlation analysis.

Demographic Characteristics of Persons with Oral Cancer

As Table 4.2 indicates (below), the majority of persons being cared for by their partners had been diagnosed with Stage I, II, or III oral cancer (63.9%), were no longer undergoing active treatment (76.7%) for oral cancer, and were in remission (66.7%). Most did not have a recurrence of their cancer. Of those who had a recurrence, it occurred within six months to one year after initial treatment was completed (9.3%).

The type of treatment most partners received was surgery, radiation, and chemotherapy (36%), followed by surgery and radiation only (29.1%), with a 3 months average duration of treatment (20.9%). Over 51% of persons with oral cancer were treated at a major medical center with a head and neck cancer department.

Table 4.3 (below) reports the demographic characteristics of the caregiver experience. Caregivers in the sample had been in the role one year or less (29.1%) followed by those in the role for one-five months (25.6).

The majority of participants were not registered members of either the Oral Cancer Foundation (OCF) (60.5%) or the Support for Persons with Head and Neck Cancer (SPOHNC) (69%) organization. Over 52% of the study participants did not actually register as members of the OCF website organization but accessed the site on a regular basis. Of this number, some visited the site once per day (10.5%), once per week (10.5%), and other frequencies (10.5%). Over 52% of those who visited stated that the website was a source of support for them.

Table 4.2: Demographic Characteristics of Persons with Oral Cancer (N = 86)

Variable	Value	Frequency	Percent	
Stage of Oral Cancer	Stage 1 thru 3	55	63.9	
	Stage 4	31	36.1	
Active Treatment	No	66	76.7	
	Yes	20	23.3	
Recurrence	No	62	72.1	
	Yes	24	27.9	
Time of Recurrence	No recurrence	60	69.8	
	0-5 months	6	7.0	
	6-12 months	8	9.3	
	1-2 years	2	2.3	
	2-3 years	4	4.7	
	3-4 years	2	2.3	
	4-5 years	1	1.2	
	7-8 years	1	1.2	
	10 years or more	2	2.3	
	Type of Treatment	Surgery, Radiation & Chemo	31	36.0
Surgery & Radiation		30	35.0	
Surgery Only		15	17.5	
Radiation & Chemo		9	10.5	
Duration of Treatment	1 months	2	2.3	
	2 months	13	15.1	
	3 months	18	20.9	
	4 months	17	19.7	
	5 months	13	15.1	
	6 months	9	10.5	
	7 months	7	8.1	
	8 months	1	1.2	
	9 months	1	1.2	
	10 months	1	1.2	
	12 months	2	2.3	
	14 months	1	1.2	
	15 months	1	1.2	
	Treatment Setting	Community Hospital	13	15.1
		Med. Ctr. Without Head & Neck Dept.	23	26.7
Med. Ctr. With Head & Neck Dept.		45	52.4	
Unaffiliated Clinic		5	5.8	
All Others		41	47.6	

Table 4.3: Demographic Characteristics of Caregiver Experience for Persons with Oral Cancer (N = 86)

Variable	Value	Frequency	Percent
Demographics			
Time in Caregiver Role	0-5 months	22	25.6
	6-12 months	25	29.1
	1-2 years	11	12.8
	2-3 years	9	10.5
	3-4 years	10	11.6
	4-5 years	3	3.5
	5-6 years	2	2.3
	7-8 years	1	1.2
	9-10 years	1	1.2
	10 years or more	2	2.3
OCF Member	No	53	60.5
	Yes	33	38.4
OCF Website Support	No	41	47.7
	Yes	45	52.3
SPOHNC Meeting Attendance	0	3	3.5
	Monthly	7	8.1
	< 6 times/year	3	3.5
	Occasionally	5	5.8
	Never	9	10.5
SPOHNC Member	Not a Member	59	68.6
	No	60	69.8
Caregiver Worry 1 (Recurrence)	Yes	26	30.2
	No	21	24.4
Caregiver Worry 2 (Undergoing Surgery)	Yes	65	75.6
	No	79	91.9
Caregiver Worry 3 (Rad/Chemo Complications)	Yes	7	8.1
	No	61	72.1
Caregiver Worry 4 (Emotional Health)	Yes	24	27.9
	No	63	73.3
Caregiver Worry 5 (Surgery Complications, Death, Financial Strain)	Yes	23	26.7
	No	76	88.4
	Yes	10	11.5

Demographic Characteristics of the Caregiver Experience

Results of the SPOHNC membership profile showed that 30.2% of the partners were members of SPOHNC and 69.8 were non-members. Over 8 % of partners who were members of SPOHNC attended regular meetings, while 91% of the 26 partners did not

attend meetings. Membership is required to attend SPOHNC meetings. Of the 8.1% who did attend meetings, 96% reported finding them to be a source of support.

Additionally, caregivers were asked to rate their concerns regarding the person they cared for with oral cancer. Over 75% of caregivers listed recurrence of oral cancer as a major worry followed by complications from radiation and chemotherapy (27.9%), maintaining emotional health of partner (26.7%), undergoing surgery (8.1%), and other worries such as complications from surgery, death, and financial strain (11.6%).

Scoring of the Study Instruments

Table 4.4 reports the means and standard deviations for participant scores on study instruments. The average score on the FamSoQOL was 79.7 (SD, 14.0) indicating that subjects caring for partners with oral cancer did experience some degree of STS. The 3 subscales of Compassion Satisfaction, Burnout, and Compassion Fatigue further refined the areas of satisfaction caring for a partner with oral cancer as well as the experience of STS. On the Compassion Satisfaction Scale, the average score was 34.4 (SD, 9.01), for the Burnout Scale the average score was 22.9 (SD, 8.0), and for the Compassion Fatigue Scale total score was 21.1 (SD, 9.1).

Biopsychosocial well-being was measured by the LSR and had an average score of 3.6 (SD, 13.8). The tool contained 8 subscales comprised of; (1) Medical Status, (2) Health/Wellness, (3) Financial Situation, (4) Housing/Transportation, (5) Employment/School, (6) Legal/Criminal, (7) Alcohol/Substance Use, and (8) Self/Social/Interpersonal.

Total score on the Medical Status subscale was 0.19 (SD, 1.80). Score on the Health/Wellness subscale was -0.65 (SD, 3.10). Score on the Financial Situation subscale was -0.43 (SD, 2.30). Score on the Housing/Transportation subscale was 1.50 (SD, 3.00). Score on the Employment/School subscale was 0.31 (SD, 1.70), Score on the Legal/Criminal subscale was 0.66 (SD, 1.90). Score on the Alcohol/Substance Use subscale was 0.26 (SD, 0.96) and total score on Self/Social/Interpersonal subscale was 1.69 (SD, 4.70).

Table 4.4: Means and Standard Deviations of Participant Scores on Study Instruments

Variable	Instrument	Mean	Standard Deviation
Family Significant Other Quality of Life Scale (FAMSOQOL)	Compassion Satisfaction Scale	34.4	9.0
	Burnout Scale	22.9	8.0
	Compassion Fatigue Scale	21.1	9.1
Life Status Review (LSR)	LSR Medical Status	0.1	0.6
	LSR Health/Wellness	-0.2	1.0
	LSR Financial Situation	-0.3	1.0
	LSR Housing/Transportation	0.4	0.8
	LSR Employment/School	0.1	0.6
	LSR Legal/Criminal	0.2	0.5
	LSR Alcohol/Substance Use	0.1	0.5
	LSR Self/Social/Interpersonal	0.3	0.8
	*Coping Skills Test-Abridged (CST-A)	--	23.5

*Instrument dropped from study due to Cronbach's Alpha internal consistency of <0.70

Preliminary Data Analyses Prior to Answering Research Questions

Prior to answering the research questions, the descriptive statistics were examined to detect any systematic missing data, marked skewness, and the presence of outliers by testing the null hypothesis,. No systematic missing data or marked skewness was detected; median substitution was used for random missing data to preserve cases.

Recoding of Demographic and Grouping Variables

In order to make sure there were sufficient numbers of cases in variable categories, the following demographic variables were recoded: marital status, highest degree attained, numbers of hours worked, caregiver relationship to the person with oral cancer, diagnosis type, type of treatment, time in caregiver role, and treatment setting. The recoded variables are shown in Table 4.5.

Table 4.5: Recoded Demographic Variables

Category	Variable	Frequency	Percent
Demographics			
Recoded Marital Status	1=Married	66	76.7
	0-All Others	20	23.3
Recoded Highest Degree Attained	1=College, Masters, Doctoral Degree	52	61.0
	0=Elementary School, High School, Some College	34	39.0
Recoded Hours Worked per Week	1=Working One or More Hours per Week	56	65.1
	All Others	56	65.1
	0=Not Working Outside Home	30	34.9
Recoded Relationship to Partner	1=Spouse/Partner	73	84.2
	0=Relative, Friend, Significant Other	13	15.8
Recoded Treatment Setting	1=Med. Ctr. With Head & Neck Dept.	45	52.4
	0=All Others Setting with No Head & Neck Dept.	41	47.0

Item 4, the marital status variable, was recoded to have two categories (1=married and 0=all others). The “all others” category included single, never married (n=4), divorced (n=6), widowed (n=5), and other (n=5). Item 5, the highest degree attained variable, was recoded to have two categories (1= college or graduate degree and 0=less than college degree). Item 8, the relationship to partner variable was recoded to have two categories (1=spouse and 0=all others). The “all others” category included unmarried partner living together (n=7), relative (n=9), friend (n=3), and significant other (n=1).

