Electronic Thesis and Dissertation Repository

10-25-2013 12:00 AM

Measuring the sixth vital sign: A descriptive analysis of distress in individuals with head and neck cancer and their caregivers

Catherine C. Bornbaum
The University of Western Ontario

Supervisor
Dr. Philip C. Doyle
The University of Western Ontario

MEASURING THE SIXTH VITAL SIGN: A DESCRIPTIVE ANALYSIS OF
DISTRESS IN INDIVIDUALS WITH HEAD AND NECK CANCER AND THEIR
CAREGIVERS

(Thesis format: Integrated Articles)

by

Catherine C. Bornbaum

Graduate Program in
Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

Abstract

Introduction: Distress has become so problematic in oncology that it has been recognized as the "sixth vital sign" implying that distress monitoring should occur as routinely as the monitoring of one's temperature or blood pressure. The research reported herein investigated the impact of head and neck cancer on levels of distress, commonly reported problems, and perceptions of quality of life in individuals with head and neck cancer and their caregivers.

Method: Two distinct studies were conducted; the first explored the patient experience of distress and quality of life while the second assessed the caregiver experience of these same constructs. A prospective, longitudinal research design was employed for the patient study while a cross-sectional design was utilized for the caregiver study. Measurement instruments included: (1) a demographic survey; (2) the Distress Thermometer and Problem Checklist; (3) the EORTC Quality of Life questionnaire (EORTC-QLQ-C30), and (4) the EORTC Head and Neck module (EORTC-QLQ-H&N35), to evaluate quality of life in individuals with head and neck cancer; and (5) the Caregiver Quality of Life-Cancer Scale (CQOLC) to assess quality of life in caregivers.

Results: Data indicate that elevated distress can exist at any point along the continuum of care in both individuals with head and neck cancer and their caregivers. Relative to the patient population, distress was most prevalent at diagnosis and length of time following diagnosis had a large effect on perceived distress. Meanwhile 45% of caregiver participants reported clinically significant distress; both caregiver sex and the treatment status (i.e., awaiting treatment,

undergoing treatment, completed treatment) of the individual for whom they were providing care influenced perceptions of distress in caregivers. Relative to quality of life, participants in both studies reported elevated burden in three primary domains: role fulfillment, physical functioning, and psychological well-being.

Conclusion: Data suggest that perceptions of distress are individualized and heterogeneous in nature. Thus, routine distress screening represents a critical first step in the identification of elevated distress in both those with head and neck cancer and their caregivers. Through early identification and effective management of distress, comprehensiveness of care may be enhanced and long-term outcomes may be optimized.

Key Words

Co-Authorship Statement

All works contained in this dissertation were conceived of independently and subsequently, implemented, analyzed and prepared by the Doctoral Candidate (C.B.). However, given that the research was conducted in a multidisciplinary oncology clinic setting under the supervision of the Candidate's doctoral supervisor, the manuscripts presented herein should be considered co-authored by the following individuals based on their assistance with supervision and/or participant recruitment.

Chapter 2: Distress and Quality of Life in Individuals Diagnosed with Head and Neck Cancer: A Prospective, Longitudinal Analysis

Co-Authors: Bornbaum, C.C., Fung, K., Franklin, J.H., Nichols, A., Yoo, J., & Doyle, P.C.

Chapter 3: A Cross-Sectional Analysis of Distress in Caregivers of Individuals Diagnosed with Head and Neck Cancer

Co-Authors: Bornbaum, C.C. & Doyle, P.C.

Epigraph

"We must embrace pain and burn it as fuel for our journey"

Kenji Miyazawa

Dedication

This work is dedicated to the memory of Anne Barbetta and her phenomenal caregivers – Kathleen, Christine, Cathy, and Angela – who know all too well the challenges of the caregiver experience.

And also to Theresa Bornbaum, who because of life's circumstances was not permitted the opportunity to pursue the formal education she so desired. I am so grateful for the many difficult sacrifices she made so that I might have this opportunity.

Acknowledgements

Phil, whether we were debating the merits of statistical methodologies or brands of bourbon, you have been the most incredible supervisor and mentor. Thank you for encouraging me to pursue research at the graduate level, for exposing me to the area of head and neck cancer, and for broadening my perspective by candidly sharing yours. Thank you for challenging me to think differently, to go back to the drawing board (when necessary), and to retain my own "voice" in my writing. Thank you for encouraging me to value my own quality of life throughout these years, and for permitting me the time to be with my family when life demanded it. As a supervisor, you are unparalleled.

To my dissertation advisory committee members, Dr. Kevin Fung and Dr. J.B. Orange, thank you kindly for your thoughtful feedback throughout the process of developing this research program. Your support and assistance throughout this process has been greatly appreciated. In particular, thanks are owed to Kevin for encouraging me to round with the team and participate fully in the clinical process. Your openness provided such a rich learning opportunity and helped to cultivate personal insights I will carry with me always. Thank you.

To my RS mentors, Drs. Elizabeth Skarakis-Doyle, Doreen Bartlett, Deborah Lucy, Sandi Spalding, and Julie Theurer. Thank you all for going beyond the requirements of your profession to share candid experiences, both professional and personal. I could not possibly have asked for a richer learning environment.

me throughout my "dissertation hibernation". Your selflessness and encouragement throughout this process have been so incredible. I don't know how I could have ever managed to get to this point without your love and support. I am so incredibly proud to call you my husband. Simply put, you are the best thing that has ever happened to me. To infinity and beyond.

To my nearest and dearest girlfriends, without whom life would be so uneventful! Thank you seems wholly inadequate but nevertheless, I remain grateful to you all. Especially, Laura Fox, Emma Ellison, and Laura Mattiussi.

To Mike Clarke, for candidly sharing your life experiences (both pre- and post-laryngectomy) with me. You have enriched my perspective beyond measure.

To the many individuals who participated in these studies during an undoubtedly challenging time in their lives – thank you for sharing your experiences so candidly with me. None of this work would have been possible without your time and energy. I am greatly indebted to each and every one of you. Thank you.

Lastly, I must also acknowledge the community of support I received from my lab mates and colleagues – the "labrats". Many thanks in particular to Marie-Eve Caty, Steve Cox, Agnes Dzioba, Melissa Nash, Grace Scott, Lindsay Sleeth, and Jade Sillick. Special thanks are owed to Adam Day for his technical and psychosocial (read: bourbon-infused) support throughout the years. This marks the end of a wonderful era.

Table of Contents

List of Tables

List of Figures

List of Appendices

List of Abbreviations

Abbreviation	Full Term
ACS	American College of Surgeons
ANOVA	Analysis of variance
APA	American Psychological Association
CAPO	Canadian Association of Psychosocial Oncology
CQOLC	Caregiver Quality of Life – Cancer Scale
DT	Distress Thermometer
EORTC	European Organisation for Research and Treatment of Cancer
EORTC-QLQ-C30	European Organisation for Research and Treatment of Cancer General Quality of Life Measure
EORTC-QLQ-H&N35	European Organisation for Research and Treatment of Cancer Head and Neck Cancer-Specific Quality of Life Measure
HADS	Hospital Anxiety and Depression Scale
HPV	Human Papillomavirus
HSD	(Tukey's) Honestly Significant Difference
LRCP	London Regional Cancer Program
NCCN	National Comprehensive Cancer Network
QOL	Quality of Life
RAFG	Rebalance Action Focus Group
WHO	World Health Organization

Chapter 1

Introduction and Review of Literature

Cancer is a disease of multiple types, sites, and etiologies. Statistics indicate that it is the leading cause of death in economically developed countries and the second leading cause of death in developing nations (WHO, 2008). This prevalence translated to approximately 12.7 million diagnoses of cancer and 7.6 million cancer-related deaths in 2008 (Jemal et al., 2011). Unfortunately, the cause for concern related to cancer extends beyond the pervasiveness of the disease to also include the myriad consequences that stem from it. Due to the current forms of treatment available (e.g., chemotherapy, radiotherapy, surgery, and multimodality protocols), there are often significant consequences related to the functioning and quality of life of individuals with cancer (Semple, Sullivan, Dunwoody, & Kernohan, 2004) in addition to that of their caregivers.

Irrespective of anatomical site, all individuals with cancer experience some level of distress related to their diagnosis and treatment (NCCN, 2013). Unfortunately, this problem is amplified in those with head and neck cancer, a population who exhibits the highest rates of anxiety, depression, and suicide compared with other cancer sites (Kendal, 2006; Misono, Weiss, Fann, Redman, & Yueh, 2008). While the specific reasons underlying the disproportionate rate of suicide and depression in individuals with head and neck cancer are unknown, researchers have speculated that the cause may be attributable to the devastating effect of the disease and its treatment on the quality of life of individuals with head and neck cancer (Misono et al., 2008). The impact of the

disease and its treatment on one's appearance and essential functions such as breathing, swallowing and speech were also cited as possible factors contributing to the elevated rates of depression and suicide in individuals with head and neck cancer (Misono et al., 2008). In addition to the concerns of the person with head and neck cancer, it is apparent that the diagnosis of cancer and its accompanying sequelae (e.g., treatment- and disease-related consequences such as impaired breathing, speech, and swallowing) create a crisis for family members and significant others (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994); these individuals are expected to grieve – or rather, respond to the loss (Lev & McCorkle, 1998) – while simultaneously supporting the health and psychosocial well-being of the individual with cancer. Given this level of burden, it is not surprising that partners of those with head and neck cancer report higher levels of anxiety than those with the disease (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). Consequently, it is apparent that elevated distress has the potential to impact not only individuals with head and neck cancer, but also their loved ones and caregivers.

Since the relationship between individuals with cancer and their caregivers appears to be interrelated, with both partners experiencing negative consequences when one is distressed (Northouse, Templin, & Mood, 2001; Segrin, Badger, Dorros, Meek, & Lopez, 2007), efforts to develop an improved understanding of the factors that contribute to elevated distress in both those with head and neck cancer and their caregivers may have important implications for

improving health-related outcomes in both caregivers and those with head and neck cancer.

Head and Neck Cancer

Head and neck cancer refers to an extensive array of diverse tumour types that arise from various anatomic sites located within the head and neck region (Pai & Westra, 2009; Walden & Aygun, 2013). These sites include, but are not limited to: craniofacial bones, skin, soft tissues, mucosal membranes, and salivary glands (Pai & Westra, 2009). More than 90% of head and neck cancer diagnoses may be histologically classified as squamous cell carcinomas; most of these tumours originate in the mucosal surfaces of the head and neck such as the nasopharynx, oropharynx, hypopharynx, larynx, and oral cavity (Marur & Forastiere, 2008; Ragin, Modugno, & Gollin, 2007; Walden & Aygun, 2013). Other less common forms of malignant neoplasms include adenocarcinomas, lymphomas, melanomas and sarcomas (Semple et al., 2004).

Head and neck cancer may present as a localized disease without lymph node involvement or it may present as regionally advanced disease with a primary tumour and/or lymph node involvement, indicating the increased potential for distant metastases (Marur & Forastiere, 2008; Vokes, 2012). Treatment may consist of surgical excision, radiotherapy, chemotherapy or a combination of these approaches (Semple et al., 2004; Vokes, 2012). Irrespective of treatment modality, individuals diagnosed with head and neck cancer face a distinct set of treatment-related challenges related to oral communication, emotional expression, social interaction, and/or physical

function. The manner in which one learns to adapt or cope with these distressing changes may significantly influence his or her perceived quality of life and level of distress. Collectively, one's ability to cope with distressing changes related to the disease and/or its treatment may impact both short- and long-term health related outcomes (Elani & Allison, 2011; Horney et al., 2011).

Incidence of head and neck cancer and mortality. In the past 20 years, the overall incidence of head and neck cancer has declined in Canada, the United States, and Western Europe (Johnson-Obaseki, McDonald, Corsten, & Rourke, 2012; Siegel, Ward, Brawley, & Jemal, 2011). Despite this decline, international incidence rates of head and neck cancer reached an estimated 633,000 new cases in 2008 (Ferlay et al., 2010). Within Canada, findings reveal an increased incidence in oropharyngeal cancer in both men and women but a decreased incidence in all other head and neck sites for both sexes (Johnson-Obaseki et al., 2012). Relative to mortality, international data indicate that an estimated 355,000 individuals succumbed to their disease in 2008 (Ferlay et al., 2010). Recent Canadian data suggest that there has been no statistically significant improvement in survival among women for any head and neck cancer site, however, slight improvements in survival were reported among men for all head and neck cancer sites, with oropharyngeal sites representing the most improved rate of survival (Johnson-Obaseki et al., 2012). The reasons for the varying incidence and mortality rates associated with oropharyngeal cancer versus other head and neck sites may be explained through an examination of etiological factors.

Etiology. The etiology of head and neck cancer stems from a variety of risk factors that contribute to the disease both independently and collectively. Namely, diet, oral hygiene, genetic predisposition, preexisting medical conditions, infectious agents, and exposure to a variety of carcinogens may all contribute to the development of head and neck cancer (Pai & Westra, 2009; Vokes, 2012; Wynder & Bross, 1957; Wynder, Bross, & Feldman, 1961). Of these potential carcinogens, tobacco usage is a well established risk factor for the development of head and neck cancer (Pai & Westra, 2009; Vokes, 2012; Wynder & Bross, 1957; Wynder et al., 1961). In fact, Rodriguez and colleagues (2004) determined that heavy smokers under the age of 46 have a 20-fold increased risk of developing oral or pharyngeal cancer compared to individuals who do not smoke. Not surprisingly, the risk associated with smoking tobacco products is directly correlated with the duration and amount of smoking (Pai & Westra, 2009; Rodriguez et al., 2004). Similar to lung cancer, environmental exposure to tobacco smoke also has been shown to increase the risk of head and neck cancer, even among those with no smoking history (Zhang et al., 2000). In addition, smokeless tobacco products have been cited as an etiologic agent for oral cancers (Cogliano et al., 2004; Cullen et al., 1986; Zhou et al., 2012).

Additionally, heavy alcohol consumption is also recognized as an independent risk factor for head and neck cancer (Hashibe et al., 2007; Sturgis & Cinciripini, 2007). Heavy alcohol consumption has been estimated to increase the risk of developing oral cancer by five-fold (Rodriguez et al., 2004). Though both alcohol and tobacco are independent risk factors for head and neck cancer,

when the two agents are combined the risk of developing oral or pharyngeal

cancer has been reported to increase by nearly 50-fold (Rodriguez et al., 2004).

In fact, it has been reported that as many as 75% of all head and neck cancers

are attributable to the synergistic influence of this carcinogenic combination

(Hashibe et al., 2007). Although alcohol itself does not act as a direct carcinogen,

its metabolite, acetaldehyde, interferes with DNA synthesis and repair

mechanisms causing irreparable damage (Brooks & Theruvathu, 2005). Since

alcohol is a chemical solvent, it is thought to amplify the carcinogenic effects of

tobacco by prolonging and enhancing the mucous membrane exposure to the

carcinogens found within tobacco (Pai & Westra, 2009). In effect, alcohol may

increase the susceptibility of the body to the harmful carcinogens found in

tobacco.

Although alcohol consumption and tobacco exposure are well-established

risk factors, recently, there has been an epidemiologic shift towards human

papillomavirus (HPV)-related head and neck cancers (Li et al., 2012; Marur,

D'Souza, Westra, & Forastiere, 2010; Marur & Forastiere, 2008). Syrjanen,

Pyrhonen, and Syrjanen (1983) first suggested the role of HPV in head and neck

carcinogenesis (Campisi & Giovannelli, 2009). Since then, epidemiological

research has shown that the risk of developing HPV-induced head and neck

cancer is increased by sexual behaviours associated with the transmission of

high-risk HPV types (Forte, Niu, Lockwood, & Bryant, 2012; Walden & Aygun,

2013) specifically HPV-16, -18, and -31 (Marur et al., 2010; Marur & Forastiere,

2008; Pai & Westra, 2009). In effect, HPV is emerging as a preeminent and

significant risk factor for oropharyngeal cancer and appears to be altering the demographics of head and neck cancer toward those who are younger and without a history of tobacco use or heavy alcohol consumption (Walden & Aygun, 2013).

In addition to tobacco, alcohol and HPV, there are several additional risk factors for head and neck cancer that include, but are not limited to: poor oral hygiene (Pai & Westra, 2009), diets deficient in vitamin A (Marur & Forastiere, 2008) or with low fruit and vegetable intake (Pai & Westra, 2009; Vokes, 2012), infectious agents such as the Epstein-Barr virus (Vokes, 2012), a family history of disease (Pai & Westra, 2009), marijuana smoke (Vokes, 2012), and occupational exposures – particularly in nickel refining, textiles, leatherworking, woodworking, metalworking, and any areas with exposure to asbestos, chromium, radiation or mustard gas (Marur & Forastiere, 2008; Vokes, 2012). All of these factors, either individually or collectively, may contribute to the development of head and neck cancer and the associated consequences and complications of the disease and its treatment. While the presence of a single etiologic factor may pose significant risk for the development of head and neck cancer, the possibility of coexisting factors must be considered in the treatment and assessment of health status and outcomes in individuals with head and neck cancer.

Impact of disease. The diagnosis of head and neck cancer carries with it a unique set of challenges that potentially exceed those associated with other sites of cancer (Howren, Christensen, Karnell, & Funk, 2012; Semple, 2001). This assertion is related to the fact that head and neck cancer treatment can be

quite complex with potentially debilitating consequences. In essence, debilitating side effects related to the disease and its treatment are present in all of those diagnosed with head and neck cancer; however for some, the consequences stemming from these side effects are more disabling than others. For instance, side effects may include difficulties related to essential functions such as breathing, eating, swallowing and speech production, in addition to a loss of smell and taste, decreased sensation, sticky saliva, excessive dry mouth, pain, swelling, and facial disfigurement (Doyle, 1994; Payakachat, Ounpraseuth, & Suen, 2012). Further, some institutions require those individuals receiving chemoradiation treatment to undergo prophylactic extraction of all dentition in an effort to prevent future dental and mandibular problems (Hunter & Jolly, 2013). Understandably, this process can be quite traumatic in and of itself. Moreover, these myriad side effects stemming from the complex treatment regimens required for the management of head and neck cancer often serve to impair daily functioning and one's ability to work.

Treatment regimens for head and neck cancer have the potential to create a debilitating and lasting impact on an individual's functional status, which may consequently limit their ability to work both during and after treatment (Penner, 2009). Research examining work-related disability in those with head and neck cancer revealed that 52% of individuals who were employed at the time of diagnosis were unable to return to work following the completion of treatment (Taylor et al., 2004). Likewise, other researchers have reported a similar inability of individuals with head and neck cancer to return to their previous employment

for extended periods of time, if at all (Shone & Yardley, 1991; Taylor et al., 2004; Verdonck-de Leeuw, Van Bleek, Leemans, & de Bree, 2010). Even if those with head and neck cancer are able to return to work following treatment, many have reported having to change their jobs because of poor health and/or physical discomfort related to treatment consequences (Liu, 2008). When compared with other types of cancer, individuals with head and neck cancer have reported the highest risk of quitting their jobs following treatment for their cancer (Short, Vasey, & Tunceli, 2005). This change in employment status may have significant implications on the financial and psychosocial well-being of these individuals (Taylor et al., 2004).

In addition to the impact on one's employment status, further concerns may arise related to one's independence and ability to participate in social activities. To elaborate, research has shown that individuals treated for head and neck cancer often either decrease the frequency of their driving or stop driving altogether during and after treatment because of treatment-related impairments (e.g., shoulder dysfunction following neck dissection) (Yuen, Gillespie, Day, Morgan, & Burik, 2007). Consequently, daily routines and tasks such as running errands or driving to and from work (if applicable) are disrupted, as those who have been treated for head and neck cancer must increasingly rely on others (e.g., caregivers) for transportation (Yuen et al., 2007). This reliance on others to perform tasks which once symbolized independence (e.g., driving) may result in feelings of dependence and decreased self-worth in those with head and neck

cancer. As a result of these myriad concerns, individuals may experience substantial problems within the context of social and family settings.

Often, these concerns are exacerbated by the very visible side effects of head and neck cancer and its treatment including the potential for physical disfigurement and scarring (Björklund, Sarvimäki, & Berg, 2010; Doyle, 1994). Society tends to place more importance on the head and neck region than any other area of the body (Semple et al., 2004). The emphasis on facial aesthetics and cosmesis may be particularly difficult for those with head and neck cancer because the visible signs of head and neck cancer and its treatment often cannot easily be concealed (Semple et al., 2004). Consequences such as these often prevent those with head and neck cancer the privacy afforded by less visible forms of illness. As a result, those treated for head and neck cancer may experience unwelcomed intrusions such as those associated with insensitive comments or staring (Björklund et al., 2010). These experiences may result in feelings of stigmatization and consequently cause additional psychological distress. Feelings of stigmatization may result in multiple levels of social penalty and consequently contribute to additional psychological and social distress for individuals with head and neck cancer (Doyle, 2005; Fife & Wright, 2000; Lebel et al., 2013). Factors such as these have led researchers to describe head and neck cancer as the most emotionally traumatic form of cancer (Björklund et al., 2010; Koster & Bergsma, 1990).

Given that research has demonstrated a relationship between the emotional experiences of individuals with cancer and their caregivers (Northouse

et al., 2001) – in essence suggesting that when one individual is distressed (e.g., person with head and neck cancer), that the other individual may also be distressed (e.g., caregiver) – there appears to be a potential to experience emotional trauma as a result of either having head and neck cancer or caring for someone with the disease. Essentially, the emotional trauma caused by head and neck cancer and its treatment may directly influence the emotional state of caregivers (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Importantly, researchers have begun to acknowledge that head and neck cancer not only has enormous consequences for the individual with the disease, but also for their loved ones and caregivers, as the entire family dynamic may be disrupted by the disease and its accompanying consequences (Björklund et al., 2010). Thus, it would seem important to understand and acknowledge the concerns of both the individual with head and neck cancer and their caregivers since improvements in our understanding of the caregiver experience may promote the identification of meaningful ways to support caregivers.

Caregivers

The definition and use of the term "caregiver" has been discussed in the literature for several years (Hunt, 2003). Caregivers have been described as unpaid individuals who participate in the experiences and activities involved in the provision of assistance to a loved one who is unable to provide for themselves (Pearlin, 1994). Recently, authors have suggested that a caregiver is 'who the person says it is' (Hodges & Humphris, 2009; Kissane & Bloch, 2002; Stenberg, Ruland, & Miaskowski, 2010), implying that the caregiver may consist

of a blood relative, neighbour, friend, or other individual. Regardless of how the

term caregiver is defined or who fulfills the role, providing care for another

individual who has been diagnosed with cancer is an experience, shared closely

with the recipient of care, which may affect numerous aspects of the caregiver's

life.

It has been well established that family members of individuals with cancer

are affected by the illness throughout the trajectory of the disease (Stenberg et

al., 2010). For instance, the consequences of the disease continue to impact

family members well into the survivorship stage for those who survive the illness

and into the end of life care for those who do not (McCorkle & Pasacreta, 2001;

Stenberg et al., 2010). Family members often provide the primary source of

emotional and social support for individuals with cancer. They also serve a key

role in how effectively an individual with cancer is able to manage the impact of

their illness and its treatment (Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi,

2011). Considering that hospital stays have decreased in length (Cohen, Stock,

Andersen, & Everts, 1997; Yueh et al., 2003), individuals with cancer are

increasingly left to manage their illness and its side effects at home. As a result,

the burden of responsibility for family members has increased; this in turn has

made the role of family-based caregiving ever more vital (Stenberg et al., 2010).

This shift towards family-based caregiving often requires a reorganization of

personal roles and responsibilities on the part of the caregiver in order to address

the needs of the individual with cancer and also ensure that the family is still able

to function effectively and perform essential tasks (e.g., raising children, paying bills, etc.).

      The role of caregivers. Most often, the spouse or significant other of the individual with cancer fulfills the role of primary caregiver (Mellon, Northouse, & Weiss, 2006). Despite the fact that these loved ones often receive minimal or no preparation, they are frequently tasked with many care-related responsibilities such as the provision of physical care, medication administration, transportation, emotional support, household management, and assistance with activities of daily living (Northouse & McCorkle, 2010). The demand for these tasks to be undertaken is often within a very short period of time following the diagnosis of their loved one's cancer. While family caregivers have historically provided significant contributions to the care of their loved ones, the level of technical, physical, and psychological support currently required of caregivers has reached unparalleled levels in recent years (Given, Given, & Kozachik, 2001). This shift in burden of care towards caregivers results from healthcare system changes which have transferred the delivery of cancer care from an in-patient, hospital-based setting to ambulatory and home-based settings much sooner following treatment than in previous years (Cohen et al., 1997; Given et al., 2001; Yueh et al., 2003). This shift in care settings has translated to an increased level of caregiver involvement in the daily care of the individual with cancer (Given et al., 2001). Thus, since individuals are providing care for those with cancer much sooner following treatment (e.g., surgery), they must also deal with a more acute set of potential issues (e.g., wound care, infection, swallowing problems).

In addition to the disease- and treatment-related factors that caregivers are responsible for (e.g., disease and treatment monitoring, symptom management, medication administration, transportation to appointments), they must also ensure that the responsibilities usually fulfilled by the individual with cancer (e.g., errands, payment of bills, care for minor children, preparation of meals) are addressed. Ensuring the fulfillment of responsibilities may be particularly burdensome when the person with cancer is a spouse or family member and the household tasks that were formerly shared between two individuals must now be accounted for by the caregiver alone. While this effort to preserve the normal level of family functioning is commendable, it can create feelings of role overload for the caregiver (Northouse & McCorkle, 2010). As the number of illness-related demands increase, caregivers experience numerous physical, psychological and social consequences that potentially may exceed those experienced by the individual with cancer (Mellon et al., 2006). Moreover, research has demonstrated that as the level of demand on caregivers increases, they are placed at an elevated risk for the development of depression (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007). This elevated risk poses a problem not only for the caregiver's well-being, but also may impact their ability to provide complex care to another when their own physical and mental health is compromised. Thus, in order to ensure optimal caregiving, efforts to understand and ameliorate the negative consequences of caregiving would appear to be a reasonable area of consideration.

The consequences of caregiving. A recent review of the effects of caring for an individual with cancer conducted by Stenberg and colleagues (2010) identified more than 200 problems and burdens associated with being a caregiver. This large range of concerns included issues related to one's physical health, psychological state, social activities, and practical responsibilities. While the range of physical health concerns was indeed quite extensive, the most commonly reported physical problems according to Stenberg et al. (2010) consisted of pain, fatigue, sleep disturbances, loss of physical strength, loss of appetite, and weight loss; symptoms which would appear to mirror those of depression (Miller & Massie, 2009). These problems seem understandable given that caregivers are often required to adjust their lifestyle (e.g., restricting leisure activity and contact with friends and family) in order to accommodate the increasing needs of the individual with cancer (Stenberg et al., 2010). These lifestyle amendments often mean that during a time when the restorative benefits of relaxation and social support are most needed, that caregivers actually have the least amount of time and resources available for their own self-care (Bevans & Sternberg, 2012).

Further complicating the situation, caregivers have been shown to prioritize the needs of the individual with cancer over their own (Williams, 2007), thus, leaving minimal time for maintaining activity and exercise, good nutrition, and regular healthcare check-ups. Consequently, caregivers experience increased health-related concerns such as fatigue and sleep disturbances, which are exacerbated as symptom burden increases and functioning decreases in the

individual with cancer (Palos et al., 2011). Symptom burden is a concept that is comprised of both the severity of symptoms and the individual's subjective perception of the impact of the symptoms on their daily life and level of functioning (Cleeland, 2007). As a result, one could infer that as the level of symptom burden increases in individuals with head and neck cancer, so too does the level of burden in caregivers.

In addition to physical consequences reported by caregivers, they have also reported a diverse range of positive and negative psychological responses to their experience as a caregiver. Specifically, caregivers have described a spectrum of emotions ranging from positive affect such as hopefulness and compassion for others, to negative emotions such as, bitterness, resentment, fear, anger, depression, and anticipatory grief (Williams & Bakitas, 2012). Regarding the ability to fulfill the responsibilities of providing care, some caregivers have noted positive feelings of accomplishment, while others report feeling overwhelmed (Williams & Bakitas, 2012). Upon reflection of the caregiving experience, some individuals have found caregiving to be positive for their self-esteem (Kim, Schulz, & Carver, 2007), while others have found that managing tasks and emotions in the context of caring for a loved one was immensely difficult (Williams & Bakitas, 2012). Given the broad spectrum of emotional responses to the experience of caregiving, it is apparent that the act of providing care to a loved one with cancer, is a complex experience that is marked by both positive and negative affect.

The provision of care for an individual with cancer is often a challenging,

disruptive, and time-consuming activity (Williams & Bakitas, 2012). Given the

level of burden facing caregivers, it is not surprising that multiple studies report

higher levels of anxiety and depression in caregivers than the patients

themselves (Mellon et al., 2006; Vickery et al., 2003). This finding is of central

importance to understanding the experience of distress in caregivers because it

acknowledges the psychological impact of the diagnosis and treatment of the

individual with cancer on the caregiver. The experience of illness and treatment

is clearly different for caregivers. They are often faced with the very real prospect

of losing their partner or loved one. Such a possibility may produce feelings of

grief and helplessness because they are unable to take a direct role in combating

the cancer (Vickery et al., 2003).

Relative to social consequences, caregivers have frequently reported

problems with employment, education, isolation, financial well-being, and the

ability to fulfill roles (Stenberg et al., 2010). When a loved one is diagnosed with

cancer, understandably, there are changes in the roles, expectations,

responsibilities and relationship dynamics of the family as individuals adjust to

the reality of such a diagnosis and impact of the disease (Northouse, Williams,

Given, & McCorkle, 2012). Accordingly, the level of burden on caregivers often

increases. This increased burden may be particularly evident in caregivers who

must balance their caregiving responsibilities with the provision of care for

children and/or ailing parents. These individuals may feel overwhelmed with the

demands on their time and energy as they try to balance their responsibilities to

their loved ones with their own personal and employment-related obligations

(Coristine, Crooks, Grunfeld, Stonebridge, & Christie, 2003). Further, caregivers without flexible jobs or employers who can accommodate such needs have often been required to use sick leave and vacation time in order to fulfill their new and potentially rapidly expanding obligations, which may subsequently create an additional level of economic strain (Stenberg et al., 2010). Thus, it is apparent that the social consequences of being a caregiver extend beyond the realm of one's daily social participation in enjoyable activities, to also include the potential limitation of one's future occupational and economic stability.

With regard to the financial burden of caregiving, an American study of the time costs associated with informal caregiving for cancer survivors found that on average, caregivers provided 8.3 hours of care per day for 13.7 months (Yabroff & Kim, 2009). When the economic burden of caregiving was evaluated relative to the value of the caregiver's time providing care, the value of lost employment, and out-of-pocket expenditures (e.g., transportation, parking, home modifications, cancer care supplies, etc.), the financial costs were considerable, ranging from $31,442 to $91,670, depending on the specific type of cancer (Van Houtven, Ramsey, Hornbrook, Atienza, & van Ryn, 2010). These estimates of time costs and out-of-pocket expenditures highlight the substantial financial burden that often may be experienced by caregivers.

In addition to the financial stressors noted previously, caregivers have reported feelings of isolation (Northouse et al., 2012; Williams & Bakitas, 2012). Not only does the work of caregiving disrupt their opportunity to engage socially with others (Stetz & Brown, 2004), but the caregiver's personal needs are often

neglected as their focus remains on the needs of the individual with cancer (Schubart, Kinzie, & Farace, 2008). Feelings of isolation and loneliness were particularly significant in caregivers without access to family or friends (Schubart et al., 2008). The inherent difficulty in serving as a caregiver to a loved one with cancer lies in both the overwhelming nature of the role and the fact that despite one's best effort, that the individual with cancer may still suffer and possibly succumb to their illness. Thus the fear of losing a loved one may in and of itself induce tremendous feelings of anticipatory grief in the caregiver.

Caregivers are often expected to grieve, while simultaneously supporting the physical, psychological, social and practical needs of their loved one. They must also work to maintain their regular family and employment-related responsibilities, while balancing their own fears, anxieties and concerns for the well-being of their loved one. In light of the essential role of caregivers and the numerous personal and care-related demands they face, it would seem important to work to understand their experiences and identify meaningful ways to assist them. Research seeking to understand the experience of caregivers has suggested that the provision of care for an individual with cancer may constitute a distressing life experience (Longacre et al., 2012; Roing, Hirsch, & Holstrom, 2008). Since the presence of elevated distress in caregivers has been identified as a factor that may compromise both the physical health and psychological well-being of both caregivers and individuals with cancer (Hagedoorn et al., 2008; Northouse et al., 2001), investigations into the factors which can influence distress may inform our understanding of the caregiver experience. Improved

knowledge regarding the factors that contribute to and/or exacerbate distress may help to identify meaningful ways to both detect and possibly alleviate distress in these individuals.

Distress

Psychosocial distress has been identified as a significant and ongoing problem among individuals diagnosed with cancer. Distress has become so prevalent that the National Comprehensive Cancer Network (NCCN) has established a Distress Management Panel to address the issue. The NCCN (2013) has defined distress as:

> *…a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis* (p.6).

As highlighted by the presence of a "continuum" of distress, there is an inherent distinction to be made between the pathologic experience of distress (e.g., clinical depression, anxiety disorders, etc.) and one's natural response to a catastrophic life event; be that the threat to one's own life, or to the life of a loved one. Transitory negative feelings are a normal part of the cancer experience and are to be expected as individuals react to an unanticipated threat, potential and actual losses, and to the potential side effects of unpleasant and/or painful

treatments (Haman, 2008). Cancer and its treatment often create feelings of uncertainty, anticipated changes to personal roles and functioning, and practical concerns related to medical care and financial well-being. As individuals and caregivers attempt to manage these concerns, they are likely to experience emotions such as sadness, anger and fear. The majority of individuals will experience brief episodes of sadness or anxiety, insomnia, loss of interest in activities, thoughts of helplessness and hopelessness, or worries about potential catastrophe (e.g., loss of life) (Haman, 2008).

While most individuals will eventually adapt to the changes brought on by the cancer experience (Vickery et al., 2003), a subset of individuals will experience distress to the extent that adaptive coping is impaired severely enough or long enough to be considered disruptive (Haman, 2008). A few days characterized by tearfulness and decreased interest in regular activities may be viewed as a component of adaptive coping to the changes and losses that are inherent in the experience for both the patient and caregiver (Haman, 2008). However, if the symptoms persist for extended periods of time – some sources suggest more than one week (Haman, 2008) while others advocate for at least two weeks or more (American Psychological Association [APA], 2000) – problems may arise with social support networks, one's physical well-being, and influence even treatment compliance and survival in individuals with cancer (Haman, 2008). Notably, certain symptoms such as suicidal ideation with accompanying plan and intent require immediate intervention, even if the symptoms only last for short periods of time. Generally, it has been suggested

that if distress persists for greater than a week, leads to noncompliance with treatment recommendations (McDonough, Boyd, Varvares, & Maves, 1996), or puts the individual (or others) in danger, intervention is required (Haman, 2008). Ideally, problematic distress in both those with cancer and their caregivers should be identified and addressed in order to avoid negative outcomes such as, fatigue, weight loss, decreased medical compliance, and increased hospital stays (DiMatteo, Lepper, & Croghan, 2000) in those with cancer, and compromised psychological functioning, and changes to the immune system that limit glucose control and increase cardiovascular vulnerability (Rohleder, Marin, Ma, & Miller, 2009) in caregivers.

Distress in individuals with cancer. Normal emotions such as sadness, worry, and fear occur in every person, and are undoubtedly exacerbated with a diagnosis of any serious disease such as cancer. Clinical psychiatric disorders such as depression and anxiety do not develop overnight; rather, they are the cumulative outcome along the continuum of mental health that extends beyond normal emotional responses and psychological reactions (Mohan & Pandey, 2002). Research has established that across the trajectory of illness – from initial diagnosis through treatment, termination of treatment, survivorship, or recurrence and palliation – psychosocial distress is evident in approximately 25% to 45% of those with cancer (Carlson, 2003; Carlson et al., 2004; Singer et al., 2012; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Moreover, large-scale studies conducted at the Tom Baker Cancer Centre in Alberta, Canada (Carlson et al., 2004) and the Johns Hopkins Kimmel Cancer Centre in

Baltimore, Maryland (Zabora et al., 2001) of a representative sample of individuals screened for psychosocial distress detected high levels of fatigue (in nearly 50% of patients), depression (24%), anxiety (24%), and pain (26%), in addition to financial hardship and other challenges. Distress is a common sequela of cancer as a disease and thus requires careful consideration in the context of understanding the individual's response to the diagnosis of malignant disease.

From a therapeutic perspective, untreated depression has been shown to affect medical compliance, appetite, wound healing, and contribute to increases in length of hospital stays (DiMatteo et al., 2000; Jenkins, Carmody, & Rush, 1998; McDonough et al., 1996). Furthermore, the impact of depression on functions such as sleep, motivation and energy level are also well documented (Roscoe et al., 2007). By intensifying fatigue and weight loss, depression has the potential to amplify treatment-related side effects for individuals with cancer, contributing to a vicious cycle that may not only worsen depression and overall rates of distress, but also negatively influence disease control through decreased medical compliance (DiMatteo et al., 2000).

Relative to the impact of depression on medical compliance, research has demonstrated that depressed individuals with cancer take more breaks in treatment and thus require a greater length of time in order to complete the prescribed treatment protocol (Archer, Hutchison, & Korszun, 2008). These findings have critical implications for individuals with head and neck cancer given that the success of radiation therapy – one of the key forms of treatment for head

and neck cancer – is dependent in part on the completion of therapy as close as possible to the prescribed time (Lydiatt, Moran, & Burke, 2009). In consideration of these factors, the chances of survival are likely to be lessened in those individuals who experience depression, when compared to those who are not depressed (Archer et al., 2008). Thus, given the numerous challenges facing an individual with cancer, support from caregivers is essential in order to facilitate successful coping, adjustment, and sometimes even survival (Foster et al., 2005). As a result, understanding the factors that contribute to elevated distress would appear to be an important component to ensuring the optimal well-being of both those with cancer and their caregivers.

Distress in caregivers. While cancer has been shown to impact the quality of life of caregivers in myriad ways, researchers have recently suggested that the psychological well-being of caregivers is the area most significantly impacted during the initial stages of the caregiving experience (Northouse, Katapodi, Schafenacker, & Weiss, 2012). When the level of demand for care that is placed on caregivers exceeds their available resources (e.g., psychological wherewithal, personal coping mechanisms, social support, etc.), caregivers report feeling overwhelmed and distressed (Drabe, Wittmann, Zwahlen, Büchi, & Jenewein, 2012). Distress in caregivers is problematic for two key reasons; first for the problems that it poses to caregivers personally, and second for the consequent impact on the individuals with cancer. Both the personal consequences of distress for caregivers and the resultant impact on those with cancer are discussed hereunder.

Relative to the personal toll of distress on caregivers, research indicates that between 20% to 40% of caregivers experience high levels of distress or depression (Edwards & Clarke, 2004; Longacre et al., 2012). However these incidence rates increased when the individual with cancer demonstrated poor physical functioning, high symptom distress, and advanced disease (Kurtz, Kurtz, Given, & Given, 2004). The prevalence of high emotional distress in caregivers is problematic for multiple reasons. Not only does it compromise their psychological well-being, but highly distressed caregivers may also experience changes to their immune system that can limit glucose control, promote flare-ups in autoimmune diseases, and increase vulnerability to cardiovascular diseases (Rohleder et al., 2009). These biologic consequences of distress increase the potential for the caregiver's own health to suffer and, consequently, impede their ability to provide adequate care to the individual with cancer. This clearly holds the potential to impact both the caregiver and the individual for whom they must provide care.

Regarding the impact of caregiver distress on individuals with cancer, research indicates that because of caregivers' negative emotional states and impaired cognitive and physical functioning, caregivers have more difficulty with the effective administration of medication (Lau et al., 2010) and provision of optimal care (Park et al., 2009; van Ryn et al., 2011) to individuals with cancer. With respect to psychological functioning, high levels of anxiety in caregivers have been shown to increase anxiety in the individuals with cancer (Segrin et al., 2007), and longitudinal data suggest that when caregivers are highly distressed, there is a significant negative effect on the long-term adjustment of the individual

with cancer (Northouse et al., 2001). Consequently, it would appear that there is

a reciprocal relationship between the psychological health of both caregivers and

individuals with cancer.

The findings of Northouse and colleagues (2001) are in line with the work

of Hagedoorn and colleagues (2008) who conducted a meta-analysis of 46

studies that examined distress in couples coping with cancer (n = 2,468 couples).

They discovered a significant relationship between distress in caregivers and

those with cancer (r = 0.29, p < .001) even after controlling for illness-related

factors (e.g., disease stage). These findings indicate that both the individual with

cancer and their caregiver's emotional responses to the illness were interrelated.

These results suggest that individuals with cancer and their caregivers react to

the experience of cancer as an "emotional system", and that both the individual

and their caregiver(s) should be viewed as the recipients of care from the

perspective of health practitioners (Northouse et al., 2012). In consideration of

the dyadic nature of the patient-caregiver relationship, a greater understanding of

the factors that influence caregiver distress may have important implications not

only for improving caregiver outcomes, but also for the individuals with cancer,

given that the distress level of one individual (e.g., the caregiver) may influence

the distress level and overall experience of the other individual (e.g., the person

with cancer), and vice versa (Northouse et al., 2001; Segrin et al., 2007).

Benefits of distress management. When the psychological needs of

individuals with cancer remain unresolved, these individuals are more likely to

visit emergency rooms and make use of community health services (Carlson &

Bultz, 2004). This increased service utilization is related to the physical symptoms resulting from psychological distress such as sleep disturbances, headaches and gastrointestinal symptoms (Carlson & Bultz, 2004). Consequently, these individuals place greater demands on the increasingly scarce time of their healthcare providers. Additionally, clinical studies have demonstrated that certain forms of psychosocial intervention (e.g., cognitive behavioural therapy, psycho-educational interventions) are beneficial to individuals with cancer (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; Fors et al., 2010; Hammerlid et al., 1999; Newell, Sanson-Fisher, & Savolainen, 2002). Newell and colleagues (2002) found that psychosocial interventions involving counseling (either structured or unstructured) and guided imagery have been shown to improve quality of life and the general functioning of individuals with cancer. Furthermore, participants from multiple studies asserted that they would use the psychological resources again and would recommend them to other individuals diagnosed with cancer (Hamilton, Miedema, MacIntyre, & Easley, 2011; Miller et al., 1998). Thus, this information suggests that if psychological distress can be identified early and addressed in a meaningful manner (i.e., lessened or alleviated), then perhaps we can improve the overall functioning of individuals with cancer and also possibly reduce the economic burden on the healthcare system that arises as a result of untreated or poorly managed distress.

Several reviews of the literature have noted that psychological therapies may assist individuals in several ways including, improving sexual functioning

(Penedo et al., 2007), enhancing quality of life, emotional adjustment, and coping skills (Hamilton et al., 2011; Henderson et al., 2011), and increasing physical health and functional adjustment (Penedo et al., 2007). Further, such intervention has been reported to reduce disease- and treatment-related symptoms in individuals with cancer (Hart et al., 2012) and general physical symptoms in caregivers (Birnie, Garland, & Carlson, 2010). Addressing negative psychosocial outcomes such as distress is a critical component to the delivery of comprehensive healthcare. Without the early identification of problematic distress levels, individuals' may experience innumerable consequences related to physical, psychological and social functioning – the core components of one's evaluation of their perceived quality of life. Therefore, these consequences may ultimately result in decreased quality of life for those living with cancer as well as their caregivers.

Thus, efforts to support the identification of distress in both individuals with cancer and their caregivers should be undertaken in an effort to inform the individuals charged with their care (and those most suited to assisting them) of when the level of psychosocial concern (e.g., distress) has reached a problematic point and specifically where intervention efforts may be directed in order to be of most benefit. Fortunately, a number of validated instruments have been devised which are capable of assessing the level of an individual's perceived distress and their accompanying multidimensional concerns. The use of these tools in both clinical and research environments may help to develop a better understanding of not only the prevalence of distress in individuals with

head and neck cancer and their caregivers, but also the specific problems that these individuals face and the consequent impact of this distress and these perceived problems on their quality of life and daily functioning. Outlined next is a summary of the measures deemed best suited to address the specific objectives of this program of research.

Measurement Instruments

The measurement instruments utilized in the studies comprising the dissertation included: (1) the Distress Thermometer and accompanying Problem Checklist to measure distress and perceived problems; (2) the EORTC Quality of Life Questionnaire (EORTC-QLQ-C30), and (3) the EORTC Head and Neck module (EORTC-QLQ-H&N35), to evaluate both global and head and neck cancer-specific quality of life, and (4) the Caregiver Quality of Life-Cancer Scale (CQOLC) to assess quality of life from the perspective of caregivers. Additionally, all participants of the studies described in this dissertation were requested to complete a brief form to assess demographic information in addition to disease- and treatment-related variables. In the case of caregivers, the form requested both their personal demographic information and the disease- and treatment-related information of their loved one with head and neck cancer.

Distress Thermometer. The Distress Thermometer was developed in 1999 by the National Comprehensive Cancer Network (NCCN) in an effort to provide a means of assessing psychological well-being in individuals with cancer in a non-stigmatizing manner (NCCN, 2013). The term "distress" was utilized because it was viewed as less stigmatizing than terms such as "psychiatric" or

"psychological" (NCCN, 2013). The "thermometer" component of the Distress

Thermometer is comprised of an 11-point Likert scale ranging from 0 (no

distress) to 10 (extreme distress). Respondents were asked to circle the number

that best described how much distress they had been experiencing throughout

the past week including the present day (NCCN, 2013). Owing to the brief nature

of the Distress Thermometer as a means of assessing distress, it has been

classified as an "ultrashort" measure based on the fact that it contains less than

five items (Vodermaier, Linden, & Siu, 2009). To date, the Distress Thermometer

has been validated extensively in oncology populations across various cancer

sites (Butt et al., 2008; Gessler et al., 2008; Hegel et al., 2008; Hoffman, Zevon,

D'Arrigo, & Cecchini, 2004; Jacobsen et al., 2005) and disease stages (Akizuki et

al., 2003; Gessler et al., 2008; Gil, Grassi, Travado, Tomamichel, & Gonzalez,

2005; Hegel et al., 2008; Recklitis, Licht, Ford, Oeffinger, & Diller, 2007). A

systematic review of distress measures determined that the Distress

Thermometer was found to have moderate reliability, validity and criterion

measures based on a review of 15 studies that used the Distress Thermometer

and comprised a total of 4,088 participants (Vodermaier et al., 2009).