Item 9, the diagnostic type and staging of oral cancer variable was recoded into 3 categories (Stage 1-2=1; Stage 3=2; Stage 4=3). Lastly, the variable treatment setting was recoded into two categories (1=major medical center with head and neck cancer department; 0=all others). The “all others” category included a community hospital (15.1%), major medical center without head and neck cancer department (26.7%), and clinic not affiliated with a major medical center (5.8%).

ANSWERING THE RESEARCH QUESTIONS

Research Question 1(RQ 1):

RQ 1: To what extent do the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiver role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explain a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer?

RQ 1 was answered using Canonical Correlation analysis. Canonical correlation is a technique that analyzes relationships between two sets of variables simultaneously. This method maximizes linear correlation between the variables and determines if a relationship exists between the independent and dependent variables (Hair et al., 1998).

In this analysis, the predictor variables (Set One) consisted of the demographic variables of age, gender, recoded marital status, time in caregiver role, and stage of partner's cancer as well as the FamSoQOL subscales of CF, Burnout, and CS. The dependent variables were the 8 LSR subscales (Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, Legal/Criminal, Alcohol/Substance Use, Self/Social/Interpersonal).

The results are shown in Table 4.6 (following page). Of the eight possible canonical variates, only the first canonical was statistically significant, with a Wilk's value of .28, a Chi Square value of 97.5 with 64 degrees of freedom and significance at the 0.004 level. The canonical correlations coefficient for the first canonical variate pair was 0.68. The seven remaining canonical correlations for the remaining canonical variate pairs were statistically non-significant. Thus, only the first canonical variate pair was interpreted.

With a cutoff canonical loading of 0.30 for interpretation, four variables in the predictor set (age, CS, Burnout, & CF), and six of the variables out of eight (medical status health/wellness, financial situation, employment/school/ SSPI/Housing) were relevant to the first canonical variate.

Total redundancy for this canonical pair was 26.3%. Taken as a pair, this significant canonical variate indicated that younger caregivers with lower Compassion Satisfaction (CS) scores and higher Burnout and Compassion Fatigue (CF) scores were

more likely to have lower Medical status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts. Thus, older caregivers with higher Compassion Satisfaction (CF), lower Burnout, and lower Compassion Fatigue (CF) scores were more likely to have higher Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts.

Table 4.6: Canonical Correlational Analysis Summary Table Between Selected Demographic Variables, 3 Subscales of the FamSoQOL and 8 Subscales of the LSR

Variable Sets	Canonical Variate
SET 1 (Predictor Variables)	
<i>Demographics</i>	
Age	.42
Gender (1=Male, 2=Female)	-.25
Recoded Marital Status (1=Married, 0=All Others)	-.04
Time in Caregiver Role	.27
Stage of Cancer	-.20
<i>FamSoQOL Subscales</i>	
Compassion Satisfaction	.56
Burnout	-.94
Compassion Fatigue	-.80
Redundancy	12.6%
SET 2 (Dependant Variables)	
<i>LSR Subscales</i>	
LSR Medical Status	.61
LSR Health/Wellness	.87
LSR Financial Situation	.56
LSR Housing/Transportation	.44
LSR Employment/School	.36
LSR Legal/Criminal	.12
LSR Alcohol/Substance Use	.12
LSR Self/Social/Interpersonal	.77
Redundancy	13.7%
Canonical Correlation	.68
Total Redundancy	26.3%
Cutoff for Interpretation = .30	

Research Question 2 (RQ 2)

RQ 2: To what extent do the selected demographic variables of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, and STS symptoms explain a caregiver's ability to cope as measured by the Coping Skills Test-Abridged (CST-A).

As demonstrated in Chapter 3, Cronbach's reliability of the CST-A was 0.68 (17.8% of explained variance, r^2 [18%]), indicating 32% of error variance and 68% true score. Given that this reliability coefficient fell below the minimum cutoff score of 0.70 reliability, multiple regression results reported in this section should be viewed extremely cautiously. Adjustment for a large number of variables (8) and artificially high predictors and minimal sample size leads to an artificially inflated r^2 (Tabachnick & Fidell, 2000). Shrinkage error was reduced to 9.2% of explained variance.

Prior to undertaking the multiple regression analysis, collinearity statistics were examined to determine if any of the predictor variables were redundant of each other. No multicollinearity was detected. Multiple regression analysis using forced entry of the predictors into the equation was used to answer RQ2. The predictor set were the same 8 variables (Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, Legal/Criminal, Alcohol/Substance Use, Self/Social/Interpersonal) used in the Canonical Correlation. The dependent variable was the CST-A total score. Table 4.7 (following page) reports a summary of the multiple regression analysis using forced entry. The table demonstrates that the multiple R was 0.42, resulting in an r^2 of 17.8% of explained variances, which when adjusted for shrinkage error became 9.2% of explained variance.

Examination of the beta weights, T values, and statistical significance indicated that no variable made a significant contribution to explaining this variance, despite the fact that the original amount of explained variances (17.8%) indicated that this was a significant amount of variance. These analyses are presented solely for the purpose of providing an answer to the research question.

Table 4.7: Summary Table of Multiple Regression Analysis Using Forced Entry of Predictors (N = 86)

Variables	R	R²	Adjusted R²	Standardized Beta	t	Sig. t
Model 1						
Gender				-.22	-1.90	.06
Age				.12	1.05	.30
Stage Cancer				-.16	-1.50	.14
Care Role				-.09	-.80	.43
Rec Marital				.06	.54	.59
Comp. Sat.				.17	1.30	.20
Burnout				.26	1.28	.21
Comp. Fat.				-.31	-1.74	.09
	.422	.178	.092			

Given the small amount of adjusted r^2 explained variances (9.2%), a post hoc power analysis was undertaken to determine the actual power of the study. Posting a 0.005 level of significance, an effect size of 0.092, and a sample size of 86, actual power was determined to be 0.46 (Norusis, 2006). It was thus determined that in addition to the lower internal consistency reliability of the dependent variable (CST-A total coping score), the post hoc power analysis showed that it was grossly underpowered. For these reasons, little (if any) confidence should be placed in the results of this analysis.

SUMMARY OF OPEN-ENDED DESCRIPTION OF CAREGIVER EXPERIENCE

Participants in the study were given the option to answer one open-ended question asking them to “describe their caregiver experience.” A total of 75 persons (88.4%) responded to the open-ended question while 11 participants (11.6%) had no comment. Commonalities of themes were identified in the responses and are presented by category below using the respondents’ words when applicable.

OVERALL PERCEPTION OF THE CANCER EXPERIENCE

Participants stated that the experience of a diagnosis of their partner’s cancer and ensuing treatment was “all consuming,” “stressful,” and “physically and emotionally exhausting.” Some participants experienced denial at the time of diagnosis and “read volumes of information on-line to try to find fault with the diagnosis.” Many used

metaphors to describe the experience such as “being in a dark tunnel,” “swimming upstream,” “being caught in a sandstorm and you can’t see,” “being lost in a fog,” “losing control of my life,” and “like a roller coaster ride”. One participant stated that receiving the diagnosis was “an out of body experience.” Another stated “I wouldn’t wish this experience on my worst enemy.” Yet another stated that “I feel I was forced into a club I never imagined” while another viewed it as “a trial that God gives us.” Overall, participants described their feelings about diagnosis and treatment as “alienated,” “fearful,” “confused,” “angry at how this could happen because we lived healthy lifestyles,” “depressed,” “lost,” and “not like the person I was before.” One participant stated she felt “helpless as I learned I could not protect him, make him better, or fix things that hurt him.”

Daily Stressors

According to the majority of respondents, the experience of having a partner with cancer took a toll on the caregiver and family unit on a daily basis. Caregivers reported feeling “overwhelmed by the sudden responsibility of caring for a home and finances solo” and “needing to keep life normal for small children.” Caregivers also reported struggling to keep up with daily responsibilities while overseeing their partner’s needs for transportation to treatment, assistance recovering from surgery, managing side effects of radiation and chemotherapy, supervising pain control, and providing supplemental nutrition.

Many caregivers reported needing to seek assistance from family and friends to handle the logistics of each day during their partner’s active treatment process. Some also turned to professional support from counselors and the use of medications, such as antidepressants, to cope with the daily stress. One participant stated “I put my emotions on the back burner and took an antidepressant so I could get by day to day.” Many stated they could not wait for the treatment process to be over so they could “get back to normal.” Lastly, some participants attended support group meetings of the SPOHNC organization or sought frequent support from the OCF website in order to feel less alone and find like company in those juggling similar demands.

Fears

Participants were astonishingly candid about their fears after their partner received a diagnosis of cancer and during the treatment process. The majority stated they were fearful of “losing my partner.” Others felt fearful of dealing with their partner’s physical disfigurement as a result of surgery.