Although assessments of acceptable coefficient values of reliability are

somewhat arbitrary, as a general guideline, reliability coefficients that fall below

0.50 indicate poor reliability, while values that range between 0.50 and 0.75

suggest moderate levels of reliability, and coefficients above 0.75 represent good

reliability (Portney & Watkins, 2009). In their review of distress screening

measures, Vodermaier et al. (2009) reported that the Distress Thermometer

demonstrated a moderate degree of reliability. Further, Vodermaier and colleagues (2009) found the measure to be generalizable based on its use in oncology-related populations including those with mixed diagnoses (e.g., multiple cancer sites), disease stages, and also in individuals awaiting bone marrow transplantation. While the Distress Thermometer has demonstrated moderate reliability and generalizability, questions may be raised as to the ability of a single item measure such as the Distress Thermometer to accurately capture the experience of distress in individuals. However, examination of the concurrent validity of the Distress Thermometer with other established measures of distress may prove to assuage these potential concerns.

With respect to validation of a screening tool such as the Distress Thermometer, data pertaining to the sensitivity and specificity of the measure may provide valuable information regarding the ability of the measure to accurately discern between the true presence, or absence, of clinically significant distress. Specifically, sensitivity measures the validity of a screening procedure and is based on the probability that an individual who is experiencing distress will test positive for distress according to the measure (e.g., a true positive), whereas a measure's specificity is based on the probability that an individual who is not distressed will test negative for distress according to the measure (Portney & Watkins, 2009).

Sensitivity values for the Distress Thermometer ranged from 0.59 to 0.89 while specificity values fell between 0.49 and 0.85 in a systematic review of distress measures (Vodermaier et al., 2009). While these values appear to be

quite divergent, it should be noted that the cutoff scores used by researchers in the systematic review varied considerably. The lowest cutoff score used was 3 (Gil et al., 2005), while the highest was 7 (Hegel et al., 2008), however scores of 4 or 5 were the most commonly used cutoff scores. Despite the varying cutoff scores used by researchers, the NCCN has recommended that scores of 4 or higher be considered clinically significant (NCCN, 2013). This recommendation has been verified through the validation efforts of other researchers in both individuals with cancer (Hoffman et al., 2004; Jacobsen et al., 2005; Ransom, Jacobsen, & Booth-Jones, 2006) and caregiver populations (Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). As such, the present study employed the recommended cutoff score for analysis purposes.

Furthermore, a recent meta-analysis of short screening tools for cancer-related distress supported the use of the Distress Thermometer and noted that it is comparable to longer distress measures, but provides superior efficiency (Mitchell, 2010). Furthermore, in his review of short distress screening measures, Mitchell (2010) noted that the best available evidence supported the use of the Distress Thermometer due to its acceptability with participants, cost-effectiveness, and overall accuracy, especially when compared with longer, multi-item screening measures, such as the Hospital Anxiety and Depression Scale (HADS). Furthermore, owing to its brief administration and simple scoring procedure (e.g., scores of greater than or equal to 4 suggest problematic distress), the Distress Thermometer provides an easy-to-use clinical screening measure that affords simple intra rater comparison of data. Hence, for busy

clinicians who may not have time to score and review longer measures, a quick comparison of an individual's previous Distress Thermometer score(s) with a current score may provide useful clinical information (e.g., on previous clinic visits, the individual regularly rated their distress as a 2, however today they reported a 7, which alerts the clinician that follow-up may need necessary). This information can then be utilized in a discussion with the individual and if necessary, the offer of referral to supportive care services can be extended.

In addition to the single-item Likert scale assessment of distress, the Distress Thermometer contains a 38-item complementary Problem Checklist. The Problem Checklist seeks to determine whether problems exist in the practical, familial, physical, or spiritual domains of an individual's life (NCCN, 2013). A key benefit of the Problem Checklist is that it may enable clinicians to identify potential sources of distress quickly and subsequently address these concerns as part of the treatment of the whole individual (Gessler et al., 2008).

With respect to the family members, recent efforts have been undertaken to validate the Distress Thermometer for use in the caregiver population (Zwahlen et al., 2008; Zwahlen et al., 2011). Findings from the validation efforts indicated that the Distress Thermometer had good diagnostic utility in caregivers and that a cutoff score of 4 maximized the sensitivity of the measure, which may reduce the risk of missing distressed family members (Zwahlen et al., 2008). Collectively, these validation efforts provide support for the use of the Distress Thermometer as a screening measure in family members of individuals diagnosed with cancer.

In summary, currently available evidence supports the use of the Distress Thermometer in both head and neck cancer and caregiver populations. Further, use of the accompanying Problem Checklist may enable clinicians to quickly identify areas of concern and determine where intervention efforts should be directed in order to provide the most benefit to those in need. Use of the Distress Thermometer and its accompanying Problem Checklist to screen for distress and related areas of concern in caregivers and those with head and neck cancer may help to elucidate the prevalence of distress in individuals in these populations and also target the specific problems facing these individuals. Additionally, in order to better understand the consequent impact of this distress and the related areas of concern, investigations into perceived quality of life among those with head and neck cancer and their caregivers are important. Thus, use of validated, multidimensional quality of life measures, such as those described next, may provide useful insight into the subjective impact of one's perceived problems and level of distress.

European Organisation for Research and Treatment of Cancer Measures. The EORTC is a series of self-administered cancer-specific measurement instruments that are designed to assess quality of life within oncology populations (Sherman et al., 2000). The core questionnaire, the EORTC-QLQ-C30 (version 3.0) (Aaronson et al., 1993), serves as a generic measure of quality of life for all cancer sites. It consists of 30 items, which are divided into five functional scales (physical, role, emotional, cognitive and social functioning), three symptoms scales (pain, fatigue, and nausea/vomiting) and a

measure of global health status, or quality of life (Fayers et al., 2001).

Additionally, there are six single item scales included on the measure (dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial concerns). The sum of all items provides an indication of an individual's overall quality of life (Scott et al., 2008). Responses for items 1 through 28 are recorded on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much). Responses for items 29 and 30 are recorded on a 7-point Likert scale where 1 indicates very poor health or quality of life and 7 indicates excellent health or quality of life. Respondents are asked to answer each item relative to how they have been feeling 'during the last week' (Bjordal et al., 2000). Completion of the core questionnaire is anticipated to take less than 10 minutes. Both the subscale and overall scores are transformed to a scale of 0-100 with higher scores implying a high level of problems or symptoms or, alternatively, a high level of functioning or global quality of life, depending on which subscale is evaluated (Bjordal et al., 2000). The core instrument has been validated in diverse samples of oncology populations within North America and Western Europe (Aaronson et al., 1993; Bjordal & Kaasa, 1992; Hjermstad, Fossa, Bjordal, & Kaasa, 1995; King, Dobson, & Harnett, 1996; Sherman et al., 2000). Overall, the core measure has demonstrated strong psychometric properties including reliability, validity and sensitivity to change (Bjordal et al., 2000; Sherman et al., 2000). Specifically, evaluations of validity and reliability have determined that all scales consistently show Cronbach's alpha coefficients of > 0.70 (Bjordal et al., 2000), which suggests that all scales demonstrated at least moderate if not good levels of reliability according to the

criteria outlined by Portney and Watkins (2009). Consequently, the EORTC-QLQ-C30 was determined to be a suitable measurement instrument for use in the current research efforts.

While it is important to address general quality of life issues that may be relevant to most individuals diagnosed with cancer, there are a number of disease-specific issues that arise in head and neck cancer that also need to be addressed. With this in mind, the creators of the EORTC-QLQ-C30 stipulated that the core instrument was intended to be used in conjunction with an accompanying site-specific module, in order to provide a more comprehensive assessment of an individual's difficulties (Sherman et al., 2000). Studies confirm that both general and site-specific measures each contribute unique and important information regarding quality of life (D'Antonio, Zimmerman, Cella, & Long, 1996; Gliklich, 1997). Notably, the EORTC has devised a range of cancer site-specific measures, which include, prostate, ovarian, esophago-gastric, esophageal, neuroendocrine carcinoid, multiple myeloma, lung, hepatocellular carcinoma, gastric, endometrial, colorectal liver metastases, colorectal, cervical, breast, brain, bone metastases, and head and neck cancer sites (EORTC, 2013).

The EORTC-QLQ-H&N35 (Aaronson et al., 1993) was designed for use among a wide variety of individuals with head and neck cancer, varying in treatment modality and disease stage (Bjordal & Kaasa, 1992; Singer et al., 2012). It is one of the most widely tested disease-specific quality of life measures for oncology populations (Bjordal et al., 2000); to date it has been used in 26 countries and 19 languages indicating broad cross-cultural acceptance (Singer et

al., 2012). In total, the head and neck module contains 35 items divided into seven multi-item scales that assess pain, swallowing, senses (taste and smell), speech, social contact, social eating, and issues pertaining to sexuality (Aaronson et al., 1993). The module also contains eleven single items. Like the core questionnaire, responses for the first 30 items on the head and neck cancer module are recorded on a 4-point Likert scale ranging from 0 (not at all) to 4 (very much), whereas the last five items are presented in a yes/no format. Respondents are asked to answer each item relative to how they have been feeling 'during the last week' (Bjordal et al., 2000). Completion of the head and neck cancer module is anticipated to take approximately less than 10 minutes (Bjordal et al., 2000). Like the core questionnaire (e.g., EORTC-QLQ-C30), the subscale and overall scores are transformed to a scale of 0-100 with higher scores implying a high level of problems or symptoms or, alternatively, a high level of functioning or global quality of life, depending on which subscale is being evaluated (Bjordal et al., 2000). The EORTC-QLQ-H&N35 module has been validated in diverse samples of head and neck cancer sites (Aaronson et al., 1993; Bjordal & Kaasa, 1992; Sherman et al., 2000; Singer et al., 2012). Overall, the EORTC-QLQ-H&N35 module has demonstrated strong psychometric properties including reliability, validity, and sensitivity to change (Bjordal et al., 2000; Sherman et al., 2000; Singer et al., 2012). Specifically, evaluations of test validity and reliability have determined that all scales consistently show Cronbach's alpha coefficients of > 0.70 (values ranged from 0.75 to 0.95), with the exception of the senses scale which demonstrated a coefficient of 0.54 in one

study (Sherman et al., 2000), 0.68 in another (Bjordal et al., 2000), and 0.61 in a more recent evaluation (Singer et al., 2012). Overall, the EORTC core questionnaire and accompanying head and neck cancer module are reported to be excellent measures with good psychometric properties. Further, the H&N35 has been used in both clinical trials and observational studies, and has proven to be well accepted and feasible in both settings (Singer et al., 2012). Owing to the sound psychometric properties, in addition to the proven record of acceptability and feasibility of the EORTC measures in previous observational research, the EORTC global and head and neck specific instruments were deemed suitable to assess perceived quality of life among the individuals diagnosed with head and neck cancer taking part in this investigation.

      Caregiver Quality of Life-Cancer Scale. The CQOLC is a 35-item self-report measure of caregiver quality of life that contains four primary factors (burden, disruptiveness, positive adaptation and financial concerns) and a total CQOLC score (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). This brief measure was designed to assess the impact of supporting a loved one with cancer on the caregiver's physical, emotional, social, financial and familial functioning (among other areas) (Edwards & Ung, 2002). Each item included in the CQOLC is rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much). Respondents are asked to 'indicate how true each statement has been for them during the past seven days'. The maximum total score on the CQOLC measure is 140 with a higher total score indicating better overall quality of life. With regard to the four subscale factors, lower scores in the burden,

disruptiveness and financial concerns domains indicate elevated levels of concern (or poorer quality of life). However, the positive adaptation factor is reverse-coded, so a lower score is indicative of better overall adaptation to the circumstances. In essence, since the positive adaptation domain assesses how well an individual is adapting to the situation and since it is reverse-coded, a lower score (e.g., -20) would indicate better adaptation than a higher score (e.g. -10). Conversely, the remaining subdomains (e.g., burden, disruptiveness, financial concerns) are not reverse-coded; therefore a higher score on each domain (e.g., 20) would indicate a higher degree of perceived penalty than a lower score (e.g., 10).

   With respect to reliability, the internal consistency coefficient (Cronbach's alpha) of the CQOLC was determined to be 0.91 while the test-retest correlation coefficient was 0.95 (Weitzner et al., 1999). Additionally, a review of the psychometric properties of quality of life measures for caregivers of individuals with cancer determined that the CQOLC was the best available quality of life measure for caregivers of individuals with cancer (Edwards & Ung, 2002). The review conducted by Edwards and Ung (2002) also noted that the CQOLC met or exceeded the minimum psychometric criteria for reliability and validity. Therefore, the CQOLC was determined to be a psychometrically sound measure. This factor, considered in conjunction with the findings of Edwards and Ung (2002) in their review of caregiver quality of life measures, contributed to the decision that the CQOLC was the most appropriate instrument for use in the evaluation of quality of life in caregivers of individuals diagnosed with head and neck cancer.

In addition to the evaluation and selection of measures, an equally important component of any research endeavour is the rationale for the design and implementation of the protocol. Thus, in addition to the description of the distress and quality of life measures and their validation characteristics, consideration for how the measures were to be distributed and the rationale surrounding the distribution method is warranted.

Measurement Rationale

As noted in the previous sections, questionnaires were selected as the means of obtaining data from participants for the present research initiatives. In general, questionnaires are structured surveys that are self-administered and utilize either pen and paper or electronic formats (Portney & Watkins, 2009). The questionnaires used in the present investigations were based on the traditional pen and paper format in an effort to ensure that participants who did not have access to the Internet were not excluded from participation. The use of questionnaires was determined to be the most efficient way to gather standardized data from a large sample of participants in a relatively short period of time (Portney & Watkins, 2009). The use of standardized written forms ensured that all participants were exposed to the same questions in the same manner, thus reducing the potential for bias from interactions with an interviewer (Portney & Watkins, 2009). Additionally, questionnaires have been found to be a useful research tool for examining phenomena that can be assessed through self-observation (Portney & Watkins, 2009), such as personal perceptions and values.

The use of written questionnaires to elicit survey data from participants is commonly referred to as self-report measurement, which offers a direct way to obtain information related to perceptions, fears, motivations and attitudes (Portney & Watkins, 2009). Additionally, due to limited time and resources during clinical encounters, it may be difficult to obtain the extensive amount of personal information and perspectives required for the proposed analyses. However, the use of written measures to evaluate the perceived level of distress and quality of life of those with head and neck cancer and their caregivers affords the possibility of gathering a great deal of subjective information in an efficient manner.

Additionally, in an effort to minimize the potential for recall bias, or the possible inaccuracy of recalling previous experiences or medical history, all measurement instruments asked individuals to report their experiences based on how they had been feeling over the past seven days in order to allow participants to reflect on their general level of distress and quality of life. The relatively short time frame may help to minimize inaccuracies in the reports that may arise out of recall bias (e.g., the inability to accurately recall events or perceptions), however the seven day time period was also deemed long enough to ensure that participant responses were reflective of one's general experience for that week rather than a reactionary or falsely elevated level of distress owing to a single event. Furthermore, research has shown that self-report measures are generally valid, despite the potential for recall bias (Portney & Watkins, 2009). Ultimately, the use of self-report measures may be particularly beneficial for evaluations of

quality of life and distress, where individuals may be hesitant to reveal sensitive mental health concerns in a time-limited clinical encounter.

Despite the fact that distress may be causing disruptions in daily functioning, many individuals may conceal their distress from their primary physician and healthcare team (Weisman, 1976). Individuals displaying such behaviour may rationalize their secretive response as an appropriate one because they believe that their physician and healthcare team need to focus their energy on the treatment of their disease. Conversely, oncologists and healthcare team members may lack the time or skills required to accurately identify and refer individuals exhibiting significant distress to the appropriate psychological resources (Carlson et al., 2004; Sollner, 2001; Zabora, Loscalzo, & Weber, 2003). The outcome of these combined elusive approaches is the collective avoidance of the problem. Consequently, distress may remain undisclosed and only become apparent when it has increased to a point where the individual is no longer able to independently manage the situation. However, the use of written, self-report measures to evaluate distress and quality of life of those with head and neck cancer and their caregivers affords the possibility of gathering a great deal of subjective information in a clinical situation where individuals may previously have chosen not to reveal sensitive mental health concerns.

Thus, in summary the Distress Thermometer, EORTC and CQOLC assessment tools are psychometrically sound measurement instruments capable of detecting levels of quality of life and the presence of clinically significant distress among individuals diagnosed with head and neck cancer and their

caregivers. Further, the utilization of self-report techniques within the present study has the advantage of deriving data from the individual centrally involved in the phenomena. Perceptions of distress and quality of life are deeply personal experiences and thus, the individual at the center of that experience can provide the most meaningful and clinically relevant information. The use of data derived from psychometrically sound self-report measures to identify distressing areas in one's life may allow for appropriate assistance and psychosocial intervention when warranted. Thus, through the valid identification of distress, the potential to improve quality of life and positively influence post-treatment outcomes may emerge.

Summary of Problem

A diagnosis of head and neck cancer carries with it a unique set of treatment-related challenges that influence physical function, social interaction and emotional expression. As a result of the anatomic characteristics of the head and neck region, treatment for head and neck cancer may result in deficits to one's physical appearance and varying degrees of dysfunction in respiration, swallowing, and speech (Vartanian et al., 2004). Consequently, individuals may experience substantial problems in family and social settings (Semple et al., 2004). Not surprisingly, treatment of head and neck cancer has been associated with some of the highest rates of anxiety, depression and suicide when compared with other cancer sites (Bjordal & Kaasa, 1995; Kendal, 2006; Misono et al., 2008). These findings suggest that head and neck cancer is highly traumatic psychosocially with a multitude of complex patient concerns emerging.

Relative to the caregiver experience, these individuals are expected to support the physical, psychological, social and practical needs of their loved one, while simultaneously grieving their own losses – both real and anticipated. They must also work to maintain their regular family and employment-related responsibilities, while balancing their fears, anxieties and concerns for the well-being of their loved one. Ultimately, the provision of care for an individual with cancer may be a challenging, disruptive, and time-consuming endeavor (Williams & Bakitas, 2012). Given the level of burden facing caregivers, it is not surprising that multiple studies report higher levels of anxiety and depression in caregivers than in the individuals with cancer (Mellon et al., 2006; Vickery et al., 2003). Since the presence of elevated distress in caregivers has been identified as a factor that may compromise both the physical health and psychological well-being of both caregivers and those with cancer (Hagedoorn et al., 2008; Northouse et al., 2001), investigations into the factors which can influence distress may inform our understanding of the caregiver experience.

Psychological distress related to cancer is a persistent and universal concern that must be addressed in a clinically meaningful manner. Distress has become so problematic that the Canadian Strategy for Cancer Control has formally recognized it as the "sixth vital sign" (Rebalance Action Focus Group [RAFG], 2005), implying that distress monitoring should be undertaken as routinely as the monitoring of one's heart rate or blood pressure. Despite this acknowledgment, less than 10% of distressed individuals are identified and referred to the appropriate psychosocial resources (Kadan-Lottick,

Vanderwerker, Block, Zhang, & Prigerson, 2005). Failure to acknowledge and treat elevated distress among individuals with head and neck cancer jeopardizes treatment outcomes, decreases quality of life, and increases healthcare costs (Zabora et al., 2001). Thus, in order to minimize the overall negative impact of head and neck cancer and address the consequences resulting from decreased quality of life and distress, efforts must be made to understand the presence of and variation in distress and quality of life across both individuals with head and neck cancer and their caregivers.

Both individuals with head and neck cancer and their caregivers experience significant disruption in their lives as a result of the physical and psychological impact of the disease and its treatment. Currently, there exists a gap in the knowledge regarding how these individuals perceive this impact and the meanings associated with these disruptions. Thus the identification of distress and its potentially negative influence on quality of life is of paramount importance. Perhaps best stated by Owen and colleagues (2001), "until a major therapeutic breakthrough takes place reducing treatment morbidity, improving patients overall quality of life and minimizing the psychosocial impact will be our greatest challenge" (p.351). In order to attend to the psychosocial needs of individuals with head and neck cancer and their caregivers, it is imperative to develop an understanding of the life factors associated with elevated distress. For this reason, instruments exploring the multidimensional factors related to quality of life will be assessed in conjunction with validated measures of distress and demographic information in an effort to identify and characterize the

relationship between distress and quality of life in both individuals with head and neck cancer and their caregivers. With this information, healthcare practitioners may be able to identify those individuals most at risk for distress and subsequently recommend the appropriate psychosocial resources as required. Thus, the purpose of the present study is to address the following objectives:

1. To assess perceived distress and quality of life in individuals with head and neck cancer and their caregivers.

2. To explore the frequency of reported concerns (e.g., practical, physical, psychosocial, spiritual, etc.) in individuals with head and neck cancer and their caregivers.

3. To determine the relationship between distress and specific disease- and/or treatment-related variables in caregivers of individuals with head and neck cancer.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., . . . Takeda, F. (1993). The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85*, 365-376.

Akizuki, N., Akechi, T., Nakanishi, T., Yoshikawa, E., Okamura, M., Nakano, T., . . . Uchitomi, Y. (2003). Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer, 97*(10), 2605-2613. doi: 10.1002/cncr.11358

American Psychological Association (APA). (2000). Diagnostic and statistical manual of mental disorders - 4th edition text revision (DSM-IV-TR, 2000) APA (Ed.) Retrieved from http://online.statref.com.proxy1.lib.uwo.ca/Document.aspx?docAddress=4 PNCnYvddqP04-isS- 3QEw%3d%3d&SessionId=1A9C4CBJVGMKQUIG&Scroll=1&goBestMat ch=true&Index=10&searchContext=DSM-IV-TR|c0||10|0|0|0|0|0||c0

Andreu, Y., Galdón, M. J., Durá, E., Martínez, P., Pérez, S., & Murgui, S. (2012). A longitudinal study of psychosocial distress in breast cancer: Prevalence and risk factors. *Psychology & Health, 27*(1), 72-87. doi: 10.1080/08870446.2010.542814

Archer, J., Hutchison, I., & Korszun, A. (2008). Mood and malignancy: Head and neck cancer and depression. *Journal of Oral Pathology & Medicine, 37*(5), 255-270. doi: 10.1111/j.1600-0714.2008.00635.x

Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Journal of the American Medical Association, 307*(4), 398-403.

Birnie, K., Garland, S. N., & Carlson, L. E. (2010). Psychological benefits for cancer patients and their partners participating in mindfulness-based stress reduction (MBSR). *Psycho-Oncology, 19*(9), 1004-1009. doi: 10.1002/pon.1651

Bjordal, K., de Graeff, A., Fayers, P. M., Hammerlid, E., van Pottelsberghe, C., Curran, D., . . . Kaasa, S. (2000). A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35) in head and neck patients. *European Journal of Cancer, 36*(14), 1796-1807.

Bjordal, K., & Kaasa, S. (1992). Psychometric validation of the EORTC core quality of life questionnaire, 30-item version and a diagnosis-specific module for head and neck cancer. *Acta Oncologica, 31*(3), 311-321.

Bjordal, K., & Kaasa, S. (1995). Psychological distress in head and neck cancer patients 7-11 years after curative treatment. *British Journal of Cancer, 71*, 592-597.

Björklund, M., Sarvimäki, A., & Berg, A. (2010). Living with head and neck cancer: A profile of captivity. *Journal of Nursing and Healthcare of Chronic Illness, 2*(1), 22-31. doi: 10.1111/j.1752-9824.2010.01042.x

Blood, G. W., Simpson, K. C., Dineen, M., Kauffman, S. M., & Raimondi, S. C. (1994). Spouses of individuals with laryngeal cancer: Caregiver strain and burden. *Journal of Communication Disorders, 27*, 19-35.

Bornbaum, C. C., Fung, K., Franklin, J. H., Nichols, A., Yoo, J., & Doyle, P. C. (2012). A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Supportive Care in Cancer, 20*(9), 2157-2165. doi: 10.1007/s00520-011-1326-2

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology, 25*(30), 4829-4834. doi: 10.1200/jco.2006.10.0909

Brooks, P. J., & Theruvathu, J. A. (2005). DNA adducts form acetaldehyde: Implications for alcohol-related carcinogenesis. *Alcohol, 35*, 187-193.

Butt, Z., Wagner, L. I., Beaumont, J. L., Paice, J. A., Peterman, A. H., Shevrin, D., . . . Cella, D. (2008). Use of a single-item screening tool to detect clinically significant fatigue, pain, distress, and anorexia in ambulatory cancer practice. *Journal of Pain and Symptom Management, 35*(1), 20-30. doi: 10.1016/j.jpainsymman.2007.02.040

Campisi, G., & Giovannelli, L. (2009). Controversies surrounding human papilloma virus infection, head & neck vs oral cancer, implications for prophylaxis and treatment. *Head & Neck Oncology, 1*(1), 8. doi: 10.1186/1758-3284-1-8

Carlson, L. (2003). Cancer distress screening needs, models, and methods. *Journal of Psychosomatic Research, 55*(5), 403-409. doi: 10.1016/s0022-3999(03)00514-2

Carlson, L., & Bultz, B. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses. *Psycho-Oncology, 13*(12), 837-849. doi: 10.1002/pon.832

Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., . . . Bultz, B. D. (2004). High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer*. doi: 10.1038/sj.bjc.6601887

Carlson, L. E., Waller, A., Groff, S. L., Giese-Davis, J., & Bultz, B. D. (2013). What goes up does not always come down: Patterns of distress, physical and psychosocial morbidity in people with cancer over a one   year period. *Psycho-Oncology, 22*(1), 168-176. doi: 10.1002/pon.2068

Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & O'Connell, D. L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education and Counseling, 85*(2), e75-e88. doi: 10.1016/j.pec.2011.01.027

Cleeland, C. S. (2007). Symptom burden: Multiple symptoms and their impact as patient-reported outcomes. *JNCI Monographs, 2007*(37), 16-21. doi: 10.1093/jncimonographs/lgm005

Cogliano, V., Straif, K., Baan, R., Grosse, Y., Secretan, B., & Ghissassi, F. E. (2004). Smokeless tobacco and tobacco-related nitrosamines. *The Lancet Oncology, 5*(12), 708. doi: 10.1016/s1470-2045(04)01633-x

Cohen, J., Stock, M., Andersen, P., & Everts, E. (1997). Critical pathways for head and neck surgery: Development and implementation. *Archives of*

Otolaryngology Head and Neck Surgery, 123(1), 11-14. doi: 10.1001/archotol.1997.01900010013001

Coristine, M., Crooks, D., Grunfeld, E., Stonebridge, C., & Christie, A. (2003). Caregiving for women with advanced breast cancer. *Psycho-Oncology, 12*(7), 709-719. doi: 10.1002/pon.696

Cullen, J. W., Blot, W., Henningfield, J., Boyd, G., Mecklenberg, R., & Massey, M. M. (1986). Health consequences of using smokeless tobacco: Summary of the advisory committee's report to the surgeon general. *Public Health Report, 101(4), 355-373., 101*(4), 355-373.

D'Antonio, L., Zimmerman, G. J., Cella, D. F., & Long, S. A. (1996). Quality of life and functional status measures in patients with head and neck cancer. *Archives of Otolaryngology, Head & Neck Surgery, 122*(5), 482-487. doi: 10.1001/archotol.1996.01890170018005

Derogatis, L. (2001). *BSI 18, Brief Symptom Inventory 18: Administration, scoring and procedures manual*: NCS Pearson, Inc.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine, 160*, 2101-2107.

Doyle, P. C. (1994). *Foundations of voice and speech rehabilitation following laryngeal cancer*: Singular Publishing Group.

Doyle, P. C. (2005). *Rehabilitation in head and neck cancer: Overview*. Texas: PRO-ED, Incorporated.

Drabe, N., Wittmann, L., Zwahlen, D., Büchi, S., & Jenewein, J. (2012). Changes in close relationships between cancer patients and their partners. *Psycho-Oncology*. doi: 10.1002/pon.3144

Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology, 13*(8), 562-576. doi: 10.1002/pon.773

Edwards, B., & Ung, L. (2002). Quality of life instruments for caregivers of patients with cancer: A review of their psychometric properties. *Cancer Nursing, 25*(5), 342-349.

Elani, H. W., & Allison, P. J. (2011). Coping and psychological distress among head and neck cancer patients. *Support Care Cancer, 19*(11), 1735-1741. doi: 10.1007/s00520-010-1013-8

European Organisation for the Research and Treatment of Cancer (EORTC). (2013). Why do we need modules? *EORTC Quality of Life*. Retrieved March 30, 2013, 2013, from http://groups.eortc.be/qol/eortc-modules

Fayers, P. M., Aaronson, N. K., Bjordal, K., Groenvold, M., Curran, D., & Bottomley, A. (2001). *The EORTC QLQ-C30 scoring manual (3rd Edition)*. Brussels: The European Organisation for Research and Treatment of Cancer.

Ferlay, J., Shin, H.-R., Bray, F., Forman, D., Mathers, C., & Parkin, D. M. (2010). Estimates of worldwide burden of cancer in 2008: Globocan 2008.

International Journal of Cancer, 127(12), 2893-2917. doi: 10.1002/ijc.25516

Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with hiv/aids and cancer. *Journal of Health and Social Behaviour, 41*, 50-67.

Fors, E. A., Bertheussen, G. F., Thune, I., Juvet, L. K., Elvsaas, I.-K. Ø., Oldervoll, L., . . . Leivseth, G. (2010). Psychosocial interventions as part of breast cancer rehabilitation programs? Results from a systematic review. *Psycho-Oncology*. doi: 10.1002/pon.1844

Forte, T., Niu, J., Lockwood, G. A., & Bryant, H. E. (2012). Incidence trends in head and neck cancers and human papillomavirus (HPV)-associated oropharyngeal cancer in canada, 1992–2009. *Cancer Causes & Control, 23*(8), 1343-1348. doi: 10.1007/s10552-012-0013-z

Foster, L. W., McLellan, L. J., Rybicki, L. A., Sassano, D. A., Hsu, A., & Bolwell, B. J. (2005). Survival of patients who have undergone allogeneic bone marrow transplantation. *Journal of Psychosocial Oncology, 22*(2), 1-20. doi: 10.1300/J077v22n02_01

Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A., & Jones, L. (2008). Screening for distress in cancer patients: Is the distress thermometer a valid measure in the uk and does it measure change over time? A prospective validation study. *Psycho-Oncology, 17*(6), 538-547. doi: 10.1002/pon.1273

Gil, F., Grassi, L., Travado, L., Tomamichel, M., & Gonzalez, J. R. (2005). Use of distress and depression thermometers to measure psychosocial morbidity among southern european cancer patients. *Supportive Care in Cancer, 13*(8), 600-606. doi: 10.1007/s00520-005-0780-0

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

Gliklich, R. E., Goldsmith, T.A., Funk, G.F. (1997). Are head and neck specific quality of life measures necessary? *Head & Neck, 19*, 474-480.

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin, 134*(1), 1-30. doi: 10.1037/0033-2909.134.1.1

Haman, K. L. (2008). Psychologic distress in head and neck cancer: Part 1 - review of the literature. *Journal of Supportive Oncology, 6*(4), 155-163.

Hamilton, R., Miedema, B., MacIntyre, L., & Easley, J. (2011). Using a positive self-talk intervention to enhance coping skills in breast cancer survivors: Lessons from a community-based group delivery model. *Current Oncology, 18*(2), e46-e53.

Hammerlid, E., Ahlner-Elmqvist, M., Bjordal, K., Biorklund, A., Evensen, J., Boysen, M., . . . Westin, T. (1999). A prospective multicentre study in sweden and norway of mental distress and psychiatric morbidity in head and neck cancer patients. *Br J Cancer, 80*(5-6), 766-774. doi: 10.1038/sj.bjc.6690420

Hart, S. L., Hoyt, M. A., Diefenbach, M., Anderson, D. R., Kilbourn, K. M., Craft, L. L., . . . Stanton, A. L. (2012). Meta-analysis of efficacy of interventions for elevated depressive symptoms in adults diagnosed with cancer. *JNCI Journal of the National Cancer Institute, 104*(13), 990-1004. doi: 10.1093/jnci/djs256

Hashibe, M., Brennan, P., Benhamou, S., Castellsague, X., Chen, C., Curado, M. P., . . . Boffetta, P. (2007). Alcohol drinking in never users of tobacco, cigarette smoking in never drinkers, and the risk of head and neck cancer: Pooled analysis in the international head and neck cancer epidemiology consortium. *JNCI Journal of the National Cancer Institute, 99*(10), 777-789. doi: 10.1093/jnci/djk179

Hegel, M. T., Collins, E. D., Kearing, S., Gillock, K. L., Moore, C. P., & Ahles, T. A. (2008). Sensitivity and specificity of the distress thermometer for depression in newly diagnosed breast cancer patients. *Psycho-Oncology, 17*(6), 556-560. doi: 10.1002/pon.1289

Henderson, V. P., Clemow, L., Massion, A. O., Hurley, T. G., Druker, S., & Hébert, J. R. (2011). The effects of mindfulness-based stress reduction on psychosocial outcomes and quality of life in early-stage breast cancer patients: A randomized trial. *Breast Cancer Research and Treatment, 131*(1), 99-109. doi: 10.1007/s10549-011-1738-1

Hjermstad, M., Fossa, S., Bjordal, K., & Kaasa, S. (1995). Test/retest study of the european organization for research and treatment of cancer core quality of life questionnaire. *Journal of Clinical Oncology, 13*, 1249-1254.

Hodges, L. J., & Humphris, G. M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology, 18*(8), 841-848. doi: 10.1002/pon.1346

Hoffman, B. M., Zevon, M. A., D'Arrigo, M. C., & Cecchini, T. B. (2004). Screening for distress in cancer patients: The NCCN rapid-screening measure. *Psycho-Oncology, 13*(11), 792-799. doi: 10.1002/pon.796

Howren, M. B., Christensen, A. J., Karnell, L. H., & Funk, G. F. (2012). Psychological factors associated with head and neck cancer treatment and survivorship: Evidence and opportunities for behavioral medicine. *Journal of Consulting and Clinical Psychology*. doi: 10.1037/a0029940

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship, 35*(1), 27-32.

Jacobsen, P. B., Donovan, K. A., Trask, P. C., Fleishman, S. B., Zabora, J., Baker, F., & Holland, J. C. (2005). Screening for psychologic distress in ambulatory cancer patients. *Cancer, 103*(7), 1494-1502. doi: 10.1002/cncr.20940

Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *Ca: A Cancer Journal for Clinicians, 61*(2), 69-90. doi: 10.3322/caac.20107

Jenkins, C., Carmody, T. J., & Rush, J. (1998). Depression in radiation oncology patients: A preliminary evaluation. *Journal of Affective Disorders, 50*, 17-21.

Johnson-Obaseki, S., McDonald, J. T., Corsten, M., & Rourke, R. (2012). Head and neck cancer in canada: Trends 1992 to 2007. *Otolaryngology -- Head and Neck Surgery, 147*(1), 74-78. doi: 10.1177/0194599812437332

Kadan-Lottick, N. S., Vanderwerker, L. C., Block, S. D., Zhang, B., & Prigerson, H. G. (2005). Psychiatric disorders and mental health service use in patients with advanced cancer. *Cancer, 104*(12), 2872-2881. doi: 10.1002/cncr.21532

Kendal, W. (2006). Suicide and cancer: A gender-comparative study. *Annals of Oncology, 18*(2), 381-387. doi: 10.1093/annonc/mdl385

Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69*(3), 283-291. doi: 10.1097/PSY.0b013e3180417cf4

King, M., Dobson, A., & Harnett, P. (1996). A comparison of two quality-of-life questionnaires for cancer clinical trials: The functional living index-cancer (FLIC) and the quality of life questionnaire core module (QLQ-C30). *Journal of Clinical Epidemiology, 49*(1), 21-29.

Kissane, D., & Bloch, S. (2002). *Family focused grief therapy.* Oxford: Oxford University Press.

Koster, M. E. T. A., & Bergsma, J. (1990). Problems and coping behaviour of facial cancer patients. *Social Science & Medicine, 30*(5), 569-578. doi: 10.1016/0277-9536(90)90155-L

Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2004). Depression and physical health among family caregivers of geriatric patients with cancer-- a longitudinal view. *Medical science monitor: International medical journal of experimental and clinical research, 10*(8), CR447.

Lam, W. W. T., Shing, Y. T., Bonanno, G. A., Mancini, A. D., & Fielding, R. (2012). Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. *Psycho-Oncology, 21*(1), 90-99. doi: 10.1002/pon.1876

Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. (2010). Exploring factors that influence informal caregiving in medication management for home hospice patients. *Journal of Palliative Medicine, 13*(9), 1085-1090. doi: 10.1089/jpm.2010.0082

Lebel, S., Castonguay, M., Mackness, G., Irish, J., Bezjak, A., & Devins, G. M. (2013). The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-Oncology, 22*(1), 140-152. doi: 10.1002/pon.2063

Lev, E., & McCorkle, R. (1998). Loss, grief, and bereavement in family members of cancer patients. *seminars in Oncology Nursing, 14*(2), 145-151.

Li, X., Gao, L., Li, H., Gao, J., Yang, Y., Zhou, F., . . . Jin, Q. (2012). Human papillomavirus infection and laryngeal cancer risk: A systematic review and meta-analysis. *Journal of Infectious Diseases, 207*(3), 479-488. doi: 10.1093/infdis/jis698

Liu, H.-E. (2008). Changes of satisfaction with appearance and working status for head and neck tumour patients. *Journal of Clinical Nursing, 17*(14), 1930-1938. doi: 10.1111/j.1365-2702.2008.02291.x

Longacre, M. L., Ridge, J. A., Burtness, B. A., Galloway, T. J., & Fang, C. Y. (2012). Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncology, 48*(1), 18-25. doi: 10.1016/j.oraloncology.2011.11.012

Lydiatt, W. M., Moran, J., & Burke, W. J. (2009). A review of depression in the head and neck cancer patient. *Clinical Advances in Hematology & Oncology, 7*(6), 397-403.

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

Marur, S., & Forastiere, A. A. (2008). Head and neck cancer: Changing epidemiology, diagnosis and treatment. *Mayo Clinic Proceedings, 83*(4), 489-501.

McCorkle, R., & Pasacreta, J. V. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control, 8*(1), 36-45.

McDonough, E., Boyd, J., Varvares, M., & Maves, M. (1996). Relationship between psychological status and compliance in a sample of patients treated for cancer of the head and neck *Head & Neck, 18*, 269-276.

Mellon, S., Northouse, L. L., & Weiss, L. K. (2006). A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing, 29*(2), 120-131.

Miller, K., & Massie, M. J. (2009). Depressive disorders. In J.C. Holland, W.S. Breitbart, P.B. Jacobsen, M.S. Ledeberg, M.J. Loscalzo (Eds), *Psycho-Oncology*, (pp.311-318). New York, NY: Oxford University Press.

Misono, S., Weiss, N. S., Fann, J. R., Redman, M., & Yueh, B. (2008). Incidence of suicide in persons with cancer. *Journal of Clinical Oncology, 26*(29), 4731-4738. doi: 10.1200/jco.2007.13.8941

Mitchell, A. J. (2010). Short screening tools for cancer-related distress: A review and diagnostic validity meta-analysis. *Journal of the National Comprehensive Cancer Network, 8*, 487-494.

Mohan, T. B., & Pandey, T. I. (2002). Development of a distress inventory for cancer: Preliminary results. *Journal of Postgraduate Medicine, 48*(1), 16-20.

National Comprehensive Cancer Network (NCCN). (2013). NCCN clinical practice guidelines in oncology: Distress management. *2.2013*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Newell, S. A., Sanson-Fisher, R. W., & Savolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute, 94*(8), 559-584.

Northouse, L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine, 24*(2), 115-136.

Northouse, L., Williams, A. I., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology, 30*(11), 1227-1234. doi: 10.1200/jco.2011.39.5798

Northouse, L. L., Katapodi, M. C., Schafenacker, A. M., & Weiss, D. (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing, 28*(4), 236-245. doi: 10.1016/j.soncn.2012.09.006

Northouse, L. L., & McCorkle, R. (2010). Spouse caregivers of cancer patients. In J. C. Holland, W. S. Breitbart, P. B. Jacobsen, M. S. Lederberg, M. J. Loscalzo & R. McCorkle (Eds.), *Psycho-oncology* (Second Ed., pp. 516-521). New York: Oxford University Press.

Pai, S. I., & Westra, W. H. (2009). Molecular pathology of head and neck cancer: Implications for diagnosis, prognosis, and treatment. *Annual Review of Pathology: Mechanisms of Disease, 4*(1), 49-70. doi: 10.1146/annurev.pathol.4.110807.092158

Palos, G. R., Mendoza, T. R., Liao, K.-P., Anderson, K. O., Garcia-Gonzalez, A., Hahn, K., . . . Cleeland, C. S. (2011). Caregiver symptom burden: The risk of caring for an underserved patient with advanced cancer. *Cancer, 117*(5), 1070-1079. doi: 10.1002/cncr.25695

Park, S. M., Kim, Y. J., Kim, S., Choi, J. S., Lim, H.-Y., Choi, Y. S., . . . Yun, Y. H. (2009). Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. *Supportive Care in Cancer, 18*(6), 699-706. doi: 10.1007/s00520-009-0668-5

Payakachat, N., Ounpraseuth, S., & Suen, J. Y. (2012). Late complications and long-term quality of life for survivors (>5 years) with history of head and neck cancer. *Head & Neck*, 1-7. doi: 10.1002/hed.23035

Pearlin, L. (1994). Conceptual strategies for the study of caregiver stress. In E. Light & G. Niederehe (Eds.), *Stress effects on family caregivers of alzheimer's patients: Research and interventions* (pp. 3-21). New York: Springer.

Penedo, F. J., Traegar, L., Dahn, J., Molton, I., Gonzalez, J. S., Schneiderman, N., & Antoni, M. H. (2007). Cognitive behavioral stress management intervention improves quality of life in spanish monolingual hispanic men treated for localized prostate cancer: Results of a randomized controlled trial. *International Journal of Behavioral Medicine, 14*(3), 164-172.

Penner, J. L. (2009). Psychosocial care of patients with head and neck cancer. *seminars in Oncology Nursing, 25*(3), 231-241. doi: 10.1016/j.soncn.2009.05.008

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (Third ed.). Upper Saddle River, NJ: Pearson Education Inc.

Ragin, C. C. R., Modugno, F., & Gollin, S. M. (2007). The epidemiology and risk factors of head and neck cancer: A focus on human papillomavirus. *Journal of Dental Research, 86*(2), 104-114. doi: 10.1177/154405910708600202

Ransom, S., Jacobsen, P. B., & Booth-Jones, M. (2006). Validation of the distress thermometer with bone marrow transplant patients. *Psycho-Oncology, 15*(7), 604-612. doi: 10.1002/pon.993

Recklitis, C. J., Licht, I., Ford, J., Oeffinger, K., & Diller, L. (2007). Screening adult survivors of childhood cancer with the distress thermometer: A comparison with the SCL-90-R. *Psycho-Oncology, 16*(11), 1046-1049. doi: 10.1002/pon.1212

Rebalance Action Focus Group. (2005). A position paper: Screening key indicators in cancer patients – pain as the 5th vital sign and distress as the 6th vital sign. *Canadian Strategy for Cancer Control Bulletin, 7*(4), 41-42.

Rodriguez, T., Altieri, A., Chatenoud, L., Gallus, S., Bosetti, C., Negri, E., . . . La Vecchia, C. (2004). Risk factors for oral and pharyngeal cancer in young adults. *Oral Oncology, 40*, 207-213. doi: 10.1016/j.oraloncology.2003.08.014

Rohleder, N., Marin, T. J., Ma, R., & Miller, G. E. (2009). Biologic cost of caring for a cancer patient: Dysregulation of pro- and anti-inflammatory signaling pathways. *Journal of Clinical Oncology, 27*(18), 2909-2915. doi: 10.1200/jco.2008.18.7435

Roing, M., Hirsch, J.-M., & Holstrom, I. (2008). Living in a state of suspension – a phenomenological approach to the spouse's experience of oral cancer. *Scandinavian Journal of Caring Science, 22*(1), 40-47.

Roscoe, J. A., Kaufman, M. E., Matteson-Rusby, S. E., Palesh, O. G., Ryan, J. L., Kohli, S., . . . Morrow, G. R. (2007). Cancer-related fatigue and sleep disorders. *The Oncologist, 12*(suppl. 1), 35-42. doi: 10.1634/theoncologist.12-S1-35

Schubart, J. R., Kinzie, M. B., & Farace, E. (2008). Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro-Oncology, 10*(1), 61-72. doi: 10.1215/15228517-2007-040

Scott, N. W., Fayers, P. M., Aaronson, N. K., Bottomley, A., de Graeff, A., Groenvold, M., . . . Sprangers, M. A. (2008). EORTC QLQ-C30 reference values   Retrieved from http://groups.eortc.be/qol/sites/default/files/img/newsletter/reference_values_manual2008.pdf

Segrin, C., Badger, T., Dorros, S. M., Meek, P., & Lopez, A. M. (2007). Interdependent anxiety and psychological distress in women with breast cancer and their partners. *Psycho-Oncology, 16*(7), 634-643. doi: 10.1002/pon.1111

Semple, C. J. (2001). The role of the CNS in head and neck oncology. *Nursing Standard, 15*(23), 39-42.

Semple, C. J., Sullivan, K., Dunwoody, L., & Kernohan, W. G. (2004). Psychosocial interventions for patients with head and neck cancer: Past, present and future *Cancer Nursing, 27*(6), 434-441.

Sherman, A. C., Simonton, S., Adams, D. C., Vural, E., Owens, B., & Hanna, E. (2000). Assessing quality of life in patients with head and neck cancer: Cross-validation of the european organization for research and treatment of cancer (EORTC) quality of life head and neck module (QLQ-H&N35). *Archives of Otolaryngology, Head and Neck Surgery, 126*, 459-467.

Shone, G. R., & Yardley, M. P. J. (1991). An audit into the incidence of handicap after unilateral radical neck dissection. *The Journal of Laryngology and Otology, 105*, 760-762.

Short, P. F., Vasey, J. J., & Tunceli, K. (2005). Employment pathways in a large cohort of adult cancer survivors. *Cancer, 103*(6), 1292-1301. doi: 10.1002/cncr.20912

Siegel, R., Ward, E., Brawley, O., & Jemal, A. (2011). Cancer statistics, 2011. *Ca: A Cancer Journal for Clinicians, 61*(4), 212-236. doi: 10.3322/caac.20121

Singer, S., Arraras, J. I., Chie, W.-C., Fisher, S. E., Galalae, R., Hammerlid, E., . . . Hofmeister, D. (2012). Performance of the EORTC questionnaire for the assessment of quality of life in head and neck cancer patients EORTC QLQ-H&N35: A methodological review. *Quality of Life Research*. [Epub ahead of print] doi: 10.1007/s11136-012-0325-1

Singer, S., Krauss, O., Keszte, J., Siegl, G., Papsdorf, K., Severi, E., . . . Kortmann, R. D. (2012). Predictors of emotional distress in patients with head and neck cancer. *Head Neck, 34*(2), 180-187. doi: 10.1002/hed.21702

Sollner, W., De Vries, A., Steixner, E., Sprinzi, G., Rumpold, G., Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer, 84*(2), 179-185. doi: 10.1054/

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*(10), 1013-1025. doi: 10.1002/pon.1670

Stetz, K. M., & Brown, M.-A. (2004). Physical and psychosocial health in family caregiving: A comparison of aids and cancer caregivers. *Public Health Nursing, 21*(6), 533-540.

Sturgis, E. M., & Cinciripini, P. M. (2007). Trends in head and neck cancer incidence in relation to smoking prevalence. *Cancer, 110*(7), 1429-1435. doi: 10.1002/cncr.22963

Syrjanen, K., Pyrhonen, S., & Syrjanen, S. (1983). Evidence suggesting human papillomavirus (HPV) etiology for the squamous cell papilloma of the paranasal sinus. *Arch Geschwulstforsch, 53*, 77-82.

Taylor, J. C., Terrell, J. E., Ronis, D. L., Fowler, K. E., Bishop, C., Lambert, M. T., . . . Duffy, S. A. (2004). Disability in patients with head and neck cancer. *Archives of Otolaryngology Head and Neck Surgery, 130*, 764-769.

Van Houtven, C. H., Ramsey, S. D., Hornbrook, M. C., Atienza, A. A., & van Ryn, M. (2010). Economic burden for informal caregivers of lung and colorectal cancer patients. *The Oncologist, 15*(8), 883-893. doi: 10.1634/theoncologist.2010-0005

van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., . . . Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology, 20*(1), 44-52. doi: 10.1002/pon.1703

Vartanian, J. G., Carvalho, A. L., Yueh, B., Priante, A., de Melo, R., Correia, L., . . . Kowalski, L. P. (2004). Long-term quality-of-life evaluation after head and neck cancer treatment in a developing country. *Archives of Otolaryngology Head and Neck Surgery, 130*, 1209-1213.

Verdonck-de Leeuw, I. M., Van Bleek, W.-J., Leemans, C. R., & de Bree, R. (2010). Employment and return to work in head and neck cancer survivors. *Oral Oncology, 46*(1), 56-60.

Vickery, L. E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck, 25*(4), 289-296. doi: 10.1002/hed.10206

Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *JNCI Journal of the National Cancer Institute, 101*(21), 1464-1488. doi: 10.1093/jnci/djp336

Vokes, E. E. (2012). Head and neck cancer. In A. S. F. D.L. Longo, D.L. Kasper, S.L. Hauser, J.L. Jameson, J. Loscalzo (Ed.), Harrison's Principles of Internal Medicine, 18th Edition. New York: McGraw-Hill. Retrieved from http://www.accessmedicine.com.proxy2.lib.uwo.ca/content.aspx?aID=911 5451

Walden, M. J., & Aygun, N. (2013). Head and neck cancer. *Seminars in Roentgenology, 48*(1), 75-86. doi: 10.1053/j.ro.2012.09.002

Weisman, A. (1976). Early diagnosis of vulnerability in cancer patients. *American Journal of Medical Science, 271*, 187-196.

Weitzner, M. A., Jacobsen, P. B., Wagner, J. H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index - Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*, 55-63.

Westra, W. H. (2009). The changing face of head and neck cancer in the 21st century: The impact of HPV on the epidemiology and pathology of oral cancer. *Head and Neck Pathology, 3*(1), 78-81. doi: 10.1007/s12105-009-0100-y

Williams, A.-l., & Bakitas, M. (2012). Cancer family caregivers: A new direction for interventions. *Journal of Palliative Medicine, 15*(7), 775-783. doi: 10.1089/jpm.2012.0046

Williams, L. A. (2007). Whatever it takes: Informal caregiving dynamics in blood and marrow transplantation. *Oncology Nursing Forum, 34*(2), 379-387.

World Health Organization (WHO). (2008). *The global burden of disease: 2004 update.* Geneva: WHO Press.

Wynder, E. L., & Bross, I. J. (1957). A study of the etiological factors in cancer of the mouth. *Cancer, 10*(6), 1300-1323.

Wynder, E. L., Bross, I. J., & Feldman, R. M. (1961). A study of etiological factors in cancer of the esophagus. *Cancer, 14*(2), 389-413.

Yabroff, K. R., & Kim, Y. (2009). Time costs associated with informal caregiving for cancer survivors. *Cancer, 115*(S18), 4362-4373. doi: 10.1002/cncr.24588

Yueh, B., Weaver, E. M., Bradley, E. H., Krumholz, H. M., Heagerty, P., Conley, A., & Sasaki, C. T. (2003). A critical evaluation of critical pathways in head and neck cancer. *Archives of Otolaryngology Head and Neck Surgery, 129*, 89-95.

Yuen, H. K., Gillespie, M. B., Day, T. A., Morgan, L., & Burik, J. K. (2007). Driving behaviors in patients with head and neck cancer during and after cancer treatment: A preliminary report. *Head & Neck, 29*(7), 675-681. doi: 10.1002/hed.20567

Zabora, J., Brintzenhofeszoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology, 10*, 19-28.

Zabora, J. R., Loscalzo, M. J., & Weber, J. (2003). Managing complications in cancer: Responding to the patient's perspective. *Seminars in Oncology Nursing, 19*(4, Suppl 2), 1-9. doi: 10.1016/S0749-2081(03)00113-X

Zhang, Z. F., Morgenstern, H., Spitz, M. R., Tashkin, D. P., Yu, G. P., Hsu, T. C., & Schantz, S. P. (2000). Environmental tobacco smoking, mutagen sensitivity and head and neck squamous cell carcinoma. *Cancer Epidemiology Biomarkers & Prevention, 9*(10), 1043-1049.

Zhou, J., Michaud, D. S., Langevin, S. M., McClean, M. D., Eliot, M., & Kelsey, K. T. (2012). Smokeless tobacco and risk of head and neck cancer: Evidence from a case-control study in new england. *International Journal of Cancer*, 132(8), 1911-1917. doi: 10.1002/ijc.27839

Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening cancer patients' families with the Distress Thermometer (DT): A validation study. *Psycho-Oncology, 17*(10), 959-966. doi: 10.1002/pon.1320

Zwahlen, D., Hagenbuch, N., Jenewein, J., Carley, M. I., & Buchi, S. (2011). Adopting a family approach to theory and practice: Measuring distress in cancer patient-partner dyads with the distress thermometer. *Psycho-Oncology, 20*(4), 394-403. doi: 10.1002/pon.1744

Chapter 2

Distress and quality of life in individuals diagnosed with head and neck cancer: A prospective, longitudinal analysis

Background

Head and neck cancer consists of a group of related malignancies that arise in the skin, oral cavity, salivary glands, pharynx, larynx, nasal cavity and paranasal sinuses (Walden & Aygun, 2013). Owing to the location of the disease, individuals with head and neck cancer not only confront a potentially life-threatening disease, but must also endure treatments which often cause significant highly visible disfigurement and disruptions to essential functions such as breathing, eating, swallowing, and speech (Doyle, 2005; Howren, Christensen, Karnell, & Funk, 2012). Even prior to treatment and depending on the primary site and extent of the disease, individuals may experience symptoms that include hoarseness, difficulty swallowing, enlarged cervical lymph nodes, nonhealing sores or ulcers in the mouth, ear pain, and/or nasal bleeding or blockage (Marur & Forastiere, 2008). As a result of these symptoms and the anatomical location of the disease, treatment considerations in head and neck cancer are often complex with a high probability of debilitating consequences.

The delivery of current treatment options in head and neck oncology (e.g., surgery, radiation therapy, chemotherapy or a combination of multiple modalities) may result in a wide range of head and neck-specific side effects including the loss of taste and smell, decreased sensation, facial disfigurement, excessive dry

mouth, sticky (or thick) saliva, and residual pain and swelling (List & Bilir, 2004).

Further, due to differences in the toxicity of treatment and the desire for organ

preservation, head and neck cancer and the consequences of its treatment may

present marked disability (List & Bilir, 2004), leaving nearly half of individuals with

the disease unable to return to work for extensive periods of time following

treatment, if at all (Shone & Yardley, 1991; Taylor et al., 2004). The treatment

and recovery process may be further complicated by additional factors such as

the presence of comorbidities (Paleri et al., 2010), continued use of tobacco and

alcohol (Danker et al., 2011; Duffy et al., 2002; Gritz et al., 1999), and

psychosocial concerns such as depression and poor social support which may

influence compliance with prescribed treatment plans (DiMatteo, Lepper, &

Croghan, 2000; McDonough, Boyd, Varvares, & Maves, 1996). Given these

myriad concerns and potential complications, coupled with the sheer visibility of

the disease and treatment sequelae, it is not surprising that researchers have

classified head and neck cancer as the most emotionally traumatic form of

cancer (Björklund, Sarvimäki, & Berg, 2010; Koster & Bergsma, 1990). This

acknowledgment of the psychological toll of head and neck cancer has led to an

increased emphasis in oncology research toward the evaluation and

consideration of an individual's subjective concerns, including perceived distress,

throughout the continuum of care (Howren et al., 2012). Consequently,

explorations into the experience of distress in individuals with head and neck

cancer throughout the disease trajectory may provide valuable insight into the

factors that have led to its designation as the most emotionally traumatic form of cancer.

Concerns throughout the continuum of care

Receiving a diagnosis of cancer represents the initial phase of what is termed the "continuum of care" in oncology. This continuum begins with the initial diagnosis of a malignancy and then proceeds to treatment, rehabilitation (if required) and then survivorship if the treatment has been successful, or palliation and death if treatment has not served to eliminate the disease (Byock, 2000). Because of the multidisciplinary nature of treatment for head and neck cancer and the length of time that is often required to complete treatment protocols and support long-term concerns, the continuum of care in head and neck cancer is particularly complex (Sharp et al., 2002). Owing to this increased complexity, a number of distinct head and neck-related concerns may arise at varying points in time. In order to better understand these multidimensional concerns, it may be useful to examine previous efforts to understand issues that arise over the period of care.

Diagnosis. Upon receiving a diagnosis of malignancy, individuals enter the initial phase of the care continuum. During this stage, individuals often find themselves overwhelmed with fear, anxiety, and thoughts related to their mortality (Ettema, Reminger, & Robbins, 2013). As they begin to interact with members of their healthcare team, individuals may find that they are required to absorb a vast amount of information and acquire new vocabulary related to their disease and its treatment; it is often not until after the healthcare team has left

the room and the reality of the diagnosis has set in, that individuals begin to process the information provided to them and formulate questions (Penson, 2006). One's initial response to receiving a diagnosis of head and neck cancer may be characterized by denial, disbelief, or despair, and researchers have reported that individuals may have difficulty making decisions and processing all of the information conveyed to them, which may increase levels of anxiety (Ettema et al., 2013). It is clear that the collective impact of a cancer diagnosis and all the subsequent, often rapidly emerging events can be overwhelming to the individual.

While most individuals will develop their own coping strategies to manage their emotional responses, it is important to acknowledge that there is no "ideal" way to cope (Ettema et al., 2013). The impact of receiving a diagnosis for head and neck cancer can be devastating as individuals must address both the physical and psychological consequences of the disease (Aarstad, Aarstad, Bru, & Olofsson, 2005). Understandably, this is a time often marked by elevated distress and anxiety (Singer et al., 2012), decreased energy, a worried outlook, difficulty sleeping, pain (Whelan et al., 1997), and head and neck-specific symptoms (Hammerlid et al., 2001). In addition to the potentially acute physical concerns, for many individuals, receiving a diagnosis of cancer can create substantial feelings of stress and worry (Johansson, Rydén, Ahlberg, & Finizia, 2012; Johansson, Rydén, & Finizia, 2008). In fact, a hazard ratio[1] concerning the

---

[1] A hazard ratio is a measure of how often a particular event happens in one group compared to how often it happens in another group, in the context of time. A hazard ratio of one indicates that there is no difference in survival between the two groups while a hazard ratio of greater than one indicates that one group had better survival rates (National Cancer Institute; NCI, 2009).

development of depressive symptoms in individuals with cancer was shown to be

3.5 times higher in those who were recently diagnosed with cancer when

compared to the general population (Polsky et al., 2005). Specific to head and

neck cancer, a prospective analysis determined that following diagnosis,

individuals reported elevated rates of depression, anxiety, anger, confusion, and

overall mood disturbance (Gritz et al., 1999). Ledeboer and colleagues (2005)

suggested that stress levels are likely to peak at the point of diagnosis

(Ledeboer, van der Velden, de Boer, Feenstra, & Pruyn, 2005), therefore,

receiving a diagnosis of cancer can be a traumatic experience, particularly when

the prognosis is guarded or unfavourable. Receiving the diagnosis may generate

anxiety and fears related to the uncertainty of what lies ahead, potentially painful

and debilitating treatments, and the potential loss of life. In consideration of these

factors, it is reasonable to suggest that the post-diagnostic period may be a time

marked by uncertainty, anxiety, and fear.

Treatment. Following the diagnostic work-up and treatment-planning

stage, individuals often proceed to treatment[2]. Research conducted by Wolff,

Leeper, Gratton, and Doyle (2004) advises that for some, the experience of head

and neck cancer treatment and its associated side effects can be more

devastating than the actual diagnosis of cancer itself. While not discounting the

sheer burden of receiving such a devastating diagnosis, Wolff and colleagues'

(2004) finding points to the overwhelming nature of the treatment and its side

effects. Side effects may include substantial changes to one's physical

---

[2] Based on the severity of disease and one's personal goals and preferences, some individuals may proceed directly to palliative care services or choose to forego medical treatment entirely.

appearance and ability to verbally communicate resulting in changes to

perceived body image, self-esteem and self-concept (Doyle, 2005). Furthermore,

treatment of head and neck cancer has been associated with some of the highest

rates of anxiety, depression and suicide when compared with other cancer sites

(Bjordal, Kaasa, & Mastekaasa, 1995; Dropkin, 1986; Misono, Weiss, Fann,

Redman, & Yueh, 2008). These findings suggest that from a psychosocial

perspective, head and neck cancer is a highly complex and traumatic form of

illness with myriad concerns. As such, when treating an individual with head and

neck cancer it is imperative to consider the multidimensional needs of the

individual in an effort to address specific concerns and improve his or her overall

quality of life and well-being.

Research has shown that during treatment, quality of life in individuals

with head and neck cancer is compromised across a broad range of domains,

including physical (Bjordal et al., 2001), emotional, social, and role functioning

(Johansson et al., 2008). Perceptions of global, or overall, quality of life also have

been reported to be substantially compromised during this time (Johansson et

al., 2008). Relative to specific physical concerns during treatment, researchers

have noted that for those with head and neck cancer, physical concerns extend

beyond those generally associated with cancer such as pain, nausea, vomiting,

dyspnea (e.g., shortness of breath), constipation, diarrhea, decreased appetite,

sleep disturbances, fatigue and issues with sexuality (Johansson et al., 2008;

Ledeboer et al., 2005), to include additional challenges such as dysphagia (i.e.,

difficulty swallowing), odynophagia (i.e., painful swallowing), trismus (i.e., deficits

in the ability to open the mouth), xerostomia (i.e., dry mouth), sticky (or thick) saliva, facial weakness, drooling, limited shoulder mobility (a consequence of neck dissection), dental issues, compromised ability to taste and smell, altered voice and speech quality, and difficulties related to the airway such as breathing, eating, laughing, and crying (Doyle, 1994; Eadie, 2007; Gritz et al., 1999; Johansson et al., 2008; Ledeboer et al., 2005; Owen, Watkinson, Parcy, & Glaholm, 2001). Additional work has noted that the side effects and problems reported by individuals treated for head and neck cancer reach their peak shortly after the completion of treatment (Hammerlid et al., 1997; Neilson et al., 2012). Further, research has suggested that the type of treatment utilized (e.g., surgery, chemotherapy, radiation therapy or a combination of therapies) may influence the mental health of those with head and neck cancer (Singer et al., 2012), which is understandable given that each treatment method has been associated with significant acute side effects. For instance, radiation therapy may result in burns, ulcers, bleeding, and mucositis (Trotti et al., 2003). Ultimately, the burden of these added physical challenges may directly influence the psychological and social dimensions of quality of life and contribute to increasing levels of overall distress in some individuals.

Palliation. Unfortunately, when treatment efforts are unsuccessful or when the cancer has progressed too far at the point of diagnosis, palliative care may be offered to individuals in order to assist with end of life support. Palliative care aims to reduce suffering and provide support and closure throughout the final stages of an individual's life (Lo, Quill, & Tulsky, 1999). Individuals with end

stage head and neck cancer experience distinct problems related to the impact of

the tumour on the airway, the upper gastrointestinal tract, and the senses

(Forbes, 1997). Assessments of the most significant physical concerns in

individuals with head and neck cancer revealed fatigue, pain, weakness,

dysphagia, xerostomia, communication deficits, and trouble with short walks

outside, as most problematic during the palliative phase of care (Forbes, 1997;

Lokker et al., 2012). With regard to psychosocial concerns, individuals with head

and neck cancer reported worrying, sadness, tenseness, depressed mood, and

feelings of powerlessness as most frequent at end of life (Lokker et al., 2012).

These needs may be more pronounced in the palliative phase of care,

particularly if the individual is experiencing problems with communication as a

result of the disease or its treatment. As such, effective communication is vitally

important to ensure optimal quality of life as one approaches the end of his or her

life; not only does it permit communication of physical problems and

requirements (e.g., pain medication), but it also allows for expression of

emotions, intentions, and desires. Loss of the ability to communicate effectively

may exacerbate distress at this important time.

Survivorship. For the purposes of this research, survivorship is defined

as the "period in a cancer patient's life, which is post treatment, separate from

diagnosis and treatment and from end-of-life care" (Twombly, 2004, p. 1415).

While the available treatments for head and neck cancer have increased the

length of time that individuals may experience as disease-free, cure rates have

not improved substantially over the last 50 years (Greene, Page, Fleming, Balch,

& Fritz, 2002). Further, the consequences of the disease and its treatment may be substantial. For instance, even after the successful completion of treatment, daily tasks such as eating, breathing, speaking and swallowing may pose significant difficulty for those treated for head and neck cancer. Consequently, survivors of head and neck cancer may require extensive rehabilitative treatment which may include swallowing rehabilitation, speech therapy, and dental and/or maxillofacial rehabilitation, in addition to physical and occupational therapies (Ward & van As-Brooks, 2007). As a result of these multifaceted challenges, individuals may experience substantial problems within the context of social and family settings and associated functioning (Semple, Sullivan, Dunwoody, & Kernohan, 2004).

In light of these potential concerns, the survivorship phase of the continuum of care highlights the importance of assisting individuals as they work to adjust to potentially distressing disease- and treatment-related changes and ongoing quality of life concerns. Irrespective of an individual's position along the continuum, the potential for elevated distress – and the negative sequelae associated with it – exists throughout all phases of one's cancer-related experience. As such, investigations into the experience of distress throughout the continuum of care may afford a deeper understanding of the factors that serve to mitigate or exacerbate distress in these individuals.

Distress in individuals with head and neck cancer

The experience of distress, whether as subclinical depressive symptomatology or as a full clinical depressive or anxiety disorder, is common

among individuals with head and neck cancer and may arise throughout the course of illness, and even persist months or years beyond the completion of treatment in cancer survivors (Bjordal & Kaasa, 1995; Hutton & Williams, 2001; Massie, 2004; Neilson et al., 2012). The source of this distress is likely multifaceted and may be related to the diagnosis itself, the consequences of disease- and treatment-related sequelae, declines in general quality of life, and/or the potential for disease progression, recurrence, or death.

Notably, the presence of distress has been reported to be more prevalent in head and neck cancer than in other types of cancer (Kendal, 2006; Massie, 2004; Misono, Weiss, Fann, Redman, & Yueh, 2008). While estimates seem to vary depending on the method of assessment (i.e., diagnostic interview versus self-report questionnaires) and the point in time, data indicate that across the trajectory of illness, distress is present in approximately 15% to 58% of individuals diagnosed with head and neck cancer (Bjordal & Kaasa, 1995; Chen et al., 2009; Katz, Kopek, Waldron, Devins, & Tomlinson, 2004; Lydiatt, Moran, & Burke, 2009; Neilson et al., 2012). Further, the presence of elevated distress in individuals with head and neck cancer has been reported to influence immunocompetence, wound healing, treatment compliance, self-care behaviour, and social participation (DiMatteo et al., 2000; McDonough et al., 1996; Spiegel & Giese-Davis, 2003). Distress in individuals with head and neck cancer may be exacerbated by the fact that distress is often not reported to, nor recognized by, healthcare team members (Pirl et al., 2007).

Relative to the experience of distress in individuals with head and neck cancer, research has yielded conflicting data. Specifically, researchers have reported trends of increased distress over time (Couper et al., 2010; Neilson et al., 2012; Wang, 2006), decreased distress over time (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Neilson et al., 2012), and also the maintenance of distress levels throughout the continuum of care (Akechi et al., 2006; Andreu et al., 2012; Carlson et al., 2013). Specifically, a recent study of distress in oncology found that over a one year period, some participants experienced a reduction in distress whereas for others, the rate remained the same (Carlson et al., 2013). Researchers noted that both demographic factors (e.g., not being married) and treatment-related factors (e.g., undergoing radiation therapy) predicted persistent distress, while the receipt of psychosocial support predicted its reduction (Carlson et al., 2013). Additionally, the maintenance of distress rates over time has been reported previously (Akechi et al., 2006; Andreu et al., 2012); whereas other longitudinal studies have reported increased rates of distress over time in individuals with breast, prostate, and lung cancer (Couper et al., 2010; Wang, 2006). It is of concern, however, that cross-sectional research conducted on long-term (7-11 years) survivors of head and neck cancer has noted a high rate of distress present in long-term survivors (e.g., 31% of study participants), which is particularly problematic given that these individuals had completed the clinical follow-up program, which was typically five years in length and, thus, they were not being offered any form of support or psychological treatment (Bjordal & Kaasa, 1995).

Recent head and neck cancer-specific inquiries have reported similarly varied results. For instance, researchers have reported elevated rates of distress around the 3-week post-diagnostic mark, and declines to lower than baseline levels in long-term (e.g., 18 months) follow-up (Neilson et al., 2012). Yet others have reported opposite findings marked by a decline in distress following discharge from the hospital when compared to baseline assessments, and increases in distress to higher than baseline levels during a six-month follow-up (Singer et al., 2012). Reasons for these differing patterns may be attributable to characteristics of each study. For instance, work conducted by Neilson and colleagues (2012) was limited to individuals treated with radiotherapy, which may differ from the experiences of individuals treated with surgery, chemotherapy, or a combination of approaches. Likewise, Singer and colleagues (2012) were limited by both their research design (i.e. lack of standardized assessment periods) and the length of time permitted for follow-up (e.g., six months). In order to determine which factors may contribute to perceived distress and quality of life in individuals with head and neck cancer, an examination of the areas currently overlooked in distress-related literature may serve to highlight specific areas worthy of further investigation.

Limitations to currently available research

Previous research focusing on distress in individuals with head and neck cancer has been limited in a number of important ways. First, owing to the heterogeneous nature of head and neck cancer and its treatment options, a number of studies have opted to focus the scope of their research on one

particular issue, such as the treatment type (Bjordal & Kaasa, 1995; Neilson et al., 2012; Singer et al., 2012), disease site (Johansson, Rydén, & Finizia, 2011; Kugaya et al., 2000), or phase along the continuum of care (Aarstad, Beisland, & Aarstad, 2012; Bjordal & Kaasa, 1995; Buchmann, Conlee, Hunt, Agarwal, & White, 2013; Elani & Allison, 2011; Horney et al., 2011; Hutton & Williams, 2001; Johansson et al., 2011; Katz et al., 2004; Kugaya et al., 2000). In terms of limitations based on treatment type, both Neilson and colleagues (2012) and Bjordal and Kaasa (1995) limited their participant pools to those undergoing only radiation therapy, while Singer et al. (2012) permitted those receiving radiation and/or chemotherapy, but not surgery. Additionally, site-specific research conducted to date has focused on either laryngeal cancer (Johansson et al., 2011), or a combination of laryngeal, oral, and pharyngeal sites (Kugaya et al., 2000). Relative to one's position along the continuum of care in oncology, a few studies centered on distress in newly diagnosed individuals (Buchmann et al., 2013; Horney et al., 2011; Kugaya et al., 2000), while a richer body of literature has examined survivorship concerns in those with head and neck cancer (Aarstad et al., 2012; Bjordal & Kaasa, 1995; Elani & Allison, 2011; Hutton & Williams, 2001; Johansson et al., 2011; Katz et al., 2004). While limiting the criteria for inclusion in a study may permit a more focused approach to the research findings, it also serves to limit the generalizability of findings.

Second, most studies investigating the issue of distress in individuals with head and neck cancer employed a cross-sectional research design (Bjordal & Kaasa, 1995; Bornbaum et al., 2012; Buchmann et al., 2013; Elani & Allison,

2011; Horney et al., 2011; M. R. Katz et al., 2004; Kugaya et al., 2000; Pandey et al., 2007; Verdonck-de Leeuw et al., 2007), which may fail to describe distress and quality of life-related experiences relative to time or one's progression through the continuum of care.

Third, there are a number of commonly used exclusion criteria in psychosocial oncology research that may serve to bias the results of the study towards a lower degree of distress. For instance, several studies have purposely excluded individuals with head and neck cancer who were not receiving treatment with a curative intent (Elani & Allison, 2011; Horney et al., 2011; Katz et al., 2004; Neilson et al., 2012; Pandey et al., 2007; Verdonck-de Leeuw et al., 2007). This effort to limit the sample of participants to those with the potential for cure may bias the data towards a healthier subset of individuals and thus, may not accurately reflect the full range of distress and quality of life-related experiences in individuals diagnosed with head and neck cancer.

Another common phenomenon in longitudinal oncology research is that individuals are frequently excluded from participation if they experience a recurrence or metastases of disease during the study (Aarstad et al., 2012; Bjordal et al., 1999; Horney et al., 2011; Neilson et al., 2012). However, exclusion of individuals during such a potentially distressing experience may serve to bias the sample towards a lower rate of distress. It also limits our understanding of how individuals react to and cope with these experiences. Some longitudinal studies excluded participants if they failed to return one of the data sets following a reminder call (Bjordal et al., 1999); this practice may not

account for myriad factors including the possibility of hospitalization and/or physical or psychological deterioration. Others have requested that participants only return follow-up questionnaires if they did not experience new serious disease (Beisland, Aarstad, Osthus, & Aarstad, 2013), which may fail to account for concerns arising during recurrence. Some researchers have opted to not include individuals who received "bad news" at follow-up appointments (Verdonck-de Leeuw et al., 2007), while others excluded participants with existing or previous psychological conditions (e.g., depression, anxiety) (Elani & Allison, 2011). Exclusion criteria that serve to restrict the pool of potential participants to only those who do not receive "bad news" at their appointments or to those with no history of psychological morbidity, fail to acknowledge the importance of identifying potential distress in these instances.

Distress-related research that purposely excludes individuals experiencing a distressing life event (e.g., receipt of "bad news", palliative phase of illness, disease recurrence, metastases, etc.) or those that may be prone to experiencing pathologic distress (e.g., those with a history of a psychological condition), fails to provide a comprehensive perspective on the very factors which may both cause and exacerbate distress. Collectively, these commonly applied exclusion criteria may serve to bias the data towards a lower rate of distress. In consideration of these existing practices, the present study was designed to broaden the range of concerns and potentially distressing factors accounted for beyond the parameters currently employed in longitudinal research in head and neck psychosocial oncology. Further, in consideration of the noted limitations to the

current literature, a number of specific objectives were developed for this research investigation.

Study-specific research objectives

The purpose of the current investigation was to explore the experience of distress in individuals with head and neck cancer at standardized three-month intervals throughout the first year following diagnosis. We further aimed to explore the pattern of commonly reported problems and perceptions of quality of life in these individuals. In addition, we sought to enhance the current body of literature to include considerations of individuals frequently excluded from participation in psychosocial oncology research, including those who had received "bad news", were not receiving treatment for a curative intent, or experienced disease recurrence or metastases.

Accordingly, a number of specific objectives for this inquiry were developed: (1) to determine the presence and trajectory of distress in individuals with head and neck cancer at standardized intervals (e.g., every three months) throughout the first year following diagnosis; (2) to describe the pattern in frequency of perceived problems (e.g., practical, familial, emotional, spiritual, physical) reported among participants at the same intervals; and (3) to assess global and disease-specific quality of life in participants over the same period.

Method

Participants

All participants (n = 102) involved in this research protocol were recruited

by their physician at the London Regional Cancer Program (LRCP) at the London Health Sciences Centre, Victoria Campus, located in London, Ontario. This sample may be considered as a sample of convenience based on the willingness of individuals to participate following a request by their physician and subsequent follow up by a member of the research team (C.B.). Prior to undertaking this study, the Ethics Review Board at The University of Western Ontario approved this protocol; Approval # 18283E (see Appendix A).

Inclusion criteria. Participants were required to be at least 18 years of age and able to provide informed consent (i.e., no known cognitive impairments). They also must have received a diagnosis for a primary malignancy of the head and neck region. At the time of enrollment, individuals were required to be between zero and one month post-diagnosis and could not have commenced treatment.

Exclusion criteria. If individuals were unable to read, write or understand English or if they were unable to visually see the questionnaires they were excluded since the tasks involved in this study required participants to read and understand the questionnaires in English, and respond to questions accordingly.

In total, 175 individuals were identified as potential participants. Of these potential participants, 20 declined to participate while 155 individuals expressed interest in taking part in the study. Reasons identified for the 20 individuals who did not desire to participate included: too upset (n = 8), not interested (n = 5), too ill (n = 3), not enough time (n = 2), too angry (n = 1), and too many other health-related concerns (n = 1). In total, 155 packages containing the letter of

information and consent, the demographic questionnaire, and the research instruments were disseminated.

The age of participants taking part in this study ranged from 23 years to 92 years (mean age 63.75, SD = 12.55). In total, the 71 male (mean age = 65.25 years, SD = 12.41) and 31 female participants (mean age = 60.33 years, SD = 12.39) resulted in a male-to-female ratio of approximately 2.3:1. Comprehensive demographic data for the participants are presented in Table 2.1, while the disease- and treatment-related data are presented in Table 2.2.

In addition, data pertaining to the status of alcohol and tobacco use (e.g., currently used, formerly used, never used) were collected throughout the first year following diagnosis. The percentage of participants actively using tobacco decreased throughout the first year from 13.3% at diagnosis, to 12.9% at three-months, 13.1% at six-months, 6.4% at nine-months, before increasing to 10.0% of participants at 12-months. Similarly, the percentage of participants actively consuming alcohol also declined throughout the first year from 53.3% at diagnosis, to 45.7% at three-months, 42.6% at six-months, 40.4% at nine-months post-diagnosis, with an increase to 50.0% of participants at 12-months. Further, if participants confirmed the active use of alcohol or tobacco products, they were asked to specify what quantity of each product was consumed in an average week. Regarding tobacco, participants decreased their mean cigarette pack use by 0.94 packs per week, while alcohol consumption decreased by a mean of 5.38 beverages per week by the 12-month assessment.

Table 2.1

Demographic Data of Individuals Diagnosed with Head and Neck Cancer

Variable	n	%
Sex		
Male	71	69.6
Female	31	30.4
Marital status		
Married/common-law	66	64.7
Separated/divorced/widowed/single	21	20.6
Unspecified	15	14.7
Education		
Completed post-secondary education or training	33	32.4
Completed high school	29	28.4
Completed some of/less than high school	16	15.7
Unspecified	24	23.5
Occupational status		
Retired	39	38.2
Working full-time	28	27.5
On disability/sick leave	15	14.7
Working part-time	4	3.9
Student	2	1.4
Unemployed/stay at home	1	0.7
Unspecified	13	12.7
Household income		
≤ $25,000	7	6.9
$25,001 - $40,000	10	9.8
$40,001 - $55,000	5	4.9
$55,001 - $70,000	7	6.9
$70,001 - $85,000	8	7.8
> $85,000	14	13.7
Unspecified	51	50.0

Table 2.2

Disease- and Treatment-Related Data for Individuals with Head and Neck

Cancer

Variable	n	%
Site of cancer		
Oral cavity	31	30.4
Oropharynx	24	23.5
Multiple sites	14	13.7
Larynx	9	8.8
Ear	7	6.9
Nasal cavity and paranasal sinuses	4	3.9
Salivary glands	3	2.9
Neck	3	2.9
Unknown primary	3	2.9
Hypopharynx	2	2.0
Scalp	1	1.0
Nasopharynx	1	1.0
Tumour stage of disease		
T1	22	21.6
T2	24	23.5
T3	20	19.6
T4	25	24.5
Unspecified	11	10.8
Treatment type		
Chemotherapy and radiation therapy	35	34.3
Surgery	24	23.5
Surgery and radiation therapy	17	16.7
Radiation therapy	13	12.7
Surgery, chemotherapy and radiation therapy	11	10.8
Surgery and chemotherapy	1	1.0
No treatment	1	1.0

Note. Data pertaining to pathological site of cancer are organized and reported according to the current standards set by the American Joint Committee on Cancer and endorsed by the American Academy of Otolaryngology – Head and Neck Surgery (Deschler & Day, 2008).

Procedure

        Data collection. All individuals who consented received a package containing a letter of information and consent (see Appendix C), a demographic questionnaire (see Appendix E), the Distress Thermometer and accompanying Problem Checklist (see Appendix I), the EORTC general quality of life assessment tool (EORTC-QLQ-C30) (see Appendix G), the EORTC head and neck cancer specific quality of life assessment tool (EORTC-QLQ-H&N35) (see Appendix H), a list with the contact information for local psychological support services (see Appendix K), and a self-addressed and prepaid return envelope to ensure that participants did not incur any undue financial burden for their participation.

        The letter of information informed the participant of the general purpose of the study, the risks and benefits associated with participating in the study, and also notified them that they were under no obligation to complete the questionnaires nor would they suffer any consequences for declining to participate. If an individual agreed to participate in the study, they were assigned a coded participant number at the outset and were assured that they would not be personally identified in any way other than by the primary researcher (C.B.) and her supervisor (P.D.). In compliance with ethical requirements, informed consent was indicated by the voluntary completion and return of the questionnaire to the researcher. This procedure of obtaining consent was explicitly stated in the letter of information. If any of the questionnaires were not completed in entirety with sufficient data to compute statistical analysis as per the

requirements specified in the standardized scoring and procedures manual for each questionnaire, they were destroyed and excluded from further data analysis.

Sample size calculations. Sample size calculations were calculated using Horatio Software (Version 3.0a) (Lee, 2004) to determine the number of participants required to obtain adequate statistical power. It was determined that "a total sample size (n) of 14 individuals would be sufficient to detect the hypothesized effect ($r^2 = 0.12$) of a five-level within-subject independent variable 81.9 percent of the time using a 0.05 alpha level and assuming a within-subject correlation of 0.30" (Lee, 2004). Despite this modest number of required participants, it was determined that a total of up to 175 individuals would be invited to participate in the study in order to account for potential attrition among participants. The decision to increase our proposed number of participants beyond the recommended sample size was informed by previous longitudinal designs in head and neck oncology populations, which have noted significant attrition rates as high as 78.5% in one study (Mehanna & Morton, 2006) and 66% in another (Kelly, Paleri, Downs, & Shah, 2007). As expected in an oncology population, significant rates of attrition have been attributed to the death of participants and/or substantial declines in physical condition (Abendstein et al., 2006; Bjordal & Kaasa, 1995; Bjordal, Kaasa, & Mastekaasa, 1994; Kelly et al., 2007; Mehanna & Morton, 2006). Collectively, these factors contributed to the decision to increase the number of participants that would be recruited in order to

ensure that the study would have enough participants to be sufficiently powered statistically.

Measurement instruments. The measurement instruments utilized in this study included: (1) the Distress Thermometer and accompanying Problem Checklist to assess distress and perceived problems (NCCN, 2010), (2) the EORTC global quality of life measure (EORTC-QLQ-C30) (Aaronson et al., 1993; Fayers et al., 2001) and (3) the EORTC head and neck quality of life module (EORTC-QLQ-H&N35) (Fayers et al., 2001), and (4) a demographic questionnaire to assess both personal demographic information and disease- and treatment-related characteristics of those with head and neck cancer. The order of the Distress Thermometer and EORTC questionnaires was randomly assigned as per predetermined stapling of the instruments (e.g., half of the packages provided the Distress Thermometer first, while the other half offered the EORTC measures first). This procedure of organizing the order of the instruments was conducted in an effort to reduce any potential response bias due to the influence of exposure to the preceding measure. Participants were instructed to complete each questionnaire as per the enclosed instructions provided on the measures themselves (e.g., the Distress Thermometer and EORTC measures) in a location of their choosing (i.e., home or private office). Additional pages were provided for participants to include any additional information that they felt was pertinent to the research topic (i.e., any concerns or life events that could serve as confounding factors influencing their distress or quality or life at the time of the survey). It was estimated that the completion of all

tasks would take 15-20 minutes. Within the packages distributed to all participants, the demographic items appeared first since they were simple and uncomplicated and helped transition the participant into answering the more sensitive items that followed in the accompanying distress- and quality of life-related questionnaires (Portney & Watkins, 2009).

Demographic and disease-related information. Demographic items consisted of the participant's age, sex, marital status, occupational status, highest level of education obtained, and approximate household income. Relative to the disease- and treatment-related characteristics, items for which data were collected included the length of time since diagnosis, the specific site of the malignancy (e.g., larynx, oral cavity, etc.), the pathological tumour stage of the disease, the type of treatment received, the status of treatment (e.g., awaiting, undergoing, completed, etc.), and whether or not the individual had experienced a recurrence of the disease. Data pertaining to the use of alcohol and tobacco products were also collected.

Data analysis

Raw data were analyzed using SPSS Statistics 20.0 for Macintosh (IBM, 2011). Descriptive data for continuous scale items and scales (e.g., Distress Thermometer and EORTC measures) were presented through mean scores while descriptive information for categorical data were presented with frequencies and percentage values of subgroups (e.g., demographic, disease-, and treatment-related variables). Given that the research design for this study was prospective and longitudinal in nature, the possibility that participants may

not return all questionnaire packages had to be accounted for. Thus, if a participant failed to return a questionnaire package for a particular point of data collection, they were still invited to complete and return subsequent data packages. This decision was made in an effort to ensure the most complete data set possible while also accounting for potential confounding factors which may not permit a participant to return all data packages (e.g., hospitalization, too ill from the disease or effects of treatment, etc.). Additionally, an a priori alpha level of $p \leq 0.05$ was used for statistical tests.

Descriptive statistics. Descriptive statistics (e.g., means, standard deviations, frequency distributions, histograms, etc.) were calculated where applicable for demographic data, treatment- and disease-related variables, and the global and specific domains of each questionnaire (e.g., Distress Thermometer, EORTC-QLQ-C30, EORTC-QLQ-H&N35). These analyses were conducted in order to evaluate the normality of the sample and assess whether parametric statistics would be appropriate for statistical analyses.

Objective one: Presence of distress. The presence of clinically significant distress was identified based on a Distress Thermometer score of ≥ 4 in accordance with the recommendations of the National Comprehensive Cancer Network (NCCN) (2013). In order to determine if parametric statistics would be appropriate to use in the present analysis of distress, applicable histograms and the Kolmogorov-Smirnov test of normality for Distress Thermometer data were

analyzed[3]. Given that distress was evaluated by a continuous measure (e.g.,

Distress Thermometer) that was distributed to participants at five standardized

time points, a repeated measures analysis of variance (ANOVA) was utilized to

assess the relationship between the variables (e.g., distress and time). However,

in an effort to maintain statistical rigor, only those participants who returned all

data packages were included in the repeated measures analyses. In addition, the

magnitude of effect for length of time since diagnosis on level of distress was

determined through calculation of Eta Squared[4] (Pallant, 2011). Effect sizes were

interpreted according to the guidelines proposed by Cohen (1988): 0.01

represented a small effect, 0.06 denoted a moderate effect, and 0.14 indicated a

large effect (p.284-7).

Despite the strict criteria of repeated measures analyses, all participant

data (regardless of the number of questionnaire packages returned) were

included in analysis of distress presence detected at each standardized interval.

Specifically, the number of cases of distress (defined by a Distress Thermometer

score of ≥ 4) were divided by the total number of respondents in order to

determine the percentage of participants at each assessment point who

experienced clinically significant distress.

Relative to anticipated outcomes, it was hypothesized that the presence of

distress detected within this sample would be highest at the point of diagnosis

---

[3] The Kolmogorov-Smirnov test evaluates whether a distribution of scores is significantly different from a normal distribution; a statistically significant value indicates a deviation from normality (Field, 2009).
[4] Eta Squared is an effect size statistic that ranges from zero to one and "represents the proportion of variance in the dependent variable that is explained by the independent (group) variable" (Pallant, 2011, p.242).

and shortly following treatment (e.g., at the post-diagnostic and three-month assessment points) (Hammerlid et al., 1997; Ledeboer et al., 2005; Neilson et al., 2012). Further, in terms of the pattern of distress, it was anticipated that the severity of distress would also peak at the point of diagnosis and shortly following treatment before gradually declining in longer-term follow up (Neilson et al., 2012).

Objective two: Perceived problems. Perceived problems were assessed through use of the Problem Checklist which accompanies the Distress Thermometer (NCCN, 2013). The specific subdomains of the Problem Checklist include practical, familial, emotional, spiritual/religious, and physical problems. Frequency data were presented for each subdomain at standardized three-month intervals in an effort to explore the most commonly reported concerns among participants. Given the potential for substantial physical impairment related to both head and neck cancer and its treatment, it was hypothesized that physical problems (e.g., pain, fatigue, nausea, mouth sores, etc.) would be the most frequently reported concerns among participants at each time interval.

Objective three: Global and head and neck cancer-specific quality of life. We sought to descriptively compare the mean differences in EORTC scores for each component of quality of life between participants at each time interval. All participant data (regardless of the number of questionnaire packages returned) were included in the analyses at each standardized interval. Furthermore, we compared the level of mean change between baseline assessments of quality of life with mean scores reported at both the three-month

and 12-month assessments in order to determine if any clinically significant differences had occurred.

In order to facilitate the interpretation of results, clinically significant differences in quality of life data were assessed. Clinical significance is denoted by the practical implications of the differences relative to the impact on an individual's health or well-being (Hammerlid et al., 2001). Clinical significance data provide important information relative to the interpretation of clinically meaningful differences between groups, or in the present case, points in time following diagnosis. Specifically, score changes of 10 points or greater indicated a clinically significant difference (Aaronson et al., 1993).

Based on previous findings in the literature, it was hypothesized that symptom burden would peak during and just after treatment (i.e., around the three-month post-diagnostic mark for most individuals) (Bjordal et al., 2001; Hammerlid et al., 1997), with a slow recovery process where most symptoms and quality of life-related concerns level off around 12-months following diagnosis (Bjordal et al., 2001). It was anticipated that role functioning would decline significantly shortly following treatment, but return to near baseline levels by the 12-month follow-up; emotional functioning was anticipated to be lowest at the point of diagnosis and increase slightly throughout time (Bjordal et al., 2001). The remaining functional domains (e.g., social, cognitive) were not anticipated to change in a clinically significant manner (Bjordal et al., 2001).

Results

Response rate. Overall, 65.8% of individuals (n = 102) completed and returned at least one questionnaire throughout the 12-month data collection period. Notably, 12.1% of participants (n = 17) returned all five data packages. Comprehensive data pertaining to the individual response rates for each standardized time interval is presented in Table 2.3.

Additionally, in an effort to enhance the current body of literature beyond the existing body of exclusion criteria, this study included participants who had developed metastases (n = 3), were not being treated with a curative intent (n = 2), experienced a recurrence of disease (n = 1), discontinued treatment prior to completion due to complications (n = 1), and had a pre-existing psychological disorder (e.g., depression) (n = 1).

Furthermore, a subset of the 155 potential participants (n = 7) opted to withdraw from the study: two withdrew after returning the three-month follow-up package, three withdrew after the six-month assessment, and two withdrew after the nine-month assessment. Reasons for withdrawal from the study were only provided by two participants; one noted that she was too ill to continue while the other reported that his treatment had not been successful and no longer wished to participate. In addition, seven individuals died during the course of the study. Notably, participants who completed all questionnaires in the study did not differ from participants who did not complete all components of the study in terms of distress when measured at both baseline (t(73) = -1.80, p = 0.076) and 12-months (t(28) = -0.482, p = 0.633) post-diagnosis.

Table 2.3

Response Rate Data for Individuals Diagnosed with Head and Neck Cancer

Point of assessment	Diagnosis	3-month	6-month	9-month	12-month	Total
Withdrawals (n)	0	0	2	3	2	7
Deceased (n)	2	1	4	0	0	7
Maximum possible participants (n)	153	152	146	143	141	155
Total responses (n)	75	70	61	47	30	102
Response rate (%)	49.0	46.1	41.8	32.9	21.3	65.8

Note. The column of total values represents a summary of participant response rate data for the entire study. As a result, data in this column may not represent a summative value of the data contained in the corresponding row.

Data analysis

Objective one: Presence of distress. Based on a Distress Thermometer score of ≥ 4 (NCCN, 2013), clinically significant distress was identified in 35 of 75 individuals (46.7%) immediately following diagnosis, in 29 of 70 individuals (41.4%) three months following diagnosis, in 19 of 61 individuals (31.2%) six months following diagnosis, in 10 of 47 individuals (21.3%) nine months following diagnosis, and in 10 of 30 individuals (33.3%) one year following diagnosis of head and neck cancer. In addition, when the frequency of Distress Thermometer scores was examined at each time point (see Figure 2.1), it was apparent that while Distress Thermometer scores of zero were most frequently reported by participants, that a diverse range of higher scores were also reported by participants at each time interval.

In addition, statistical tests evaluating the parametric nature of data revealed that none of the Kolmogorov-Smirnov statistic values for Distress Thermometer scores were found to be statistically significant (e.g., post-diagnosis, $p = 0.200$; three-month, $p = 0.178$; six-month, $p = 0.200$; nine-month, $p = 0.186$; 12-month, $p = 0.052$). These Kolmogorov-Smirnov findings, taken in conjunction with the relatively normal distributions of data evident in the histograms of Distress Thermometer data (see Appendix L), indicated that parametric statistics were appropriate to assess the trajectory of distress in this participant sample. Consequently, a repeated measures ANOVA was employed for temporal-based statistical analysis.