Many participants also stated that it was difficult to see their partner in pain and this made them feel helpless. Comments included “I couldn’t stand to see my husband in pain” and “I was afraid to go to sleep at night when he was so uncomfortable so I stayed up to make sure he was breathing.”

Feedback about the Medical Establishment

Comments about the medical system varied along the spectrum from extremely positive to very negative. Some participants credited their medical providers with being “professional,” “compassionate,” “informative,” and “concerned.” Less positively, an approximately equal number said they thought “the medical staff did not give comprehensive information” and “did not provide needed resources.” Several participants felt their needs were overlooked by medical and nursing staff while their partner was undergoing treatment, including one who stated “I was disappointed by the medical system and its failure to recognize the needs of the caregiver.”

Positive Outcomes of the Cancer Experience on the Partnership and the Family Unit

The experience of caring for a person with oral cancer was identified by participants as having unexpected positive benefits, including effects on partner-patient relationships such as “cancer made me aware of how much love and caring I have for my spouse,” “it was a privilege to be there for him and to help,” “it was rewarding,” “I felt committed,” and “I learned I want to be beside him every step of the way,” “it was a positive growth experience for both of us as a couple,” and “we accepted this new chapter in our lives and became closer to each other.” One respondent eloquently stated:

I learned that my primary role as caretaker was to be there for him, listen to him, recognize that his complaints and feelings are valid, understand that he is still captain of his body, his life, and his decisions as well as his need to have control over some things in this new environment of illness.

Participants also credited the cancer experience as being a catalyst that strengthened the nuclear and extended family unit. Comments included “the experience drew my family closer together,” “we relied on the prayers of family and friends to get through,” and “I was grateful for the tremendous outpouring of support from friends and I was surprised by who you would expect and who you would not expect to be your most caring friends.”

OUTCOMES OF THE CANCER EXPERIENCE ON THE CAREGIVER

Despite the stress of the cancer experience, many participants credited the experience with changing them for the better. One participant stated she was now aware that “I was capable of change,” another said “my compassion for others is enhanced,” and yet another said “I discovered strengths and weaknesses I didn’t know I had.” Many stated a similar sentiment, in a variety of ways, that the role of caregiver was “terrifying, stressful, draining, and rewarding but I would do it again in a minute if needed.” Others stated they were “proud of themselves for rising to the occasion” and that “living in the new normal is actually better.”

Several participants did identify that the long-term positive benefits of caring for someone with oral cancer were not readily apparent during the active treatment process. The benefit of time and a return to health of their spouse enabled some participants to reflect positively on their perceptions. Others who were currently engaged in active treatment or dealing with a recurrence were less able to identify positive factors and were more focused on their current feelings of stress and exhaustion.

CONCLUSION

Prior to answering the research questions, data were cleaned and median substitution performed. RQ1 was answered using Canonical Correlation analysis and demonstrated that caregivers who care for persons with oral cancer and who reported increased CS, and moderate Burnout, were at risk for and the development of STS symptoms as evidenced by increased CF. STS subscales did explain the biopsychosocial findings on the LSR.

RQ2, using Multiple Regression analysis, showed results that were highly suspect due to an unreliable instrument (CST-A). The small sample size and underpowered status of the analysis did not lead to reliable interpretable data or meaningful results.

The additional open-ended qualitative question yielded abundant and rich subjective data that supported the findings in RQ1 and provided correlation and elaboration on the phenomena of CS, Burnout, and CF as well as a self-reported commentary of stressors that impact the caregiving experience for the person with oral cancer.

Chapter Five will present the major findings and conclusions of the study. The findings will be correlated to the theoretical framework and literature review. Implications for nursing and recommendations for further research will also be discussed.

CHAPTER 5: DISCUSSION, RECOMMENDATIONS, AND CONCLUSIONS

INTRODUCTION

Chapter 5 summarizes the study, reviews major conclusions derived from the data, and discusses findings in the context of the theoretical framework and prior research. The chapter also provides a synopsis of implications for action and recommendations for further research.

SUMMARY OF THE STUDY

Previously, oral cancer was a condition primarily seen in older males. Prevalence rates of oral cancer have been steadily rising, with an estimated 35,720 men and women diagnosed with the disease annually (Horner et al, 2009). An oral cancer diagnosis and the treatment that ensues have a profound impact on patients' biopsychosocial well-being. Undergoing treatment for oral cancer can cause long-term effects for patients such as pain, fatigue, changes in facial appearance, alterations in speech and swallowing, dry mouth, decreased quality of life, emotional distress, and psychological suffering.

Similarly, partners of patients with oral cancer are at risk for experiencing disruption of their biopsychosocial well-being due to the secondary traumatic exposure that results when a loved one is diagnosed with oral cancer. Caregivers share the burden of the treatment process and its sequelae. Meeting the patient's needs on a daily basis may lead to covert and overt distress in the caregiver, including lifestyle disruption, lack of attention to his or her own medical needs, social isolation, economic hardship, familial strain, impaired intimacy, anxiety, and depression (Verdonck-de Leeuw et al., 2007). Thus, oral cancer patients' caregivers may have as much of a need for attention, support, and assistance as the patients themselves.

PURPOSE STATEMENT, AIMS, AND RESEARCH QUESTIONS

The purpose of this study was to explore the existence of Secondary Traumatic Stress (STS) in caregivers of persons with oral cancer, describe the nature of the

experience of STS and its relationship to other variables of interest, and generate substantive contributions to emerging theory.

Specific aims and related research questions of this study were:

1. Determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, Compassion Satisfaction (CS), and Compassion Fatigue (CF) explain a caregiver's biopsychosocial well-being as measured by the Life Status Review (LSR) subscales in a sample of caregivers of persons with oral cancer.
RQ1: To what extent do the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's biopsychosocial well-being as measured by the LSR subscales in a sample of caregivers of persons with oral cancer?
2. Determine the extent to which the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's biopsychosocial well-being as measured by the Coping Skills Test Abridged (CST-A).
RQ2: To what extent do the selected demographic factors of age, gender, marital status, stage of partner's cancer, length of time in caregiving role, CS, and CF explain a caregiver's biopsychosocial well-being as measured by the CST-A?

OVERVIEW OF THE METHODOLOGY

Design, Setting, Sample, Instruments, Human Subjects, Procedure, Data Analysis

A descriptive correlational design was used to conduct this study. The study environments were comprised of an online forum for information and support known as the Oral Cancer Foundation (OCF) and face-to-face meetings of the Support for Persons with Oral Head and Neck Cancer (SPOHNC) group. The population for this study was a non-random volunteer sample (n=86) that met study inclusion criteria: 18 years and older, sufficient English comprehension, and self-identification as caregiver of a person diagnosed with oral cancer. Institutional Review Board (IRB) approval for the project was obtained from The University of Texas Medical Branch (UTMB), and all human rights relevant to the student were protected.

Study packets were distributed to subjects who wished to participate. Packets contained a biodemographic questionnaire aimed at describing the sample and facilitating examination of relationships between the variables of interest and specific caregiver characteristics. Three instruments, the Family Significant Other Quality of Life Scale (FamSoQOL), the Life Status Review (LSR), and the Coping Skills Test Abridged (CST-A), measured caregivers' self-reports of STS symptoms, perceived quality of life, and coping ability. Statistical Social Sciences (SPSS) software was used to analyze the data.

The study identified and described types and strengths of relationships between scores on self-reports of STS symptoms, perceived quality of life, and stress-coping experiences among caregiving partners of persons diagnosed with oral cancer. RQ1 was answered using Canonical Correlation to analyze relationships between two sets of variables. The presence of linear correlation between the variables was established and helped to determine if a relationship existed between the independent and dependent variables. RQ2 was answered using multiple regression analyses with forced entry of the predictors into the equation.

FINDINGS

RQ1: Results indicated that younger caregivers with lower CS scores and higher Burnout and CF scores were more likely to have lower Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts. In contrast, older caregivers with a higher CS score, lower Burnout, and lower CF scores were more likely to have higher Medical status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts.

RQ2: After examination of the beta weights, T values, and statistical significance, no variable was found to have made a significant contribution to explaining the variance (17.8%). The results were not found to be suitable to attribute meaning and were reported solely to provide an answer to the research question. Thus, findings related to this question cannot be analyzed accurately in comparison to previous literature.

Findings Related to the Literature

This study found that the phenomenon of STS existed and was more prevalent in younger caregivers than older caregivers as determined by their scores on the FamSoQOL and LSR inventories and related subscales. Findings in the current study were consistent with those noted by Fletcher et al. (2008), who studied female partners of patients with prostate cancer. Fletcher et al. (2008) noted that younger female partners who had more education and who were working experienced higher levels of depression, morning fatigue, sleep disturbance, higher levels of evening fatigue, had overall lower quality of life scores than their partners with prostate cancer.