A one-way repeated measures ANOVA was conducted to compare scores
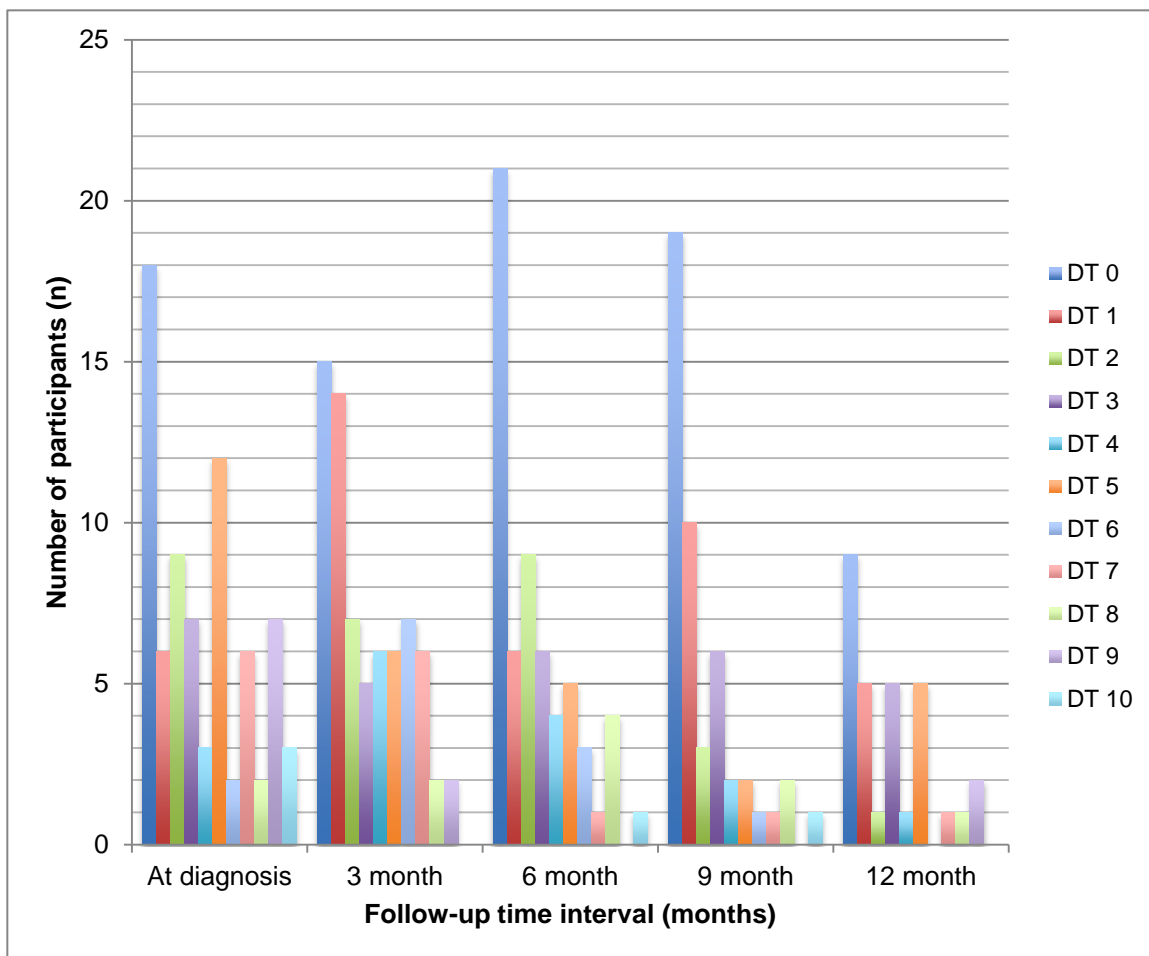
Figure 2.1. Frequency of Distress Thermometer Scores at Each Assessment

Point for All Participants (n = 102)

on the Distress Thermometer at the point of diagnosis, and the three-, six-, nine-, and 12-month follow-up assessments. The means and standard deviations of the data included in the repeated measures analysis are presented in Table 2.4.

Findings related to Mauchly's test[5] indicated that the assumption of sphericity had been violated $\chi^2(9) = 20.34$, p = 0.017, thus, degrees of freedom were corrected using the Greenhouse-Geisser estimate of sphericity (Epsilon; $\varepsilon =$ 0.72) (Field, 2009). Results from the repeated measures ANOVA indicated that there was a significant effect of time on distress, F (2.87, 40.19) = 4.11, p = 0.01, Multivariate Partial Eta Squared = 0.45. Notably, when the F-statistic from the present analysis (F = 4.11) was compared with the critical value[6] for the F-distribution ($F_{Critical}$ = 2.83) (Field, 2009), it was determined to be greater than the critical value, thus indicating that the length of time since diagnosis *did* influence perceived distress. Further, when the magnitude of effect (Multivariate Partial Eta Squared = 0.45) was evaluated according to the guidelines for effect size (Cohen, 1988), it was apparent that the length of time since diagnosis demonstrated a very large effect on the perceived level of distress.

Since an F-ratio is an omnibus test, post-hoc tests were required in order to determine specifically which time point(s) significantly influenced the perceived level of distress in individuals with head and neck cancer. Consequently, pairwise

---

[5] Mauchly's test evaluates the hypothesis that the variances of the differences between time points are equal. Therefore, if Mauchly's test is significant it indicates that there are significant differences between the variances of differences, and thus the condition of sphericity (i.e. the equality of variances of the *differences* between time intervals) is not met (Field, 2009).
[6] The critical value is the number that a test statistic must exceed in order to reject the null hypothesis (Field, 2009).

Table 2.4

Descriptive Statistics for Distress Thermometer Scores for Individuals Diagnosed with Head and Neck Cancer throughout the First Year Following Diagnosis Who Returned all Packages

Assessment time	n	Distress Thermometer Score ≥ 4 (n)	Mean Distress Thermometer Score	SD
At diagnosis	17	13	5.27	2.79
3-month follow-up	17	8	3.07	1.98
6-month follow-up	17	7	3.80	2.96
9-month follow-up	17	5	2.67	2.66
12-month follow-up	17	6	3.07	3.04

comparisons[7] of Distress Thermometer scores were conducted. Since multiple comparisons were conducted, a Bonferroni correction was applied to the alpha level in order to control the overall Type I error rate (Field, 2009). Interestingly, only the nine-month follow-up assessment demonstrated a statistically significant improvement from baseline (e.g., at diagnosis) Distress Thermometer scores (p = 0.05). No other statistically significant differences were detected between the assessment times.

With respect to the specific trajectories of distress evident in those participants who returned all data packages (n = 17), a number of specific patterns of distress emerged (see Figure 2.2). Specifically, several participants initially noted high levels of distress, which gradually decreased with time (n = 6; see P1-P6 in Figure 2.2). Other participants reported elevated distress following diagnosis with a decline following treatment and subsequent increase at long term follow-up (n = 3; P7, P9, P15). Some participants reported low levels of distress during both the initial and long-term (e.g., 12-month) follow-up assessments, but noted a peak in distress following treatment (n = 2; P10, P11), while others noted consistently low levels of distress throughout the entire trajectory (n = 2; P12, P13). Conversely, a number of participants reported persistently high levels of distress throughout the entire trajectory of assessment (n = 3; P8, P14, P16). One additional participant reported generally low levels of distress with two peaks of distress at both the diagnostic and six-month follow-up points (n = 1; P17).

---

[7] Pairwise comparisons are comparisons of pairs of the mean values for scores at each interval of time (Field, 2009).
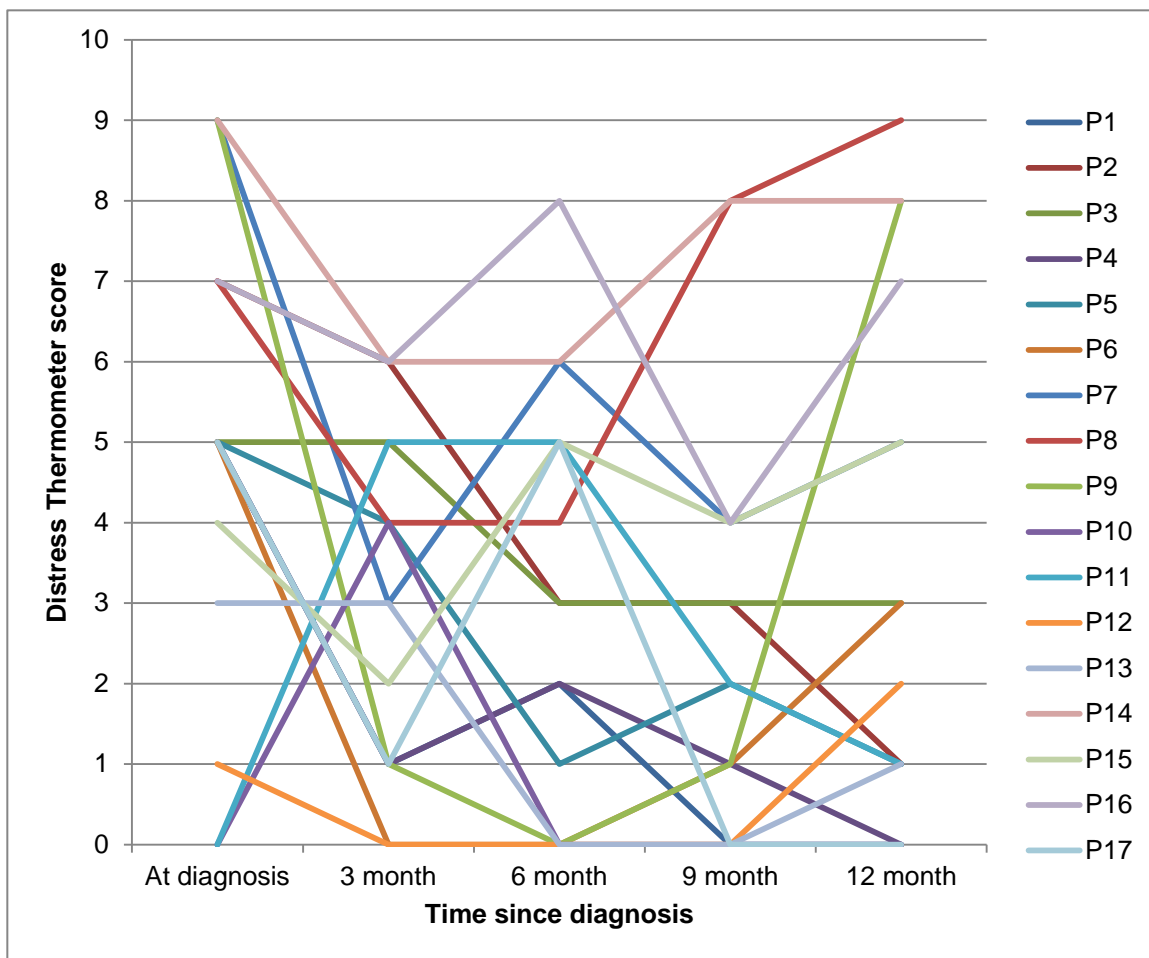
Figure 2.2. Trajectory of Distress via Distress Thermometer Data for Participants

Who Returned Data at All Assessment Points (n = 17)

Objective two: Perceived problems. Perceived problems were assessed through use of the Problem Checklist (NCCN, 2013) and organized into five subdomains (practical, familial, emotional, spiritual/religious, and physical). Notably, participants cited emotional and physical problems frequently at all time intervals. In particular, worry was reported as the most commonly cited emotional problem with 58.7% of participants reporting it at diagnosis. Reports of problematic worry declined to 38.6% at three-months, and 32.8% at six-months before increasing to 36.2% at nine-months and 40.0% at 12-months. Most of the other emotional problems (e.g., depression, fears, nervousness) displayed a similar pattern of peaked frequency at diagnosis and one-year follow-up. Relative to physical concerns, problems with eating, fatigue and sleep presented ongoing challenges for participants. Comprehensive data pertaining to the frequency of reported problems on the Problem Checklist are presented in Table 2.5

Objective three: Global and head and neck cancer-specific quality of life. Clinically significant change was evaluated at three- and 12-months following baseline assessments at diagnosis. Clinically significant differences in quality of life scores were defined by a difference in EORTC scores of greater than or equal to 10 points (Aaronson et al., 1993; Osoba et al., 1998). Comprehensive data pertaining to the quality of life scores among participants throughout the three-month standardized intervals are presented in Table 2.6. With regard to the general quality of life measure (e.g., EORTC-QLQ-C30), a clinically significant decline in role functioning was detected at the three-month follow-up, but appeared to resolve by the 12-month follow-up when compared to

Table 2.5

Problem Checklist Data for Individuals Diagnosed with Head and Neck Cancer

throughout the First Year Following Diagnosis

Variable	At diagnosis n (%)	3 month n (%)	6 month n (%)	9 month n (%)	12 month n (%)
n	75	70	61	47	30
Practical problems					
Child care	1 (1.3)	1 (1.3)	0 (0.0)	0 (0.0)	0 (0.0)
Housing	1 (1.3)	3 (4.3)	5 (8.2)	1 (2.1)	3 (10.0)
Insurance/Financial	13 (17.3)	9 (12.9)	7 (11.5)	7 (14.9)	4 (13.3)
Transportation	8 (10.7)	10 (14.3)	5 (8.2)	2 (4.3)	2 (6.7)
Work/School	10 (13.3)	5 (7.1)	4 (6.6)	2 (4.3)	3 (10.0)
Family problems					
Dealing with children	8 (10.7)	0 (0.0)	1 (1.6)	0 (0.0)	1 (3.3)
Dealing with partner	7 (9.3)	6 (8.6)	4 (6.6)	5 (10.6)	4 (13.3)
Emotional problems					
Depression	25 (33.3)	21 (30.0)	15 (24.6)	7 (14.9)	5 (16.7)
Fears	32 (42.7)	21 (30.0)	11 (18.0)	11 (23.4)	9 (30.0)
Nervousness	32 (42.7)	17 (24.3)	14 (23.0)	11 (23.4)	9 (30.0)
Sadness	20 (26.7)	24 (34.3)	13 (21.3)	8 (17.0)	8 (26.7)
Worry	44 (58.7)	27 (38.6)	20 (32.8)	17 (36.2)	12 (40.0)
Loss of interest in usual activities	20 (26.7)	21 (30.0)	19 (31.2)	9 (19.2)	6 (20.0)
Spiritual/religious problems					
Spiritual/religious	7 (9.3)	3 (4.3)	3 (4.9)	1 (2.1)	3 (10.0)
Physical problems					
Appearance	19 (25.3)	24 (34.3)	14 (23.0)	9 (19.2)	9 (30.0)
Bathing/dressing	6 (8.0)	3 (4.3)	4 (6.6)	0 (0.0)	1 (3.3)
Breathing	14 (18.7)	11 (15.7)	11 (18.0)	2 (4.3)	4 (13.3)
Changes in urination	3 (4.0)	7 (10.0)	6 (9.8)	4 (8.5)	3 (10.0)
Constipation	14 (18.7)	14 (20.0)	12 (19.7)	4 (8.5)	6 (20.0)
Diarrhea	10 (13.3)	10 (14.3)	6 (9.8)	2 (4.3)	2 (6.7)
Eating	30 (40.0)	35 (50.0)	20 (32.8)	16 (34.0)	10 (33.3)
Fatigue	36 (48.0)	34 (48.6)	18 (29.5)	17 (36.2)	12 (40.0)
Feeling swollen	14 (18.7)	14 (20.0)	10 (16.4)	9 (19.2)	8 (26.7)
Fevers	2 (2.7)	3 (4.3)	4 (6.6)	1 (2.1)	0 (0.0)
Getting around	7 (9.3)	14 (20.0)	9 (14.8)	1 (2.1)	4 (13.3)
Indigestion	10 (13.3)	8 (11.4)	10 (16.4)	5 (10.6)	5 (16.7)
Mouth sores	18 (24.0)	24 (34.3)	10 (16.4)	5 (10.6)	3 (10.0)
Nausea	10 (13.3)	14 (20.0)	7 (11.5)	5 (10.6)	4 (13.3)
Nose dry/congestion	18 (24.0)	29 (41.4)	15 (24.6)	11 (23.4)	9 (30.0)
Pain	33 (44.0)	29 (41.4)	19 (31.2)	10 (21.3)	10 (33.3)
Sexual	14 (18.7)	15 (21.4)	11 (18.0)	6 (12.8)	2 (6.7)
Skin dry/itchy	18 (24.0)	26 (36.6)	19 (31.2)	16 (34.0)	11 (36.7)
Sleep	41 (54.7)	23 (32.9)	19 (31.2)	8 (17.0)	7 (23.3)
Tingling in hands/feet	13 (17.3)	13 (18.6)	15 (24.6)	9 (19.2)	11 (36.7)

Note. n = number of patients at each assessment point (some did not return all questionnaires).

Table 2.6

EORTC Quality of Life Mean Score Data for Individuals Diagnosed with Head

and Neck Cancer throughout the First Year Following Diagnosis

Variable	At diagnosis	3 month	6 month	9 month	12 month	0 → 3 month Δ	0 → 12 month Δ
n	75	70	61	47	30	---	---
EORTC QLQ-C30							
Global health status	64.04	56.57	59.84	68.97	63.89	-7.47	+0.15
Functioning scales							
Physical functioning	80.27	73.90	72.51	83.12	81.72	-6.37	+1.45
Role functioning	72.52	60.33	66.80	79.79	75.81	-12.19*	+3.29
Emotional functioning	69.41	74.30	73.57	79.61	77.15	+4.89	+7.74
Cognitive functioning	80.82	77.93	80.46	85.11	81.18	-2.89	+0.36
Social functioning	72.83	65.96	67.62	79.08	77.69	-6.87	+4.86
Symptom scale/single items							
Fatigue scale	33.93	41.63	39.44	28.37	32.97	-7.70	-0.96
Nausea/vomiting scale	7.88	17.84	7.79	4.07	11.83	-9.96	+3.95
Pain scale	26.58	28.05	23.77	19.86	24.73	-1.47	+1.85
Dyspnea	13.96	17.84	19.67	13.12	16.13	-3.88	+2.17
Insomnia	39.19	29.11	30.60	17.73	23.66	+10.08*	-15.53*
Appetite loss	22.52	39.44	28.96	25.53	25.81	-16.92*	-3.29
Constipation	14.86	17.37	16.94	9.93	13.98	-2.51	-0.88
Diarrhea	5.02	10.80	6.01	3.55	4.30	-5.78	-0.72
Financial difficulties	17.81	19.48	21.86	15.60	13.98	-1.67	-3.83
EORTC QLQ-H&N35							
Pain scale	27.14	29.11	21.72	17.91	15.32	-1.97	+11.82*
Swallowing scale	18.58	26.64	22.61	18.62	17.75	-8.06	+0.83
Senses scale	18.02	32.04	37.16	31.38	33.33	-14.02*	-15.31*
Speech scale	20.87	24.33	22.13	17.02	17.92	-3.46	-2.95
Social eating scale	23.20	31.92	28.42	21.16	25.00	-8.72	+1.80
Social contact scale	14.68	18.22	16.12	14.26	15.05	-3.54	+0.37
Sexuality scale	26.58	33.80	37.16	24.61	33.32	-7.22	+6.74
Teeth problems	16.67	15.49	21.86	13.48	22.58	+1.18	+5.91
Opening mouth	17.12	27.70	20.77	13.48	24.73	-10.58*	+7.61
Dry mouth	31.53	41.31	54.64	49.65	47.31	-9.78	-15.78*
Sticky saliva	29.28	48.36	52.19	46.81	36.56	-19.08*	+7.28
Coughing	30.59	39.20	27.05	26.95	21.47	-8.61	-9.12
Feeling ill	15.77	23.00	13.11	4.96	13.98	-7.23	-1.79
Pain killers	56.76	43.66	42.62	36.88	48.39	+13.10*	+8.37
Nutritional supplementation	41.89	56.34	52.46	36.17	51.61	-14.45*	+9.72
Feeding tube	5.41	14.08	11.48	12.77	12.90	-8.67	-7.49
Weight loss	31.08	42.25	31.15	19.15	32.26	-11.17*	+1.18
Weight gain	14.86	22.54	29.51	21.28	25.81	-7.68	+10.95*

Note. n = number of patients at each assessment point (some did not return all questionnaires).
[a]High score on function scales and the global quality of life scale imply high function.
[b]High score on symptom scales/single items imply high level of perceived problems.
[c]Δ = mean individual change over time (Δ ≥ 10 = clinical significance).
[d]+ = improved function or reduced level of symptoms over time.
[e]- = deteriorated function or increased level of symptoms over time.
* = *clinically* significant difference.

baseline values. Further, a clinically significant increase in symptom burden between baseline and three-month assessment scores was reported for loss of appetite, while a clinically significant reduction in symptom burden was observed for insomnia at both the three- and 12-month assessments.

With respect to the EORTC-QLQ-H&N35, data revealed the presence of clinically significant differences in a number of the head and neck-specific items detected for changes to senses (e.g., taste and smell), difficulty opening mouth (e.g., trismus), sticky saliva, and reductions in weight. Further, the use of nutritional supplementation appeared to increase in a clinically significant manner, while the use of pain medication appeared to decrease in a clinically significant manner when three-month assessments were compared with baseline values. Furthermore, at the 12-month follow-up assessment, clinically significant reductions in head and neck symptom burden were reported in assessments of pain and weight gain, while clinically significant increases in head and neck symptom burden were reported for dry mouth (e.g., xerostomia) and senses (e.g., taste and smell). No other changes in symptoms or functional domains were found to be clinically significant when evaluated at the three- and 12-month assessments and compared to mean baseline values.

Discussion

This investigation explored the experience of distress in individuals with head and neck cancer at standardized three-month intervals throughout the first year following diagnosis. We further sought to describe the pattern of commonly

reported problems and perceptions of quality of life of these individuals while including considerations of those frequently excluded from psychosocial oncology research. With regard to the specific objectives of this study, the presence of distress, perceived problems, and quality of life concerns were explored.

Presence of distress

With respect to the presence and trajectory of distress, it was anticipated that the level of distress detected within this sample would be highest shortly following treatment (e.g., at the post-diagnostic and three-month assessment points) and then gradually decline throughout long-term follow-up. However, while the mean pattern of distress appeared to almost meet the hypothesized trajectory (see Table 2.4); in fact, the rates of distress appeared to increase in severity at both the six- and 12-month follow-ups, which was contrary to the predicted trend of declining presence and severity. Further, data revealed that clinically significant distress was present in a portion of participants throughout the first year following diagnosis. In particular, when the mean scores from *all* participants (regardless of how many envelopes they returned) were examined, distress appeared to peak at the point of diagnosis and subsequently declined at nine-month follow-up, but was followed by a surge at the 12-month follow-up. Thus, the hypothesis that the *presence* of distress reported by participants would be highest at the point of diagnosis and shortly following treatment (e.g., at the post-diagnostic and three-month assessment points) was supported by the present findings. A similar pattern was detected when the mean scores of the 17

participants who returned all envelopes were examined. While the frequency and pattern of these data might suggest that in general, distress is most elevated at the point of diagnosis and declines gradually following treatment (Coyne, 2013), in fact, examination of mean and frequency/proportion-related data alone may only reveal a small fragment of this phenomenon.

To elaborate, Coyne's (2013) suggestion that distress in individuals with cancer decreases following the diagnosis and treatment stages of cancer is widely accepted, but it has recently been shown to be an incomplete observation (Fielding & Lam, 2013). The problem with this generalized description of the phenomenon of distress in oncology centers on the manner in which distress data are analyzed; in particular, the use of group mean values as the primary (and often sole) outcome of the trajectory of distress. For instance, as noted by Fielding and Lam (2013),

> *If in a study 50% of the sample score 10 out of 10 on a notional distress scale declining to 0 out of 10 over time, whereas the other 50% score 0 out of 10 increasing to 10 out of 10 over the same period, the observed group mean will remain at 5 out of 10 and the conclusion would be there is no change in distress.* (p.1).

Based on this anecdote, the conclusion that there was no change in distress is inaccurate based on the individual scores; however, when data are evaluated based on mean scores alone, it does appear as though the distress remained unchanged throughout the study. In an effort to overcome the limitations of mean-based analyses, some researchers have begun to utilize a method of

statistical analysis termed growth mixture modeling[8], which essentially breaks down longitudinal data samples into distinct patterns or trajectories (Fielding & Lam, 2013). When this growth mixture modeling technique was applied to distress data from individuals with cancer, distinct patterns of distress emerged that were substantially different from the commonly accepted notion that distress declines over time (Henselmans et al., 2010; Lam et al., 2011; Lam, Shing, Bonanno, Mancini, & Fielding, 2012).

Ultimately, four distinct patterns of distress emerged through analyses of multiple participant groups in varying disease sites (e.g., breast cancer, nasopharyngeal cancer) (Henselmans et al., 2010; Lam, Ye, & Fielding, 2012; Lam et al., 2009; Lam et al., 2011). The first and most commonly occurring pattern suggests that the majority of individuals with cancer (approximately 60 percent) are resilient and experience persistently low levels of distress with minimal and transient increases in distress throughout the cancer experience (Fielding & Lam, 2013). The second pattern more closely resembles the classic pattern of high levels of perceived distress early in the trajectory of disease with a gradual decline in distress over time. The third is represented by those who report low levels of distress early in the trajectory of disease with a gradual increase in distress that peaks around the end of treatment before declining substantially afterwards. Finally, the fourth pattern, evident in approximately 5-

---

[8] Growth mixture modeling "represents unobserved heterogeneity between subjects in their development using random effects and finite mixtures. This allows different sets of parameter values for mixture components corresponding to different unobserved subgroups of individuals, capturing latent trajectory classes with different growth curve shapes", p.143-144). Thus, this modeling approach permits detection of individual nuances in the data that might remain unidentified using other analytic approaches.

20% of individuals with cancer, demonstrates consistent levels of high distress that persist throughout the cancer trajectory (Fielding & Lam, 2013; Henselmans et al., 2010; Lam et al., 2012; Lam et al., 2009; Lam et al., 2011; Lam et al., 2012). Consequently, these chronically distressed individuals present the largest psychosocial need and would likely benefit most from psychosocial interventions when compared to those with lower grade, and/or transient distress.

While the sample size of the present investigation was too small to permit the mixture growth modeling technique described above, examination of the individual trajectories of participants who completed all data sets provided some interesting insights. In particular, all four patterns described above were detected within the present sample. Specifically, out of the 17 participants who returned all data sets, 11.8% of participants noted persistently low levels of distress, consistent with the most commonly occurring pattern described by Fielding and Lam (2013). A further 35.3% of participants reported the classic pattern of high initial distress that decreased over time, while an additional 17.7% of participants reported high initial distress followed by a decline, however, for these individuals, distress levels increased for a second time during long-term follow-up. In addition, 17.7% participants demonstrated low initial distress with a gradual increase that peaked around the end of treatment before declining substantially afterwards, while a further 17.7% participants reported chronic levels of high distress throughout the entire study, thus representing the fourth pattern described by Fielding and Lam (2013). Additionally, one participant (5.9%) reported elevated distress at both diagnosis and the six-month follow-up. This

participant could likely be classified according to the pattern marked by persistently low levels of distress accompanied by periodic and transient increases in distress throughout the continuum of care (Fielding & Lam, 2013).

While the course of distress is a deeply personal experience that may be influenced by a number of potential factors, ultimately, developing a deeper understanding of distress is important because distress patterns in the first year following diagnosis can predict distress levels up to six years later (Lam et al., 2011; Lam et al., 2012). Thus, if we can determine which trajectory of distress an individual is experiencing within the first year, we will likely be able to better target psychosocial resources to the individuals who will require them and may receive the greatest benefit. Further, in addition to enhancing our understanding of both the presence and trajectory of distress in individuals with head and neck cancer, it is also important to identify and attend to the range of perceived problems that may contribute to elevated levels of distress.

Perceived problems

Throughout the first year following diagnosis, both physical and emotional concerns represented the most commonly reported problems among participants. Notably, a number of physical and emotional concerns were consistently reported by a high proportion of participants; in particular, problems with fatigue, eating, and worrying were cited by at least 30 percent of participants at each follow-up interval, with myriad additional concerns arising in varying proportion throughout the trajectory of disease. These results were contrary to the hypothesis that physical concerns would be cited most frequently at all time

points. In fact, physical concerns (e.g., eating) were reported to be most frequent at only the three-month follow-up. While the Problem Checklist was not intended to be a comprehensive measure of the potential range of problems facing the participants, it does offer insight into some of the most commonly reported areas of concern. For instance, "problems with eating" was a frequently reported concern among participants. However, when "problems with eating" are considered through a qualitative context, it is apparent that the meaning associated with such symptoms may actually change significantly over the trajectory of disease.

For example, a recent qualitative study reported that during the acute phase of illness (i.e., during treatment) some individuals with head and neck cancer were unable to eat due to the side effects of treatment (e.g., mucositis, pain, difficulty swallowing, etc.) and, thus, were reliant on nutritional support such as feeding tubes or fortified drinks (Ottosson et al., 2013). Others who were still able to eat reported having to adjust their food intake to soft or liquid foods that were quite neutral in flavour (i.e. no dry or spicy foods). These changes were perceived as stressful by participants as they struggled to consume an adequate amount of calories to continue treatment (Ottosson et al., 2013). As time progressed, attitudes concerning eating shifted from a requirement for survival to the attempt to accept that eating may never again be a pleasurable activity for some (Ottosson et al., 2013). Thus, while "problems with eating" were noted during treatment and in long-term follow-up in the present study, the meaning associated with these problems to the individual may be varied and significant.

An additional treatment-related problem that may also create substantial physical, psychological and social losses for individuals with head and neck cancer is fatigue. Research indicates that fatigue is common in individuals with cancer, but unfortunately it can be difficult to treat (Cruciani, 2006). It is important to understand the impact of fatigue on individuals with head and neck cancer in order to ascertain why such a high proportion of participants in the present study reported fatigue as being problematic. Similar to our findings, a qualitative study conducted by Molassiotis and Rogers (2012) noted that for individuals with head and neck cancer, fatigue persisted throughout the first year following diagnosis and actually worsened at the one-year follow-up. The worsened fatigue noted during the long-term follow-up by Molassiotis and Rogers (2012) may have been attributable to the recent return to work by some of their participants who noted that their fatigue made the return to work experience very stressful. In general, fatigue appeared to cause considerable frustration for participants who reported that they were unable to do the things they used to do, which resulted in restrictions to their activity level, ability to complete household tasks and errands, and overall social participation (Molassiotis & Rogers, 2012). While the burden of fatigue is substantial on its own, the problem with fatigue is that it often serves to exacerbate other problems (e.g., swallowing problems, pain, altered taste, dry mouth) (Ottosson et al., 2013). Furthermore, fatigue has recently been related to depression and negative perceptions of quality of life (Sawada et al., 2012), suggesting that the consequences of fatigue extend beyond the physical realm into psychological and social domains.

In addition to physical concerns, participants in the present study reported a number of ongoing emotional problems. In particular, worrying was reported by a high proportion of participants at all assessment points. While research specific to the term "worry" in head and neck cancer is sparse, researchers have previously classified this concern in individuals with cancer into two domains, namely cancer-specific worries (e.g., future diagnostic tests, cancer recurrence, diagnosis of another type of cancer) and health-related worries (e.g., health, dying) (Gotay & Pagano, 2007). While these domains are certainly not exhaustive, they do highlight the fact that thoughts of one's own mortality are deeply connected to the source of worry in individuals with cancer. Additionally, for those living with cancer who have significant others, aging parents, and/or young children, worries related to the long-term security and well-being of these individuals may also be pervasive (Davis-Ali, Chesler, & Chesney, 1993). Also, worries related to one's cancer experience may shift as time progresses and even after the successful completion of treatment, worries about the potential recurrence of disease may persist (Savard & Ivers, 2013). While the present study did not investigate specific sources of participants' worry, the high proportion of participants who reported it to be problematic throughout the trajectory of disease, suggests it to be a pervasive problem.

Relative to commonly reported problems, the present study observed that in general participants noted problems with eating, fatigue, and worry most often. Recent evidence increasingly suggests that unresolved symptoms (including problems with eating and fatigue), can significantly predict trajectories of distress

in individuals with cancer (Lam et al., 2012). Thus, while the course of distress is a deeply personal experience that may be influenced or exacerbated by a number of potential factors, it is important to acknowledge that physical and psychological symptoms are not mutually exclusive. Furthermore, data derived from the Problem Checklist in the present study have provided empirical confirmation of the qualitative accounts articulated by both Ottosson and colleagues (2013) with regard to problems with eating and Molassiotis and Rogers (2012) in relation to problems with fatigue. While emotional and physical problems represented the highest proportion of reported concerns among participants in the present study, the prevalence of these reports should in no way diminish the impact of less frequently reported problems such as "work/school", "insurance/financial" or "dealing with partner", since issues such as these have the potential to be immensely distressing. In essence, the subjective experience of an item such as, "problems dealing with partner" cannot be inferred through mere acknowledgment on a brief questionnaire. As such, considerations of an individual's subjective perception of quality of life remain important in order to better understand the experience of distress in individuals with head and neck cancer.

Global and head and neck cancer-specific quality of life

The concept of quality of life has been defined by the World Health Organization (WHO) as:

> *an individual's perception of their position in life, in the context of their*
>
> *culture and values system where they live, and in relation to their goals,*

expectations, standards and concerns. It is a broad ranging concept,

incorporating in a complex way a person's physical health, psychological

state, level of independence, social relationships, personal beliefs and

relationship to salient features of the environment. (WHO, 1998, p.17).

An essential component to the concept of quality of life is the notion that these

domains are interrelated and must be considered collectively; they must also be

evaluated relative to the meaning and value that the individual places on each

component. Consequently, in order for assessments of quality of life to have

clinical or research utility, they must be capable of accounting for the factors

most relevant to one's current life situation – in this case, his or her experience

with head and neck cancer and its accompanying consequences.

Owing to the myriad potential concerns of an individual with head and

neck cancer, a key objective of the present study explored the perceived quality

of life globally, and relative to a number of specific areas known to be

problematic for those with head and neck cancer. As such, numerous specific

concerns (e.g., role functioning, symptom burden) were found to change in a

clinically significant manner over the course of the study; consequently, these

areas are explored below.

Role functioning. Within the context of the EORTC-QLQ-C30, role

functioning was assessed according to an individual's ability to meet work-related

obligations, engage in daily activities, and pursue hobbies and/or other leisure

time activities (Aaronson et al., 1993). Data from the present study were

consistent with predictions and indicated a clinically significant decline in one's

ability to fulfill meaningful roles at the three-month assessment when compared to evaluations at diagnosis. These findings are in line with previous longitudinal work (Bjordal et al., 2001; Hammerlid et al., 1997). Similar to the findings of Bjordal and colleagues (2001) and Hammerlid et al. (1997), the clinically significant decline in role functioning observed at the three-month assessment appeared to resolve by the one-year follow-up. Previous research into the factors that contribute to role functioning in individuals with cancer has determined that one's level of symptom burden (e.g., fatigue, appetite loss, insomnia, etc.) is closely aligned with one's ability to fulfill role-based activities and obligations (Aaronson et al., 1993; Bjordal et al., 2001). As predicted, in the present study participants' symptom-related burden peaked at the three-month assessment and leveled off around 12-months for most items, however, certain exceptions to this pattern were evident. Specifically, items such as insomnia, senses, sexuality, problems with teeth, dry mouth, pain killers, and weight gain demonstrated alternative patterns in symptom burden. As such, exploration into the clinically significant differences in symptom burden detected at the three-month assessment (e.g., insomnia, pain, appetite loss, etc.) may provide some context regarding the temporary depletion of role functioning among individuals with head and neck cancer.

Insomnia. Insomnia has been characterized as difficulty associated with sleeping that may involve challenges with initiating sleep and/or trouble maintaining effective sleep (Savard & Morin, 2001). Sleep disturbances, including insomnia, have been shown to decrease mental health, quality of life, and work

productivity, to increase utilization of healthcare resources, and also to predict future complications in individuals with cancer (Katz & McHorney, 2002; Manocchia, Keller, & Ware, 2001; Roscoe et al., 2007). Previous research has indicated that sleep disorders such as insomnia are common in individuals with head and neck cancer (Duffy et al., 2008; Shuman et al., 2010). The present study detected a similar problem with sleep-related concerns as evidenced by the high proportion of participants reporting problematic sleep and/or fatigue at multiple assessment points on the Problem Checklist. Relative to the specific influence of these perceived problems on one's quality of life, evidence from the present study indicated a clinically significant decline in reported insomnia at both the three- and 12-month assessments when compared with assessments at diagnosis. These findings were contrary to our prediction that symptom-related burden would peak in severity at the three-month post-diagnostic point. However, our findings were in line with the work of both Savard and colleagues (Savard, Ivers, Villa, Caplette-Gingras, & Morin, 2011) and Shuman et al. (Shuman et al., 2010) who both observed elevated rates of insomnia prior to treatment with gradual declines as time progressed. Additionally, Shuman et al. (2010) postulated that the elevated rates of pre-treatment insomnia could possibly be attributed to anxiety related to the recent diagnosis in conjunction with symptoms stemming from the malignancy, such as pain.

     Pain. Within the present sample, a clinically significant reduction in perceived pain was observed at 12-month assessments when compared with values obtained at diagnosis. Despite the rich body of literature noting the

presence of long-term pain in individuals with head and neck cancer (Breivik et al., 2009; Chua et al., 1999; Funk et al., 2012; Shuman, 2012; Whale et al., 2001), the present data are in line with the recent work of Shuman and colleagues (2012) who noted an improvement in pain in individuals with head and neck cancer one-year following diagnosis when compared to pre-treatment levels.

Interestingly, a clinically significant reduction in the use of painkillers was observed at the three-month follow-up in the present study, suggesting that pre-treatment pain (as inferred through the elevated use of pain alleviation medication prior to treatment) was actually *worse* than pain levels during and/or shortly following treatment. While surprising, this finding of elevated pre-treatment pain suggests that the physical burden associated with an untreated tumour in the head and neck region can be substantial (Shuman, 2012). Consequently, assessments of quality of life in head and neck cancer would be remiss if they failed to acknowledge the impact of pain on an individual's perceived well-being and overall functioning. Not only can elevated pain negatively influence one's perceived quality of life (Funk et al., 2012), but it has also been shown to reduce functional capacity (Vallerand, Templin, Hasenau, & Riley-Doucet, 2007), and to predict disability (Taylor et al., 2004), depression (Shuman, 2012) and insomnia (Shuman, 2012), and further, to compromise nutritional intake and weight maintenance (Paillaud et al., 2003) in individuals with head and neck cancer. As a result, addressing pain may help to reduce or alleviate numerous multidimensional concerns.

Weight-related changes. In the present study, participants reported clinically significant weight loss, reductions in appetite, and increased use of nutritional supplementation three months following diagnosis. Fortunately, by the 12-month assessment, participants reported a clinically significant increase in weight when compared to assessments at diagnosis. The weight loss observed in the present study (at the three-month post-diagnostic mark) is significant because the involuntary loss of even five percent of one's body weight over a six month period has been related to increased treatment toxicities, treatment delays, complications, extended hospital stays, and decreased survival (Dewys et al., 1980; Kubrak et al., 2009). Further, individuals with cancer who are nutritionally compromised are at an increased susceptibility to infections and generally demonstrate poorer responses to treatment (Nitenberg & Raynard, 2000), which likely contributes to the decreased rates of survival among these individuals.

Furthermore, the type of treatment employed may also influence nutrition and one's ability to maintain their weight. Specifically, chemotherapy and radiation therapies have been shown to cause acute mucositis, loss of taste sensation, compromised salivary gland function, dysphagia, odynaphagia, nausea, vomiting, loss of appetite, etc. – all of which may negatively influence nutritional and subsequent functional status (Garg, Yoo, & Winquist, 2010; Paccagnella et al., 2009; Payakachat, Ounpraseuth, & Suen, 2012). Moreover, severe malnutrition can cause unintentional treatment breaks and hospitalizations, which may consequently reduce treatment efficacy (Barret et al.,

2012; Cox et al., 1992). These nutrition-related complications have been associated with significant costs to both the individuals and the healthcare system (Garg et al., 2010; Paccagnella et al., 2009). Thus, attending to the quality of life concerns of individuals with head and neck cancer may serve to not only improve individual well-being, but may also provide economic benefits to the healthcare system at large. Thus, it is imperative to be aware of these problems so that the consequences of head and neck cancer may be alleviated whenever possible in order to optimize quality of life.

Possible confounding factors

Since the source of distress is certainly not limited to the consequences of cancer and its treatment-related sequelae, participants were invited to disclose any information that they felt may have influenced their perceived level of distress or quality or life at the time of the survey. Regarding specific disclosures, one participant reported being worried about his spouse's health in addition to his own health-related concerns. Another participant disclosed that he was experiencing residual problems related to a car accident several years prior. Understandably, these experiences may have influenced how these individuals were able to cope with their disease and its treatment. Relative to the distress of these participants, the individual who had been in a car accident reported clinically significant distress at the three-month assessment. However, the participant who was concerned about his spouse's health did not report clinically significant distress at any of the assessment intervals. While the frequency of these potentially confounding factors is too low to draw any firm conclusions,

future research into the influence of co-existing stressful life events may provide interesting insights into how individuals cope with the experience of cancer while managing significant co-existing life challenges.

Limitations of Current Study

First, the sample size and rate of attrition serve as noteworthy limitations to the present study. While substantial declines in participant responses occurred throughout the 12-month data collection period, the rates of attrition were particularly elevated at the nine- (67.1% attrition) and 12-month (78.7%) follow-up assessments. While attrition in the present study was higher than rates reported in previous longitudinal studies in head and neck oncology – 78.5% reported by Mehanna and Morton (2006) and 66% reported by Kelly et al. (2007) – the differences are not substantial. Furthermore, despite the high proportion of participants who did not complete all of the follow-up assessments, we did gather a total of 17 completed participant data sets; based on sample size calculations, only 14 completed participant data sets were required for the study to be sufficiently powered (Lee, 2004). In an effort to ensure that those participants who completed all data sets did not differ substantially from participants who did not complete all data sets, t-test analyses were performed in order to compare the mean Distress Thermometer scores of respondents at both baseline and 12-months post-diagnosis. Since no statistically significant differences were detected at either point in time, we believe that the rate of attrition detected in this sample did not bias the results relative to the levels of perceived distress observed.

Second, this study design did not permit assessment of pre-diagnostic distress given that participants were recruited following their diagnosis. Previous research conducted in women with breast cancer has shown that the period of time prior to diagnosis (i.e. following detection and symptoms and throughout diagnostic workup) may be slightly more distressing than other points along the continuum of care, including during treatment and in long-term follow-up (Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Vahdaninia, Omidvari, & Montazeri, 2009). Given this potential for elevated distress prior to receiving a confirmed diagnosis, it is possible that the trajectories of distress detected in the present sample would be altered if pre-diagnostic distress-related data were included. Consequently, future work examining the influence of pre-diagnostic distress on the trajectory of distress in individuals with head and neck cancer is recommended.

Furthermore, the length of current follow-up time was restricted to 12 months. While the literature pertaining to distress-related concerns in long-term survivors of head and neck cancer is well established (Mehanna & Morton, 2006; Semple, 2001; Ward & van As-Brooks, 2007), the decision to limit the length of study inquiry to 12 months was based on two primary factors. The first was due to the feasibility of the study given that the data collection procedure was conducted primarily by a single investigator (C.B.). The second factor supporting a 12-month follow-up assessment period was the collective findings of Lam et al. (2011) and Lam et al. (2012) who have shown that the trajectory of distress in the first year following diagnosis significantly predicts one's level of distress up to six

years following diagnosis. Thus, the decision to limit the length of inquiry to 12 months following diagnosis was deemed appropriate given the predictive relationship between the trajectories of distress reported in the first year post-diagnosis with long-term levels of distress in individuals with cancer.

Conclusion

This study investigated distress, quality of life, and commonly reported problems in 102 individuals diagnosed with head and neck cancer. Data indicate that: (1) distress was most prevalent at the point of diagnosis and (2) that the length of time following diagnosis had a large effect on the level of perceived distress. Additionally, clinically significant declines in role functioning and increases in symptom burden (e.g., pain, insomnia, senses, trismus, xerostomia, sticky saliva, appetite loss, and weight loss) were observed early on following treatment, but with exception of xerostomia and reduced senses, appeared to resolve by the one-year follow-up. In addition, participants most frequently reported physical and emotional concerns as being problematic throughout the trajectory of disease.

While most individuals with cancer are resilient and tend to experience persistently low levels of distress (Fielding & Lam, 2013), this is not the case for all individuals. Recent evidence increasingly suggests that the presence of unresolved symptoms (e.g., pain, fatigue, etc.) is a major predictive factor in the trajectory of cancer-related distress (Lam et al., 2012). The results of the present investigation would seem to provide support for this notion. Further, the connection between unresolved symptoms and persistent distress suggests that

improving symptom management in individuals with cancer may provide a cost-effective means of reducing some cancer-related distress (Fielding & Lam, 2013). Although Fielding and Lam (2013) have suggested that most individuals find a way to cope with the experience and challenges of cancer, the challenge for healthcare practitioners lies in seeking to identify and assist those who cannot. The present findings support the systematic monitoring of distress and the factors which may compromise quality of life, and through this process, healthcare providers may efficiently identify those individuals who are experiencing elevated distress and/or disease-related burden in hopes of optimizing short- and long-term outcomes.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., . . . Takeda, F. (1993). The european organisation for research and treatment of cancer qlq-c30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85*, 365-376.

Aarstad, A. K., Aarstad, H. J., Bru, E., & Olofsson, J. (2005). Psychological coping style versus disease extent, tumour treatment and qol in successfully treated head and neck squamous cell carcinoma patients. *Clinical Otolaryngology, 30*, 530-538.

Abendstein, H., Nordgren, M., Boysen, M., Jannert, M., Silander, E., Ahlner-Elmqvist, M., . . . Bjordal, K. (2006). Quality of life and head and neck cancer: A 5 year prospective study *The Laryngoscope, 115*, 2183-2192. doi: 10.1097/01.MLG.0000181507.69620.14

Akechi, T., Okuyama, T., Akizuki, N., Azuma, H., Sagawa, R., Furukawa, T. A., & Uchitomi, Y. (2006). Course of psychological distress and its predictors in advanced non-small cell lung cancer patients. *Psycho-Oncology, 15*(6), 463-473. doi: 10.1002/pon.975

Andreu, Y., Galdón, M. J., Durá, E., Martínez, P., Pérez, S., & Murgui, S. (2012). A longitudinal study of psychosocial distress in breast cancer: Prevalence and risk factors. *Psychology & Health, 27*(1), 72-87. doi: 10.1080/08870446.2010.542814

Barret, M., Malka, D., Aparicio, T., Dalban, C. c., Locher, C., Sabate, J.-M., . . . Attar, A. (2012). Nutritional status affects treatment tolerability and survival in metastatic colorectal cancer patients: Results of an ageo prospective multicenter study. *Oncology, 81*(5-6), 395-402.

Beisland, E., Aarstad, A. K. H., Osthus, A. A., & Aarstad, H. J. (2013). Stability of distress and health-related quality of life as well as relation to neuroticism, coping and tnm stage in head and neck cancer patients during follow-up. *Acta Oto-Laryngologica, 133*(2), 209-217. doi: 10.3109/00016489.2012.720032

Bjordal, K., Ahlner-Elmqvist, M., Hammerlid, E., Boysen, M., Evensen, J., Biorklund, A., . . . Kaasa, S. (2001). A prospective study of quality of life in head and neck cancer patients. Part ii: Longitudinal data. *Laryngoscope, 111*, 1440-1452.

Bjordal, K., Hammerlid, E., Ahlner-Elmqvist, M., de Graeff, A., Boysen, M., Evensen, J. F., . . . Kaasa, S. (1999). Quality of life in head and neck cancer patients: Validation of the european organization for research and treatment of cancer quality of life questionnaire h&n35. *Journal of Clinical Oncology, 17*, 1008-1019.