Study findings also support those reported by Wagner et al. (2006), who explored quality of life of husbands whose wives had breast cancer; they concluded that husbands screened for an association between quality of life, social support, and coping scored lower with regard to their general health, vitality, and role-emotional and mental health subscales. While one aspect of the Wagner et al. (2006) study aligned with findings from the current study, there was a difference in another area. Findings of the study by Wagner et al. (2006) differ from findings in the current study in that husbands of wives with breast cancer did not score poorly on subscales of specific physical functioning, bodily pain, or social functioning, while some partners of patients with oral cancer did experience deficits in the areas of medical status, health/wellness, and self/social/interpersonal relationships. It is unclear why there is not an association between lower general health and vitality scores, and role-emotional and mental health subscales and impaired physical functioning, bodily pain, or social functioning in the Wagner et al. (2006) study.

Study findings were also compared to studies of patients with oral cancer and their partners as previously described in Chapter Two. Vickery et al. (2002) examined the impact of head and neck cancer and facial disfigurement on quality of life for patients and their partners. Vickery et al. (2002) concluded head and neck patients and their partners were not predisposed to psychological difficulties and lower quality of life due to the experience. Findings from the current study differ from those reported by Vickery et al. (2002) with regard to the propensity for disruption of biopsychosocial well-being and lower quality of life found in some participants. It is proposed that the study by

Vickery focused solely on facial disfigurement as it related to quality of life in head and neck cancer patients and did not address global aspects of the caregiving experience.

Verdonck-de Leeuw et al. (2007) investigated distress in spouses and patients after treatment for head and neck cancer. Mean age of the spousal group (58 years old) was slightly higher than in this study. Health status of patients and spouses as well as coping styles and level of functional and social impairment were measured. Most importantly, caregiver burden was measured using an instrument designed to assess positive and negative reactions to caregiving among partners. The tool was similar to the one used in the current study in that the subscales of the instruments measured the impact of caregiving on disrupted schedules, financial problems, lack of family support, health problems, and the caregiver's self-esteem. Although clinical levels of psychological distress were documented in only 20% of spouses, Verdonck-de Leeuw et al. (2007) noted that spouses reported disrupted schedules from caregiving (31%), financial problems (26%), lack of family support (11%), health problems (31%), and positive self-esteem as a result of caring (32%). Current study findings are most closely aligned with and confirm findings by Verdonck-de Leeuw et al. (2007) in all areas except for positive self-esteem that ensued as a result of caregiving. In the current study, higher levels of satisfaction and enhanced self-esteem due to caring were more pervasive in older caregivers with higher levels of CS and lower levels of CF, and less pervasive in younger caregivers with lower levels of CS and higher levels of CF.

Lastly, findings from this study were compared to a study conducted by Drabe et al. (2008), which examined psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. The study conducted by Drabe et al. (2008) used scales to assess levels of psychological distress and quality of life including physical health, psychological health, social relationships, and environment. Quality of the dyadic relationship between patients and spouses as well as a screen for Axis I psychiatric diagnoses in partners were assessed. Findings revealed that 38.7% of wives were diagnosed with Axis I disorders including substance-related disorders, social phobia, generalized anxiety disorder, hypomania, dysthymia, and major depression. Additionally, 22.6% of wives reported having agoraphobia.

The study by Drabe et al. (2008) stated that although some patients' wives had more Axis I diagnoses than the general population, scores on the quality of life and dyadic satisfaction scale were also high in wives without diagnosed anxiety disorders. Further, wives did not have a significantly decreased quality of life, especially in the physical domain. Wives with diagnosed anxiety disorders had a significantly lower quality of life, especially in the physical domain. The current study findings differ from the results of the Drabe et al. (2008) study. The current study found that younger caregivers with lower CS scores and higher Burnout and CF scores were more likely to have lower Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores on the LSR than their counterparts. This researcher must now consider how participants in the current study might have scored had they been screened for psychiatric morbidities during the course of the study. The study by Drabe et al. (2008) informed this researcher to consider results in other contexts and consider co-factors that may impact and explain findings.

Findings Related to the Theoretical Framework

Underpinning this study was the Constructivist Self-Development Theory (CSDT) (McCann & Pearlman, 1990a), a heuristic theoretical model focused on the interactions between persons and situations, with an additional focus on the positive and negative personal development that occurs as a result of exposure to a traumatic event. CSDT framed the explanation of the phenomenon of STS in caregivers of persons with oral cancer. For the purposes of this study, the major stressor of an oral cancer diagnosis in one's partner and the diagnosis's ensuing consequences on the caregiver, constituted a traumatic event.

DESCRIPTIONS OF ASPECTS OF THE SELF AND THEIR FUNCTIONS AS COMPONENTS OF CSDT

CSDT (McCann & Pearlman, 1990a), views the self as being comprised of attributes that include basic capacities, ego resources, psychological needs that motivate behavior, and cognitive schemas, which are the beliefs and assumptions through which individuals organize and interpret their experiences. Current study findings validated the

assertions of CSDT, demonstrating that disruption of a caregiver's biopsychosocial well-being led to less positive self-esteem manifested as CS, disruption of the ego resources related to meeting one's own psychological needs manifested as CF, and problems establishing mature relationships with others as evidenced by low scores of some participants on the Medical Status, Health/Wellness, and Self/Social/Interpersonal subscales of the LSR. In particular, this researcher found that impairment of the Self/Social/Interpersonal component of the LSR correlated with the facet of CSDT related to disruptions of critical cognitive schemas, which resulted in caregivers having difficulty in maintaining family and intimate relations, spirituality and belief systems, children's health and well-being, communication with friends and family members, and memberships in community organizations.

Self-Capacities

CSDT (McCann & Pearlman, 1990a) posited that self-capacities were vital to maintaining a consistent sense of identity and positive self esteem, and were comprised of the ability to experience both pain and joy without disrupting psychological stability, the ability to enjoy time alone without feeling empty or lonely, the ability to use self-soothing behaviors to calm oneself in the event of emotional disturbance, and the ability to accept constructive criticism and negative feedback without damage to one's self-esteem.

Current study findings revealed a reciprocal relationship between experiencing the joy and pain of being a caregiver and the resulting disruption to psychological well-being that can occur. Younger caregivers with lower CS (less joy) and higher CF (more pain) with more biopsychosocial instability were found to be in stark contrast to the older caregivers who had higher CS (more joy) and lower CF (less pain) and less biopsychosocial instability.

Psychological Needs

According to CSDT, psychological needs are individual in nature and function to set people apart from one another. They also drive behavior and interpersonal relationships. McCann and Pearlman (1990a) identified psychological needs as central to

CSDT, and are the result of inborn, genetic, and environmental factors. Psychological needs include frame of reference, safety, trust/dependency, esteem, interdependence, power, and intimacy. Current study findings support that the environmental factor of day-to-day caregiving for a person with oral cancer did impede caregivers' quest for intimacy in the relationship with their patient partners.

MAJOR ASSUMPTIONS OF CSDT

According to McCann and Pearlman (1990a), major assumptions of CSDT relate to individuals constructing their own realities: the self as the seat of identity, the self developing over time and accommodation, and the coding of traumatic experiences in memory, traumatic disruption of any or all parts of the self, and adaptation to trauma reflecting the interaction between life experiences and the self.

Current study findings fully supported the assumption that, over time, exposure to trauma such as that experienced by the caregiver of a partner with oral cancer became coded in memory and caused disruption to the caregiver's self. Further, the current study supported the notion that exposure to the secondary stress of trauma resulted in decreased positive adaptation to the trauma and negative consequence in the day-to-day interaction between life experience and the self.

Frame of Reference: A Critical Schema

Within CSDT, the schema "Frame of Reference" is superior to all other psychological needs. The schema refers to perspective and meaning used to interpret life events. Persons revert to familiar schemas to process events. In the case of secondary exposure to a partner with oral cancer, the caregiver may not have an existing schema or frame of reference from which to process the event. The event will then become overwhelming and be viewed negatively by the person.

The current study supports the aspect of CSDT related to the chronic nature of negative schemas. Over time, younger caregivers with lower CS scores, higher Burnout scores, and a high degree of CF may develop persistently negative schemas and ignore positive information about the event. A disruptive psychological impact can result and become chronic. On a positive note, some participants, when responding to the open-

ended qualitative question, credited the caregiving experience as assisting them to know they were “capable of change,” and helped one individual to “discover strengths and weaknesses I didn’t know I had.”

CSDT and the Trauma Survivor

In concert with the definition of a traumatic event as outlined in CSDT (McCann & Pearlman, 1990a), a partner’s diagnosis of oral cancer is sudden, unexpected, may exceed an individual’s ability to meet his or her demands, and may disrupt an individual’s frame of reference. Chronic, predictable events are excluded from the definition. A disconnect ensues between the demands of the situation and the individuals’ perceived ability to meet the demands. A schematic titled “STS Prevention Model” depicts a synopsis of study findings in Figure 5.1 (following page).

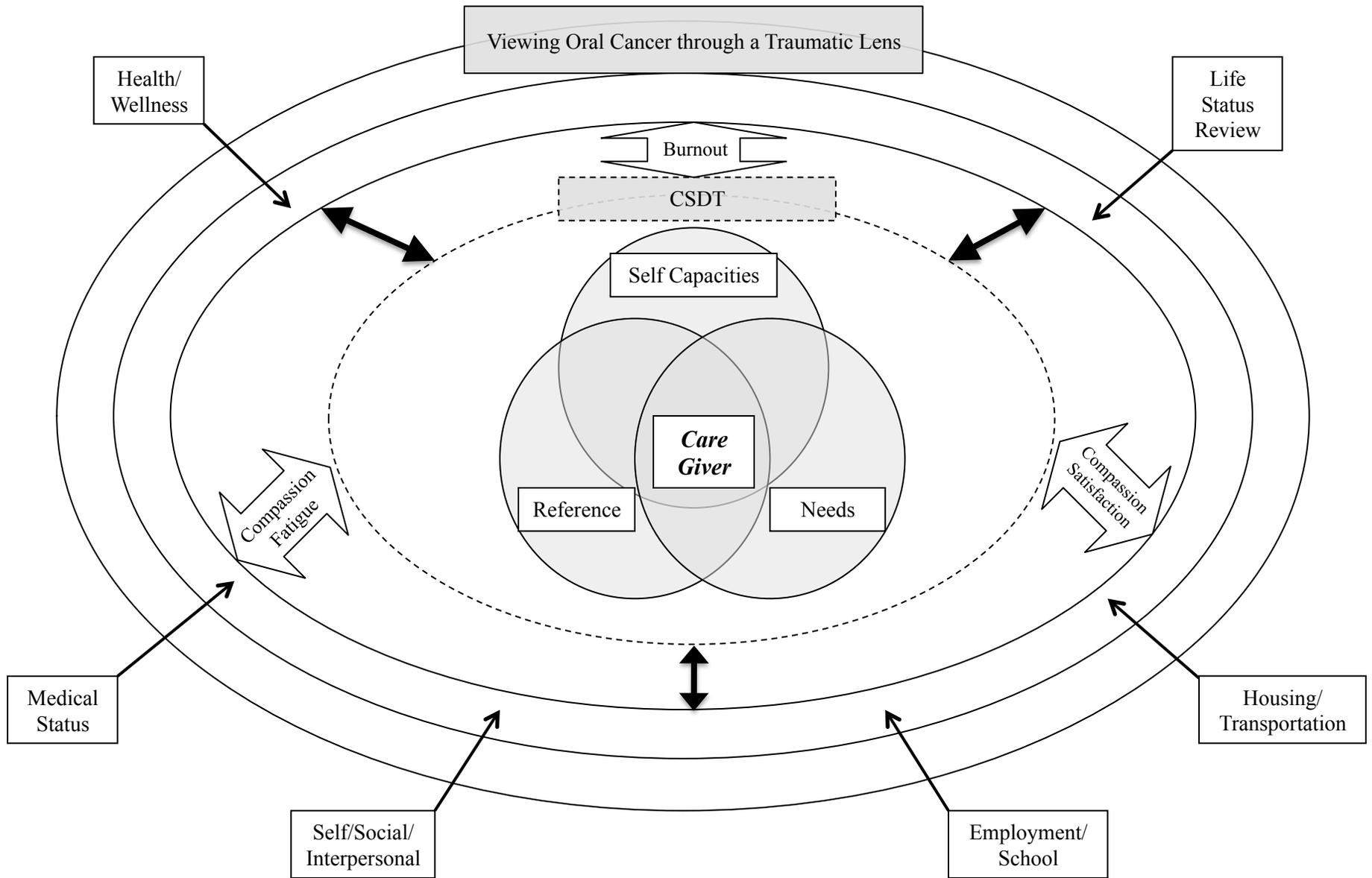
Current study findings fully supported likening the experience of being a caregiver of a person with oral cancer to that of being a victim of a traumatic event, which may result in disordered day-to-day functioning consistent with sequelae of STS. Additionally, as dictated by the responses to the open-ended question, meeting the caregiving demands of a partner with oral cancer can be “all consuming,” “stressful,” “like being in a dark tunnel,” and “losing control of my life.” One participant noted that, “I put my emotions on the backburner and took an antidepressant so I could get by day-to-day.”

POST-TRAUMA RESPONSE PATTERNS

Emotional Response Patterns

Following exposure to a traumatic event, common emotional response patterns include fear, anxiety, depression, decreased self-esteem or identity problems, and anger. Current study findings supported “fear of recurrence” as the primary concern expressed by caregivers, ahead of all other concerns related to their partner’s experience with oral cancer.

Figure 5.1: Secondary Traumatic Stress Prevention Model



Cognitive Response Patterns

Survivors of trauma are susceptible to perceptual disturbances, flashbacks about the event, and feelings of reliving the event. Findings from this study, and in particular on the use of the FamSoQOL to measure for risk of STS symptoms, found this response pattern to be prevalent in younger caregivers with a low level of CS, high degree of burnout, and high amount of CF.

Biological Response Patterns

Physiological disturbances associated with post-traumatic stress of a primary or secondary nature are characterized by hyper-arousal and somatic disturbances such as generalized anxiety to a range of somatic complaints, which result in an increase in the number of health problems in trauma survivors (McCann & Pearlman, 1990a).

Current study findings correlated this occurrence to younger caregivers with STS who were noted to report lower Medical Status and Health/Wellness. Conversely, older caregivers who experienced fewer symptoms of STS had higher Medical Status and Health/Wellness scores.

Behavioral Response Patterns

Survivors of trauma may be prone to anger and antisocial behaviors, suffer from serious depression or exhibit suicidal tendencies, engage in substance overuse, and demonstrate impaired social functioning including withdrawal and isolation (McCann & Pearlman, 1990a). Participants in the current study were screened for history of civil, family, or criminal problems and probation status. They were also screened for a history of alcohol and substance use. Study findings did not corroborate this aspect of CS—participants did not exhibit positive scores in any of the areas mentioned above.

Interpersonal Response Patterns

Persons who experience trauma have distinct difficulties in the areas of interpersonal relationships. Sexual dysfunction is common, as is decreased trust, marital discord, and skewed familial relationships.

Current study findings validated that younger caregivers with lower CS, higher Burnout, and higher CF scores have lower Self/Social/Interpersonal scores than their counterparts. Older caregivers with higher CS, lower Burnout, and lower CF measurements have higher Self/Social/Interpersonal scores. The current study did not screen for problems in the areas of family and intimate relations, spirituality/belief systems, children's health and well-being, friend and family communication, and membership in organizations such as clubs and religious groups. Decreased trust and marital discord were not specifically assessed.

In summary, no prior studies of oral cancer caregivers were found that attempted to view the caregiving experience through the lens of a traumatic event or to correlate the caregiving experience with the development of STS. Utilizing CSDT in the current study has served to fill the void, and the results may be seminal and illuminating.

LIMITATIONS

This study had some inherent boundaries that can be considered limiting factors. Data collection for this study lasted seven months. It is possible that those who did not participate may have been unable to attend a support group or to access online support services to learn that the study was available. The data collection method did not allow for identification of caregivers choosing not to participate or their reasons for non-participation. Findings may be applied only to caregivers of persons with oral cancer and to those who use support services offered by the OCF and the SPOHNC organization. Due to limitations of the recruitment strategies used, no study enrollment opportunities were provided to oral cancer caregivers who were not members of or participants in the aforementioned support groups or their online services. This limitation may have also skewed the study findings; therefore, generalization to other groups is not recommended. Study participants qualified themselves for enrollment by responding to study announcements and determining that they were a partner of and caregiver for a person with oral cancer.

There were also some limitations to the size and demographic characteristics of the sample. Limitations included a small sample size (n=86) comprised predominantly of females (84.9%) and whites (95.3%). The small sample size subjects the study to a

possible lack of generalizability. A sample comprised primarily of one gender may not have captured the experience of male caregivers. Most of the participants were married spouses (76.7%) of oral cancer patients. The study was not able to fully report the experience of an unmarried domestic partner or partner who did not live in the same location to share the day-to-day cost of living with the patient. While the age of participants ranged from 26 to 81 years, the average age was 54.7 years. The study may have benefited from a more even distribution of ages across the lifespan. Most participants (59.3%) had a college degree or higher. This research asserts that those persons may have been more likely to be interested in the research process due to their educational backgrounds. The study may have been more inclusive if it had included more participants with a maximum educational level of high school. Lastly, the majority of partners (63.9%) cared for a patient with Stage I-III oral cancer. The study may have been more complete had it encompassed partners who cared for patients with advanced Stage IV oral cancer.

Another limitation may have been that participants in this study were not screened for co-existent Axis I psychiatric disorders. In retrospect, and after analyzing another study of partners of patients with oral cancer (Drabe et al., 2008), it may have been prudent to assess caregivers for co-existent psychiatric conditions that may have affected symptoms of STS and lower Medical Status, Health/Wellness, Financial Situation, Housing/Transportation, Employment/School, and Self/Social/ Interpersonal scores.

The final limitation of this study was the use of the CST-A tool in an attempt to measure coping in caregivers. Despite cleaning the data and performing median substitution prior to Multiple Regression analysis, results were highly suspect due to the unreliable nature of the instrument, small sample size, and underpowered status of the analysis. Thus, the answer to RQ2 was not interpretable in a meaningful way.