Bjordal, K., & Kaasa, S. (1995). Psychological distress in head and neck cancer patients 7-11 years after curative treatment. *British Journal of Cancer, 71*, 592-597.

Bjordal, K., Kaasa, S., & Mastekaasa, A. (1994). Quality of life in patients treated for head and neck cancer: A follow-up study 7 to 11 years after

radiotherapy. *International Journal of Radiation Oncology Biology Physics, 28*(4), 847-856.

Björklund, M., Sarvimäki, A., & Berg, A. (2010). Living with head and neck cancer: A profile of captivity. *Journal of Nursing and Healthcare of Chronic Illness, 2*(1), 22-31. doi: 10.1111/j.1752-9824.2010.01042.x

Bornbaum, C. C., Fung, K., Franklin, J. H., Nichols, A., Yoo, J., & Doyle, P. C. (2012). A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Support Care Cancer, 20*(9), 2157-2165. doi: 10.1007/s00520-011-1326-2

Breivik, H., Cherny, N., Collett, B., de Conno, F., Filbet, M., Foubert, A. J., . . . Dow, L. (2009). Cancer-related pain: A pan-european survey of prevalence, treatment, and patient attitudes. *Annals of Oncology, 20*(8), 1420-1433. doi: 10.1093/annonc/mdp001

Buchmann, L., Conlee, J., Hunt, J., Agarwal, J., & White, S. (2013). Psychosocial distress is prevalent in head and neck cancer patients. *The Laryngoscope*, n/a-n/a. doi: 10.1002/lary.23886

Byock, I. (2000). Completing the continuum of cancer care: Integrating life-prolongation and palliation. *Ca: A Cancer Journal for Clinicians, 50*(2), 123-132.

Carlson, L. E., Waller, A., Groff, S. L., Giese-Davis, J., & Bultz, B. D. (2013). What goes up does not always come down: Patterns of distress, physical and psychosocial morbidity in people with cancer over a one year period. *Psycho-Oncology, 22*(1), 168-176. doi: 10.1002/pon.2068

Chen, A. M., Jennelle, R. L., Grady, V., Tovar, A., Bowen, K., Simonin, P., . . . Vijayakumar, S. (2009). Prospective study of psychosocial distress among patients undergoing radiotherapy for head and neck cancer. *Int J Radiat Oncol Biol Phys, 73*(1), 187-193. doi: S0360-3016(08)00637-8 [pii]

Chua, K., Reddy, S., Lee, M., & Patt, R. (1999). Pain and loss of function in head and neck cancer survivors. *Journal of Pain and Symptom Management, 18*(3), 193-202. doi: 10.1016/S0885-3924(99)00070-6

Cohen, J. W. (1988). *Statistical power analysis for the behavioral sciences* (Second ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Couper, J. W., Love, A. W., Duchesne, G. M., Bloch, S., Macvean, M., Dunai, J. V., . . . Kissane, D. (2010). Predictors of psychosocial distress 12 months after diagnosis with early and advanced prostate cancer. *Medical Journal of Australia, 193*(5), S58-S61.

Cox, J., Pajak, T., Marcial, V., Coia, L., Mohiuddin, M., Fu, K., . . . Ortiz, H. (1992). Interruptions adversely affect local control and survival with hyperfractionated radiation therapy of carcinomas of the upper respiratory and digestive tracts. New evidence for accelerated proliferation from radiation therapy oncology group protocol 8313. *Cancer 69*, 2744–2748.

Cruciani, R. (2006). Understanding and treating cancer-related fatigue. *The Journal of Supportive Oncology, 4*(2), 72.

Danker, H., Keszte, J., Singer, S., Thoma, J., Taschner, R., Brahler, E., & Dietz, A. (2011). Alcohol consumption after laryngectomy. *Clinical Otolaryngology, 36*, 336-344.

Davis-Ali, S. H., Chesler, M. A., & Chesney, B. K. (1993). Recognizing cancer as a family disease: Worries and support reported by patients and spouses. *Social Work in Health Care, 19*(2), 45-65.

Deschler, D. D., & Day, T. (2008). Pocket guide to tnm staging of head and neck cancer and neck dissection classification   Retrieved from http://www.sld.cu/galerias/pdf/sitios/cirugiamaxilo/neckdissectionpart1.pdf

Dewys, W. D., Begg, C., Lavin, P. T., Band, P. R., Bennett, J. M., Bertino, J. R., . . . Ezdinli, E. Z. (1980). Prognostic effect of weight loss prior tochemotherapy in cancer patients. *The American journal of medicine, 69*(4), 491-497.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine, 160*, 2101-2107.

Doyle, P. C. (1994). *Foundations of voice and speech rehabilitation following laryngeal cancer*: Singular Publishing Group.

Doyle, P. C. (2005). *Rehabilitation in head and neck cancer: Overview*. Texas: PRO-ED, Incorporated.

Duffy, S. A., Khan, M. J., Ronis, D. L., Fowler, K. E., Gruber, S. B., Wolf, G. T., & Terrell, J. E. (2008). Health behaviors of head and neck cancer patients the first year after diagnosis. *Head & Neck, 30*(1), 93-102. doi: 10.1002/hed.20665

Duffy, S. A., Terrell, J. E., Valenstein, M., Ronis, D. L., Copeland, L. A., & Connors, M. (2002). Effect of smoking, alcohol, and depression on the quality of life of head and neck cancer patients. *General Hospital Psychiatry, 24*, 140-147.

Eadie, T. (2007). Application of the icf in communication after total laryngectomy. *Seminars in Speech and Language, 28*(4), 291-300. doi: 10.1055/s-2007-986526

Elani, H. W., & Allison, P. J. (2011). Coping and psychological distress among head and neck cancer patients. *Support Care Cancer, 19*(11), 1735-1741. doi: 10.1007/s00520-010-1013-8

Ettema, S., Reminger, S., & Robbins, K. T. (2013). The neuropsychological aspects of head and neck cancer. In C. Noggle & R. Dean (Eds.), *Neuropsychology of cancer and oncology* (pp. 111-122). New York: Springer Publishing Company.

Fayers, P. M., Aaronson, N. K., Bjordal, K., Groenvold, M., Curran, D., & Bottomley, A. (2001). *The eortc qlq-c30 scoring manual (3rd edition)*. Brussels: The European Organisation for Research and Treatment of Cancer.

Field, A. (2009). *Discovering statistics using spss* (Third ed.). Thousand Oaks: CA: SAGE Publications Inc.

Fielding, R., & Lam, W. W. T. (2013). Unresolved problems with distress screening. *British Journal of Cancer*. doi: 10.1038/bjc.2013.137

Forbes, K. (1997). Palliative care in patients with head and neck cancer. *Clinical Otolaryngology, 22*, 117-122.

Funk, G. F., Karnell, L. H., & Christensen, A. J. (2012). Long-term health-related quality of life in survivors of head and neck cancer. *Archives of Otolaryngology - Head and Neck Surgery, 138*(2), 123-133. doi: 10.1001/archoto.2011.234

Garg, S., Yoo, J., & Winquist, E. (2010). Nutritional support for head and neck cancer patients receiving radiotherapy: A systematic review. *Supportive Care in Cancer, 18*(6), 667-677. doi: 10.1007/s00520-009-0686-3

Gotay, C. C., & Pagano, I. S. (2007). Assessment of survivor concerns (asc): A newly proposed brief questionnaire. *Health and Quality of Life Outcomes, 5*(1), 15. doi: 10.1186/1477-7525-5-15

Greene, F. L., Page, D. L., Fleming, I. D., Balch, C. M., & Fritz, A. G. (2002). *Ajcc cancer staging handbook: From the ajcc cancer staging manual*: Springer Verlag.

Gritz, E., Carmack, C., de Moor, C., Schacherer, C., Meyers, E., & Abemayor, E. (1999). First year after head and neck cancer: Quality of life. *Journal of Clinical Oncology, 17*, 352-360.

Hammerlid, E., Bjordal, K., Ahlner-Elmqvist, M., Boysen, M., Evensen, J. F., Biorklund, A., . . . Sullivan, M. (2001). A prospective study of quality of life in head and neck cancer patients. Part i: At diagnosis *Laryngoscope, 111*, 669-680.

Hammerlid, E., Bjordal, K., Ahlner-Elmqvist, M., Jannert, M., Kaasa, S., Sullivan, K., & Westin, T. (1997). Prospective, longitudinal quality-of-life study of patients with head and neck cancer: A feasibility study including the eortc qlq c30. *Otolaryngology Head and Neck Surgery, 116*, 666-673.

Henselmans, I., Helgeson, V. S., Seltman, H., de Vries, J., Sanderman, R., & Ranchor, A. V. (2010). Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. *Health Psychology, 29*(2), 160-168. doi: 10.1037/a0017806

Horney, D. J., Smith, H. E., McGurk, M., Weinman, J., Herold, J., Altman, K., & Llewellyn, C. D. (2011). Associations between quality of life, coping styles, optimism, and anxiety and depression in pretreatment patients with head and neck cancer. *Head & Neck, 33*(1), 65-71. doi: 10.1002/hed.21407

Howren, M. B., Christensen, A. J., Karnell, L. H., & Funk, G. F. (2012). Psychological factors associated with head and neck cancer treatment and survivorship: Evidence and opportunities for behavioral medicine. *Journal of Consulting and Clinical Psychology*. doi: 10.1037/a0029940

Hutton, J., & Williams, M. (2001). An investigation of psychological distress in patients who have beentreated for head and neck cancer. *British Journal of Oral and Maxillofacial Surgery, 39*(5), 333-339. doi: 10.1054/bjom.2001.0645

IBM. (2011). IBM SPSS statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.

Johansson, M., Rydén, A., Ahlberg, K., & Finizia, C. (2012). "Setting boundaries" – mental adjustment to cancer in laryngeal cancer patients: An interview study. *European Journal of Oncology Nursing, 16*(4), 419-425. doi: 10.1016/j.ejon.2011.09.007

Johansson, M., Rydén, A., & Finizia, C. (2008). Self evaluation of communication experiences after laryngeal cancer – a longitudinal questionnaire study in patients with laryngeal cancer. *BMC Cancer, 8*(1), 80. doi: 10.1186/1471-2407-8-80

Johansson, M., Rydén, A., & Finizia, C. (2011). Mental adjustment to cancer and its relation to anxiety, depression, hrql and survival in patients with laryngeal cancer - a longitudinal study. *BMC Cancer, 11*(1), 283. doi: 10.1186/1471-2407-11-283

Katz, D., & McHorney, C. (2002). The relationship between insomnia and health-related quality of life in patients with chronic illness. *Journal of Family Practice, 51*, 229–235.

Katz, M. R., Kopek, N., Waldron, J., Devins, G. M., & Tomlinson, G. (2004). Screening for depression in head and neck cancer. *Psycho-Oncology, 13*(4), 269-280. doi: 10.1002/pon.734

Kelly, C., Paleri, V., Downs, C., & Shah, R. (2007). Deterioration in quality of life and depressive symptoms during radiation therapy for head and neck cancer. *Otolaryngology - Head and Neck Surgery, 136*(1), 108-111. doi: 10.1016/j.otohns.2006.06.1278

Kendal, W. (2006). Suicide and cancer: A gender-comparative study. *Annals of Oncology, 18*(2), 381-387. doi: 10.1093/annonc/mdl385

Koster, M. E. T. A., & Bergsma, J. (1990). Problems and coping behaviour of facial cancer patients. *Social Science & Medicine, 30*(5), 569-578. doi: 10.1016/0277-9536(90)90155-L

Kubrak, C., Olson, K., Jha, N., Jensen, L., McCargar, L., Seikaly, H., . . . Baracos, V. E. (2009). Nutrition impact symptoms: Key determinants of reduced dietary intake, weight loss, and reduced functional capacity of patients with head and neck cancer before treatment. *Head & Neck*, NA-NA. doi: 10.1002/hed.21174

Kugaya, A., Akechi, T., Okuyama, T., Nakano, T., Mikami, I., Okamura, H., & Uchitomi, Y. (2000). Prevalence, predictive factors and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer, 88*, 2817-2823.

Lam, W., Ye, M., & Fielding, R. (2012). Trajectories of quality of life among chinese patients diagnosed with nasopharyngeal cancer. . *PLoS One 7(9): e44022., 7*(9), e44022. doi: 10.1371/journal.pone.0044022

Lam, W. W. T., Bonanno, G. A., Mancini, A. D., Ho, S., Chan, M., Hung, W. K., . . . Fielding, R. (2009). Trajectories of psychological distress among chinese women diagnosed with breast cancer. *Psycho-Oncology, 19*(10), 1044-1051. doi: 10.1002/pon.1658

Lam, W. W. T., Li, W. W. Y., Bonanno, G. A., Mancini, A. D., Chan, M., Or, A., & Fielding, R. (2011). Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes. *Breast Cancer Research and Treatment, 131*(3), 957-967. doi: 10.1007/s10549-011-1798-2

Lam, W. W. T., Shing, Y. T., Bonanno, G. A., Mancini, A. D., & Fielding, R. (2012). Distress trajectories at the first year diagnosis of breast cancer in

relation to 6 years survivorship. *Psycho-Oncology, 21*(1), 90-99. doi: 10.1002/pon.1876

Ledeboer, Q. C. P., van der Velden, L.-A., de Boer, M. F., Feenstra, L., & Pruyn, J. F. A. (2005). Physical and psychosocial correlates of head and neck cancer: An update of the literature and challenges for the future (1996-2003) *Clinical Otolaryngology, 30*, 303-319.

Lee, C. J. (2004). Horatio (Version 3.0). London: Faculty of Health Sciences, The University of Western Ontario. Retrieved from http://publish.uwo.ca/~cjlee/horatio/]

List, M., & Bilir, S. (2004). Functional outcomes in head and neck cancer. *Seminars in Radiation Oncology, 14*(2), 178-189. doi: 10.1053/j.semradonc.2003.12.008

Lo, B., Quill, T., & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of Internal Medicine, 130*, 744-749.

Lokker, M. E., Offerman, M. P., van der Velden, L.-A., De Boer, J. D., Pruyn, J. F., & Teunissen, S. C. (2012). Symptoms of patients with incurable head and neck cancer: Prevalence and impact on daily functioning. *Head & Neck, Early online.* doi: 10.1002/hed.23053

Lydiatt, W. M., Moran, J., & Burke, W. J. (2009). A review of depression in the head and neck cancer patient. *Clinical Advances in Hematology & Oncology, 7*(6), 397-403.

Manocchia, M., Keller, S., & Ware, J. (2001). Sleep problems, healthrelated quality of life, work functioning and health care utilization among the chronically ill. . *Quality of Life Research, 10*, 331–345.

Marur, S., & Forastiere, A. A. (2008). Head and neck cancer: Changing epidemiology, diagnosis and treatment. *Mayo Clinic Proceedings, 83*(4), 489-501.

Massie, M. J. (2004). Prevalence of depression in patients with cancer. *Journal of the National Cancer Institute Monographs, 2004*(32), 57-71. doi: 10.1093/jncimonographs/lgh014

McDonough, E., Boyd, J., Varvares, M., & Maves, M. (1996). Relationship between psychological status and compliance in a sample of patients treated for cancer of the head and neck *Head & Neck, 18*, 269-276.

Mehanna, H. M., & Morton, R. P. (2006). Deterioration in quality-of-life of late (10 year) survivors of head and neck cancer. *Clinical Otolaryngology, 31*, 204-211.

Misono, S., Weiss, N. S., Fann, J. R., Redman, M., & Yueh, B. (2008). Incidence of suicide in persons with cancer. *Journal of Clinical Oncology, 26*(29), 4731-4738. doi: 10.1200/jco.2007.13.8941

Molassiotis, A., & Rogers, M. (2012). Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliative and Supportive Care, 10*(03), 197-204. doi: 10.1017/s147895151200020x

Muthen, B., & Asparouhov, T. (2006). Growth mixture modeling: Analysis with non-gaussian random effects. In T. E. Duncan, S. C. Duncan & L. A.

Strycker (Eds.), *An introduction to latent variable growth curve modeling: Concepts, issues, and applications* (pp. 143-165): Routledge.

National Comprehensive Cancer Network (NCCN). (2010). *NCCN clinical practice guidelines in oncology (NCCN guidelines): Distress management version 1.2010*: National Comprehensive Cancer Network.

National Comprehensive Cancer Network (NCCN). (2013). NCCN clinical practice guidelines in oncology: Distress management. *2.2013*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

National Cancer Institute (NCI). (2009). Dictionary of cancer terms. Retrieved July 9, 2013, 2013, from http://www.cancer.gov/dictionary/?CdrID=618612

Neilson, K., Pollard, A., Boonzaier, A., Corry, J., Castle, D., Smith, D., . . . Couper, J. (2012). A longitudinal study of distress (depression and anxiety) up to 18 months after radiotherapy for head and neck cancer. *Psycho-Oncology*, n/a-n/a. doi: 10.1002/pon.3228

Nitenberg, G., & Raynard, B. (2000). Nutritional support of the cancer patient: Issues and dilemmas. *Critical Reviews in Oncology/Hematology, 34*, 137-168.

Nosarti, C., Roberts, J. V., Crayford, T., McKenzie, K., & David, A. S. (2002). Early psychological adjustment in breast cancer patients: A prospective study. *Journal of Psychosomatic Research, 53*, 1123-1130.

Osoba, D., Rodrigues, G., Myles, J., Zee, B., & Pater, J. (1998). Interpreting the significance of changes in health-related quality-of-life scores. *Journal of Clinical Oncology, 16*(1), 139-144.

Ottosson, S., Laurell, G., & Olsson, C. (2013). The experience of food, eating and meals following radiotherapy for head and neck cancer: A qualitative study. *Journal of Clinical Nursing, 22*(7-8), 1034-1043. doi: 10.1111/jocn.12151

Owen, C., Watkinson, J. C., Parcy, P., & Glaholm, J. (2001). The psychosocial impact of head and neck cancer. *Clinical Otolaryngology, 26*, 351-356.

Paccagnella, A., Morello, M., Mosto, M. C., Baruffi, C., Marcon, M. L., Gava, A., . . . Marchiori, C. (2009). Early nutritional intervention improves treatment tolerance and outcomes in head and neck cancer patients undergoing concurrent chemoradiotherapy. *Supportive Care in Cancer, 18*(7), 837-845. doi: 10.1007/s00520-009-0717-0

Paillaud, E., Bories, P.-N., Aita, S. L., Scherman, E., Jeanfaivre, V., Lejonc, J.-L., & Campillo, B. (2003). Prognostic value of dietary intake and inflammation on survival in patients with advanced cancer: Relationship with performance status, pain, and digestive disorders. *Nutrition and Cancer, 45*(1), 30-35. doi: 10.1207/s15327914nc4501_4

Paleri, V., Wight, R. G., Silver, C. E., Haigentz, M., Takes, R. P., Bradley, P. J., . . . Ferlito, A. (2010). Comorbidity in head and neck cancer: A critical appraisal and recommendations for practice. *Oral Oncology, 46*(10), 712-719. doi: 10.1016/j.oraloncology.2010.07.008

Pallant, J. (2011). *Spss survival manual: A step by step guide to data analysis using spss* (4th ed.). Crows Nest, NSW: Allen & Unwin.

Pandey, M., Devi, N., Thomas, B. C., Kumar, S. V., Krishnan, R., & Ramdas, K. (2007). Distress overlaps with anxiety and depression in patients with head and neck cancer. *Psychooncology, 16*(6), 582-586. doi: 10.1002/pon.1123

Payakachat, N., Ounpraseuth, S., & Suen, J. Y. (2012). Late complications and long-term quality of life for survivors (>5 years) with history of head and neck cancer. *Head & Neck*, 1-7. doi: 10.1002/hed.23035

Penson, R. T. (2006). Teams: Communication in multidisciplinary care. *The Oncologist, 11*(5), 520-526. doi: 10.1634/theoncologist.11-5-520

Pirl, W. F., Muriel, A., Hwang, V., Kornblith, A., Greer, J., Donelan, K., . . . Schapira, L. (2007). Screening for psychosocial distress: A national survey of oncologists. *The Journal of Supportive Oncology, 5*(10), 499-504.

Polsky, D., Doshi, J. A., Marcus, S., Oslin, D., Rothbard, A., Thomas, N., & Thompson, C. L. (2005). Long-term risk for depressive symptoms after a medical diagnosis. *Archives of Internal Medicine, 165*, 1260-1266.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of Clinical Research: Applications to Practice (Third Edition)*. Upper Saddle River, NJ: Pearson Education Inc.

Roscoe, J. A., Kaufman, M. E., Matteson-Rusby, S. E., Palesh, O. G., Ryan, J. L., Kohli, S., . . . Morrow, G. R. (2007). Cancer-related fatigue and sleep disorders. *The Oncologist, 12*(suppl_1), 35-42. doi: 10.1634/theoncologist.12-S1-35

Savard, J., & Ivers, H. (2013). The evolution of fear of cancer recurrence during the cancer care trajectory and its relationship with cancer characteristics. *Journal of Psychosomatic Research, 74*(4), 354-360. doi: 10.1016/j.jpsychores.2012.12.013

Savard, J., Ivers, H., Villa, J., Caplette-Gingras, A., & Morin, C. M. (2011). Natural course of insomnia comorbid with cancer: An 18-month longitudinal study. *Journal of Clinical Oncology, 29*(26), 3580-3586. doi: 10.1200/jco.2010.33.2247

Savard, J., & Morin, C. (2001). Insomnia in the context of cancer: A review of a neglected problem. *Journal of Clinical Oncology, 19*, 895-908.

Sawada, N. O., Paula, J. M., Sonobe, H. M., Zago, M. M. F., Guerrero, G. P., & Nicolussi, A. C. (2012). Depression, fatigue, and health-related quality of life in head and neck cancer patients: A prospective pilot study. *Supportive Care in Cancer, 20*(11), 2705-2711. doi: 10.1007/s00520-012-1390-2

Semple, C. J. (2001). The role of the cns in head and neck oncology. *Nursing Standard, 15*(23), 39-42.

Semple, C. J., Sullivan, K., Dunwoody, L., & Kernohan, W. G. (2004). Psychosocial interventions for patients with head and neck cancer: Past, present and future *Cancer Nursing, 27*(6), 434-441.

Sharp, L., Lewin, F., Hellborg, H., Lundgren, J., Hemmingsson, E., & Rutqvist, L. E. (2002). When does my treatment start? The continuum of care for patients with head and neck cancer. *Radiotherapy and Oncology, 62*, 293-297.

Shone, G. R., & Yardley, M. P. J. (1991). An audit into the incidence of handicap after unilateral radical neck dissection. *The Journal of Laryngology and Otology, 105*, 760-762.

Shuman, A. G. (2012). Predictors of pain among patients with head and neck cancer. *Archives of Otolaryngology–Head & Neck Surgery, 138*(12), 1147. doi: 10.1001/jamaoto.2013.853

Shuman, A. G., Duffy, S. A., Ronis, D. L., Garetz, S. L., McLean, S. A., Fowler, K. E., & Terrell, J. E. (2010). Predictors of poor sleep quality among head and neck cancer patients. *The Laryngoscope*, n/a-n/a. doi: 10.1002/lary.20924

Singer, S., Krauss, O., Keszte, J., Siegl, G., Papsdorf, K., Severi, E., . . . Kortmann, R. D. (2012). Predictors of emotional distress in patients with head and neck cancer. *Head Neck, 34*(2), 180-187. doi: 10.1002/hed.21702

Spiegel, D., & Giese-Davis, J. (2003). Depression and cancer: Mechanisms and disease progression. *Biological Psychiatry, 54*(3), 269-282. doi: 10.1016/s0006-3223(03)00566-3

Taylor, J. C., Terrell, J. E., Ronis, D. L., Fowler, K. E., Bishop, C., Lambert, M. T., . . . Duffy, S. A. (2004). Disability in patients with head and neck cancer. *Archives of Otolaryngology Head and Neck Surgery, 130*, 764-769.

Trotti, A., Bellm, L. A., Epstein, J. B., Frame, D., Fuchs, H. J., Gwede, C. K., . . . Zilberberg, M. D. (2003). Mucositis incidence, severity and associated outcomes in patients with head and neck cancer receiving radiotherapy with or without chemotherapy: A systematic literature review. *Radiotherapy and oncology: journal of the European Society for Therapeutic Radiology and Oncology, 66*(3), 253.

Twombly, R. (2004). What's in a name: Who is a cancer survivor? *Journal of the National Cancer Institute, 96*(19), 1414-1415.

Vahdaninia, M., Omidvari, S., & Montazeri, A. (2009). What do predict anxiety and depression in breast cancer patients? A follow-up study. *Social Psychiatry and Psychiatric Epidemiology, 45*(3), 355-361. doi: 10.1007/s00127-009-0068-7

Vallerand, A. H., Templin, T., Hasenau, S. M., & Riley-Doucet, C. (2007). Factors that affect functional status in patients with cancer-related pain. *Pain, 132*(1-2), 82-90. doi: 10.1016/j.pain.2007.01.029

Verdonck-de Leeuw, I. M., Eerenstein, S. E., Van der Linden, M. H., Kuik, D. J., de Bree, R., & Leemans, C. R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope, 117*(2), 238-241. doi: 10.1097/01.mlg.0000250169.10241.58

Walden, M. J., & Aygun, N. (2013). Head and neck cancer. *Seminars in Roentgenology, 48*(1), 75-86. doi: 10.1053/j.ro.2012.09.002

Wang, X. S. (2006). Longitudinal study of the relationship between chemoradiation therapy for non-small-cell lung cancer and patient symptoms. *Journal of Clinical Oncology, 24*(27), 4485-4491. doi: 10.1200/jco.2006.07.1126

Ward, D. E. C., & van As-Brooks, C. J. (2007). *Head and neck cancer: Treatment, rehabilitation, and outcomes*: Cambridge Univ Press.

Whale, Z., Lyne, P. A., & Papanikolaou, P. (2001). Pain experience following radical treatment for head and neck cancer. *European Journal of Oncology Nursing, 5*(2), 112-120. doi: 10.1054/ejon.2000.0113

Whelan, T., Mohide, E. A., Willan, A. R., Arnold, A., Tew, M., Sellick, S., . . . Levine, M. N. (1997). The supportive care needs of newly diagnosed cancer patients attending regional cancer center. *Cancer, 80*, 1518-1524.

WHO. (1998). Health promotion glossary   Retrieved from http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf

Wolff, T. J., Leeper, H. A., Gratton, D. G., & Doyle, P. C. (2004). The psychosocial aspects of prosthetic use scale (papus): Preliminary data. *Journal of Speech-Language Pathology and Audiology, 28*(1), 34-39.

Chapter 3

A Cross-Sectional Analysis of Distress in Caregivers of Individuals Diagnosed

with Head and Neck Cancer

Background

The diagnosis of head and neck cancer brings with it profound changes

for not only the individual with cancer, but also for the loved ones who often play

a critical role in their care. Owing to the broad range of potential impairments and

psychosocial needs of individuals with head and neck cancer (Bornbaum et al.,

2012; Doyle, 1994; Payakachat, Ounpraseuth, & Suen, 2012), caregivers often

fulfill an indispensable role in an individual's support team throughout the

treatment and post-treatment period (Kagan, Clarke, & Happ, 2005). Caregivers

provide a wide range of support to their loved ones which often includes

emotional support (e.g., talking about worries, fears, etc.), instrumental support

(e.g., liaising with medical team, communicating with distant family members),

tangible support (e.g., assistance with transportation, finances, household tasks),

and medical support (e.g., accompaniment to treatments, help with administering

medications) (Yabroff & Kim, 2009).

A recent review into the role of caregiving in head and neck cancer

evaluated both the presence of distress and the factors known to influence such

caregiving (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). Longacre and

colleagues observed that throughout the studies included in their review,

between 20-40% of caregivers reported experiencing clinically significant levels

of distress. Further, caregivers of individuals with head and neck cancer were more likely to experience poorer rates of psychological wellbeing when compared to both population norms (e.g., the general public, assumed healthy individuals) (Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004; Vickery, Latchford, Hewison, Bellew, & Feber, 2003) and those with head and neck cancer (Hodges & Humphris, 2009; Vickery et al., 2003). Longacre and colleagues (2012) noted that, in general, caregivers of those with head and neck cancer were primarily female spouses in their mid- to late-fifties, a finding that is understandable given that men are most often afflicted with the disease and that the median age of diagnosis was recently reported as between 50-59 years of age (Cooper et al., 2009). While acknowledgement of the most common characteristics of those providing care for individuals with head and neck cancer remains important, it may fail to adequately convey the gravity of precisely what the role of providing care to a person with head and neck cancer actually entails and the impact that caregiving has on those who serve in that capacity.

The diagnosis of head and neck cancer forces both the individual with cancer and their caregiver to confront not only a life threatening disease, but also a series of potential and actual losses related to the disease and its treatment. Owing to the anatomic characteristics of the head and neck region, treatment of head and neck cancer may result in deficits to the individual's physical appearance that cannot easily be hidden, in addition to varying degrees of dysfunction in respiration, eating, swallowing, and communication (Chen et al., 2009; Katz, Irish, Devins, Rodin, & Gullane, 2003; Koster & Bergsma, 1990).

Following treatment for head and neck cancer, additional undesirable side effects such as facial weakness, drooling, trismus (i.e., difficulty opening the jaw), physical scarring, and poor speech intelligibility may persist (Doyle, 2005; Jeremic et al., 2011; Katz et al., 2003). The presence of these side effects may cause embarrassment and significantly impact not only the individual's internalized feelings of self-esteem and self-concept, but also their willingness to interact socially (Doyle, 2005; Semple, Sullivan, Dunwoody, & Kernohan, 2004). Formerly simple pleasures such as dining out at a restaurant may become a source of tremendous stress and embarrassment for those with head and neck cancer. As a result, individuals may choose to not participate in these types of social situations which may then coincidently restrict the social activities of the caregiver if the caregiver is a spouse or family member of the individual with cancer (Roing, Hirsch, & Holstrom, 2008).

Although the individual with cancer sits at the core of diagnosis and treatment, the needs of caregivers are often forgotten or overlooked throughout the cancer care process (Eton, Lepore, & Helgeson, 2005; Northouse, 2002; Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi, 2011). Though such exclusion is not intentional, failure to acknowledge the caregiver in the context of the person with cancer is problematic because the role of caregiving is immensely challenging. The role of caregiving is complex, yet highly unique to every individual; this is not only due to the numerous medical terms and procedures that a caregiver may have to understand or be able to perform (e.g., wound cleaning, dressing changes, etc.), but also because caregivers must learn to

reconcile their own sense of helplessness during a time when strength and support are required (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994). Undoubtedly, the challenges of cancer and its treatment have an enormous impact on the psychosocial functioning of both individuals with head and neck cancer and their caregivers. As a result, it is important to evaluate the psychosocial functioning of these caregivers in order to identify factors that may influence distress so that the appropriate resources and interventions can be offered when required.

At present, a key barrier to the recognition of distress in caregivers lies in the fact that throughout the continuum of care, the individual with cancer, as opposed to their caregiver, is the focus of the cancer care team. As a result, the individual with cancer has a higher probability of receiving a referral for supportive care services (Zwahlen et al., 2011) such as psychological counseling, support groups, and assistance with practical concerns through social work departments. Caregivers of individuals with cancer have reported receiving low levels of support from others, including specialists (Northouse, 2002) and from the individual with cancer themselves (Eton, Lepore, & Helgeson, 2005). Understandably, caregiver concerns often remain relegated to the background, while attention is focused on the individual with cancer (Zwahlen et al., 2011). Caregivers have reported finding it challenging, and have even reported feeling guilty, when seeking support for themselves (Eriksson & Lauri, 2000). However, when caregivers do not directly seek out assistance for their distress and/or broader concerns, these problems often go unnoticed by those

most able to provide direct assistance (e.g., medical professionals and support staff) (Zwahlen et al., 2011). As a result, it is important to understand the factors that may contribute to elevated distress in caregivers of individuals with head and neck cancer so that those most at risk of experiencing elevated distress may be identified in order to ensure that the appropriate resources and interventions can be recommended when required. The ability to understand the impact of cancer on both "patient" and caregiver, cannot be discounted and efforts to understand the phenomena associated with distress is clearly warranted.

Distress in caregivers of individuals with head and neck cancer

In an effort to understand and describe the variables related to distress in caregivers of individuals with cancer, Sherwood and colleagues (2008) developed a conceptual framework to address these types of concerns. In their framework they posited that a caregiver's psychological health (e.g., distress, depressive symptoms, anxious symptoms, etc.) is influenced by two primary factors; these factors include both the disease characteristics of the individual with cancer (e.g., time since diagnosis, disease stage, patient functioning and needs) and the caregiver's personal characteristics and resources (e.g., sociodemographic factors, social support, coping style) (Sherwood et al., 2008).

Relative to the known disease-related characteristics associated with psychological health in caregivers of those with head and neck cancer, data indicate that the time frame following diagnosis and during treatment (e.g., 2-6 months post-diagnosis) is particularly stressful for caregivers (Blood et al., 1994). Following this time period, the level of burden experienced by caregivers was

perceived to decrease in association with increasing time following diagnosis (Blood et al., 1994). Further, while not extensively assessed to date, some researchers have noted that caregivers report a high degree of fear related to the possibility that the cancer will recur (Watt-Watson & Graydon, 1995); these fears in caregivers are sometimes even stronger than those of the patients themselves (Hodges & Humphris, 2009). Thus, the very real emotional fears that may be experienced by caregivers can have a substantial impact on their psychological health and overall well-being.

With regard to the relationship between caregiver psychological health and personal characteristics and/or resources, several variables have been examined to date. Specifically, research into one's level of education has revealed somewhat mixed results. Some authors have found no relationship between education and psychological health (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010), whereas others have reported that caregivers with higher education levels placed increased value on the use of psychological support (for both themselves and the patient) and subsequently, actively sought more contact with psychological resources (e.g., self-help groups) (Baghi et al., 2007). Research into the effect of sex on perceived distress again has been mixed, with some investigators noting an increased desire for psychological support among women (Baghi et al., 2007), while others have reported no significant associations between sex and psychological health (Ross et al., 2010; Verdonck-de Leeuw et al., 2007). To date, no significant associations have been detected between age and psychological health in caregivers of individuals with

head and neck cancer (Ross et al., 2010; Verdonck-de Leeuw et al., 2007). Nevertheless, research into the factors that underlie and contribute to distress and decreased quality of life are important because perceptions of burden and lowered quality of life in caregivers have been established as early predictors of prolonged hospital stays in individuals with dementia (Lang et al., 2010). It is possible that a similar effect may be present when considering caregivers of individuals with head and neck cancer. Investigating the factors that predict distress may facilitate the early identification of vulnerable individuals, which may allow for the delivery of targeted services and interventions that prevent severe and/or persistent symptoms of distress and ultimately facilitate long-term adjustment (Neilson et al., 2012) of caregivers. Hence, developing a greater understanding of the factors that contribute to caregiver distress and quality of life may have important implications not only for improvement of caregiver outcomes, but also for the individual with head and neck cancer. In order to determine which specific factors may contribute to caregiver distress and perceptions of quality of life, an examination of areas that are currently overlooked in the caregiver distress literature may serve to highlight avenues of research that warrant investigation.

Limitations of the current literature

Previous research into distress in caregivers of individuals with head and neck cancer has been limited in a number of important ways. First, currently available resources related to the caregiving experience of individuals with head and neck cancer have included participants who cared for individuals who were

generally between two and 48 months post-diagnosis (Baghi et al., 2007; Hodges & Humphris, 2009; Ross et al., 2010; Verdonck-de Leeuw et al., 2007). These studies included a range of lengths in time since diagnosis which included, three to six months post-diagnosis (Hodges & Humphris, 2009), six to 24 months post-diagnosis (Baghi et al., 2007; Ross et al., 2010; Verdonck-de Leeuw et al., 2007), and two to 48 months post-diagnosis (Blood et al., 1994). There has also been a subset of research focused on issues arising in early survivorship; more specifically, studies have included caregivers of individuals who were between one and five years post-diagnosis (Drabe et al., 2008; Mellon, Northouse, & Weiss, 2006). However, since distress-related concerns have been reported in individuals with head and neck cancer in both the newly diagnosed (Haisfield-Wolfe, McGuire, & Krumm, 2012) as well as long-term survivorship phases (Bjordal & Kaasa, 1995), and since previous research has demonstrated a relationship between distress levels of those with cancer and their caregivers (Zwahlen et al., 2011), it would appear reasonable to assume that distress-related concerns may arise in primary caregivers during both the newly diagnosed and long-term survivorship phases. As such, the present investigation sought to broaden the spectrum of exploration into caregiver concerns relative to the length of time since diagnosis.

In addition to research related to the specific length of time since provision of a diagnosis, to the author's knowledge, research exploring the relationship between caregiver distress and the treatment status of the individual with head and neck cancer (e.g., awaiting treatment, undergoing treatment, completed

treatment) has not previously been explored. While data do exist related to concerns that may arise in the context of survivorship (e.g., post-treatment) for caregivers of individuals who have been treated for head and neck cancer (Drabe et al., 2008; Mellon et al., 2006), there is a paucity of comparative data related specifically to the relationship between stage of treatment and caregiver distress. This paucity of data is particularly problematic because research into those with head and neck cancer has revealed that the presence of distress is related to one's treatment status (Neilson et al., 2012; Zabora et al., 1997), and further, the transmission of distress from the person receiving treatment to their caregiver may be particularly strong in "caregiver-care recipient" systems (Hodges, Humphris, & Macfarlane, 2005; Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007). Thus, research which explores the direct effect of treatment status on caregiver distress may be beneficial since information related to highly distressing periods throughout the continuum of care may help clinicians to better target their psychosocial resources to the most distressing events known to exist along the continuum of care in caregivers.

Furthermore, all distress-related research efforts to date in this population have involved the use of multi-item distress measures (Longacre et al., 2012). This includes the use of measures such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), the Mental Health Inventory (Veit & Ware, 1983), and the Global Assessment of Recent Stress (Linn, 1985), among others (Longacre et al., 2012). The utility of an "ultrashort" (Vodermaier, Linden, & Siu, 2009) measure such as the Distress Thermometer has been established in

caregiver oncology populations (Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008; Zwahlen et al., 2011), and ultrashort measures have been found particularly useful and effective for distress screening purposes in busy, clinical environments (Vodermaier et al., 2009). Yet despite these findings, to date, the Distress Thermometer has only been utilized to assess distress in caregivers of individuals with brain cancer (Keir, Calhoun-Eagan, Swartz, Saleh, & Friedman, 2008). Consequently, use of an ultrashort measure, such as the Distress Thermometer, to assess distress in caregivers of individuals with head and neck cancer may enhance the opportunity to promote the regular screening of distress in this population, given the tool's reliability and ease of clinical use (Vodermaier et al., 2009). In consideration of these noted limitations to the current literature, a number of specific objectives were developed related to this research investigation and are discussed below.

Study-specific research objectives

The overarching purpose of the present investigation was to determine what factors were associated with elevated distress among caregivers of individuals with head and neck cancer. We further aimed to explore how distress may be related to certain outcomes in those caregivers. Specifically, we sought to understand how both the caregiver's personal demographic factors and the disease- and treatment-related characteristics (e.g., treatment status) of the individual with head and neck cancer may contribute to elevated distress and decreased quality of life in caregivers of individuals with head and neck cancer. Distress in caregivers was assessed through use of an ultrashort distress

screening tool, the Distress Thermometer (National Comprehensive Cancer Network [NCCN], 2013). Further, because current resources are limited to the experiences of head and neck cancer caregivers between two months and five years following the point of diagnosis, we sought to enhance the literature to include considerations of caregivers in both the newly diagnosed and long-term follow-up (e.g., survivorship) phases of the continuum of care. Accordingly, a number of specific objectives for this inquiry were developed: (1) to determine the presence of distress in caregivers of individuals diagnosed with head and neck cancer; (2) to describe the range of perceived problems (e.g., practical, familial, emotional, spiritual, physical) reported among caregiver participants; (3) to assess the relationship between distress and quality of life in caregivers of individuals with head and neck cancer; (4) to evaluate if a relationship existed between perceived distress level and specific demographic characteristics of caregivers; and (5) to determine if a relationship existed between caregiver distress and the disease- and/or treatment-related characteristics of the individual with head and neck cancer.

Method

Participants

Participants (n = 119) involved in this research protocol were recruited in-person through one of two possible venues. The first was through their physician in the London Regional Cancer Program (LRCP) at the London Health Sciences Centre, Victoria Campus, located in London, Ontario. The second possible venue

was the annual meeting of the International Association of Laryngectomees. The decision to recruit at two venues was based on the effort to increase the maximum possible number of participants in the sample and also to enhance the generalizability of the data to a group beyond Southwestern Ontario. This sample may be considered as a sample of convenience based on the willingness of individuals to participate following a request by their physician or a member of the research team (e.g., C.B., P.D.). Prior to undertaking this study, the Ethics Review Board at The University of Western Ontario approved this protocol; Approval # 18019E (see Appendix B).

Inclusion criteria. In order to be included in this study, participants were required to be at least 18 years of age and able to provide informed consent (i.e., no known cognitive impairments). They were also required to identify themselves as the primary caregiver of an individual diagnosed with head and neck cancer.

Exclusion criteria. If individuals were unable to read, write or understand English or if they were unable to visually see the questionnaires they were excluded since the tasks involved in this study required participants to read and understand the questionnaires in English, and respond to questions accordingly.

In total, 200 individuals were identified as potential participants and subsequently received packages containing the letter of information and consent, the demographic questionnaire, and the research instruments. The age of participants in this study ranged from a minimum of 28 years to a maximum of 83 years. The mean age for all participants was 61.60 years (SD = 11.19). In total,

the 90 female (mean age = 59.03 years) and 29 male participants (mean age =

61.56 years) resulted in a female-to-male ratio of approximately 3:1.

In addition, the length of time since the individual with head and neck

cancer had received his or her diagnosis ranged from 0 to 274 months (mean =

26.59; SD = 49.92). When divided into intervals of time since diagnosis, data

revealed a large number of participants in the newly diagnosed phase including

those less than one month from diagnosis (n = 14) and those who were between

one and three months post-diagnosis (n = 31). Other lengths of time following

diagnosis reported by caregivers included: four to six months (n = 10), seven to

nine months (n = 8), 10 to 12 months (n = 9), 13 to 18 months (n = 9), 19 to 24

months (n = 3), 25-60 months (n = 15), 61 to 120 months (n = 7), 121-240

months (n = 8), and greater than 240 months (n = 1). Comprehensive

demographic data for these participants are presented in Table 3.1, while the

disease- and treatment-related data for the individuals for whom they were

providing care are presented in Table 3.2.

Procedure

Data collection. All individuals who consented to participate received a

package containing a letter of information and consent form (see Appendix D), a

demographic questionnaire (see Appendix F), the Distress Thermometer and

accompanying Problem Checklist (NCCN, 2013) (see Appendix I), the Caregiver

Quality of Life-Cancer Scale (CQOLC) (Weitzner, Jacobsen, Wagner, Friedland,

& Cox, 1999) (see Appendix J), a list with the contact information for local

psychological support services (see Appendix K), and a self-addressed and

Table 3.1

Demographic Data of Caregiver Participants

Variable	n	%
Sex		
Female	90	75.6
Male	29	24.4
Relationship to patient		
Spouse	98	82.4
Family member	19	16.0
Friend	2	1.7
Marital status		
Married/common-law	107	89.9
Separated/divorced/widowed/single	11	9.2
Unspecified	1	0.8
Education		
Completed college/university	61	51.3
Completed high school	46	38.7
Completed less than high school	12	10.1
Occupational status		
Retired	60	50.4
Working full-time	33	27.8
Working part-time	15	12.6
Unemployed/stay at home	6	5.0
Receive disability benefits	5	4.2
Household income		
≤ $25,000	8	6.7
$25,001 - $40,000	15	12.6
$40,001 - $55,000	17	14.3
$55,001 - $70,000	12	10.1
$70,001 - $85,000	5	4.2
> $85,000	27	22.7
Unspecified	35	29.4

Table 3.2

Disease- and Treatment-Related Data for Individuals with Head and Neck Cancer Cared for by Caregiver Participants

Variable	n	%*
Site of cancer		
Oral cavity	39	32.8
Larynx	24	20.2
Pharynx	18	15.1
Multiple sites	11	9.2
Sinuses/paranasal sinuses	6	5.0
Salivary glands	6	5.0
Neck	6	5.0
Ear	5	4.2
Scalp	1	0.8
Unknown primary	3	2.5
Stage of disease		
T1	13	10.9
T2	7	5.9
T3	15	12.6
T4	29	24.4
Unspecified	55	46.2
Treatment status		
Awaiting treatment	42	35.5
Undergoing treatment	25	21.0
Completed treatment	46	38.7
Unspecified	6	5.0
Treatment type		
Surgery	36	30.3
Surgery and radiation therapy	25	21.0
Chemotherapy and radiation therapy	22	18.5
Surgery, radiation therapy, chemotherapy	11	9.2
Radiation therapy	10	8.4
Unspecified	8	6.7
Surgery and chemotherapy	5	4.2
Chemotherapy	2	1.7
Recurrence of cancer		
Recurrence	29	24.4
No recurrence	90	75.6

Note. Not all columns add to 100.

prepaid return envelope to ensure that participants did not incur any undue financial burden for their participation in this study.

The letter of information informed the participant of the general purpose of the study, the risks and benefits associated with participating in the study, and also notified them that they were under no obligation to complete the questionnaires nor would they suffer any consequences for declining to participate. In compliance with ethical requirements, informed consent was indicated by the voluntary completion and return of the questionnaire to the researcher. This procedure of obtaining consent was explicitly stated in the letter of information. If any of the questionnaires were not completed in entirety with sufficient data to compute statistical analysis as per the requirements specified in the standardized scoring and procedures manual for each questionnaire, they were destroyed and excluded from data analysis.

Sample size calculations. Sample size calculations were conducted using G*Power 3 Software (Version 3.1) (Faul, Erdfelder, Lang, & Buchner, 2007) in order to identify the number of participants required to obtain adequate statistical power. It was determined that a total sample size (n) of 54 individuals would be sufficient to detect the hypothesized effect (d = 0.5) of a within-subject independent variable design 95.0 percent of the time using a 0.05 alpha level (Faul et al., 2007). Despite this relatively low number of required participants, it was determined that a total of 200 individuals would be invited to participate in the study with the goal of obtaining a response rate of approximately 50% (Baruch, 1999).

Measurement instruments

The measurement instruments utilized in this study included: (1) the CQOLC to assess quality of life, (2) the Distress Thermometer and accompanying Problem Checklist to assess distress and perceived problems, and (3) a demographic questionnaire to assess both the caregiver's personal demographic information and the disease- and treatment-related characteristics of the individual for whom they were providing care (i.e. the individual with head and neck cancer). The order of the Distress Thermometer and CQOLC questionnaires was randomly assigned as per predetermined stapling of the instruments (e.g., half of the packages provided the Distress Thermometer first, while the other half offered the CQOLC first). This procedure of organizing the order of the instruments was conducted in an effort to reduce any response bias due to the influence of exposure to the preceding measure. Participants were instructed to complete each questionnaire as per the enclosed instructions provided on the measures themselves (e.g., the Distress Thermometer and CQOLC) in a location of their choosing (i.e., home or private office). Additional pages were provided for participants to include any additional information that they felt was pertinent to the research topic (i.e., any concerns or life events that could serve as confounding factors influencing their distress or quality or life at the time of the survey). It was anticipated that completion of all tasks would take approximately 10-15 minutes.