STRENGTHS

Strengths of the study included recruitment of a sample of participants who were willing and eager to share their experience with the researcher. The researcher was able to demonstrate that oral cancer patients' caregivers who reported increased CS and moderate Burnout were at-risk for the development of STS symptoms as evidenced by

increased CFR. The STS subscales did adequately explain the biopsychosocial findings on the LSR.

UNEXPECTED FINDINGS

The single most unexpected finding of the study was the richness of the data and commonality of themes obtained from asking participants to answer one open-ended question: to describe their caregiving experience. The majority of participants (88.4%) answered the question, and many attached additional sheets of paper with stories and lengthy commentary. The outpouring of emotion that ensued and the commonality of the responses truly surprised this researcher.

Rich and abundant themes emerged from the responses to the open-ended questions. Themes included “overall perception of the cancer experience,” “daily stressors,” “fears,” “feedback about the medical establishment,” “positive outcomes of the cancer experience on the partnership and the family unit,” and “outcomes of the cancer experience on the caregiver.” The data obtained may serve as the basis for an article or continued study of caregivers using a qualitative methodology.

CONCLUSIONS

Implications for Action

Findings from this study contribute valuable information to the literature on STS in partners of patients with oral cancer. This study supported the need for formal assessment and support of oral cancer patients’ partners who experience biopsychosocial stress or disruption of their well-being during and after patients undergo treatment. This researcher recommends that study findings and recommendations be shared with medical and nursing professionals directly involved with the care of patients undergoing treatment for oral cancer. Creation and implementation of on-line and face-to-face forums for oral cancer caregivers dedicated to the topic of STS in caregivers is recommended. Lastly, findings and recommendations should be shared with members of OCF and SPOHNC.

RECOMMENDATIONS FOR FURTHER RESEARCH

There are several recommendations for future studies. The first recommendation is to replicate the study using a larger sample size with more diverse demographic characteristics, including more men and non-spousal partners.

A second recommendation is to conduct an intervention over time, such as providing structured support sessions for partners, and measuring their levels of CS, CF, and coping before and after the intervention. Additionally, it is recommended the study is replicated with two distinct sample groups consisting of caregivers less than 55 years old and greater than 55 years old, and to compare the results. This recommendation is based on findings in this study that noted younger caregivers who had lower CS, higher Burnout, and higher CF scores were at higher risk for developing STS and impairment of their biopsychosocial well-being (LSR subscales). Conversely, older caregivers with higher CF, lower Burnout, and lower CF scores were at lower risk of developing STS and impairment of their biopsychosocial well-being (LSR subscales).

The third recommendation is that subsequent studies should use a tool to measure coping in partners of patients with oral cancer. Developing a reliable and valid tool would enhance the findings and provide more substantive data about positive and negative coping in partners.

The fourth recommendation is that the study should be replicated with the inclusion of screening partners for Axis I psychiatric disorders. This would provide a comparative analysis of the presence of a disorder and the incidence of STS and low scores on the LSR.

Lastly, this researcher recommends conducting a qualitative study on lived experience of being a caregiver of a person with oral cancer. The richness of the replies to the open-ended question included in the study, and the clear emergence of themes derived therein, supports further study using qualitative methodology. Some participants referenced the oral cancer experience as a catalyst that strengthened their nuclear and extended family unit. Exploration of this transformative occurrence may uncover positive insight that could be helpful in assisting other caregivers.

CONCLUDING REMARKS

This study provided information on the occurrence of STS in caregivers of persons with oral cancer and the sequelae of the experience on many facets of their lives. While the study was not able to fully analyze caregivers' ability to cope, the data generated were significant and substantive.

This study was the only one to this researcher's knowledge to observe caregiving for a patient with oral cancer through the lens of a traumatic experience. Further, the study examined the existence of STS in caregivers of persons with oral cancer, described the nature of the experience, and correlated the secondary traumatic effects with other factors including caregivers' daily life status. This study contributed valuable information on this understudied topic and may lead to further research studies.

APPENDIX A: SUBJECT CONSENT FORM

SUBJECT CONSENT FORM

You are being asked to participate in a research project entitled, “Secondary Traumatic Stress Experiences of Caregivers of Survivors of Oral Cancer: A Descriptive Study”. This is a dissertation study being conducted by Ms. Kimberly Crocker Crowther MS, RN, CS, FNP, who is a nursing doctoral student in the Graduate School of Biomedical Sciences (GSBS) at the University of Texas Medical Branch (UTMB). She is conducting this study under the supervision of Dr. Judith C. Drew, Ph.D., RN, Associate Professor in the School of Nursing and GSBS.

PURPOSE OF THE STUDY

The purpose of this study is to explore and describe the secondary stress experiences of caregivers for partners with oral cancer so that the findings of the study can contribute to the development of stress management programs for caregivers. The researcher wants to learn about the stress experiences of caregivers, how caregivers recognize and manage their stress, and what resources caregivers want to engage in to help them cope with the stress. Although there have been several studies conducted over the years that have asked caregivers to discuss how they deal with their partners’ cancer diagnoses, few have explored with caregivers how the diagnosis of oral cancer in their partner traumatizes them, personally.

You are being asked to participate in this study because you, through your voluntary use of the Oral Cancer Foundation’s (OCF) website, have identified yourself as a caregiver for a partner with oral cancer. Aspects of your experiences as a caregiver will be explored through the use of an on-line survey that is confidential and requires approximately 30 minutes to complete. The survey procedure asks you to click on fixed responses you can choose to give to statements about the feelings you have as a caregiver. You will also be asked to provide information about your age, educational level, familiarity with the use of computers, and how long you have been caregiving. The surveys will be cleared of any identifying information by the webmaster prior to the data being reviewed and analyzed by Kimberly Crocker Crowther and her supervising professor, Dr. Judith C. Drew.

PROCEDURES

1. You will find the study’s description and consent form by accessing the Oral Cancer Foundation’s (OCF) website online and by clicking on the study link. There you will be given the opportunity to read about the study and consider your voluntary participation. If you wish to participate you will be able to access the survey through a confidential link after reading the consent statement and selecting to proceed by clicking the icon for the study’s survey. Selecting to proceed with the survey and actually responding to the questions then constitutes your giving your consent to participate. If for any reason you become unable to

comfortably participate in or complete the survey and background questions, you may quit at any time without any penalty or prejudice of any kind.

2. The background information you will be asked to complete is for purposes of describing the average ages, educational levels, and computer competencies of the study's participants as well as how they know the person with oral cancer. You will also be given the opportunity to offer your employment status, marital status, and how often you access the OCF website. Both the background information and the survey responses will be coded so that no names of those submitting responses can be identified. In addition to coding the response sets, findings from this study will be reported in the aggregate, meaning that the conclusions about the data will be presented as coming from the group as a whole and not any one individual.
3. The code number you are assigned for purposes of confidentiality will be recorded only by the researcher who will keep the list of code numbers in a locked file drawer in her office.
4. Your participation in this study will not affect your membership in the Oral Cancer Foundation. Any information gained in this study that could benefit you in your role as a caregiver for a partner with oral cancer will be made available to you at the conclusion of the study.

NUMBER OF SUBJECTS PARTICIPATING

The anticipated number of subjects involved in this study will be 300 community-dwelling adult men and women who care for a partner with oral cancer.

RISKS OF PARTICIPATION

The potential risks from participation in this study are minimal but include psychological fatigue from exploring your stress experiences and the possible loss of confidentiality, although safeguards have been built into the online survey procedures.

BENEFITS TO THE SUBJECT

There are no direct benefits to you for your participation in this study, however the survey questions and the responses you provide may offer you an opportunity to enhance your understanding of the stressors and feelings you experience as a caregiver of a person with oral cancer.

ALTERNATIVE TREATMENT

The alternative is not to participate in the study.

REIMBURSEMENT FOR EXPENSES

You will not be reimbursed for your participation in this study.

COSTS OF PARTICIPATION

There will be no cost to me for my participation in this study.

USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provide safeguards for privacy, security, and authorized access of your records. All of the interview and questionnaire information collected from you during this study are collected only because you are in this study. The study results will be shared with you in summary form and will be published only as aggregate data, without identifying you in any way, in professional journals. Your records may be reviewed in order to meet federal or state regulations. Reviewers may include, for example, representatives of the UTMB Institutional Review Board. This authorization for the use and disclosure of your information as described above expires upon the conclusion of the research study.

REQUIRED CLAUSES

1. Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.
2. The principal and alternate procedures, including the experimental procedures in this project, have been identified and explained to you in language that you understood.
3. The risks and discomforts from the procedures have been explained to you.
4. The expected benefits from the procedures have been explained to you.
5. An offer has been made to answer any questions that you may have about these procedures. If you have any questions before, during or after the study, or if you need to report a research related injury, you may contact Ms. Kimberly Crocker Crowther at 508-785-1708 at any time, or contact Dr. Judith Drew at 409-772-8227, page her at 409-643-3682, or e-mail her at jdrew@utmb.edu.
6. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without prejudice and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. All new findings during the course of this research that may influence your desire to continue or not to continue to participate in this study will be provided to you as such information becomes available.

7. If you are injured or have an adverse reaction because of this research, you should immediately contact one of the personnel listed in Clause #5 above. Emergency medical treatment will be available at The University of Texas Medical Branch hospitals at no cost to you. No additional compensation will be provided. Agreeing to this does not mean that you are giving up any legal rights that you may have.
8. If you have any questions regarding your rights as a subject participating in this study, you may contact Dr. Wayne R. Patterson, Institutional Review Board Director, at (409) 772-3481.
9. You have a right to privacy, and all information that is obtained in connection with this study and that can be identified with you will remain confidential as far as possible within state and federal law. However, information gained from this study that can be identified with you may be released to no one other than the investigators, your personal physician, and the UTMB Institutional Review Board. The results of this study may be published in scientific journals without identifying you by name.

The purpose of this study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Ms. Kimberly Crocker Crowther at 508-785-1708 or Dr. Judith Drew at 409-772-8227. You will be given a copy of the consent form you have signed.

Date

Signature of Subject

Signature of Witness

Signature of Authorized Representative
(if applicable)

Description of Representative's Authority to Act for Subject (if applicable)

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his/her authorized representatives.

Date

Signature of Person Obtaining Consent

APPENDIX B: DEMOGRAPHIC DATA QUESTIONNAIRE

Date: _____ Study ID: _____

1. What is your gender: Male ____ Female ____

2. What is your date of birth: _____

3. What is your ethnicity: (please check your best response)

- White, non-Hispanic _____
- Black, non-Hispanic _____
- Hispanic _____
- American Indian _____
- Alaskan Native _____
- Asian or Pacific Islander _____
- Other (please specify) _____
- Unknown _____

4. What is your marital status:

- Single, never married _____
- Married _____
- Divorced _____
- Widowed _____
- Other _____

5. What educational degrees have you attained:

6. How many hours a week do you work outside of the home in addition to your caregiving responsibilities:

- 0 _____
- 8 – 16 _____
- 17 – 24 _____
- 25 – 32 _____
- 33 – 40 _____
- Other (specify) _____

7. What is your area of employment:

Please specify _____

8. What is your relationship to the person you provide care and support for who has been diagnosed with oral cancer?

Spouse _____
Unmarried Partner living together _____
Unmarried partner not living together _____
Relative _____
Friend _____
Significant Other _____
Other (Please Name) _____

9. If you know this information, what is the diagnostic type(s) and staging of the oral cancer that the person you care for has/had?

10. Is the person you provide care and support for who has been diagnosed with oral cancer currently undergoing active treatment (excluding follow-up care)?

Yes____
No_____

11. Is this person's cancer in remission?

Yes_____
No_____

12. Has this person had any recurrences or new primary site cancers since the initial diagnosis of oral cancer?

Yes_____
No_____

13. If yes, please indicate how long after initial diagnosis that the recurrence was discovered:

0-5 months_____
6 months-1year _____
1-2 years_____
2-3 years_____
3-4 years_____
4-5 years_____
5-6 years_____
6-7 years_____
7-8 years_____

- 8-9 years_____
- 9-10 years____
- 10 years or more_____

14. Please indicate the type(s) of initial cancer treatment(s) that the person you care for received when first diagnosed with oral cancer:

- No treatment_____
- Radiation only_____
- Radiation and chemotherapy_____
- Surgery only_____
- Surgery and radiation____
- Surgery and radiation and chemotherapy_____

15. How long was the treatment process from start to completion? _____

16. How long have you been in a caregiving role?

- 0-5 months_____
- 6 months-1year _____
- 1-2 years_____
- 2-3 years_____
- 3-4 years_____
- 4-5 years_____
- 5-6 years_____
- 6-7 years_____
- 7-8 years_____
- 8-9 years_____
- 9-10 years____
- 10 years or more_____

17. Please indicate the setting that best describes the location where the person you care for with oral cancer received treatment.

- Community hospital_____
- Major medical center without head and neck cancer department_____
- Major medical center with head and neck cancer department____
- Clinic not affiliated with a major medical center_____

18. How often did/do you accompany the person you care for with oral cancer to appointments or treatments?

- Never____
- Occasionally_____
- Often_____
- Always_____

19. Are you a member of the Oral Cancer Foundation (OCF)?

Yes _____
No _____

20. Are you a member of SPOHNC?

Yes _____
No _____

21. If you are a member of OCF, how often do you visit the Survivors' Forum of the OCF website?

2 or more times per day _____ Once a day _____
Once a week _____ Once a month _____ Other (specify) _____

22. How many years of experience do you have using a computer:

_____ months
_____ years

25. Do you consider the OCF website to be a source of support for you?

Yes _____
No _____

26. If you are a member of SPOHNC, how often do you attend support group meetings?

Monthly_____

Less than six times per year_____

More than six times per year but not monthly_____

Occasionally_____

Rarely_____

Never_____

26. Do you consider SPOHNC to be a source of support for you?

Yes _____
No _____

27. What do you worry most about the person you care for who has been diagnosed with oral cancer?

Recurrence_____

Undergoing surgery_____

Dealing with complications of radiation and/or chemotherapy_____

Maintaining emotional health_____

Other (please state)_____

28. Please feel free to describe what the experience of caring for a person diagnosed with oral cancer has been like for you:

Thank you for your time in completing this demographic questionnaire.

**APPENDIX C: FAMILY/SIGNIFICANT OTHER QUALITY OF LIFE
(FAMSOQOL) INSTRUMENT; COMPASSION SATISFACTION,
BURNOUT, AND COMPASSION FATIGUE SUBSCALES**

Family/Significant Other Quality of Life (FamSoQOL) Instrument

Helping and caring for someone with a serious or life threatening condition puts you in direct contact with that person's life-threatening illness experience. As you have probably experienced, your compassion for the person you are helping has both positive and negative aspects. We would like to ask you questions about your experiences, both positive and negative, as a helper/caregiver. Consider each of the following questions about you and your current situation. Select the number that honestly reflects how frequently you experienced these characteristics **in the last 30 days**. Write the number you select for each question on the line next to the item number.

0=Never 1=Rarely 2=A Few Times 3=Somewhat Often 4=Often 5=Very Often

- ___ 1. I am happy.
- ___ 2. I am preoccupied with the person I help.
- ___ 3. I get satisfaction from being able to help my family member/partner/friend.
- ___ 4. I feel connected to others.
- ___ 5. I jump or am startled by unexpected sounds.
- ___ 6. I feel invigorated after helping my family member/partner/friend.
- ___ 7. I find it difficult to separate my personal life from my life as a helper/caregiver.
- ___ 8. I am losing sleep over the traumatic experiences of my family member/partner/friend.
- ___ 9. I think I may have been "infected" by the traumatic stress of the person I help/care for.
- ___ 10. I feel trapped by my role as a helper/caregiver.
- ___ 11. Because of my helping/caregiving, I have felt "on edge" about various things.
- ___ 12. I like my work as a helper/caregiver.
- ___ 13. I feel depressed as a result of my role as a helper/caregiver.
- ___ 14. I feel as though I am experiencing the trauma of the person I help/care for.
- ___ 15. I have beliefs that sustain me.
- ___ 16. I am pleased with how I am able to keep up with new treatment information and helping strategies.
- ___ 17. I am the person I always wanted to be.
- ___ 18. My role as a helper/caregiver makes me feel satisfied.
- ___ 19. Because of my role as a helper/caregiver, I feel exhausted.
- ___ 20. I have happy thoughts and feelings for the person I care for and how I could help him/her more.
- ___ 21. I feel overwhelmed by the amount of helping/caregiving I have to deal with on a daily basis.
- ___ 22. I believe I can make a difference through my helping/caregiving.
- ___ 23. I avoid certain activities or situations because they remind me of frightening experiences of the person I help provide care for.
- ___ 24. I am proud of what I can do to help.
- ___ 25. As a result of my helping/caregiving, I have intrusive/frightening thoughts.
- ___ 26. I feel "bogged down by the healthcare system.
- ___ 27. I have thoughts that I am a "success" as a helper/caregiver.
- ___ 28. I can't recall important parts of my time with the person I help care for.
- ___ 29. I am a very sensitive person.
- ___ 30. I am happy that I chose to be a helper/caregiver.

APPENDIX D: LIFE STATUS REVIEW QUESTIONNAIRE

This questionnaire asks you to identify and appraise how each of the eight areas of your life has changed since the person you help or care for was diagnosed with oral cancer. Be sure to mark the box alongside each item that best represents the way things are for you now in comparison to they were before. The response sets allow for positive, negative, and neutral appraisals that range from “worse” to “great” with “an issue”, “fine”, and “good” as choices as well.