Demographic information. Demographic items consisted of the participant's age, sex, relationship to the individual with head and neck cancer

(e.g., spouse, family member, friend, etc.), marital status, occupational status, highest level of education obtained, and approximate household income. Relative to the disease- and treatment-related characteristics of the individual for whom they were providing care, items for which data were collected included the length of time since diagnosis, the specific site of the malignancy (e.g., larynx, oral cavity, etc.), the tumour stage of the disease, the type of treatment received, the status of treatment (e.g., awaiting, undergoing, completed, etc.), and whether or not the individual had experienced a recurrence of the disease.

Data analysis

Raw data from the current study were analyzed using SPSS 20.0 for Macintosh (IBM, 2011). Moreover, an a priori alpha level of $p \leq 0.05$ was used for statistical tests.

Descriptive statistics. Initially, descriptive statistics (e.g., means, standard deviations, frequency distributions, histograms, etc.) were calculated for demographic data, treatment- and disease-related variables, and the global and specific domains of each questionnaire (e.g., Distress Thermometer, CQOLC). These analyses were conducted in order to evaluate the normality of the sample and to assess whether parametric statistics would be appropriate for statistical analyses.

Objective one: Presence of distress. The presence of clinically significant distress was identified based on a Distress Thermometer score of ≥ 4 in accordance with the recommendations of the National Comprehensive Cancer Network (NCCN) (2013). Rates of distress detected in this sample were then

compared to previous findings in the literature. It was hypothesized that the rate of distress detected within this sample would fall within 20-40% of participants, in accordance with the rates described in current literature (Longacre et al., 2012).

Objective two: Perceived problems. Data pertaining to perceived problems were derived from the Problem Checklist, which accompanies the Distress Thermometer (NCCN, 2013). Frequency data were presented for each of the Problem Checklist items in an effort to explore the most commonly reported concerns among caregivers of individuals with head and neck cancer. It was hypothesized that emotional problems (e.g., worry, fears, sadness, nervousness, decreased interest, depression) would be the most frequently reported concerns among participants.

Objective three: Relationship with quality of life. Relationships between distress level and the global (e.g., overall) and specific domains (e.g., burden, disruptiveness, financial concerns, and positive adaptation) of quality of life were evaluated. Given that both the Distress Thermometer and the CQOLC outcomes were comprised of continuous variables, a correlation coefficient was utilized. Additionally, coefficients of determination[9] were calculated for any quality of life outcomes that demonstrated a significant relationship with distress in order to describe the level of variance shared by the two variables (Pallant, 2011). Interpretation of the correlations was based on the evaluation criteria cited in Portney and Watkins (2009).

---

[9] A coefficient of determination (r^2) is the "coefficient representing the amount of variance in one variable (Y) that can be explained (accounted for) by a second variable (X)" (Portney & Watkins, 2009, p.865).

In addition, it was hypothesized that there would be a moderate degree of association between distress and global quality of life in caregivers of individuals with head and neck cancer. Based on previous work related to quality of life and distress in individuals with head and neck cancer (Bornbaum et al., 2012; Pandey, Devi, Ramdas, Krishnan, & Kumar, 2009), it was also predicted that this correlation would be negative, indicating that as one's level of distress increased, that their perceived quality of life would decrease. Relative to the specific domains of quality of life (e.g., burden, disruptiveness, financial concerns, and positive adaptation), it was hypothesized that both burden and disruptiveness would demonstrate a moderate degree of relationship with distress. Both level of burden and perceived disruptiveness have been related to psychological health (e.g. distress) in previous investigations of the caregiver experience in head and neck oncology (Longacre et al., 2012).

Objective four: The influence of demographic characteristics. To assess the relationship between perceived distress level and the demographic characteristics of caregivers, variables such as sex, age, marital status, occupational status, household income, level of education, and relationship to the individual with cancer were evaluated. Given that both age and Distress Thermometer scores were continuous variables, and since several of the demographic variables (e.g., occupational status, household income, level of education) were ordinal variables, the Spearman's Ranked Correlation Coefficient was employed. In addition, coefficients of determination were

calculated for variables that indicated a significant relationship with distress (Pallant, 2011).

Lastly, since sex was a nominal, dichotomous variable and it was evaluated relative to a continuous variable (e.g., Distress Thermometer score), an unpaired, or independent-samples, t-test was utilized for statistical analysis. The magnitude of effect was determined through calculation of Eta Squared[10] (Pallant, 2011). Interpretation of the effect size of a variable was based on the guidelines proposed by Cohen (1988).

Relative to hypotheses, it was anticipated that caregiver sex would demonstrate a moderate relationship with distress. This hypothesis was based on previous research into the relationship between sex and caregiver distress, which found that female caregivers typically reported a higher rate of perceived distress than their male counterparts (Baghi et al., 2007). Consistent with previous findings (Ross et al., 2010; Verdonck-de Leeuw et al., 2007), a strong relationship with age was not anticipated. Moreover, no significant relationships were expected between distress and the remaining demographic variables (e.g., marital status, occupational status, household income, level of education).

Objective five: Distress and patient-related characteristics. To assess the relationship between perceived distress level and the disease- and treatment-related characteristics of the individual with head and neck cancer, variables such as disease stage, number of treatment methods, and time since diagnosis

---

[10] Eta squared is an effect size statistic that ranges from zero to one and "represents the proportion of variance in the dependent variable that is explained by the independent (group) variable" (Pallant, 2011, p.242).

149

were explored. Given that both the Distress Thermometer score and length of time since diagnosis were continuous variables and since several of the disease- and treatment-related variables (e.g., disease stage, number of treatment methods) were ordinal variables, Spearman's Ranked Correlation Coefficient was utilized for statistical analysis. Coefficients of determination were calculated for any variables that demonstrated a significant relationship with distress (Pallant, 2011).

Since disease recurrence was a nominal, dichotomous variable and it was evaluated relative to a continuous variable (e.g., Distress Thermometer score), an unpaired t-test was employed for statistical analysis. Lastly, a one-way between-groups analysis of variance (ANOVA) was performed in order to explore the impact of treatment stage on level of distress. Treatment stage was divided into three groups; those awaiting treatment, those currently undergoing treatment, and those who had completed treatment. Magnitude of effect for both the t-test and ANOVA was determined through calculation of Eta Squared (Pallant, 2011).

Similar to previous findings we hypothesized that disease recurrence (Hodges & Humphris, 2009; Watt-Watson & Graydon, 1995), and time since diagnosis (Blood et al., 1994) would each demonstrate small, but significant relationships with distress. To the authors' knowledge, a relationship between caregiver distress and treatment stage (e.g., awaiting, undergoing, completed) has not been reported previously. Nevertheless, we predicted that distress and treatment stage would reveal a significant relationship. We further anticipated

that disease stage would not demonstrate a significant relationship with distress, despite conflicting evidence on the topic (Kugaya et al., 2000; Verdonck-de Leeuw et al., 2007).

Results

Participants

Response rate. Overall, 59.5% of individuals (n = 119) returned the completed questionnaire package. Most participants were recruited through the LRCP at the London Health Sciences Centre (n = 109; 91.6%), while only a small percentage of participants were successfully recruited through the annual meeting of the International Association of Laryngectomees (n = 10; 8.4%).

Data analysis

Descriptive statistics. In order to assess the normality of the data sample, descriptive statistics (e.g., means, standard deviations, frequency distributions, and histograms) were calculated for demographic data, treatment- and disease-related variables, and the global and specific domains of each questionnaire (e.g., Distress Thermometer, CQOLC). While the majority of variables were normally distributed, both age (SD = 11.19) and time since diagnosis (SD = 49.92) demonstrated a high degree of variance. Consequently, histograms for both age and time since diagnosis were reviewed (see Figure 3.1). In essence, these data indicate that most participants in the present study fell within the middle-aged range (e.g., between mid-forties and late-sixties) and provided care for an individual who had received a diagnosis within the previous

five years. Additionally, the CQOLC global and specific outcomes demonstrated moderate-to-high degrees of variance. Consequently, statistical analyses pertaining to these items employed the use of non-parametric statistics. The results of the histogram analyses are shown in Figure 3.1 while additional descriptive analyses are presented in Table 3.3.

Objective one: Presence of distress. When based on a Distress Thermometer score of ≥ 4 (NCCN, 2013), clinically significant distress was identified in 54 of the 119 participants (45.4%). Consequently, the incidence of distress was higher than the predicted range of 20-40%, which was based on currently available literature (Longacre et al., 2012). Comprehensive data on the frequency of Distress Thermometer scores is presented in Figure 3.2.

Objective two: Perceived problems. While emotional concerns comprised five of the eight most frequently reported problems among caregivers (e.g., worry, 64.7%; fears, 44.5%; sadness, 43.7%; nervousness, 41.2%; decreased interest in typical activities, 20.2%), certain physical concerns were also prominent (e.g., sleep, 44.5%; fatigue, 43.7%; eating, 20.2%). Comprehensive data pertaining to the frequency of perceived problems reported by caregivers are presented in Figure 3.3.

Objective three: Relationship with quality of life. Correlations between the dependent variables: distress, global quality of life, and the specific domains of quality of life (e.g., burden, disruptiveness, financial concerns, and positive adaptation) were assessed. Since the variables were continuous and because
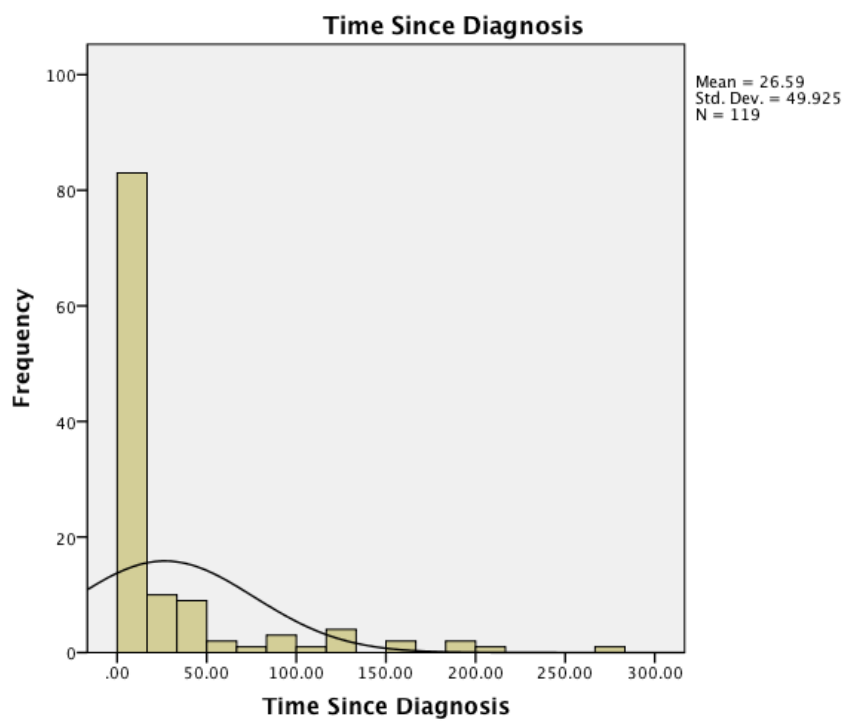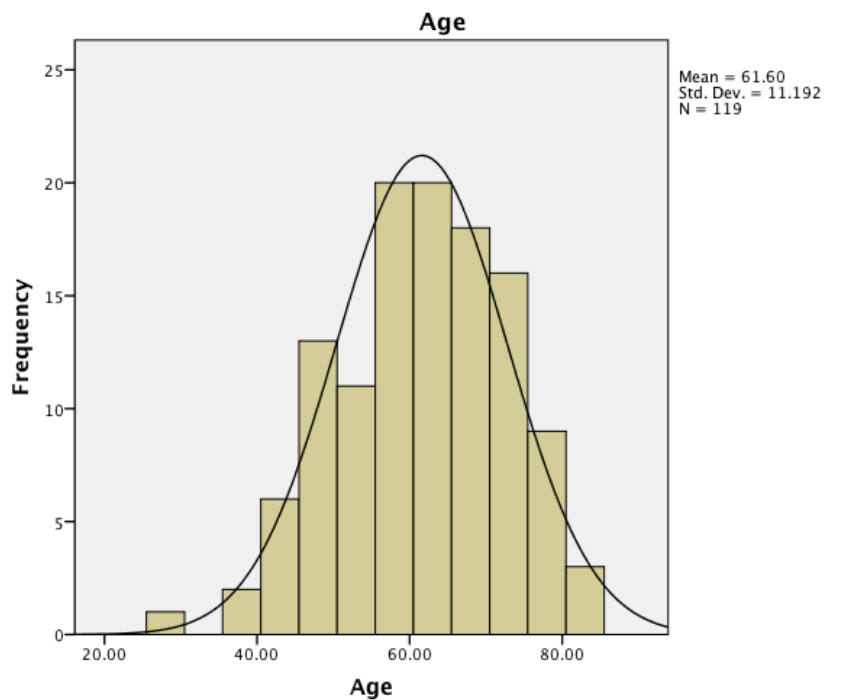
Figure 3.1. Histogram Representations of the Distribution of Age and Time (Months) Since Diagnosis Data for Caregiver Participants (n = 119)

Table 3.3

Descriptive Statistics for Caregiver Data

| Variable	n	Range	Min.	Max.	Mean	SD
Age (years)	119	55	28	83	61.60	11.19
Sex	119	1	0	1	0.24	0.43
Marital status	119	2	0	2	1.08	0.31
Education	119	2	0	2	1.41	0.67
Occupational status	119	4	0	4	2.08	1.40
Household income	119	6	0	6	2.72	2.31
Relationship to patient	119	2	1	3	1.19	0.43
Time since diagnosis (months)	119	274	0	274	26.59	49.92
Recurrence	119	1	0	1	0.24	0.43
Cancer site	119	9	1	10	4.28	2.64
Speech method	119	5	0	5	0.44	1.17
Stage	119	4	0	4	1.58	1.71
Surgery?	119	1	0	1	0.65	0.48
Radiation?	119	1	0	1	0.57	0.50
Chemotherapy?	119	1	0	1	0.34	0.47
No. treatment methods	119	3	0	3	1.54	0.79
Treatment stage	119	3	0	3	1.93	0.97
Burden (CQOLC)	119	40	0	40	22.77	9.30
Disruptiveness (CQOLC)	119	28	0	28	21.74	5.74
Positive adaptation (CQOLC)	119	28	-28	0	-15.95	5.80
Financial concerns (CQOLC)	119	12	0	12	9.77	3.19
Total quality of life (CQOLC)	119	98	0	98	50.93	20.61
Distress (DT score)	119	10	0	10	3.61	2.90
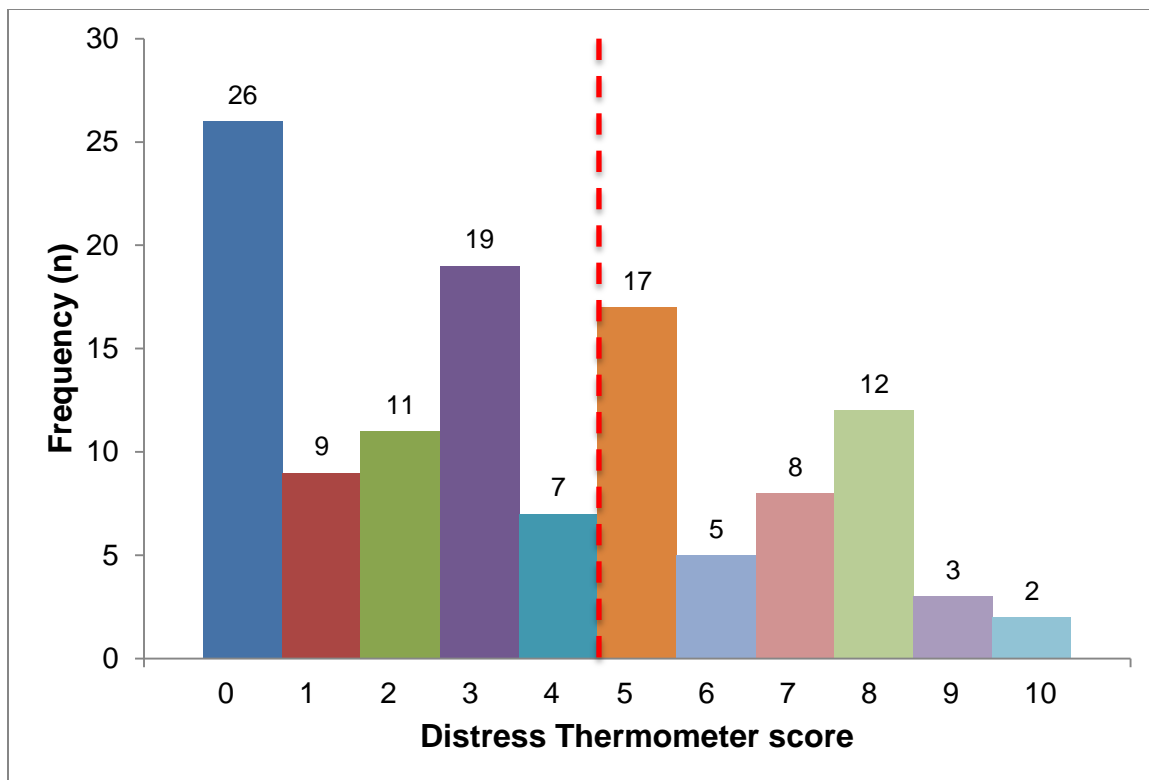
Figure 3.2. Frequency of Distress Thermometer Scores Reported Among

Caregivers of Individuals with Head and Neck Cancer

= Clinically significant distress (Distress Thermometer scores ≥ 4)
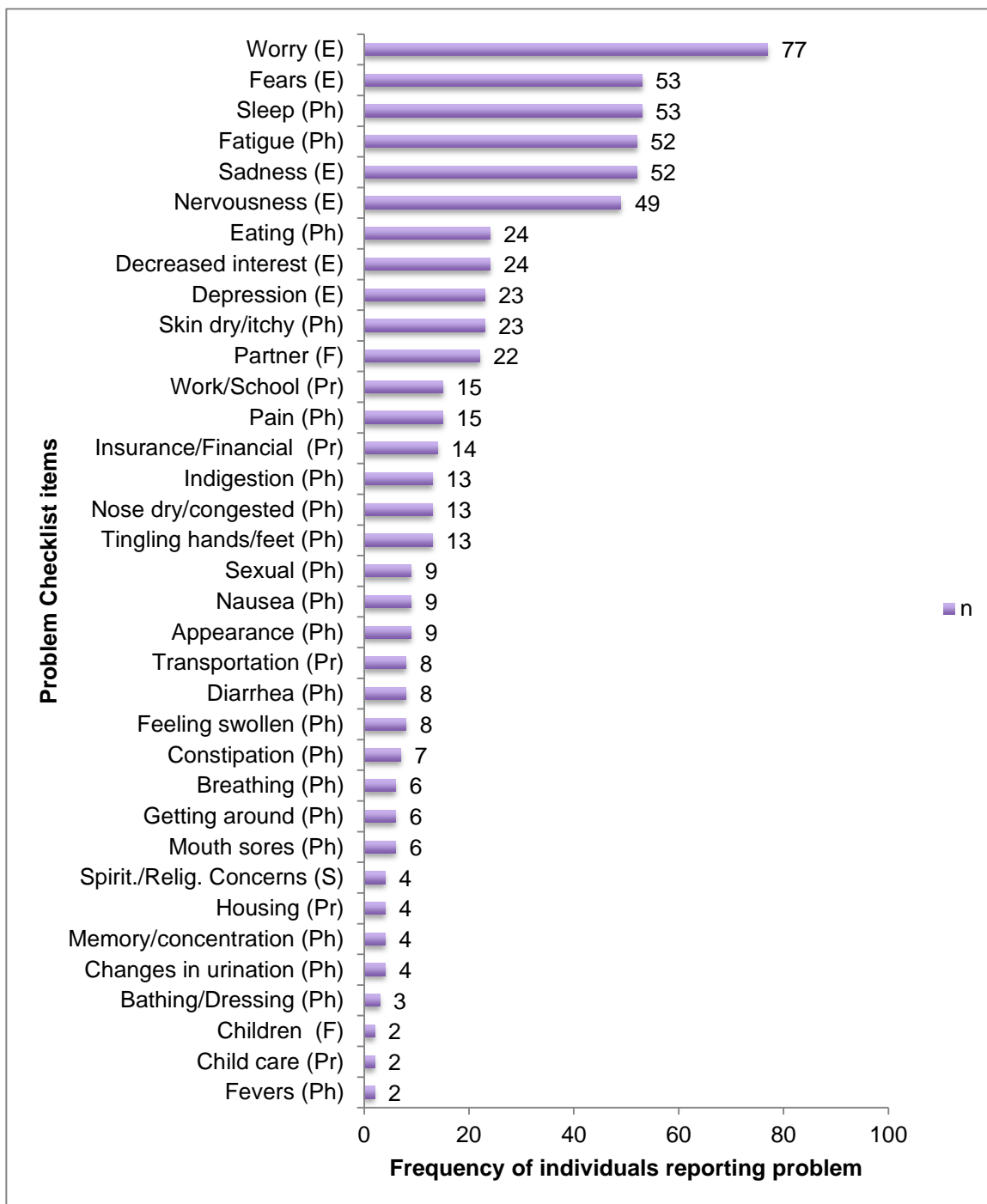
Figure 3.3. Frequency of Reported Problems in Caregivers of Individuals with

Head and Neck Cancer

Note. (Pr) = Practical concerns; (F) = Family concerns; (E) = Emotional concerns; (S) = Spiritual/Religious concerns; (Ph) = Physical concerns

CQOLC scores did not demonstrate a normal distribution (see Table 3.3), the Spearman's Rank Correlation Coefficient was utilized. Data indicate that there was a moderate-to-good degree of correlation observed between distress and global quality of life (r_s = -.521, p = .000). This statistically significant relationship accounted for 27.14% of variance in the sample. Significant correlations were also detected between distress and perceived burden (r_s = -.606, p = .000) and disruptiveness (r_s = -.405, p = .000) subscales of the CQOLC quality of life measure. While the burden subscale demonstrated a moderate-to-good degree of association and explained 36.72% of the variance in respondents' scores on the Distress Thermometer, the disruptiveness subscale demonstrated only a fair degree of association and, thus, only accounted for 16.40% of variance. The relationships between distress and both financial concerns (r_s = -.095, p = .305) and positive adaptation (r_s = .048, p = .604) did not reveal statistically significant relationships.

The negative correlations between global quality of life and distress indicated that there was an inverse relationship between distress and one's overall quality of life implying that as distress increases, one's perceived level of quality of life decreases. The same principle applies to the positive adaptation subdomain; that is, as one's level of positive adaptation increases, the level of perceived distress decreases. However, due to scoring practices, inverse correlations between the remaining subdomains of quality of life (e.g., burden, disruptiveness, financial concerns) do not imply an inverse effect. For instance, as one's level of perceived burden increases, so does one's level of distress.

Comprehensive data pertaining to the correlations between distress and quality

of life scores among participants are presented in Table 3.4.

Objective four: The influence of demographic characteristics.

Statistical analysis was conducted utilizing Spearman's Ranked Correlation

Coefficient for several of the variables (e.g., distress, sex, age, marital status,

occupational status, household income, level of education, and relationship to the

individual with cancer). Although data pertaining to age was collected as a

continuous variable, it did not demonstrate a normal distribution when subjected

to descriptive analysis (see Figure 3.1) and, thus, was included in the

Spearman's Rank Correlation Coefficient analysis. Data revealed that none of

the demographic variables demonstrated a statistically significant relationship

with the perceived level of distress (see Table 3.5). Thus, no coefficients of

determination were calculated for any of the variables. Comprehensive data

pertaining to the correlations between distress and the demographic

characteristics of participants are available in Table 3.5.

In addition, an independent-samples t-test was conducted to compare

distress scores for male and female caregivers. Prior to analyzing the output of

data, Levene's test for equality of variances was performed[11]. Since Levene's

test was significant ($F = 8.866$, $p = .004$), equal variances between male and

female participants were not assumed. Data indicated that there was a significant

difference in scores between female participants ($M = 3.92$, $SD = 3.05$) and male

---

[11] Levene's test compares the level of variance between the two groups and when the difference
between the groups is statistically significant, equal levels of variance between the variables
cannot be assumed (Portney & Watkins, 2009).

Table 3.4

Correlations Between Distress and Quality of Life (n = 119)

		Burden	Disruptive	Positive Adapt.	Finance	Global QOL	Distress
Burden	Spearman's rho Correlation	1	.579*	.168	.274*	.889*	-.606*
	p level		.000	.067	.003	.000	.000
Disruptiven ess	Spearman's rho Correlation		1	-.017	.334*	.723*	-.405*
	p level			.852	.000	.000	.000
Positive Adaptation	Spearman's rho Correlation			1	.015	.381*	.048
	p level				.867	.000	.604
Financial Concerns	Spearman's rho Correlation				1	.398*	-.095
	p level					.000	.305
Global QOL	Spearman's rho Correlation					1	-.521*
	p level						.000
Distress	Spearman's rho Correlation						1
	p level						

* Correlation is significant at the minimum level of p ≤ 0.05 level (2-tailed).

Table 3.5

Correlations Between Distress and Demographic Characteristics (n = 119)

		Age	Marital Status	Occup. Status	Income	Educat.	Relation ship	Distress
Age	Spearman's rho Correlation	1	-.217	-.584*	-.387*	-.212	-.311*	-.173
	p level		.018	.000	.000	.020	.001	.060
Marital Status	Spearman's rho Correlation		1	.195	-.041	.112	.382*	-.024
	p level			.033	.660	.225	.000	.796
Occupation Status	Spearman's rho Correlation			1	.216*	.145	.187*	.076
	p level				.018	.115	.041	.411
Household Income	Spearman's rho Correlation				1	.267*	.110	.177
	p level					.003	.233	.054
Education	Spearman's rho Correlation					1	.100	.017
	p level						.277	.857
Relationship to patient	Spearman's rho Correlation						1	-.010
	p level							.915
Distress	Spearman's rho Correlation							1
	p level							

* Correlation is significant at the minimum level of p ≤ 0.05 level (2-tailed).

participants (M = 2.655, SD = 2.13; t (68.06) = 2.49, p = .015, two-tailed),

suggesting higher perceived distress among female caregivers. However, the

magnitude of the differences in the means (mean difference = 1.27, 95% CI: .25

to 2.28) was small (Eta Squared = 0.02) (Cohen, 1988), since only 2% of the

variance in caregiver distress was explained by sex.

Objective five: Distress and patient-related characteristics. Data

revealed that disease stage, number of treatment methods, and length of time

since diagnosis did not demonstrate a significant correlation with distress. As a

result, no coefficients of determination were calculated for the variables.

Comprehensive data pertaining to the correlations between caregiver distress

and the disease- and treatment-related variables of individuals diagnosed with

head and neck cancer are presented in Table 3.6.

In addition, an independent-samples t-test was conducted to compare

distress scores for caregivers of individuals with head and neck cancer who had

experienced a recurrence in disease versus those who had not experienced a

recurrence. Since Levene's test for equality of variances was not significant (F =

1.22, p = .271), equal variances between the groups were assumed. Contrary to

our prediction, there was no significant difference in distress scores for

caregivers of individuals who had experienced a recurrence (M = 4.31, SD =

2.56) versus caregivers of those who had not experienced a recurrence (M =

3.39, SD = 2.97; t (117) = -1.489, p = .137, two-tailed). The magnitude of the

differences in the means (mean difference = -.92, 95% CI: -2.14 to .30) was small

(Eta Squared = 0.01) since only 1% of the variance in caregiver distress was

Table 3.6

Correlations Between Distress and Patient-Related Variables (n = 119)

		Disease Stage	Number of Treatment Methods	Time Since Diagnosis	Distress
Disease Stage	Spearman's rho Correlation	1	.375	.095	-.034
	p level		.000	.303	.710
Number of Treatment Methods	Spearman's rho Correlation		1	.208	-.037
	p level			.023	.686
Time Since Diagnosis	Spearman's rho Correlation			1	-.168
	p level				.068
Distress	Spearman's rho Correlation				1
	p level				

* Correlation is significant at the minimum level of $p \leq 0.01$ level (2-tailed).

explained by disease recurrence. Thus disease recurrence was neither a statistically, nor clinically significant factor influencing caregiver distress in this sample of participants.

A one-way between-groups ANOVA was also performed in order to explore the impact of treatment stage on level of distress. Participants were divided into three groups according to their stage in the treatment process (e.g., awaiting treatment, undergoing treatment, completed treatment) with a fourth group denoting those who did not specify the treatment stage of their loved one. Levene's test was not violated ($p = .112$). There was a statistically significant difference at the $p < .05$ level in distress scores between the treatment status-related groups: $F(3, 115) = 6.90$, $p = .000$. In addition to reaching statistical significance, the actual difference in mean scores between the groups was substantial. The effect size, calculated using Eta Squared, was .15, indicating a large effect (Cohen, 1988). Post-hoc comparisons using the Tukey's Honestly Significant Difference[12] (HSD) test indicated that the mean distress score for caregivers of individuals awaiting treatment ($M = 4.81$, $SD = 2.74$) was significantly different from caregivers of those who had completed treatment ($M = 2.28$, $SD = 2.29$). Caregivers of individuals currently undergoing treatment ($M = 3.76$, $SD = 3.02$), and caregivers who did not specify treatment stage ($M = 4.83$, $SD = 3.92$) did not differ significantly from caregivers of those who had either completed treatment or were awaiting treatment.

---

[12] Tukey's honestly significant difference is "a multiple comparison test for comparing multiple means following a significant analysis of variance" (Portney & Watkins, 2009, p.878).

Discussion

The overarching aim of this investigation sought to explore the factors that contribute to elevated distress and decreased quality of life in caregivers of individuals with head and neck cancer. Specifically, this inquiry aimed to expand the literature on caregiver distress to include considerations of the influence of treatment status on caregiver distress, in addition to both the newly diagnosed and long-term follow-up (e.g., survivorship) phases of the continuum of care. Further, this project utilized an ultrashort measure of distress (e.g., the Distress Thermometer) in a sample of caregivers of individuals who had been diagnosed with head and neck cancer. Relative to the precise objectives of this study, a number of areas of inquiry related to distress were explored.

Incidence of distress

With regard to the first objective concerning the presence of distress in caregivers of individuals diagnosed with head and neck cancer, data revealed that distress was present in approximately 45% of participants, which is notably higher than our prediction and previously reported rates of between 20% in one sample (Verdonck-de Leeuw et al., 2007) to 38% in others (Drabe et al., 2008; Ross et al., 2010). The variability in reported incidence rates of distress in caregivers may be related to a number of factors including the severity of disease, which has previously been shown to influence distress in individuals with head and neck cancer (Kugaya, Akechi, Okamura, Mikami, & Uchitomi, 1999; Kugaya et al., 2000). For instance, earlier research has noted a predictive relationship between advanced stage head and neck cancer and psychologic

distress (Kugaya et al., 2000). This relationship between advanced stage of disease and distress in head and neck cancer may be attributed to several potential factors including malnutrition (Neilson et al., 2012), physiologic dysfunction (Ettema, Reminger, & Robbins, 2013), and poor performance status (Kirkova et al., 2009), among others. Furthermore, the sheer fact that an individual has been diagnosed with a late-stage level of disease (e.g., T3 or T4) may produce feelings of distress (Kugaya et al., 2000).

Additionally, differences in the way that distress is defined and/or diagnosed may contribute to the variability in reported rates of distress in caregivers; for instance, studies utilizing formal, structured diagnostic instruments or interviews tend to detect lower rates of distress than those which utilize self-report inventories (Miller & Massie, 2009), such as the one utilized in this study. The reason for this disparity may be related to the fact that diagnostic instruments and/or interviews seek specific information related to the presence of a diagnosable, pathologic condition (e.g., clinical depression, generalized anxiety disorder), whereas self-report distress measures generally seek to identify a broad continuum of distress-related experiences (e.g., lower threshold of distress), and may include more inclusive criteria related to distress-inducing factors (e.g., symptom distress, practical problems). Consequently, the higher incidence rate of distress detected in the present study may be related to the use of the self-report distress screening measure (e.g., the Distress Thermometer), as opposed to a structured diagnostic measure of clinical depression. Additionally, a number of authors have also suggested that the recommended

cutoff score for determining clinically significant distress on the Distress Thermometer (e.g., scores greater than or equal to four) should be altered (e.g., raised or lowered) in order to optimize the accuracy of the Distress Thermometer (Akizuki et al., 2003; Dolbeault et al., 2008; Gessler et al., 2008; Gil, Grassi, Travado, Tomamichel, & Gonzalez, 2005; Hegel et al., 2008; Vodermaier et al., 2009).

Despite the recommendation by the creators of the Distress Thermometer to use a cutoff score of four (NCCN, 2013), previous research conducted with the Distress Thermometer has used both the recommended cutoff score, and other self-designated cutoff scores which included scores of three (Dolbeault et al., 2008; Dolbeault et al., 1999; Gil et al., 2005) and seven (Hegel et al., 2008; Vodermaier et al., 2009), with a cutoff score of five (Akizuki et al., 2003; Butt et al., 2008; Gessler et al., 2008; Trask et al., 2002; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008) representing the most common alternative to the creator-recommended score of four (NCCN, 2013).

The debate over which cutoff score provides the most accurate assessment of actual distress appears to stem from a series of validation studies performed on individuals afflicted with a range of cancer sites (e.g., breast, lung, brain, colorectal, prostate, ovarian, head and neck, bone, bladder, non-Hodgkin's lymphoma, etc.) (Butt et al., 2008; Jacobsen et al., 2005), and treatment states including those awaiting treatment (Trask et al., 2002), in active treatment (Butt et al., 2008; Jacobsen et al., 2005) and those in survivorship (Recklitis, Licht, Ford, Oeffinger, & Diller, 2007). The creators of the Distress Thermometer have

recommended utilization of a cutoff score of 4 for distress screening purposes. This recommendation has been verified through the validation efforts of other researchers in both patient (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Ransom, Jacobsen, & Booth-Jones, 2006) and caregiver (Zwahlen et al., 2008) populations. As such, the present study employed the recommended cutoff score for analysis purposes and consequently, the lower cutoff score (in contrast to a score of five, or even seven) may have contributed to the elevated rate of distress detected in this sample. Interestingly, if the frequently used cutoff score of five had been utilized in the present study, the presence of distress would have been reduced to 39.5% of participants (n = 47) in contrast to the current rate of 45.4% of participants (n = 54). Thus, in terms of difference between groups, the actual percentage of difference when comparing Distress Thermometer cutoff scores of four versus five is relatively small (5.9%) in the present sample. In addition, the elevated rate of distress detected in this sample may have been related to a host of other factors including the range of perceived problems experienced by caregivers.

Perceived problems

As predicted, emotional concerns such as worry, fear, sadness, nervousness, and decreased interest in usual activities, represented the most frequently reported problems among caregiver participants. However, physical concerns such as difficulties with sleep, fatigue and appetite were also noted frequently, followed by problems with one's partner and additional practical and physical concerns. Interestingly, the most commonly reported physical concerns

(e.g., sleep, fatigue, appetite) were well aligned with the diagnostic criteria for depression (Miller & Massie, 2009). A diagnosis of major depression consists of symptoms, which last for at least two weeks, and include depressed mood or anhedonia (i.e., the inability to experience pleasure from activities typically found to be enjoyable) in addition to four of the following symptoms experienced daily: altered appetite; fatigue; guilt; worthlessness; diminished concentration; insomnia or hypersomnia; psychomotor retardation or agitation; or recurrent thoughts of death including suicidal ideation (Miller & Massie, 2009). Notably, the development of major depression is not a typical or anticipated response in caregivers of individuals with head and neck cancer, however, it may be considered a significant complication of the caregiver role that requires individualized assessment and treatment given its potential to compromise the quality of life and functional status (Miller & Massie, 2009) of the caregiver. Regardless of the severity of the symptoms detected, the identification of elevated distress and perceived problems in caregivers of individuals with head and neck cancer may permit healthcare practitioners to offer targeted psychosocial support and interventions in an effort to decrease distress and reported problems in caregivers. While the Problem Checklist is by no means a comprehensive measure of the potential range of problems facing a caregiver, it does provide some insight into some of the most commonly reported areas of concern.

While emotional and physical problems were the most frequently reported concerns among caregivers in the present study, the prevalence of these reports

should not in any way diminish the impact of less frequently reported problems such as "memory/concentration" or "dealing with children", since issues such as these have the potential to be tremendously distressing for caregivers. In essence, the subjective experience of an item such as, "problems dealing with partner" cannot be inferred through simple acknowledgment on a questionnaire. Consequently, considerations of one's subjective quality of life remain important in order to better understand the experience of distress in caregivers of individuals with head and neck cancer.

Relationship with quality of life

Quality of life refers to an individual's subjective perception of their position in life relative to a variety of factors that may include one's "physical health, psychological state, level of independence, social participation" (WHO, 1998, p.17), among other components. Key to this broad-ranging concept is the fact that all of these factors must be considered collectively and from the perspective of the individual in order to account for the meaning and emphasis that may be placed on one area over another. Therefore, in order for assessments of quality of life to be useful for clinical or research purposes, they must be able to account for the factors most relevant to one's current life situation. Due to the numerous potential concerns of a caregiver of an individual with head and neck cancer, a key objective of the present study was to evaluate the perceived quality of life of caregivers both globally, and relative to a number of specific areas known to be problematic for caregivers. Thus, caregiver quality of life was measured through an individual's experience of burden, the disruption

caused to their life, their financial concerns, and any positively adaptive behaviour that may have reduced the negative impact of the disease. In addition, one's overarching assessment of quality of life was also evaluated. It is clear that multiple facets of concern influence perceived quality of life, thus, the ability to address an array of areas that may be impacted for the caregiver is essential.

Relative to global quality of life, the current data indicated that caregiver distress and quality of life were inversely related to a moderate extent. This inverse relationship between the two constructs suggests that as one's level of distress increased, perceived quality of life decreased. This finding is similar to previous work in samples of individuals diagnosed with head and neck cancer (Bornbaum et al., 2012; Pandey et al., 2009). Given that there is often a tremendous burden placed on caregivers to provide physical, psychological, and practical support (Blood et al., 1994), disruptions to one's quality of life and psychological well-being are understandable. In addition to global quality of life, significant relationships were also detected between the burden and disruptiveness domains of the caregiver quality of life measure; a finding that aligned with our earlier predictions.

Caregiver burden is a commonly acknowledged phenomenon among psychosocial oncology scholars (Stenberg, Ruland, & Miaskowski, 2010). The concept of burden in head and neck oncology has been evaluated as both a correlate of distress (Verdonck-de Leeuw et al., 2007) and as a psychological outcome of providing care for an individual with cancer (Blood et al., 1994; Chen et al., 2009). Similar to Verdonck-de Leeuw et al. (2007), the present study

demonstrated a significant relationship between caregiver burden and perceived distress. Ultimately, because measures of caregiver burden purportedly assess the psychological impact of providing care, its significant correlation with perceived distress, also a psychological construct, is logical. In addition, the concept of disruptiveness (also commonly referred to as "caregiver strain") measured the adverse impact of providing care on the life of the caregiver (Longacre et al., 2012). Relative to the CQOLC measure, disruptiveness was evaluated through such item subjects as, "impact on daily schedule", "maintenance of outside activities", and "responsibility for patient's care", among others (Weitzner et al., 1999). When correlated with distress, disruptiveness demonstrated a fair relationship that was determined to be statistically significant. These findings are particularly salient given that previous research has determined that greater perceived disruption to an individual's daily routine was associated with poorer psychological health (Blood et al., 1994).

Interestingly, results from the present study suggest that one's ability to adapt positively to the situation did not impact the perceived level of distress detected among participants. These findings are consistent with previous research conducted by Ross and colleagues (2010). Additionally, financial concerns, evaluated through items related to "financial strain", "insurance coverage", and one's "anticipated economic future" (Weitzner et al., 1999), were not shown to influence caregiver distress. This finding was consistent with frequency data obtained through the Problem Checklist, where just over 10% of participants noted problems with finances and/or insurance. Previous

researchers have also noted the lack of a relationship between caregiver distress and socioeconomic factors (Ross et al., 2010). In order to further explore the role of financial status and other personal characteristics of caregivers, analysis of the demographic factors relative to distress may provide useful insights.

The influence of demographic characteristics

As anticipated, no statistically significant correlations were detected between perceived distress level and the majority of demographic characteristics of caregivers. While the literature on existing relationships between caregiver distress and demographic factors is mixed (Baghi et al., 2007; Ross et al., 2010; Verdonck-de Leeuw et al., 2007), our data suggesting no significant correlations with caregiver distress were aligned with the findings of earlier research (Ross et al., 2010; Verdonck-de Leeuw et al., 2007). Interestingly, a small but significant difference in perceived distress was detected between male and female participants, with a higher level of distress reported by female caregivers. Thus, the hypothesis that sex would demonstrate a moderate relationship with distress was not entirely supported given the small magnitude of effect detected in this sample. Several other authors have reported similar results when investigating differences between the sex of caregivers (Baghi et al., 2007; Blood et al., 1994; Zwahlen et al., 2011). However, when the effect size of the current data was determined, the actual effect of this difference was found to be quite small suggesting that the influence of one's sex only accounted for a small proportion of the variance in perceived distress among participants. Given that the demographic characteristics of participants did not serve to explain the high rate

of distress detected in this sample, examination of the disease- and treatment-related characteristics of the individuals with cancer may provide a greater degree of insight into the factors related to elevated distress in caregivers of individuals with head and neck cancer.

Distress and patient-related characteristics

As predicted, disease stage and number of treatment methods did not demonstrate a statistically significant relationship with the perceived level of distress. Additionally, in line with earlier findings (Blood et al., 1994), it was hypothesized that the length of time since diagnosis would demonstrate a small, but significant relationship with distress. While this prediction did not prove to be accurate in the present sample, it did highlight some items that warrant further consideration. Relative to the length of time since diagnosis, the present study included a wide range of caregiving experiences. Specifically, this sample consisted of a range of caregivers of individuals who were less than a week from the point of diagnosis to those supporting long-term survivors (>20 years). Existing research into the experience of caregivers of individuals with head and neck cancer centers around data collected between two and 48 months post-diagnosis (Hodges & Humphris, 2009; Ross et al., 2009; Verdonck-de Leeuw et al., 2007; Blood et al., 1994), in addition to a subset of work focused on issues in short- to medium-term survivorship (e.g., one to five years following diagnosis) (Mellon et al., 2007). However, concerns may arise at any point along the continuum of care in oncology, from the point of a new diagnosis continuing through long-term survivorship (e.g., greater than 10 years following diagnosis)

phases. While no statistically significant effect was found related to the length of time since the individual's diagnosis, current findings suggest that perhaps it is not the length of time that influences distress, but rather one's position along the continuum of care. For instance, analysis of the impact of treatment stage (e.g., awaiting treatment, currently undergoing treatment, completed treatment) revealed a significant difference in distress scores between caregivers of those who were awaiting treatment when compared with those who had completed treatment. Further, this difference demonstrated a large effect, suggesting that one's treatment stage may have a sizeable and significant impact on perceptions of caregiver distress. While additional work is required in order to verify this relationship, the present findings suggest an interesting area for future research, particularly given the potential implications for providing caregiver-targeted psychosocial interventions. In addition, any examination of caregiver distress would be remiss without consideration of factors that may serve to potentially confound the results of the analyses.

Possible confounding factors

Distress is a natural human experience, which may arise from, or be exacerbated by consequences unrelated to the cancer or the role of providing care (NCCN, 2013). Consequently, information related to possible confounding factors was collected from caregivers in an effort to identify any life events that may have potentially influenced the distress level of the caregivers. Relative to the collection of the data, no specific criteria for the type of information to be disclosed were outlined, however participants were invited to share any

information that they felt may have influenced their distress or quality or life at the time of the survey. Consequently, a broad range of responses was collected from participants.

Regarding the specific disclosures of possible confounding factors, one participant reported the recent loss of a sibling while another informed the team that she had recently undergone surgery and was still recovering despite providing care for her husband. One participant disclosed that she was a breast cancer survivor while another noted that he had been a caregiver twice before. Understandably, these experiences may have directly influenced, either positively or negatively, the manner in which these individuals approached their role as a caregiver.

Relative to the perceived level of reported distress, both the individual who had recently lost her sibling and the participant who had recently undergone surgery reported clinically significant levels of distress according to the Distress Thermometer (both participants reported Distress Thermometer scores of five). However, the cancer survivor and the participant who had previously served as a caregiver reported low levels of distress (Distress Thermometer scores of three and zero, respectively). While the frequency of these reports is far too low to draw any definite conclusions, future research into the influence of personal survivorship from cancer and previous experience as a caregiver may provide interesting insights into how individuals cope and experience the caregiver role following these life experiences.

Limitations

As with any research protocol, certain limitations must be considered. First, while two venues were used for recruitment in an effort to enhance the external validity of the data to a group beyond Southwestern Ontario, data accrual from the international site was minimal. Consequently, the increased generalizability that was sought cannot be assumed in the present sample.

Second, the demographic measure used in the present study did not directly assess whether the participant had previously served as a caregiver for an individual with cancer (or another chronic illness). It also did not directly assess if the caregiver themselves had previously been diagnosed with or treated for cancer. In retrospect, data of this type may have provided valuable information relative to one's perceived levels of distress and quality of life throughout their caregiving experience. Future research regarding distress in caregivers should ensure to take one's previous experience as a caregiver and/or as a cancer survivor into consideration in order to comprehensively address the multidimensional issues related to distress in caregivers of individuals with cancer.

Third, this study did not evaluate psychological characteristics of caregivers, existing social support, or coping mechanisms, all of which may have provided useful information related to the high levels of distress detected in participants. For instance, a pessimistic attitude, poor levels of social support, and maladaptive coping styles have been associated with psychological strain in individuals with cancer (Shapiro, Lopez, Schwartz, Braden, & Kurker, 2001). Thus, in order to account for a broader range of psychosocial factors that may

have contributed to perceptions of distress in caregivers of individuals with head and neck cancer, it is recommended that future inquiries assess a broader range of psychological characteristics of the participants.

Lastly, in an effort to broaden the spectrum of time since diagnosis in caregiver participants to include both newly diagnosed and long-term survivors, a cross-sectional research design was employed for this study. However, cross-sectional research designs do not permit causal analysis of factors that may contribute to distress and perceived quality of life. Consequently, it is recommended that future research into distress and quality of life in caregivers of individuals with head and neck cancer employ research designs that are prospective and longitudinal in nature. Such designs are appropriate in efforts that seek to evaluate potential causal relationships between distress and the factors which serve to induce and/or exacerbate it.

Conclusion

This study was designed to investigate and describe distress, quality of life, and commonly reported problems in caregivers of individuals diagnosed with head and neck cancer. Data indicated that distress was present in approximately 45% of all participants and that both caregiver sex and the treatment status of the individual with head and neck cancer influenced perceptions of distress in participants. Additionally, an inverse relationship between quality of life and distress was evident, suggesting that as one's level of distress increases, perceived quality of life may consequently decrease. Perceived burden and the level of disruptiveness to one's life were significantly related to a caregiver's

reported level of distress. Emotional concerns were most frequently identified as problematic by caregivers, followed closely by physical concerns that are closely related to experiences of depression and grief (e.g., problems with sleeping, fatigue, eating) (American Psychological Association, 2000; Miller & Massie, 2009). This study further revealed that being a female caregiver who provides care for an individual who is either awaiting treatment or who has completed treatment may contribute to elevated levels of perceived distress. In addition, the Distress Thermometer proved to be a valuable screening tool for distress within the present study.

Since data from the present investigation revealed that distress and the problems associated with it, are indeed prevalent in caregivers of individuals with head and neck cancer, and since caregivers often do not directly request assistance for their distress and/or broader concerns (Zwahlen et al., 2011), caregiver distress and the factors which serve to exacerbate it are often overlooked by those most able to provide assistance (e.g., medical professionals, psychologists, social workers, etc.). Ultimately, the goal of conducting research into caregiver distress is to support caregivers' ability to provide effective care without sacrificing their own health and well-being (Northouse, Katapodi, Schafenacker, & Weiss, 2012). Consequently, an important first step in the process is to identify the factors that most significantly influence distress in caregivers and thus inhibit their ability to deliver care. Therefore, if distress can be identified early through efficient distress screening mechanisms and addressed in a constructive manner, then perhaps the quality of life of caregivers

– and by extension the experience of the individuals for whom they provide care

– may be enhanced.

References

Akizuki, N., Akechi, T., Nakanishi, T., Yoshikawa, E., Okamura, M., Nakano, T., . . . Uchitomi, Y. (2003). Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer, 97*(10), 2605-2613. doi: 10.1002/cncr.11358

American Psychological Association (APA). (2000). Diagnostic and statistical manual of mental disorders - 4th edition text revision (DSM-IV-TR, 2000) American Psychological Association (Ed.)   Retrieved from http://online.statref.com.proxy1.lib.uwo.ca/Document.aspx?docAddress=4 PNCnYvddqP04-isS-3QEw%3d%3d&SessionId=1A9C4CBJVGMKQUIG&Scroll=1&goBestMat ch=true&Index=10&searchContext=DSM-IV-TR|c0||10|0|0|0|0|0||c0

Baghi, M., Wagenblast, J., Hambek, M., Radeloff, A., Gstoettner, W., Scherzed, A., . . . Knecht, R. (2007). Demands on caring relatives of head and neck cancer patients. *The Laryngoscope, 117*, 712-716.

Baruch, Y. (1999). Response rate in academic studies: A comparative analysis. *Human Relations, 52*(4), 421-438.

Bjordal, K., & Kaasa, S. (1995). Psychological distress in head and neck cancer patients 7-11 years after curative treatment. *British Journal of Cancer, 71*, 592-597.

Blood, G. W., Simpson, K. C., Dineen, M., Kauffman, S. M., & Raimondi, S. C. (1994). Spouses of individuals with laryngeal cancer: Caregiver strain and burden. *Journal of Communication Disorders, 27*, 19-35.

Bornbaum, C. C., Fung, K., Franklin, J. H., Nichols, A., Yoo, J., & Doyle, P. C. (2012). A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Supportive Care in Cancer, 20*(9), 2157-2165. doi: 10.1007/s00520-011-1326-2

Butt, Z., Wagner, L. I., Beaumont, J. L., Paice, J. A., Peterman, A. H., Shevrin, D., . . . Cella, D. (2008). Use of a single-item screening tool to detect clinically significant fatigue, pain, distress, and anorexia in ambulatory cancer practice. *Journal of Pain and Symptom Management, 35*(1), 20-30. doi: 10.1016/j.jpainsymman.2007.02.040

Chen, A. M., Jennelle, R. L., Grady, V., Tovar, A., Bowen, K., Simonin, P., . . . Vijayakumar, S. (2009). Prospective study of psychosocial distress among patients undergoing radiotherapy for head and neck cancer. *Int J Radiat Oncol Biol Phys, 73*(1), 187-193. doi: S0360-3016(08)00637-8 [pii]

Chen, S.-C., Tsai, M.-C., Liu, C.-L., Yu, W.-P., Liao, C.-T., & Chang, J. (2009). Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nursing, 32*(6), 473-481.

Cohen, J. W. (1988). *Statistical power analysis for the behavioral sciences* (Second ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Cooper, J. S., Porter, K., Mallin, K., Hoffman, H. T., Weber, R. S., Ang, K. K., . . . Langer, C. J. (2009). National cancer database report on cancer of the head and neck: 10-year update. *Head & Neck, 31*(6), 748-758. doi: 10.1002/hed.21022

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (Third ed.). Thousand Oaks, CA: Sage Publications, Inc.

Dolbeault, S., Bredart, A., Mignot, V., Hardy, P., Gauvain-Piquard, A., Mandereau, L., . . . Medioni, J. (2008). Screening for psychological distress in two french cancer centers: Feasibility and performance of the adapted distress thermometer. *Palliative & Supportive Care, 6*(02). doi: 10.1017/s1478951508000187

Dolbeault, S., Szporn, A., & Holland, J. C. (1999). Psycho-oncology: Where have we been? Where are we going? *European Journal of Cancer, 35*(11), 1554-1558.

Doyle, P. C. (1994). *Foundations of voice and speech rehabilitation following laryngeal cancer*: Singular Publishing Group.

Doyle, P. C. (2005). *Rehabilitation in head and neck cancer: Overview*. Texas: PRO-ED, Incorporated.

Drabe, N., Zwahlen, D., Büchi, S., Moergeli, H., Zwahlen, R. A., & Jenewein, J. (2008). Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. *Psycho-Oncology, 17*(2), 199-204. doi: 10.1002/pon.1199

Eriksson, E., & Lauri, S. (2000). Informational and emotional support for cancer patients' relatives. *European Journal of Cancer, 9*, 8-15.

Eton, D. T., Lepore, S. J., & Helgeson, V. S. (2005). Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer, 103*(11), 2412-2418. doi: 10.1002/cncr.21092

Ettema, S., Reminger, S., & Robbins, K. T. (2013). The neuropsychological aspects of head and neck cancer. In C. Noggle & R. Dean (Eds.), *Neuropsychology of cancer and oncology* (pp. 111-122). New York: Springer Publishing Company.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191.

Field, A. (2009). *Discovering statistics using SPSS* (Third ed.). Thousand Oaks: CA: SAGE Publications Inc.

Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A., & Jones, L. (2008). Screening for distress in cancer patients: Is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-Oncology, 17*(6), 538-547. doi: 10.1002/pon.1273

Gil, F., Grassi, L., Travado, L., Tomamichel, M., & Gonzalez, J. R. (2005). Use of distress and depression thermometers to measure psychosocial morbidity among southern european cancer patients. *Supportive Care in Cancer, 13*(8), 600-606. doi: 10.1007/s00520-005-0780-0

Haisfield-Wolfe, M. E., McGuire, D. B., & Krumm, S. (2012). Perspectives on coping among patients with head and neck cancer receiving radiation. *Oncology Nursing Forum, 39*(3), E249-E257.

Hegel, M. T., Collins, E. D., Kearing, S., Gillock, K. L., Moore, C. P., & Ahles, T. A. (2008). Sensitivity and specificity of the distress thermometer for depression in newly diagnosed breast cancer patients. *Psycho-Oncology, 17*(6), 556-560. doi: 10.1002/pon.1289

Hodges, L. J., & Humphris, G. M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology, 18*(8), 841-848. doi: 10.1002/pon.1346

Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine, 60*(1), 1-12. doi: 10.1016/j.socscimed.2004.04.018

Hoffman, B. M., Zevon, M. A., D'Arrigo, M. C., & Cecchini, T. B. (2004). Screening for distress in cancer patients: The NCCN rapid-screening measure. *Psycho-Oncology, 13*(11), 792-799. doi: 10.1002/pon.796

IBM. (2011). Ibm spss statistics for windows, version 20.0. . Armonk, NY: IBM Corp.

Jacobsen, P. B., Donovan, K. A., Trask, P. C., Fleishman, S. B., Zabora, J., Baker, F., & Holland, J. C. (2005). Screening for psychologic distress in ambulatory cancer patients. *Cancer, 103*(7), 1494-1502. doi: 10.1002/cncr.20940

Jeremic, G., Venkatesan, V., Hallock, A., Scott, D., Hammond, A., Read, N., . . . Fung, K. (2011). Trismus following treatment of head and neck cancer. *Journal of Otolaryngology-Head & Neck Surgery, 40*(4), 323.

Kagan, S., Clarke, S., & Happ, M. (2005). Head and neck cancer patient and family member interest in and use of e-mail to communicate with clinicians. *Head & Neck, 27*(11), 976-981.

Katz, M. R., Irish, J. C., Devins, G. M., Rodin, G. M., & Gullane, P. J. (2003). Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support. *Head & Neck, 25*(2), 103-112. doi: 10.1002/hed.10174

Keir, S. T., Calhoun-Eagan, R. D., Swartz, J. J., Saleh, O. A., & Friedman, H. S. (2008). Screening for distress in patients with brain cancer using the nccn's rapid screening measure. *Psycho-Oncology, 17*(6), 621-625. doi: 10.1002/pon.1271

Kirkova, J., Walsh, D., Rybicki, L., Davis, M. P., Aktas, A., Tao, J., & Homsi, J. (2009). Symptom severity and distress in advanced cancer. *Palliative Medicine, 24*(3), 330-339. doi: 10.1177/0269216309356380

Koster, M. E. T. A., & Bergsma, J. (1990). Problems and coping behaviour of facial cancer patients. *Social Science & Medicine, 30*(5), 569-578. doi: 10.1016/0277-9536(90)90155-L

Kugaya, A., Akechi, T., Okamura, H., Mikami, I., & Uchitomi, Y. (1999). Correlates of depressed mood in ambulatory head and neck cancer patients. *Psychooncology, 8*, 494-499.

Kugaya, A., Akechi, T., Okuyama, T., Nakano, T., Mikami, I., Okamura, H., & Uchitomi, Y. (2000). Prevalence, predictive factors and screening for

psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer, 88*, 2817-2823.

Lang, P., Zekry, D., Michel, J., Drame, M., Novella, J., Jolly, D., & Blanchard, F. (2010). Early markers of prolonged hospital stay in demented inpatients: A multicentre and prospective study. *The Journal of Nutrition, Health & Aging, 14*(2), 141-147.

Linn, M. W. (1985). A global assessment of recent stress (GARS) scale. *The International Journal of Psychiatry in Medicine, 15*(1), 47-59. doi: 10.2190/XP8N-RP1W-YE2B-9Q7V

Longacre, M. L., Ridge, J. A., Burtness, B. A., Galloway, T. J., & Fang, C. Y. (2012). Psychological functioning of caregivers for head and neck cancer patients. *Oral Oncology, 48*(1), 18-25. doi: 10.1016/j.oraloncology.2011.11.012

Mellon, S., Kershaw, T. S., Northouse, L. L., & Freeman-Gibb, L. (2007). A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-Oncology, 16*(3), 214-223. doi: 10.1002/pon.1074

Mellon, S., Northouse, L. L., & Weiss, L. K. (2006). A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing, 29*(2), 120-131.

Miller, K., & Massie, M. J. (2009). Depressive disorders. In Holland, J.C., Breitbart, W.S., Jacobsen, P.B., Ledeberg, M.S. & Loscazalo, M.J. (Eds.) *Psycho-Oncology* (pp. 311-318). New York, NY: Oxford University Press Inc.

National Comprehensive Cancer Network (NCCN). (2013). NCCN clinical practice guidelines in oncology: Distress management. *2.2013.* Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Neilson, K., Pollard, A., Boonzaier, A., Corry, J., Castle, D., Smith, D., . . . Couper, J. (2012). A longitudinal study of distress (depression and anxiety) up to 18 months after radiotherapy for head and neck cancer. *Psycho-Oncology*, n/a-n/a. doi: 10.1002/pon.3228

Northouse, L. L. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology, 20*(19), 4050-4064. doi: 10.1200/jco.2002.02.054

Northouse, L. L., Katapodi, M. C., Schafenacker, A. M., & Weiss, D. (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing, 28*(4), 236-245. doi: 10.1016/j.soncn.2012.09.006

Ostroff, J. S., Ross, S., Steinglass, P., Ronis-Tobin, V., & Singh, B. (2004). Interest in and barriers to participation in multiple family groups among head and neck cancer survivors and their primary family caregivers. *Family Process, 43*(2), 195-208.

Pallant, J. (2011). *SPSS survival manual: A step by step guide to data analysis using SPSS* (4th ed.). Crows Nest, NSW: Allen & Unwin.

Pandey, M., Devi, N., Ramdas, K., Krishnan, R., & Kumar, V. (2009). Higher distress relates to poor quality of life in patients with head and neck

cancer. *International Journal of Oral and Maxillofacial Surgery, 38*(9), 955-959. doi: 10.1016/j.ijom.2009.04.004

Payakachat, N., Ounpraseuth, S., & Suen, J. Y. (2012). Late complications and long-term quality of life for survivors (>5 years) with history of head and neck cancer. *Head & Neck*, 1-7. doi: 10.1002/hed.23035

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (Third ed.). Upper Saddle River, NJ: Pearson Education Inc.

Ransom, S., Jacobsen, P. B., & Booth-Jones, M. (2006). Validation of the distress thermometer with bone marrow transplant patients. *Psycho-Oncology, 15*(7), 604-612. doi: 10.1002/pon.993

Recklitis, C. J., Licht, I., Ford, J., Oeffinger, K., & Diller, L. (2007). Screening adult survivors of childhood cancer with the Distress Thermometer: A comparison with the SCL-90-R. *Psycho-Oncology, 16*(11), 1046-1049. doi: 10.1002/pon.1212

Roing, M., Hirsch, J.-M., & Holstrom, I. (2008). Living in a state of suspension – a phenomenological approach to the spouse's experience of oral cancer. *Scandinavian Journal of Caring Science, 22*(1), 40-47.

Ross, S., Mosher, C. E., Ronis-Tobin, V., Hermele, S., & Ostroff, J. S. (2010). Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Supportive Care in Cancer, 18*(2), 171-178. doi: 10.1007/s00520-009-0641-3

Semple, C. J., Sullivan, K., Dunwoody, L., & Kernohan, W. G. (2004). Psychosocial interventions for patients with head and neck cancer: Past, present and future *Cancer Nursing, 27*(6), 434-441.

Shapiro, S., Lopez, A., Schwartz, G., Braden, C., & Kurker, S. (2001). Quality of life and breast cancer: Relationship to psychosocial variables. *Journal of Clinical Psychology, 57*(4), 501-519.

Sherwood, P. R., Given, B. A., Donovan, H., Baum, A., Given, C. W., Bender, C. M., & Schulz, R. (2008). Guiding research in family care: A new approach to oncology caregiving. *Psycho-Oncology, 17*(10), 986-996. doi: 10.1002/pon.1314

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*(10), 1013-1025. doi: 10.1002/pon.1670

Trask, P., Paterson, A., Riba, M., Brines, B., Griffith, K., Parker, P., . . . Ferrara, J. (2002). Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplantation, 29*, 917-925.

Tuinman, M. A., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2008). Screening and referral for psychosocial distress in oncologic practice. *Cancer, 113*(4), 870-878. doi: 10.1002/cncr.23622

Veit, C. T., & Ware, J. E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology, 51*(5), 730-742.

Verdonck-de Leeuw, I. M., Eerenstein, S. E., Van der Linden, M. H., Kuik, D. J., de Bree, R., & Leemans, C. R. (2007). Distress in spouses and patients

after treatment for head and neck cancer. *Laryngoscope, 117*(2), 238-241. doi: 10.1097/01.mlg.0000250169.10241.58

Vickery, L. E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck, 25*(4), 289-296. doi: 10.1002/hed.10206

Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *JNCI Journal of the National Cancer Institute, 101*(21), 1464-1488. doi: 10.1093/jnci/djp336

Watt-Watson, J., & Graydon, J. (1995). Impact of surgery on head and neck cancer patients and their caregivers. *The Nursing Clinics of North America, 30*(4), 659.

Weitzner, M. A., Jacobsen, P. B., Wagner, J. H., Friedland, J., & Cox, C. (1999). The caregiver quality of life index - cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*, 55-63.

World Health Organization (WHO). (1998). Health promotion glossary   Retrieved from http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf

Yabroff, K. R., & Kim, Y. (2009). Time costs associated with informal caregiving for cancer survivors. *Cancer, 115*(S18), 4362-4373. doi: 10.1002/cncr.24588

Zabora, J. R., Blanchard, C. G., Smith, E. D., Roberts, C. S., Glajchcn, M., Sharp, J. W., . . . Hedlund, S. C. (1997). Prevalence of psychological distress among cancer patients across the disease continuum. *Journal of Psychosocial Oncology, 15*(2), 73-87. doi: 10.1300/J077v15n02_05

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. doi: 10.1111/j.1600-0447.1983.tb09716.x

Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening cancer patients' families with the distress thermometer (DT): A validation study. *Psycho-Oncology, 17*(10), 959-966. doi: 10.1002/pon.1320

Zwahlen, D., Hagenbuch, N., Jenewein, J., Carley, M. I., & Buchi, S. (2011). Adopting a family approach to theory and practice: Measuring distress in cancer patient-partner dyads with the distress thermometer. *Psycho-Oncology, 20*(4), 394-403. doi: 10.1002/pon.1744

Chapter 4

General Discussion and Integration of Findings

The overarching purpose of this program of research sought to provide insight into the experience of distress and quality of life in individuals with head and neck cancer and that of their caregivers. The first study (Chapter 2) examined both the presence and trajectory of distress in addition to quality of life concerns and commonly reported problems among individuals with head and neck cancer. This focus was also enhanced with the solicitation of information at standardized three-month intervals throughout the first year following diagnosis. The second study (Chapter 3) explored these same dimensions (e.g., distress, quality of life, and commonly reported problems) from the perspective of caregivers of individuals with head and neck cancer. Collectively, this program of research sought to provide a multidimensional perspective on how living with head and neck cancer – either as a person with the disease or as a caregiver – may contribute to perceptions of distress and quality of life at various points throughout the continuum of care. To this end, the integration of findings from both the individual- and caregiver-based studies will be discussed in the following sections; this will include interpretation in the context of both research and clinical implications.

Distress in head and neck cancer

In general, findings from the present studies have demonstrated that elevated distress can exist at any point along the continuum of care in both

individuals with head and neck cancer and their caregivers. In particular, data pertaining to individuals with head and neck cancer indicated that distress was most prevalent at the point of diagnosis and that the length of time following diagnosis had a large effect on the level of perceived distress. These findings suggest that for some individuals, time may be an important factor in adapting to the challenges associated with the diagnosis of head and neck cancer and its treatment. However, the elevated rates of distress detected throughout the continuum of care in individuals with head and neck cancer suggest that for others, distress may remain an ongoing concern. Meanwhile, data from the caregiver study indicated that distress was present in approximately 45 percent of all caregiver participants. Further, both the sex of the caregiver and the treatment status (i.e., awaiting treatment, undergoing treatment, completed treatment) of the individual for whom they were providing care influenced perceptions of distress in caregivers. Additionally, the level of perceived burden and disruptiveness to one's life were significantly related to a caregiver's reported level of distress. Despite these trends, it is important to acknowledge that individualized responses and variability in data can be expected due to the multidimensional subjective nature of distress.

Notably, an important finding from this program of research was that analyses based on mean or frequency-related data alone may reveal only a small fragment of the phenomenon of distress in oncology. To elaborate, when individual trajectories of distress were analyzed longitudinally, distinct patterns emerged (e.g., high-decreasing, low-increasing, consistently low, persistently

high reports of distress). This finding provides clear evidence that perceptions of distress are indeed individualized and heterogeneous in nature. Similar patterns of distress have also been reported in caregiver populations (Choi et al., 2012). Consequently, future work that centers on elucidating trajectories of distress (i.e., through growth mixture modeling) in both patient and caregiver populations may be important for enhancing our understanding of persistent, or chronic distress in these individuals. However, despite the potential benefits of trajectory-based research, the sheer prevalence and perceived severity of distress observed in the present studies suggests that better identification of distress is important in order to facilitate the provision of support for those who require it most. As such, the employment of routine distress screening represents a critical first step in the identification of elevated distress in both those with head and neck cancer and their caregivers.

Accordingly, use of the Distress Thermometer with its accompanying Problem Checklist revealed that the potential sources of distress in participants were often multifaceted. As such, data from the present studies suggest that not everyone who experienced clinically significant distress would necessarily meet the standard criteria for a diagnosis of major depression or an anxiety disorder (American Psychological Association [APA], 2000). These findings are important because they broaden our understanding regarding the range of factors (e.g., problems with partner, children, insurance, finances, work, housing, concentration, etc.) that may contribute to elevated distress in both caregivers and those with head and neck cancer. Currently, most of the commonly used

distress assessment measures (e.g., Brief Symptom Inventory, Beck Depression Inventory, Hospital Anxiety and Depression Scale, etc.) evaluate the construct of distress according to the criteria for depression and/or anxiety disorders (Beck, Steer, & Brown, 1993; Derogatis, 2001; Zigmond & Snaith, 1983). Granted, distress is defined as an unpleasant emotional experience, but as noted in the definition offered by the National Comprehensive Cancer Network (NCCN), it is also a *multifactorial* and *multidetermined* experience (NCCN, 2013). That is, distress emerges as a clinical entity due to the multiple domains that are influenced by myriad factors that may change dramatically over time, even over relatively short temporal periods. Consequently, it is important that assessments of distress in oncology utilize an accompanying multidimensional Problem Checklist (or similar multi-item measure) to ascertain specific information regarding the myriad potential sources of distress in individuals with head and neck cancer and their caregivers (e.g., problems with family, employment, nutrition, spirituality, etc.). It is through the consideration of these perceived problems and the subjective experience of them, that we may be able to better target the sources of support that are required in order to alleviate or mitigate elevated distress in these individuals.

Considerations of quality of life and commonly reported problems

It is apparent from the present studies that the concerns facing individuals with head and neck cancer and their caregivers are diverse and multidimensional in nature. Relative to the subjective experiences of participants, findings from the present work suggest that numerous quality of life concerns exist for both

individuals with head and neck cancer and caregivers at various stages throughout the continuum of care. While the specific concerns cited by participants were diverse and clearly based on each person's experience as either the individual with cancer or the caregiver, the common theme that emerged from participants in both studies pertained to the perception of elevated burden in three primary domains: role fulfillment, physical functioning, and psychological well-being.

Specifically, concerns related to one's ability to fulfill meaningful roles and responsibilities were cited by both caregivers and individuals with cancer. Role functioning was assessed according to an individual's ability to meet work-related obligations, engage in daily activities, and pursue hobbies and/or other leisure time activities (Aaronson et al., 1993; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). The ability to fulfill one's "roles" in life (e.g., as an employee, spouse, parent, etc.), or more importantly, the potential inability to fulfill roles due to illness or the demands associated with caring for one who is ill, serves as a critical barometer of perceived well-being and associated quality of life. Given that previous research has determined that greater perceived disruption to an individual's daily routine resulted in poorer psychological health (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994), the decreased role functioning observed in both participant sets in the present studies suggests that these individuals may be more susceptible to experiencing elevated distress. A recent investigation into the relationship between role functioning and distress has reported similar findings (Mols, Thong, de Poll-Franse, Roukema, & Denollet, 2012).

Furthermore, existing data on factors that contribute to role functioning in individuals with cancer and caregivers has determined that one's level of symptom burden (e.g., fatigue, appetite loss, insomnia, etc.) directly influences one's ability to fulfill role-based activities and obligations (Aaronson et al., 1993; Bjordal et al., 2001; Given et al., 2004). Collectively, these data suggest that the experience of head and neck cancer, whether as a patient or caregiver, is marked by disruption to multiple interrelated domains of functioning, with an emphasis on decrements to psychological, role and physical functioning (i.e. symptom burden).

With regard to the issue of reported symptom burden in the present studies, not unexpectedly, physical concerns were reported by most individuals with head and neck cancer throughout the year following diagnosis. Clinically significant increases in symptom burden were observed for several symptoms at the three-month assessment (e.g., pain, trismus, xerostomia, sticky saliva, etc.). While most symptoms had resolved by the one-year follow-up, clinically significant problems related to xerostomia and decreased taste and smell persisted. Given that several of the participants underwent radiation therapy as a component of their treatment protocol, and since radiation therapy to the head and neck region is known to cause these types of treatment-related problems (Hunter & Jolly, 2013), these findings were consistent with previous research. Additionally, while one might anticipate physical concerns to be prevalent for an individual with head and neck cancer given that he or she must live with the physical consequences of the disease and its treatment, results from the

caregiver study suggest that caregivers also experience an increased level of perceived physical burden while serving as a caregiver.

Interestingly, the most prominent physical concerns reported by caregivers (e.g., problems with sleep, fatigue, appetite) were closely aligned with the diagnostic criteria for depression (Miller & Massie, 2009). While a formal assessment of depression was not conducted in the present study for the caregivers, the presence of physical symptoms that have been established as physical correlates of depression, suggests that this is an area worth investigating further relative to the caregiver experience. While development of depression is not believed to be a typical response in caregivers, it may be characterized as a significant complication secondary to the increasing demands of the caregiver role. As such, it may require individualized assessment and treatment given its potential to compromise quality of life and functional status (Miller & Massie, 2009).

With respect to elevated psychological burden, in several instances in the present work both caregivers and those with head and neck cancer revealed the highest proportion of concerns on the Problem Checklist as emotional problems including worry, fears, sadness, nervousness, among others. While the Problem Checklist does not assess the perceived severity of the problem experienced, the fact that such a high proportion of participants in both studies reported multiple emotional items as being problematic (and in the case of the patient study, these concerns persisted over time) suggests that emotional problems are common. As such, emotional concerns in those with head and neck cancer and those that

emerge in caregivers likely warrant further investigation and subsequent action towards the mitigation of these concerns where possible. Adding support to this interpretation, previous researchers have also suggested that "the ideal screening system would include a useful distress screening tool in combination with a Problem Checklist" (Zabora & MacMurray, 2012, p.632). Ultimately, the present findings support the notion that multidimensional concerns in caregivers and individuals with head and neck cancer do in fact exist and that these issues must be carefully considered and addressed as part of the comprehensive care process. If such a consideration is avoided or disregarded, it is possible that one's level of distress (and the factors contributing to its exacerbation) would increase in severity with consequent reductions to one's perceived quality of life. Ultimately, distress is a dynamic experience that can become increasingly elevated and burdensome when significant concerns are not addressed in a timely manner. As such, the early identification and management of clinically significant distress is imperative.

Identifying and responding to psychological distress

In order to respond to the consequences of distress among individuals with head and neck cancer and their caregivers, it is imperative to first recognize its presence. Despite the fact that distress may be causing disruptions in daily functioning, many individuals may actively conceal their distress from their primary physician and healthcare team (Weisman, 1976; Zabora & MacMurray, 2012). Individuals displaying such behaviour may rationalize their secretive response as an appropriate one because they believe that their physician and

healthcare team members need to focus their energy on the treatment of the disease (Zabora & MacMurray, 2012), or in the case of caregivers, of their loved one's disease (Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi, 2011). Additionally, individuals may not feel comfortable acknowledging that they are not coping as well as they believe they should be and that, in fact, they require assistance. Conversely, oncologists and healthcare team members may lack the time or skills required to accurately identify and refer individuals exhibiting significant distress to the appropriate psychological resources (Carlson & Bultz, 2004; Sollner, 2001; Zabora, Loscalzo, & Weber, 2003). The intersection between these two areas of concern (i.e., the inability or unwillingness of either the patient or clinician to address the problem) may have devastating consequences. More specifically, the outcome of these combined elusive approaches is the collective avoidance of the problem in both those with cancer and their loved ones. Consequently, distress may remain undisclosed and only become apparent when it has increased to a point where the individual is no longer able to independently manage the situation. This in turn may then create a cascade of psychosocial consequences that become increasingly problematic throughout the post-diagnostic trajectory.

Undetected and untreated distress in individuals with cancer has been associated with poorer medical outcomes, decreased compliance and patient satisfaction, and increased healthcare costs (Carlson & Bultz, 2004; Zabora, Loscalzo, & Smith, 2000). Furthermore, unidentified distress may manifest physically as a variety of somatic complaints (e.g., pain, fatigue, etc.), which

physicians may respond to by ordering diagnostic tests and treatments that may be costly and unnecessary (Breslau, Curbow, Zabora, & Britzenhofeszoc, 2001; Zabora & MacMurray, 2012). This manifestation of physical symptoms in connection with one's psychological state highlights an important observation pertaining to the relationship between physical and psychological domains. That is, while domains of functioning (e.g., physical, psychological, social, spiritual, role, etc.) may appear to be discrete entities, in fact they are intrinsically dynamic and deeply interrelated with one another. Furthermore, the biopsychosocial consequences of this connection between functional domains are evident in not only those with head and neck cancer, but also in their caregivers.

Research has indicated that untreated caregiver distress not only compromises psychological well-being, but may also result in physical changes to the immune system that can limit glucose control, promote flare-ups in autoimmune diseases, and increase vulnerability to cardiovascular diseases (Rohleder, Marin, Ma, & Miller, 2009). Thus, a pervasive consequence evident in research related to unresolved distress, is that of elevated symptom burden both in those with cancer (Aaronson et al., 1993; Bjordal et al., 2001; Given et al., 2004) and their caregivers (Stenberg, Ruland, & Miaskowski, 2010). Interestingly, quality of life data from the present study of individuals with head and neck cancer found that all but one domain (i.e., role functioning) of the observed clinically significant changes in quality of life scores to be symptom-related (e.g., pain, weight, appetite loss, eating, insomnia, trismus, xerostomia, sticky saliva, decreased senses). Furthermore, the Problem Checklist data from the present

study of caregivers found a high proportion of participants reporting personal physical concerns (e.g., problems with sleep, fatigue, eating, etc.) with equal or similar frequency to the psychological concerns (e.g., worry, fears, sadness, etc.). While these physical consequences were not directly assessed relative to their relationship with distress, findings from the present studies seem to suggest that elevated symptom burden represents a negative experience that can compromise one's perceived quality of life, and possibly level of distress. Future research is required in order to verify these suggestions. Moreover, the ability to identify key symptom-related factors that contribute to elevated distress (e.g., fatigue, poorly managed pain, inadequate nutritional intake, etc.) may permit clinicians to offer simple, yet effective means of reducing distress-related symptoms, thereby also potentially reducing the experience of elevated distress.

In order to ensure that problems such as distress and the factors contributing to its development or exacerbation are identified in a timely manner, researchers and clinicians alike have recommended the use of systematic distress screening in order to identify those individuals who are experiencing elevated distress (NCCN, 2013). Researchers and psychologists have noted the importance of distress screening given that individuals who need psychosocial support often do not seek out resources for themselves (Waller, Williams, Groff, Bultz, & Carlson, 2011). Without screening and proper identification of distress many problems may remain unresolved even after the first year following diagnosis (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013). While the problem of distress in oncology was first described in the mid 1970's by Weisman

(Weisman, 1976)[13], the impetus for systematically identifying distress through

screening programs in oncology has only gained global momentum over the past

decade (Bultz & Johansen, 2011). In particular, relative to the acknowledgement

of distress from a research perspective, there has been a significant increase in

the number of research publications addressing the identification and

management of distress in oncology since 2006, with a marked increase

occurring in 2010 (Bultz & Johansen, 2011). However, despite this increased

level of research and scholarship on this topic, questions remain regarding how

to adequately address the problem of distress in oncology.

Research has indicated that distress screening can be performed through

a number of procedures including open interview, semi-structured interviews, or

more frequently and pragmatically, through utilization of self-report

questionnaires (Laraway & Rogers, 2012). Recently, standards for distress

screening procedures have been developed by national psychosocial oncology

organizations such as the Canadian Association for Psychosocial Oncology

(CAPO) (CAPO, 2010) and the NCCN (NCCN, 2013). These recommendations

have subsequently been endorsed by the American College of Surgeons (ACS)

(ACS, 2012) and Canadian cancer accreditation agencies (Bultz et al., 2011).

Further, several of these organizations (e.g., ACS, CAPO, NCCN) have

recommended the routine use of self-report questionnaires that are specifically

designed to screen for distress, such as the Distress Thermometer (NCCN,

---

[13] Karnofsky and Burchenal (1949) also noted the important role of "mood" in their early
assessments of performance status in palliative care.

2013) and an accompanying Problem Checklist, in order to facilitate the identification of distress (ACS, 2012; CAPO, 2010; NCCN, 2013).

Distress screening provides a simple and reliable method of identifying individuals who are experiencing problematic levels of distress. The use of self-report surveys may be particularly useful for individuals who do not openly reveal their distress when speaking with physicians and healthcare professionals (Zabora et al., 2003; Zabora & MacMurray, 2012). That is, while some individuals may not be comfortable verbalizing their concerns, they may have a willingness to acknowledge a concern in this written, self-report format. By doing so, they may then provide an opportunity for the problem to be recognized by the healthcare team and, hopefully, provide the option to address the problem more directly. It may also promote the opportunity for the practitioner and the patient and/or caregiver to engage in a broader and more meaningful discussion relative to how the patient or caregiver is really doing. Moreover, the use of distress-screening tools may communicate to individuals that the healthcare team is concerned about their quality of life and psychological well-being (Zabora & MacMurray, 2012). Based on its potential for quick scoring and interpretation, the Distress Thermometer and an accompanying Problem Checklist may be an appropriate distress-screening tool for clinical use. Additionally, the Distress Thermometer is quick to use, efficient to administer, and most importantly (from a research perspective) it is a statistically valid tool (Patrick-Miller, Broccoli, Much, & Levine, 2004; Ransom, Jacobsen, & Booth-Jones, 2006; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). Ultimately the routine use of distress-screening

tools may provide a cost-effective means of identifying clinically significant levels of distress for individuals with head and neck cancer and their caregivers. However, it is also imperative to note that while distress screening may provide significant advantages towards the identification of problematic distress in those with head and neck cancer and their caregivers, screening alone is insufficient. Consequently, identification of distress is only the initial step in the clinical effort to alleviate the areas of concern that contribute to elevated distress in both those with head and neck cancer and their caregivers.

Management of distress

In essence, the process of distress screening involves determining the level of risk presented by an individual's psychosocial challenges and unmet needs and subsequently, ascertaining the degree to which assistance is desired or needed (Mitchell, 2011). Once the concerns have been identified and the desire for assistance has been expressed, the process of distress management may commence. Ideally, as soon as possible following the disclosure of clinically significant distress, a healthcare team member should meet with the individual to conduct a comprehensive assessment (Clark et al., 2012). This assessment should seek to gather, analyze, and synthesize information regarding the presence of psychosocial issues that may compromise the individual's ability to make healthcare-related decisions, manage their illness (or their loved one's illness), or maintain a desirable level of quality of life (Clark et al., 2012). Specifically, the assessment should include a discussion regarding psychological and behavioural symptoms (e.g., anxiety, worry, inability to experience pleasure

from usually enjoyable activities, etc.), physical symptoms (e.g., appetite, sleep,

fatigue, etc.), the need for financial and/or spiritual support, concerns about body

image, sexuality, and suicidal ideation, in addition to an assessment of existing

coping mechanisms and social support networks (NCCN, 2013). Specific

strategies for the management of distress will likely vary based on the

information provided by the distressed individual. But it is clear that identification

of concerns provides the pivotal starting point from which problems identified can

be directly addressed as part of the cancer care process. Avoiding such

identification, or acquisition of incomplete information is likely to contribute

negatively to both short- and long-term cancer care outcomes.

      Multiple studies have demonstrated that certain forms of psychosocial

intervention, including cognitive behavioural therapy and psycho-educational

interventions, can be beneficial towards the goal of reducing distress in oncology

(Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; Fors et al., 2010;

Hammerlid et al., 1999; Newell, Sanson-Fisher, & Savolainen, 2002). For

instance, psychosocial interventions involving counseling (either structured or

unstructured) and guided imagery improved quality of life and the general

functioning of individuals with cancer (Newell et al., 2002), whereas psycho-

educational interventions (i.e., support group information sessions), skills

training, and therapeutic counseling proved effective for caregivers (Northouse,

Katapodi, Song, Zhang, & Mood, 2010). Additionally, online counseling and

support groups have also been found to reduce distress in both caregivers and

individuals with cancer when moderated by a registered mental health

professional (e.g., psychologist, social worker) (Ruland et al., 2013; Taylor &

Luce, 2003). The proliferation of internet-based resources such as support

groups that are conducted by registered health practitioners may provide another

useful resource for caregivers and individuals with head and neck cancer,

particularly if individuals live in a rural and remote setting or if they feel

uncomfortable disclosing personal issues in a face-to-face forum. Irrespective of

the specific type of intervention that is utilized, the key matter of importance is

that distress is treatable (Carlson, Waller, Groff, Zhong, & Bultz, 2012) and its

effective management has demonstrated worthwhile cost-benefit savings to the

healthcare system (Bultz & Carlson, 2005). Moreover, this economic perspective

provided by Bultz and Carlson (2005) suggests that if distress can be identified

early and managed effectively, then we may be able to not only improve the

overall functioning of those with cancer and their caregivers, but we may also

potentially reduce the economic burden on the healthcare system that arises as a

result of untreated or poorly managed distress. Therefore, a comprehensive

discussion of the problem of distress in oncology would be remiss without

acknowledgment of the economic implications of failing to address this problem.

Economic Implications

Despite acknowledgement by the medical community of the significant

psychological burden and distress associated with a cancer diagnosis and the

consequences of its treatment, there has been minimal effort to modify clinical

practice, increase relevant hospital budgets, or implement third-party coverage

for this key component of healthcare (Bultz & Carlson, 2005). Within Canada

where the provision of healthcare is both publicly funded and delivered, a survey of provincial cancer centers found that less than three percent of cancer agency operating dollars were directed towards psychosocial care (Bultz, 2002; as cited in, Bultz & Carlson, 2005). However, many forms of psychosocial intervention such as peer-counseling or support groups place little to no economic burden on the healthcare system and have been shown to be effective means of decreasing distress (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; Northouse et al., 2010; Ruland et al., 2013). The failure to identify and appropriately manage distress in oncology results in increased costs – both personal costs to the individual and financial costs to the healthcare system.

In terms of the financial impact of psychosocial support on the healthcare system, a number of studies have noted benefits to individuals with either no added cost to the system or even reductions in overall costs. For instance, a meta-analysis of 90 studies established that psychosocial interventions were able to offset health expenditures by an average of 20% (Chiles, Lambert, & Hatch, 1999), providing a considerable financial benefit to the system. Additionally, a recent systematic review on the economic value of psychosocial interventions determined that psychosocial interventions are inexpensive on a per patient basis and have the potential to improve quality adjusted life years with minimal financial input on the part of the healthcare system (Gordon, Beesley, & Scuffham, 2011). Thus, through reduction of the emotional and personal burden of cancer, it may also be possible to reduce its associated economic burden. Full acknowledgment of the "human side" of cancer care and a family-based

approach to the delivery of care are essential components of a compassionate and well-managed oncology program.

Summary of contributions

This program of inquiry into distress represents a salient and timely contribution to the literature. An important contribution of the first study (Chapter 2) was the inclusion of participants often excluded from head and neck psychosocial oncology research; namely, those individuals who had received "bad news", were not receiving treatment for a curative intent, had previously been diagnosed with depression, or those who had experienced a recurrence or metastases of their disease. While we acknowledge that there may be instances where inviting an individual to participate in a research protocol may be inappropriate and/or insensitive to the circumstances they are facing, distress-related research that *purposely excludes* individuals who are experiencing a distressing life event, or those who may be prone to experiencing pathologic distress, arguably fails to provide a comprehensive perspective on the very factors which may both cause and exacerbate distress in these individuals. To willingly exclude this data from such individuals runs contrary to the intent of seeking to accurately understand the presence and impact that distress has across the disease trajectory. Consequently, we believe that the purposeful inclusion of individuals typically excluded from psychosocial oncology research in head and neck cancer represents an important first step in encouraging a more inclusive approach to psychosocial oncology research practices. As a result, we

believe this inclusionary approach may serve to identify a more accurate representation of distress that occurs in this unique clinical population.

To the authors' knowledge, the second study (Chapter 3) is the first to explore perceived distress and quality of life concerns in caregivers of individuals with head and neck cancer who have been either recently diagnosed (e.g., less than one week from diagnosis) or those who are long-term survivors (e.g. more than 20 years from diagnosis). Furthermore, this study also represents the first effort to utilize a single-item distress measure (e.g., Distress Thermometer) in caregivers of individuals with head and neck cancer. Ultrashort measures such as the Distress Thermometer have proven to be useful and effective for distress screening in busy, clinical environments (Vodermaier, Linden, & Siu, 2009). Consequently, use of the Distress Thermometer in head and neck cancer caregiver populations may afford the opportunity to promote the regular screening of distress, given its reliability and ease of use clinically (Vodermaier et al., 2009). Finally, this study is the first to report that the level of perceived distress in caregivers is related to the treatment status of the individuals with head and neck cancer (e.g., awaiting treatment, undergoing treatment, completed treatment) rather than the length of time since diagnosis, a suggestion that has been a prevailing hypothesis within psychosocial oncology literature (Hodges, Humphris, & Macfarlane, 2005). Further, we determined that this difference represented a large effect, which suggests that one's treatment stage may have a sizeable and significant impact on perceptions of caregiver distress. While additional work is certainly required in order to verify this relationship, the

present findings suggest several specific recommendations for study.

Directions for future research

First, since data from the caregiver study (Chapter 3) revealed that the treatment status of the individual with head and neck cancer (i.e., one's position relative to the progression of treatment – awaiting, undergoing, completed) was significantly related to the distress level of the caregiver, additional research that investigates perceived distress relative to treatment status is recommended. In order to evaluate this potential relationship in a rigorous manner, the use of prospective, longitudinal designs are advised. Longitudinal analysis that employs regular follow-up with participants at each stage of treatment progression (e.g., awaiting, undergoing, completed) will likely elicit the most comprehensive data relative to potential facets of the relationship between caregiver distress and an individual's treatment status.

Furthermore, the assessment of trajectories of distress in both individuals with head and neck cancer and their caregivers is strongly recommended. To date, research conducted using mixed growth modeling techniques has revealed distinct patterns of distress that have challenged the accepted notion that distress declines over time (Choi et al., 2012; Fielding & Lam, 2013; Helgeson, Snyder, & Seltman, 2004; Lam, Ye, & Fielding, 2012; Lam et al., 2009; Lam et al., 2011; Lam, Shing, Bonanno, Mancini, & Fielding, 2012). Further, since research has suggested that between 5-20% of individuals with cancer experience chronically high levels of distress throughout the duration of the cancer trajectory (Lam et al., 2012; Lam et al., 2009; Lam et al., 2011; Lam et al.,

2012), the ability to identify these chronically distressed individuals and subsequently provide psychosocial support should be a key goal of future clinical inquiry. Through this enhanced knowledge, we may be better able to understand the process of distress in oncology with the goal of working towards its reduction or alleviation.

Additionally, given the highly individualized and heterogeneous nature of distress in both those with head and neck cancer and their caregivers, results of the present investigation would seem to support the acknowledgement of distress as the sixth vital sign, indicating that it should be monitored routinely. Thus, it may be valuable to investigate the feasibility and utility of implementing a standard distress screening program for both those with cancer and their caregivers. Owing to the brief nature of its administration and scoring procedures, an ultrashort instrument such as the Distress Thermometer has been recommended for use in busy clinical environments (Vodermaier et al., 2009). However, given that caregivers of individuals with head and neck cancer may not be physically present at each clinical appointment, the ability to screen caregivers in-person during clinical visits may not always be feasible. Similarly, ongoing distress screening and management also may be challenging for individuals who live in rural or remote settings. Consequently, research that examines how health technology (e.g., Internet, Telehealth, smart phones, etc.) can be effectively used to identify and manage distress in individuals with head and neck cancer and their caregivers may be beneficial. The use of novel sources of health-related technology to engage in distress screening and

management may help to facilitate the routine and universal screening of distress in those with cancer and their caregivers. Ultimately, future research that builds on the insights gained within the present program of research could enhance the understanding of distress in oncology, as well as improve efforts to both identify and manage it in both individuals with head and neck cancer and their caregivers. By doing so, the comprehensiveness of care may be enhanced and long-term outcomes for both individuals with head and neck cancer and their caregivers may be optimized.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., . . . Takeda, F. (1993). The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85*, 365-376.

American Cancer Society (ACS). (2012). Cancer program standards 2012: Ensuring patient-centered care (Vol. 1.1, pp. 1-140). Illinois: American College of Surgeons.

American Psychological Association (APA). (2000). Diagnostic and statistical manual of mental disorders - 4th edition text revision (DSM-IV-TR, 2000) American Psychological Association (Ed.)   Retrieved from http://online.statref.com.proxy1.lib.uwo.ca/Document.aspx?docAddress=4 PNCnYvddqP04-isS- 3QEw%3d%3d&SessionId=1A9C4CBJVGMKQUIG&Scroll=1&goBestMat ch=true&Index=10&searchContext=DSM-IV-TR|c0||10|0|0|0|0|0||c0

Beck, A. T., Steer, R. A., & Brown, G. K. (1993). Beck Depression Inventory-II (BDI-II). *Manual for Beck Depression Inventory-II*.

Bjordal, K., Ahlner-Elmqvist, M., Hammerlid, E., Boysen, M., Evensen, J., Biorklund, A., . . . Kaasa, S. (2001). A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. *Laryngoscope, 111*, 1440-1452.

Blake-Mortimer, J., Gore-Felton, C., Kimerling, R., Turner-Cobb, J. M., & Spiegel, D. (1999). Improving the quality and quantity of life among patients with cancer: A review of the effectiveness of group psychotherapy. *European Journal of Cancer, 35*(11), 1581-1586.

Blood, G. W., Simpson, K. C., Dineen, M., Kauffman, S. M., & Raimondi, S. C. (1994). Spouses of individuals with laryngeal cancer: Caregiver strain and burden. *Journal of Communication Disorders, 27*, 19-35.

Breslau, E. S., Curbow, B., Zabora, J., & Britzenhofeszoc, K. (2001). *Psychological distress in post-surgical women with breast cancer.* Paper presented at the 2001 ASCO Annual Meeting.

Bultz, B. D. (2002). *Changing the face of cancer care for patients, community and the healthcare system. Report to the Romanow Commission on the Future of Healthcare in Canada.*: Canadian Association of Psychosocial Oncology.