Area of Life	Worse -2	An Issue -1	Fine 0	Good +1	Great +2
Medical Status					
health					
medication					
hospitalization					
Health/Wellness					
exercise					
rest/relaxation					
nutrition/access to food					
Financial Situation					
debts					
income					
SSI/Disability/Assistance					
Housing/Transportation					
apartment/home					
access to shops, services, environmental conditions					
access to transportation					
<p>Compared to last time, would you say your overall psychological well-being is; better? worse? about the same? (e.g. 100% better, 100% worse, about the same, 50% better, 50% worse?)</p> <p>-100% 50 0 50 100%</p> <p>worse the same better</p>					

Area of Life	Worse -2	An Issue -1	Fine 0	Good +1	Great +2
Employment/School					
stability					
working conditions					
relationships at work/school					
Legal/Criminal					
civil					
family					
criminal					
parole/probation					
Alcohol/Substance Use					
other's complaining					
arrested/hospitalized					
problems related to use					
Self/Social/Interpersonal					
family relations					
intimate relations					
spirituality/belief systems					
children's health & wellbeing					
friend/family communication					
organizations (clubs, religious group...)					
<p>How satisfied are you overall with your life?</p> <p>-100% 50 0 50 100%</p> <p>not at all neither satisfied completely</p> <p>satisfied nor dissatisfied satisfied</p>					

APPENDIX E: COPING SKILLS TEST—ABRIDGED

<i>Instructions: Read each statement carefully. Mark one box to the right of every statement that best represents the degree to which the statement applies to you. In order for the test to be valid, all the questions must be answered. Thank you.</i>	Almost never	Rarely	Sometimes	Quite often	Most of the time
1. I get easily discouraged.					
2. When the situation changes, I adjust my plans.					
3. When I am stressed, my mind goes blank.					
4. I know where to find the information I need.					
5. I trust my judgment.					
6. I accept my mistakes as a learning opportunity.					
7. When something I wanted doesn't work out, I get rapidly back on my feet.					
8. When a situation requires a change of plan or strategy, I feel confused or anxious.					
9. When I fail, I am devastated for a long time.					
10. I am able to apply what I have learned to new situations.					

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APPENDIX F: COVER LETTER TO ACCOMPANY MAILED SURVEYS/QUESTIONNAIRES

September 2006

Dear SPOHNC or OCF Participant:

Thank you for your interest in this study about secondary stress and coping in partners and caregivers of persons with oral cancer. You have this packet because you either requested that I send it to you or you picked it up following a meeting of a SPOHNC group. I am Kimberly Crocker Crowther and this is my dissertation research. I am a nurse practitioner and I hope to learn about any types of stress you experience and how other aspects of your life are affected now that someone you care about has oral cancer. The professor at the University of Texas Medical Branch (UTMB) who supervises my research is Dr. Judith Drew. If you want to call her about this study, or me, she can be reached at 409-772-8227. She can also be reached by e-mail at jdrew@utmb.edu.

If you think you want to participate in this study, there are several pages of questions you will need to answer. It should take you about 40 minutes to answer everything. You do not have to answer every question at one sitting. You can take breaks or do some today and complete the rest tomorrow. Before you get started and even after you begin, call me if you have anything you want me to clarify or explain. If you would rather that I read the questions to you and record your answers by phone, I can help you with that. Feel free to call me about any of this. My number is 508-785-1708. Leave a voice mail message for me with your name and phone number and I will call you back if I'm not right there to take your call. You can also e-mail me at Kimcrocfnp@comcast.net and I will reply as soon as I can.

Enclosed with this letter and the questionnaires is a postage-paid envelope addressed to me. Please use it to send all of your completely answered questionnaires back to me. To protect your identity I am asking you not to write your name anywhere on the questionnaires or on the envelope you will use to return them to me. That way, the information I learn from all 300 persons who participate in this study cannot be traced back to any one person. While your input is extremely important and valuable, it is my job to protect your identity so that no one else can find out that you participated or what you said if you did participate. Even if I talk to you by phone, I will not put your name on any of the papers that I read from or write on. Findings from this study will be reported in the aggregate, meaning that the conclusions about the data will be presented as coming from the group as a whole and not any one individual.

Remember, your participation in this study is voluntary. That means that even though you have this packet of questionnaires, you are not obligated to complete them or send them back to me. If you do want to participate, please go ahead and answer all the questions and mail the papers back

to me in the addressed, postage-paid envelope provided. Doing this tells me you have consented to participate. You should keep this letter for your records.

If you would like to receive a summary of the study at its completion, please let me know that by leaving me a voice mail message or by sending me an e-mail at the contact numbers I provided earlier in this letter. We expect that the findings will help guide the development of more specific types of support for those of us facing the challenges of knowing and caring for someone special who has oral cancer.

Thank you very much.

Sincerely yours,

Kimberly Crocker Crowther

APPENDIX G: RECRUITMENT SCRIPT AND POSTING FLYER

FACE-TO-FACE SCRIPT FOR SUBJECT RECRUITMENT

Good evening, my name is Kimberly Crocker Crowther. I am a SPOHNC member and a doctoral nursing student and researcher in the Graduate School of Biomedical Sciences at the University of Texas Medical Branch in Galveston, Texas. I am conducting a study to describe the types of things that cause you to feel stress since the person you help or care for was diagnosed with oral cancer. I am conducting this study under the direction of Dr. Judith C. Drew, RN, Ph.D., Professor in the School of Nursing.

The purpose of this study is to identify and describe the stress you as the caregiver, and not the person with oral cancer, may feel which is sometimes called “Secondary Traumatic Stress.” The written surveys you complete for this study will ask how you recognize and manage your stress, how your life has changed since your partner’s cancer diagnosis, and what things affect the quality of your life as a caregiver. I am seeking to gain insight into what the experience of being a caregiver of a person with oral cancer is like for you.

Each survey will be coded so the data can be entered into a statistical analysis program. Your name will never appear on any study questionnaires. The findings of this study will be reported in the aggregate so that no one person’s data can be identified. The surveys/questionnaires and demographic data you complete and return to me in a postage-paid return envelope will be retained in a locked file cabinet in my home-office. Learning about your experience as a caregiver of a person with oral cancer may help in the development of more effective support services for you, your partner, and your family.

The University of Texas Medical Branch's Institutional Review Board must approve this study before it can be conducted. Their guidelines will be followed at all times. If you want to learn more about this study or discuss how you might participate, please let me know. You can call or e-mail me about your interest in participating. I can be reached at:

Phone: 508-785-1708

E-mail: Kimcrocfnp@comcast.net

Thank you for your attention. Please take my business card in case you wish to call and get more information.

FLYER FOR POSTING

VOLUNTEERS NEEDED FOR RESEARCH STUDY

I am Kimberly Crocker Crowther, a UTMB doctoral nursing student and this study is my dissertation. The purpose of this study is to identify and describe the challenges that face helpers and caregivers of persons with oral cancer. If you or someone you know helps or cares for a person with oral cancer, you may want to read more of the following information. The study involves answering surveys/questionnaires about stressful aspects of your life, how your life has changed since your family member's/friend's/partner's cancer diagnosis, and what things affect the quality of your life as a partner/caregiver. The study takes approximately 40 minutes to complete. You do not have to meet with anyone. You can complete these surveys in the privacy of your home and mail them back to me anonymously in a postage-paid envelope. The University of Texas Medical Branch's Institutional Review Board must approve this study before it can be conducted. Their guidelines will be followed at all times. If you want to know more about this study or inquire about participating in it, please call or e-mail me. Please take one of these fliers or my card that has my contact information and e-mail address. I can be reached at:

Phone: 508-785-1708

E-mail: Kimcrocfnp@comcast.net

Thank you.

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VITA

Kimberly Crocker Crowther was born on October 2, 1964 in Newton, Massachusetts to Jeannette and Peter Ligor. She graduated from Ursuline Academy in 1982. She was married to Julian H. Crocker from 1989-1999 and has two sons, J. Cary Crocker and Brett Peter Hutchins Crocker. She married Dr. David Crowther in 2004 and has one stepdaughter, Siobhan Elizabeth Crowther.

Kimberly first became a registered nurse in 1984 after earning a diploma from Newton-Wellesley Hospital School of Nursing. Immediately upon graduation, she commenced study toward her BSN at Boston College while working as a registered nurse. Over the next several years, she worked in the Boston area predominantly in acute care including medical surgical, oncology, and intensive care units during which time she held first line management positions. Kimberly earned a Master of Science in Nursing with a specialization in Community Health Nursing in 1995 and earned certified as a Family Nurse Practitioner. She has worked in both private and public health as an expanded role practitioner. As a nurse educator since 1987, Kimberly has taught at the ADN, BSN, and MSN levels in the classroom, laboratory, and clinical settings.

Kimberly ventured from the Northeast to the South in 1999 to attend the doctoral program at UTMB. She worked as a graduate assistant while living in Galveston from 1999-2001. Upon completion of her doctoral course work, Kimberly returned to the Boston area and to teaching and practicing nursing while completing her doctoral degree. Currently, Kimberly holds the position of Director of the Practical and Associate Degree Nursing Programs at Massachusetts Bay Community College in Framingham, Massachusetts.

She is a member of the following professional organizations and honor societies: Sigma Theta Tau International Honor Society of Nursing-Eta Omega Chapter, Phi Kappa Phi, Association of College Honor Societies, UTMB Chapter, National League for Nursing Accreditation Commission, Massachusetts Board of Registration in Nursing, and the Massachusetts/Rhode Island League of Nursing.

Education

Diploma, 1984, Newton-Wellesley Hospital School of Nursing, Newton, Massachusetts
 B.S.N., 1987, Boston College, Chestnut Hill, Massachusetts
 M.S., 1995, University of Massachusetts Lowell, Lowell, Massachusetts