Bultz, B. D., & Carlson, L. (2005). Emotional distress: The sixth vital sign in cancer care. [Correspondence]. *Journal of Clinical Oncology, 23*(26), 6440-6441. doi: 10.1200/JCO.2005.01.9232

Bultz, B. D., Groff, S. L., Fitch, M., Blais, M. C., Howes, J., Levy, K., & Mayer, C. (2011). Implementing screening for distress, the 6th vital sign: A Canadian strategy for changing practice. *Psycho-Oncology, 20*(5), 463-469. doi: 10.1002/pon.1932

Bultz, B. D., & Johansen, C. (2011). Screening for distress, the 6th vital sign: Where are we, and where are we going? *Psycho-Oncology, 20*(6), 569-571. doi: 10.1002/pon.1986

Canadian Association of Psychosocial Oncology (CAPO). (2010). Standards of psychosocial health services for persons with cancer and their families. Retrieved from: http://www.capo.ca/pdf/CAPOstandards.pdf

Carlson, L., & Bultz, B. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses. *Psycho-Oncology, 13*(12), 837-849. doi: 10.1002/pon.832

Carlson, L. E., Waller, A., Groff, S. L., Giese-Davis, J., & Bultz, B. D. (2013). What goes up does not always come down: Patterns of distress, physical and psychosocial morbidity in people with cancer over a one   year period. *Psycho-Oncology, 22*(1), 168-176. doi: 10.1002/pon.2068

Carlson, L. E., Waller, A., Groff, S. L., Zhong, L., & Bultz, B. D. (2012). Online screening for distress, the 6th vital sign, in newly diagnosed oncology outpatients: Randomised controlled trial of computerised vs personalised triage. *British Journal of Cancer, 107*(4), 617-625. doi: 10.1038/bjc.2012.309

Carlson, L. E., Waller, A., Groff, S. L., Zhong, L., & Bultz, B. D. (2013). Reply: Benefits of screening for distress still not demonstrated. *British Journal of Cancer, 108*, 738-739. doi: 10.1038/bjc.2013.17

Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & O'Connell, D. L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education and Counseling, 85*(2), e75-e88. doi: 10.1016/j.pec.2011.01.027

Chiles, J. A., Lambert, M. J., & Hatch, A. L. (1999). The impact of psychological interventions on medical cost offset: A meta-analytic review. *Clinical Psychology: Science and Practice, 6*(2), 204-220.

Choi, C.-W. J., Stone, R. A., Kim, K. H., Ren, D., Schulz, R., Given, C. W., . . . Sherwood, P. R. (2012). Group-based trajectory modeling of caregiver psychological distress over time. *Annals of Behavioral Medicine, 44*(1), 73-84. doi: 10.1007/s12160-012-9371-8

Clark, P. G., Bolte, S., Buzaglo, J., Golant, M., Daratsos, L., & Loscalzo, M. (2012). From distress guidelines to developing models of psychosocial care: Current best practices. *Journal of Psychosocial Oncology, 30*(6), 694-714. doi: 10.1080/07347332.2012.721488

Clover, K., Carter, G. L., Mackinnon, A., & Adams, C. (2009). Is my patient suffering clinically significant emotional distress? Demonstration of a probabilities approach to evaluating algorithms for screening for distress. *Supportive Care in Cancer, 17*(12), 1455-1462. doi: 10.1007/s00520-009-0606-6

Derogatis, L. (2001). *BSI 18, Brief Symptom Inventory 18: Administration, scoring and procedures manual*: NCS Pearson, Inc.

Fielding, R., & Lam, W. W. T. (2013). Unresolved problems with distress screening. *British Journal of Cancer, 118,* 1922-1923. doi: 10.1038/bjc.2013.137

Fors, E. A., Bertheussen, G. F., Thune, I., Juvet, L. K., Elvsaas, I.-K. Ø., Oldervoll, L., . . . Leivseth, G. (2010). Psychosocial interventions as part of breast cancer rehabilitation programs? Results from a systematic review. *Psycho-Oncology.* doi: 10.1002/pon.1844

Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). *Burden and depression among caregivers of patients with cancer at the end of life.* Paper presented at the Oncology Nursing Forum.

Gordon, L. G., Beesley, V. L., & Scuffham, P. A. (2011). Evidence on the economic value of psychosocial interventions to alleviate anxiety and depression among cancer survivors: A systematic review. *Asia-Pacific Journal of Clinical Oncology, 7*(2), 96-105. doi: 10.1111/j.1743-7563.2011.01395.x

Hammerlid, E., Ahlner-Elmqvist, M., Bjordal, K., Biorklund, A., Evensen, J., Boysen, M., . . . Westin, T. (1999). A prospective multicentre study in sweden and norway of mental distress and psychiatric morbidity in head and neck cancer patients. *British Journal of Cancer, 80*(5-6), 766-774. doi: 10.1038/sj.bjc.6690420

Helgeson, V., Snyder, P., & Seltman, H. (2004). Psychological and physical adjustment to breast cancer over 4 years: Identifying distinct trajectories of change. . *Health Psychology, 23*(1), 3-15. doi: 10.1037/0278-6133.23.1.3

Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine, 60*(1), 1-12. doi: 10.1016/j.socscimed.2004.04.018

Hunter, K. U., & Jolly, S. (2013). Clinical review of physical activity and functional considerations in head and neck cancer patients. *Supportive Care in Cancer, 21*(5), 1475-1479. doi: 10.1007/s00520-013-1736-4

Karnofsky, D., & Burchenal, J. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C. MacLeod (Ed.), *Evaluation of chemotherapeutic agents*: Columbia University Press.

Lam, W., Ye, M., & Fielding, R. (2012). Trajectories of quality of life among chinese patients diagnosed with nasopharyngeal cancer. . *PLoS One 7(9): e44022., 7*(9), e44022. doi: 10.1371/journal.pone.0044022

Lam, W. W. T., Bonanno, G. A., Mancini, A. D., Ho, S., Chan, M., Hung, W. K., . . . Fielding, R. (2009). Trajectories of psychological distress among chinese women diagnosed with breast cancer. *Psycho-Oncology, 19*(10), 1044-1051. doi: 10.1002/pon.1658

Lam, W. W. T., Li, W. W. Y., Bonanno, G. A., Mancini, A. D., Chan, M., Or, A., & Fielding, R. (2011). Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes. *Breast Cancer Research and Treatment, 131*(3), 957-967. doi: 10.1007/s10549-011-1798-2

Lam, W. W. T., Shing, Y. T., Bonanno, G. A., Mancini, A. D., & Fielding, R. (2012). Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. *Psycho-Oncology, 21*(1), 90-99. doi: 10.1002/pon.1876

Laraway, D. C., & Rogers, S. N. (2012). A structured review of journal articles reporting outcomes using the university of washington quality of life scale. *British Journal of Oral and Maxillofacial Surgery, 50*(2), 122-131. doi: 10.1016/j.bjoms.2010.12.005

Miller, K., & Massie, M. J. (2009). Depressive disorders. In J. C. Holland, W. S. Breitbart, P. B. Jacobsen, M. S. Ledeberg & M. J. Loscalzo (Eds.), *Psycho-oncology* (pp. 311-318). New York: Oxford University Press.

Mitchell, A. J. (2011). Detecting and managing psychological distress in women with cancer: An update of recent evidence. *The Obstetrician & Gynaecologist, 13*(1), 22-28.

Mols, F., Thong, M. S. Y., de Poll-Franse, L. V. v., Roukema, J. A., & Denollet, J. (2012). Type d (distressed) personality is associated with poor quality of life and mental health among 3080 cancer survivors. *Journal of Affective Disorders, 136*(1-2), 26-34. doi: 10.1016/j.jad.2011.08.034

National Comprehensive Cancer Network (NCCN). (2013). NCCN clinical practice guidelines in oncology: Distress management. *2.2013*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Newell, S. A., Sanson-Fisher, R. W., & Savolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute, 94*(8), 559-584.

Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010). Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *Ca: A Cancer Journal for Clinicians*. doi: 10.3322/caac.20081

Patrick-Miller, L. J., Broccoli, T. L., Much, J. K., & Levine, E. (2004). *Validation of the distress thermometer: A single item screen to detect clinically significant psychological distress in ambulatory oncology patients.* Paper presented at the 2004 American Society of Clinical Oncology Annual Meeting Proceedings (Post-Meeting Edition).

Ransom, S., Jacobsen, P. B., & Booth-Jones, M. (2006). Validation of the distress thermometer with bone marrow transplant patients. *Psycho-Oncology, 15*(7), 604-612. doi: 10.1002/pon.993

Rohleder, N., Marin, T. J., Ma, R., & Miller, G. E. (2009). Biologic cost of caring for a cancer patient: Dysregulation of pro- and anti-inflammatory signaling pathways. *Journal of Clinical Oncology, 27*(18), 2909-2915. doi: 10.1200/jco.2008.18.7435

Ruland, C. M., Andersen, T., Jeneson, A., Moore, S., Grimsbø, G. H., Børøsund, E., & Ellison, M. C. (2013). Effects of an internet support system to assist cancer patients in reducing symptom distress. *Cancer Nursing, 36*(1), 6-17. doi: 10.1097/NCC.0b013e31824d90d4

Sollner, W., De Vries, A., Steixner, E., Sprinzi, G., Rumpold, G., Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer, 84*(2), 179-185. doi: 10.1054/

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*(10), 1013-1025. doi: 10.1002/pon.1670

Taylor, C. B., & Luce, K. H. (2003). Computer-and internet-based psychotherapy interventions. *Current Directions in Psychological Science, 12*(1), 18-22.

Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *JNCI Journal of the National Cancer Institute, 101*(21), 1464-1488. doi: 10.1093/jnci/djp336

Waller, A., Williams, A., Groff, S. L., Bultz, B. D., & Carlson, L. E. (2011). Screening for distress, the sixth vital sign: Examining self-referral in people with cancer over a one-year period. *Psycho-Oncology*. doi: 10.1002/pon.2102

Weisman, A. (1976). Early diagnosis of vulnerability in cancer patients. *American Journal of Medical Science, 271*, 187-196.

Weitzner, M. A., Jacobsen, P. B., Wagner, J. H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index - Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*, 55-63.

Zabora, J., Loscalzo, M., & Smith, E. (2000). *Psychosocial Rehabilitation.* New York: Churchill Livingstone.

Zabora, J. R., Loscalzo, M. J., & Weber, J. (2003). Managing complications in cancer: Responding to the patient's perspective. *Seminars in Oncology Nursing, 19*(4, Suppl 2), 1-9. doi: 10.1016/S0749-2081(03)00113-X

Zabora, J. R., & MacMurray, L. (2012). The history of psychosocial screening among cancer patients. *Journal of Psychosocial Oncology, 30*(6), 625-635. doi: 10.1080/07347332.2012.721491

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. doi: 10.1111/j.1600-0447.1983.tb09716.x

Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening cancer patients' families with the Distress Thermometer (DT): A validation study. *Psycho-Oncology, 17*(10), 959-966. doi: 10.1002/pon.1320

Zwahlen, D., Hagenbuch, N., Jenewein, J., Carley, M. I., & Buchi, S. (2011). Adopting a family approach to theory and practice: Measuring distress in cancer patient-partner dyads with the distress thermometer. *Psycho-Oncology, 20*(4), 394-403. doi: 10.1002/pon.1744

Appendix A

Research Ethics

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Philip Doyle
File Number:101050
Review Level:Delegated
Approved Local Adult Participants:175
Approved Local Minor Participants:0
Protocol Title:A prospective, longitudinal analysis of distress and quality of life in individuals diagnosed with head and neck cancer
- 18283E
Department & Institution:Health Sciences\Communication Sciences & Disorders,Western University
Sponsor:
Ethics Approval Date:July 10, 2013 Expiry Date:August 31, 2016
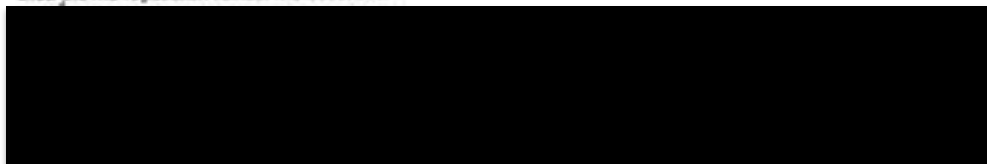Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Letter of Information & Consent	Letter of information (version 2012-2016)	
Revised Western University Protocol	Western protocol	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

This is an official document. Please retain the original in your files.

Appendix B

Use of Human Participants - Ethics Approval Notice

Research
Western

Principal Investigator: Dr. Philip Doyle
File Number:100499
Review Level:Delegated
Approved Local Adult Participants:200
Approved Local Minor Participants:0
Protocol Title:An exploratory analysis of distress and quality of life in caregivers of individuals diagnosed with head and neck cancer - 18091E
Department & Institution:Health Sciences\Communication Sciences & Disorders,Western University
Sponsor:
Ethics Approval Date:April 26, 2012 Expiry Date:April 30, 2016
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Western University Protocol	Administrative changes have been made to the resource list and the Western Protocol.	
Increase in number of local Participants	The number of participants has been increased to 200.	
Other	Resource List	
Revised Letter of Information & Consent	2012	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement:Â Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

This is an official document. Please retain the original in your files.

The University of Western Ontario

Appendix C

Letter of Information

Title: A Prospective, Longitudinal Analysis of Distress and Quality of Life in Individuals Diagnosed with Head and Neck Cancer

Study Investigators: Catharine Bornbaum M.Sc., Ph.D.(Candidate), Dr. Philip Doyle, Ph.D., Kevin Fung, M.D., Dr. Anthony Nichols, M.D., Dr. Jason Franklin & Dr. John Yoo, M.D.

1. Introduction

You are being invited to participate in a research project investigating issues related to distress level and quality of life among individuals diagnosed with and treated for head and neck cancer. We are asking you to take part in this research study because you have been diagnosed with head and neck cancer and we are interested in how this experience may have impacted your quality of life and level of distress.

The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research. This letter contains information to help you decide whether or not to participate in this research study. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear or there are words or phrases you do not understand. You will be given a copy of this letter to keep for your records.

2. Purpose of Study

The purpose of this study is to investigate the impact of head and neck cancer on the quality of life and level of distress throughout the first two years following your diagnosis. We are conducting this study in order to determine how the experience of living with head and neck cancer affects specific areas of your life (e.g., physical impact, emotional strain, social isolation, etc.). We are specifically interested in understanding the areas that you find distressing and how these areas influence your quality of life. This study will examine areas of concern affecting quality of life in approximately 175 individuals with head and neck cancer.

The specific questions to be addressed are:

a.) What is the overall presence of distress in a sample of individuals with head and neck cancer and how does this rate compare to previous findings in the literature?

b.) Is there a relationship between distress level and quality of life among individuals diagnosed with head and neck cancer?

c.) Does the amount of time since the diagnosis influence the level of distress and quality of life of individuals with head and neck cancer?

This study represents a portion of a doctoral research project for one of the investigators (C.B.).

3. Activities Participant Will Take Part In

If you agree to participate, you will receive a package containing one (1) page of demographic information (i.e., age, sex, marital status, etc.) to complete and four (4) questionnaires to complete regarding your personal feelings related to your quality of life and distress level in relation to your cancer. The questionnaires have been used before in research and include the Distress Thermometer (DT) and the Brief Symptom Inventory 18 (BSI-18) to measure distress, in addition to the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (EORTC-QLQ-C30), and the EORTC Head and Neck module (EORTC-QLQ-H&N35), which measure your quality of life. The order of these questionnaires will be randomly assigned, and each questionnaire should be filled out according to the enclosed instructions in a location of your choosing (i.e., your home or private office).

Since this study will assess your quality of life and level of distress throughout the first two years since receiving your diagnosis, you will be mailed packages identical to the one described above at the following intervals: three months, six months, nine months, 12 months, 18 months, and 24 months following your diagnosis. We anticipate that it will take approximately 20-25 minutes to complete these tasks each time.

Once you have completed all tasks, please place all of the completed material in the addressed and stamped envelope and place it in the mail to return the package to the investigators. If you should have any questions while completing the contents of the package, please contact ███

Please note that you will not be compensated for your participation in this research.

4. Exclusion Criteria

You will be excluded from participating in the study if you are younger than 18 years of age, if you do not read/speak English, or if you are unable to see the questionnaires. Requirements regarding the ability to speak and read English as well as the ability to see are necessary, as the tasks involved in this study require participants to read and understand the questionnaires in English.

5. Possible Risks Involved

There are no foreseeable risks, harms, nor discomforts incurred from the participation in this study. However, you will be asked to complete questionnaires that may delve into sensitive topics affecting your quality of life and distress level and as a result you may experience negative emotions. If this occurs, we would request that you contact your physician, or a member of the research team should you require assistance in managing these negative emotions. Please note that if at any time you inform us that you are experiencing thoughts of suicide, we will have a member of our team contact you in order to follow up on this information.

Additionally, self-addressed stamped envelopes will be provided to you in order to prevent any economic burden associated with your study participation. There will not be any costs for you associated with your participation. After completing the forms, should you experience feelings of elevated or worrisome distress, we ask that you notify your physician or the research team immediately. We will assist you in locating the appropriate support services. Additionally, a list of head and neck cancer support services has been included in the study package for your convenience.
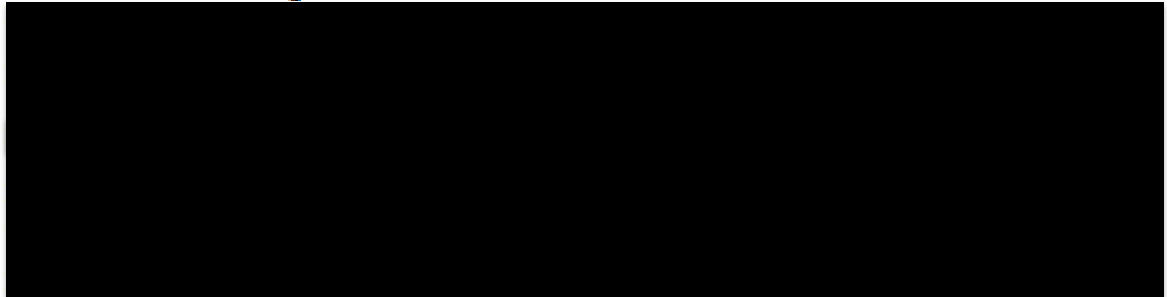
6. Possible Benefits Involved

There are few direct benefits to you as a result of your participation in this study. However, due to your participation, you may gain a better understanding and awareness of the various areas that affect your overall quality of life and distress level. At a societal level, information gathered from this study will provide health care practitioners with specific information pertaining to the physical, psychological, and social consequences that are experienced by individuals living with head and neck cancer. This information may have direct implications on future psychosocial care and may assist health care practitioners in identifying those individuals who are most likely to experience high distress levels. Also, the results may offer health care providers insight into the areas of concern that are potentially different for any given person.

7. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no negative consequences. You do not waive any legal rights by signing the consent form.

8. Confidentiality

All data collected will remain confidential. No personally identifying information will be linked with your data. All data will be kept in a secure locked location at the University of Western Ontario. If the results are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure. Please note that representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

8. Contacts for Further Questions

By completing and returning the questionnaires, you indicate your consent to participate in the study

This letter is for you to keep.

Appendix D

Letter of Information

Title: An Exploratory Analysis of Distress and Quality of Life in Caregivers of Individuals with Head and Neck Cancer

Study Investigators: Catherine Bornbaum M.Sc., Ph.D.(Candidate), Dr. Philip Doyle, Ph.D., Kevin Fung, B.Sc., M.D.

1. Introduction

You are being invited to participate in a research project investigating issues related to distress level and quality of life among caregivers (e.g., spouse, partner, significant other, parent, adult child, etc.) of individuals diagnosed with and treated for head and neck cancer. We are asking you to take part in this research study because you have identified yourself as the caregiver of someone diagnosed with head and neck cancer and we are interested in how this experience may have impacted your quality of life and level of distress.

The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research. This letter contains information to help you decide whether or not to participate in this research study. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear or there are words or phrases you do not understand. You will be given a copy of this letter to keep for your records.

2. Purpose of Study

The purpose of this study is to investigate the impact of head and neck cancer on the quality of life and level of distress of caregivers. We are conducting this study in order to determine how the experience of being a caregiver to someone with head and neck cancer affects specific areas of your life (e.g., physical impact, emotional strain, social isolation, etc.). We are specifically interested in understanding the areas that you find distressing and how these areas influence your quality of life. This study will examine areas of concern affecting quality of life in approximately 200 caregivers of individuals with head and neck cancer.

The specific questions to be addressed are:

a.) What is the overall presence of psychological distress in a sample of caregivers of those with head and neck cancer and how does this rate compare to previous findings in the literature?

b.) Is there a relationship between distress level and quality of life among caregivers of individuals diagnosed with head and neck cancer?

c.) Does the amount of time since the diagnosis influence the level of distress and quality of life of caregivers for individuals with head and neck cancer?

This study represents a part of a doctoral research project for one of the investigators (C.B.).

3. Activities Participants Will Take Part In

If you agree to participate, you will receive a package containing one (1) page of demographic information (i.e., age, sex, marital status, etc.) to complete and three (3) questionnaires to complete regarding your personal feelings related to your quality of life and distress level in relation to your cancer. The questionnaires have been used before in research and include the Distress Thermometer (DT) and the Brief Symptom Inventory 18 (BSI-18) to measure distress, in addition to the Caregiver Quality of Life Index – Cancer Scale (CQOLC), which measures your quality of life. The order of these questionnaires will be randomly assigned, and each questionnaire should be filled out according to the enclosed instructions in a location of your choosing (i.e., your home or private office). Additional pages will be provided for you to include any additional information you would like to share on the given subject. We anticipate that it will take approximately 15 minutes to complete these tasks.

Once you have completed all tasks, please return the completed questionnaires to the research team. If you are completing the questionnaires at the Annual Meeting of the International Association of Laryngectomees, please note that the questionnaires will be transported back to The University of Western Ontario by one of the investigators (C.B.) in a locked briefcase. No personally identifying information will be attached to your data so there is no risk of you ever being personally identified should the data be lost or stolen in transit. If you choose to complete the questionnaires at home or at another time that is more convenient for you, please place all of the completed materials in the addressed and stamped envelope and place it in the mail to return the package to the investigators. If you should have any questions while completing the contents of the package, please contact

Please note that you will not be compensated for your participation in this research.

4. Exclusion Criteria

You will be excluded from participating in the study if you are younger than 18 years of age, if you do not read/speak English, or if you are unable to see the questionnaires. Requirements regarding the ability to speak and read English as well as the ability to see are necessary, as the tasks involved in this study require participants to read and understand the questionnaires in English.

5. Possible Risks Involved

There are no foreseeable risks, harms, nor discomforts incurred from the participation in this study. However, you will be asked to complete questionnaires that may delve into sensitive topics affecting your quality of life and distress level and as a result you may experience negative emotions. If this occurs, we would request that you contact your physician, or a member of the research team should you require assistance in managing these negative emotions.

Additionally, should you require it, self-addressed stamped envelopes will be provided to you in order to prevent any economic burden associated with your study participation. There will not be any costs for you associated with your participation. After completing the forms, should you experience feelings of elevated or

worrisome distress, we ask that you notify your physician or the research team immediately. We will assist you in locating the appropriate support services. Additionally, a list of head and neck cancer support services has been included in the study package for your convenience.

6. Possible Benefits Involved

There are few direct benefits to you as a result of your participation in this study. However, due to your participation, you may gain a better understanding and awareness of the various areas that affect your overall QOL and distress level. At a societal level, information gathered from this study will provide health care practitioners with specific information pertaining to the physical, psychological, and social consequences that are experienced by caregivers of individuals living with head and neck cancer. This information may have direct implications on future psychosocial family care and may assist health care practitioners in identifying those caregivers who are most likely to experience high distress levels. Also, the results may offer health care providers insight into the areas of concern that are potentially different for any given person.
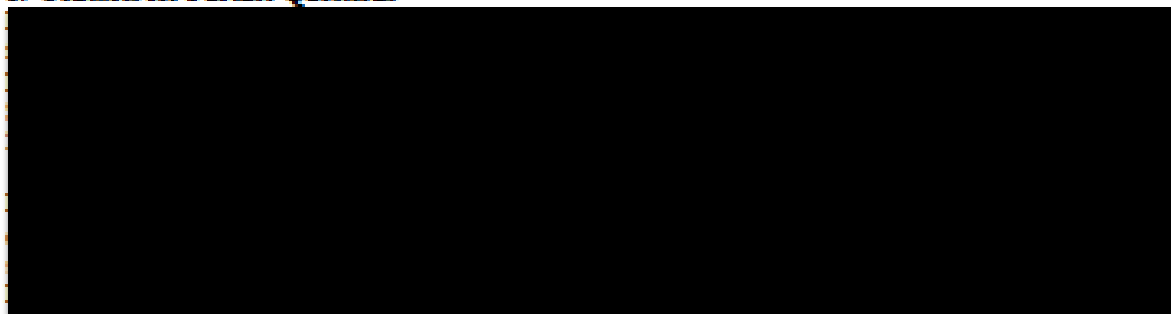
7. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no negative consequences. You do not waive any legal rights by signing the consent form.

8. Confidentiality

All data collected will remain confidential. No personally identifying information will be linked with your data. All data will be kept in a secure locked location at the University of Western Ontario. If the results are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure. Please note that representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

8. Contacts for Further Questions

By completing and returning the questionnaires, you indicate your consent to participate in the study

This letter is for you to keep.

Appendix E

Demographic Information Survey

Title: A Prospective, Longitudinal Analysis of Distress and Quality of Life in Individuals Diagnosed with Head and Neck Cancer

Study Investigators: Catherine Bornbaum, M.Sc., Ph.D.(Candidate), Dr. Philip Doyle, Ph.D., Kevin Fung, M.D., Dr. Anthony Nichols, Dr. Jason Franklin & Dr. John Yoo, M.D.

Please read the following questions carefully and provide answers as accurately as possible. For multiple choice options, please place an "X" next to all choices that apply to you. If no suitable options exist, please use the space provided to explain. If there is any additional information that you feel is important to report regarding your experience with distress or your quality of life, please explain using the back of these pages.

Age: _____ years & _____ months

Sex: Male / Female

Time since your diagnosis: _____ years & _____ months

Occupational status:

Working: Full-time		Working: Part-time		Volunteer	
Retired		On disability benefits		Other	

If "other", please specify: _____

Marital status:

Married		Separated		Divorced	
Widowed		Common-law		Single	

Site of cancer:

Larynx (voice box)		Thyroid		Sinuses/Paranasal sinuses	
Oral cavity (e.g., lip, tongue, cheek, tonsil, etc.)		Throat (e.g., hypopharynx, oropharynx, nasopharynx)		Other	

If "other", please specify: _____

If you have had a laryngectomy, what method of speech do you now use?

Tracheoesophageal speech		Esophageal speech	
Electrolaryngeal speech		Writing	

If known, what is/was your stage of cancer?

Stage I		Stage II	
Stage III		Stage IV	

What is your current treatment status?

Currently waiting for treatment		Currently undergoing treatment		Completed treatment	

If treatment has been completed, please specify date of completion if known:

_____

If you have undergone treatment, what type of treatment have you received? (Check all that apply)

Surgery		Chemotherapy		Radiation therapy	

Highest level of education completed:

Less than high school		Some high school		High school graduate	
Some college/post-secondary education		College graduate		Apprenticeship	
Trade School		Bachelor's degree		Master's degree	
Professional degree		Doctorate		Other	

If "other", please specify: _____

Tobacco use status:

Currently use tobacco products		Formerly used tobacco products		Never used tobacco products	

If you currently use, or used to use tobacco products, approximately what quantity of what product (e.g., cigarettes, chewing tobacco, cigars, etc.) do/did you consume in an average week? _____

Alcohol use status:

Currently consume alcohol		Formerly consumed alcohol		Never consumed alcohol	

If you currently consume, or used to consume alcohol, approximately how many beverages do/did you consume in an average week? _____

Household Income (optional):

Less than $25,000		$25,000 – $40,000		$40,001 – $55,000	
$55,001 – $70,000		$70,001 – $85,000		Greater than $85,000	
Would prefer not to say					

Appendix F

Demographic Information Survey

Title: An Exploratory Analysis of Distress and Quality of Life in Caregivers of Individuals with Head and Neck Cancer

Study Investigators: Catherine Bornbaum, M.Sc., Ph.D.(C), Kevin Fung, M.D., Anthony Nichols, M.D., Jason Franklin, M.D., John Yoo, M.D., Philip Doyle, Ph.D.

Please read the following questions carefully and provide answers as accurately as possible. For multiple choice options, please place an "X" next to all choices that apply to you. If no suitable options exist, please use the space provided to explain. If there is any additional information that you feel is important to report regarding your experience with distress or your quality of life, please explain using the back of these pages.

Age: _____ years & _____ months

Sex: Male / Female

What is your relationship to your loved one (the individual with cancer)?

(e.g., spouse, sibling, parent, child, etc.) _____

Time since your loved one was first diagnosed: _____ years & _____ months

Has your loved one experienced a recurrence? _____ Yes _____ No

Site of cancer for your loved one:

Larynx (voice box)		Thyroid		Sinuses/Paranasal sinuses	
Oral cavity (e.g., lip, tongue, cheek, tonsil, etc.)		Throat (e.g., hypopharynx, oropharynx, nasopharynx)		Other	

If "other", please specify: _____

If your loved one had a laryngectomy, what method of speech do they now use?

Tracheoesophageal speech		Electrolaryngeal speech	
Esophageal speech		Writing/Gesturing/Other	

If known, what was your loved one's stage of cancer?

Stage I		Stage II	
Stage III		Stage IV	

If known, what type of treatment did your loved one receive? (Check all that apply)

Surgery		Radiation therapy		Chemotherapy	

Treatment status of your loved one:

Currently waiting for treatment		Currently undergoing treatment		Completed treatment	

If treatment has been completed, please specify date of completion if known:

_____

Your marital status:

Married		Separated		Divorced	
Widowed		Common-law		Single	

Highest level of education you have completed:

Less than high school		Some high school		High school graduate	
Some college/post-secondary education		College graduate		Apprenticeship	
Trade School		Bachelor's degree		Master's degree	
Professional degree		Doctorate		Other	

If "other", please specify: _____

Your occupational status:

Working: Full-time		Working: Part-time		Volunteer	
Retired		On disability benefits		Other	

If "other", please specify: _____

Your household income (optional):

Less than $25,000		$25,000 – $40,000		$40,001 – $55,000	
$55,001 – $70,000		$70,001 – $85,000		Greater than $85,000	
Would prefer not to say					

Appendix G

EORTC-QLQ-C30 images removed due to copyright restrictions

Appendix H

EORTC-QLQ-H&N35 images removed due to copyright restrictions

Appendix I

Distress Thermometer image removed due to copyright restrictions

Appendix J

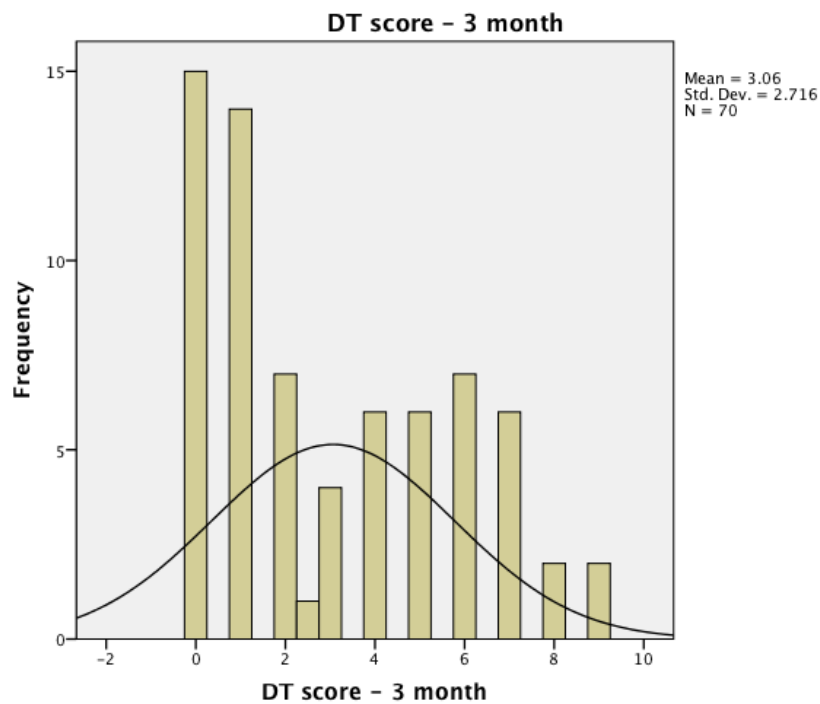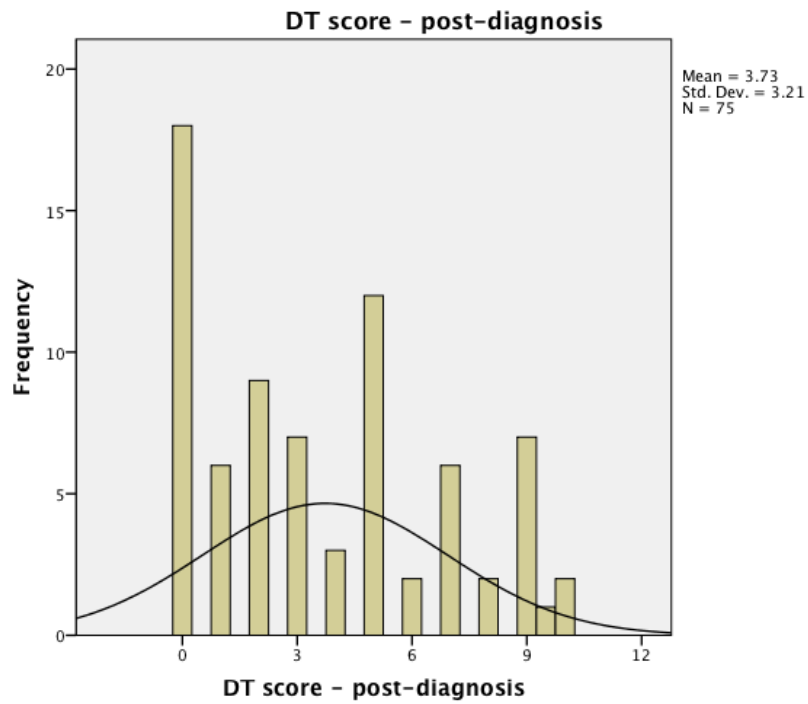**CQOLC images removed due to copyright restrictions**
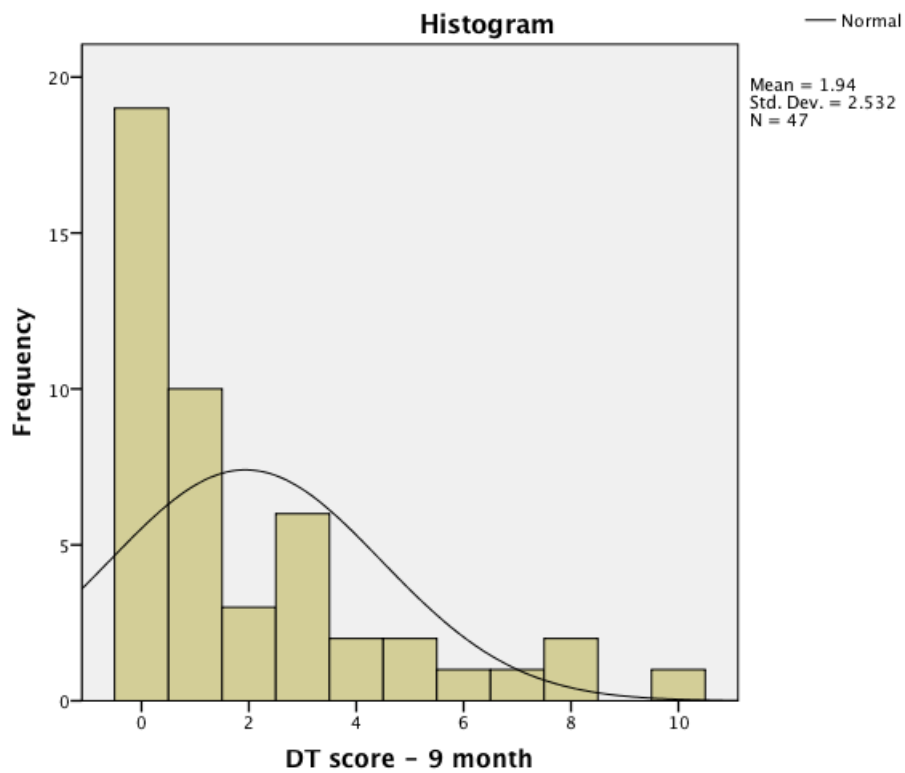
Appendix K

HEAD AND NECK CANCER SUPPORT SERVICES
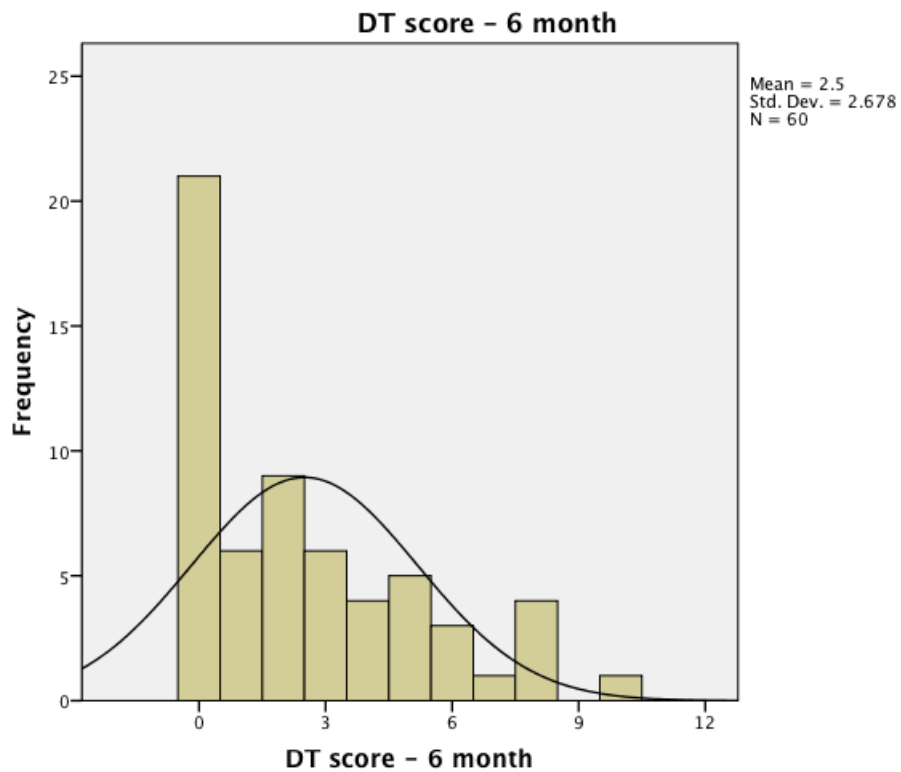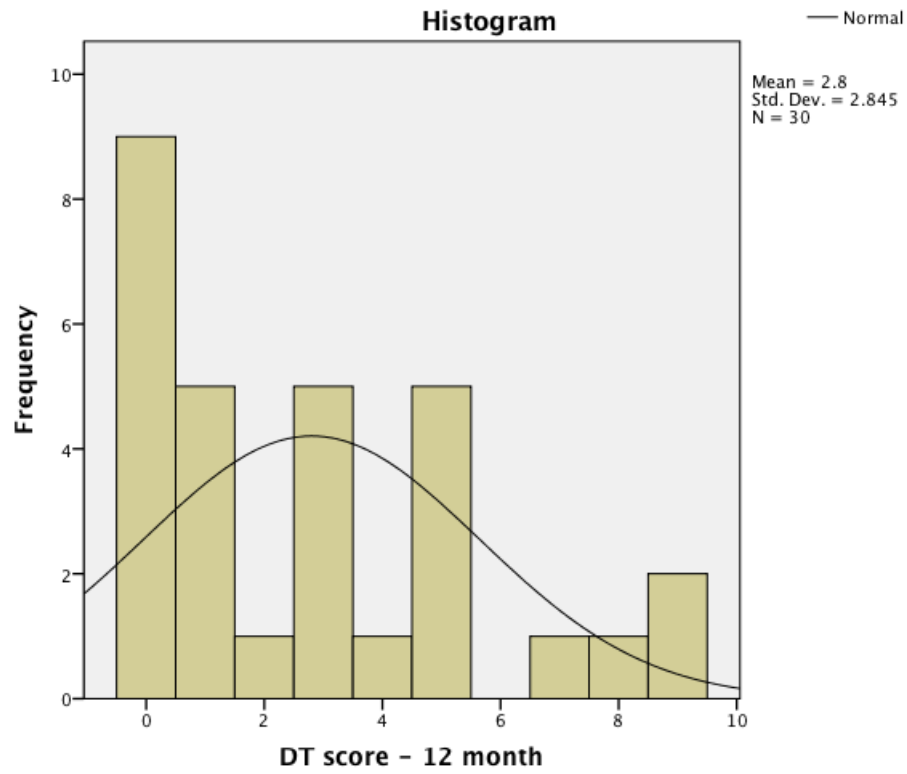
RESOURCE LIST

Source	Contact Information
Canadian Cancer Society	www.cancer.ca Phone: 1-800-263-6750 TTY: 1-866 786-3934 (Available Mon-Fri 9:00 a.m. – 5:00 p.m.)
American Cancer Society	http://www.cancer.org/ Phone: 1-800-227-2345 (Available 24 hours a day, 7 days a week)
London Mental Health Crisis Service	Phone: 1-866-933-2023 (Available 24 hours a day, 7 days a week)
Supportive Care at the London Regional Cancer Program	Phone: 519-685-8622
Wellspring London and Region Cancer Support Centre	www.wellspringlondon.ca Phone: 519-438-7379
London and District New Voice Association	The Canadian Corps, 1051 Dundas St E. London, ON, N5W 3A4 Phone: 519-471-1378
International Association of Laryngectomees (IAL)	http://www.larynxlink.com/ Phone: 1-866-425-3678
AboutFace	http://www.aboutface.ca Phone: 1-800-665-3223
Canadian Thyroid Cancer Support Group (Thry'vors) Inc.	http://www.thryvors.org Phone: 1-416-487-8267
The Head & Neck Cancers Online Support Group listserv	http://listserv.org/archives/head-neck-onc.html
Support for People with Oral and Head and Neck Cancer	http://www.spohnc.org
The Yul Brynner Head and Neck Cancer Foundation	http://www.headandneck.org
Head and Neck Cancer Site	http://www.hncancer.com
Head and Neck Cancer Resources	http://www.cancerindex.org/clinks2h.htm
National Cancer Institute Head and Neck Cancer Resources	http://cancernet.nci.nih.gov/cancertopics/types/head-and-neck
Web Whispers	http://www.webwhispers.org/
The Oral Cancer Foundation	http://oralcancerfoundation.org/

Appendix L

Histograms for Longitudinal Distress Thermometer Findings (Chapter 2)

DT score – post-diagnosis

Mean = 3.73
Std. Dev. = 3.21
N = 75

DT score – 3 month

Mean = 3.06
Std. Dev. = 2.716
N = 70

DT score – 6 month

Mean = 2.5
Std. Dev. = 2.678
N = 60

DT score – 6 month

Histogram

Normal

Mean = 1.94
Std. Dev. = 2.532
N = 47

DT score – 9 month

Histogram

Mean = 2.8
Std. Dev. = 2.845
N = 30

Curriculum Vitae

a) **Name:** Catherine Bornbaum

Status: Doctoral Candidate – Year 4

Full-time or part-time status: Full-time

b)

Degree	University	Department	Year
Ph.D.	Western University	Health & Rehabilitation Sciences	2010-2013
M.Sc.	Western University	Health & Rehabilitation Sciences	2008-2009
B.H.Sc.	Western University	Health Sciences	2004-2008

c) **Employment History:**

Date	Rank & Position	Department	Institution
Sept 2013 - Present	Senior Research Coordinator, Knowledge Broker	Public Health Sciences	Public Health Ontario
Oct 2013 - Present	Research Consultant	Laboratory for Well-Being and Quality of Life in Oncology	University of Western Ontario
Jan 2010 – Oct 2013	Senior Research Associate	Laboratory for Well-Being and Quality of Life in Oncology	University of Western Ontario
Oct 2008 – Aug 2013	Research Assistant	Department of Otolaryngology Head & Neck Surgery	London Health Sciences Centre – Victoria Hospital, London, Ontario
Sept 2010 – Dec 2010	Teaching Assistant HS3500 – Health Related Quality of Life	School of Health Studies	University of Western Ontario
Apr 2010 – Sept 2010	Research Assistant	School of Health Studies – Knowledge Translation Laboratory	University of Western Ontario
Sept 2009 – Dec 2009	Teaching Assistant HS1000 – Introduction to Health Sciences	School of Health Studies	University of Western Ontario
Sept 2008 – Dec 2008	Teaching Assistant HS2800 – Measurement and Methods	School of Health Studies	University of Western Ontario
Jan 2008 – Apr 2008	Class Assistant (Undergraduate Teaching Assistant) HS345b – Health and Aging	School of Health Studies	University of Western Ontario

d) **Academic Honours: (not research grants)**

2013 – Faculty of Health Sciences Travel Award
2013 – Faculty of Health Sciences Graduate Student Conference Travel Award
2013 – Health & Rehabilitation Sciences Graduate Research Forum
　　　　Oral Presentation Award (1st place)
2012 – Faculty of Health Sciences Thesis Research Award
2011 – Western Fund Ontario Graduate Scholarship
2011 – Graduate Student Teaching Award Nominee
2011 – Faculty of Health Sciences Travel Award
2011 – Alumni Western Multidisciplinary Poster Competition (First place)
2011 – Faculty of Health Sciences Graduate Student Conference Travel Award
2010 – Faculty of Health Sciences Travel Award
2009 – Graduate Student Teaching Award Nominee
2008 – Bachelor of Health Sciences Award of Recognition
2008 – Faculty of Health Sciences Dean's Honor List
2007 – McGraw-Hill Ryerson Student Scholarship Award Nominee

e) **Scholarly and Professional Activities:** (from 2008 to present)

2012 – 2013　Senate Review Board Academic, Graduate Student Member
2008 – 2013　Rehabilitation Sciences Journal Club, Student Member
2011 – 2012　University Research Board, Graduate Student Member
2010 – 2011　Rehabilitation Sciences Journal Club, Coordinator
2009 – 2011　Faculty of Health Sciences Faculty Council, Graduate Student
　　　　　　　 Representative
2008 – 2010　Health & Rehabilitation Sciences Graduate Student Society, Executive
　　　　　　　 Member

　　　Journal Referee:

2010 – Present Disability & Rehabilitation (9 manuscripts reviewed to date)
2012 – Present Supportive Care in Cancer (5 manuscripts reviewed to date)
2012 – Present Oral Oncology (1 manuscript reviewed to date)

h) **Research Funding:** (from 2008 to present)

Start Date	End Date	Principal Investigator	Funding Agency	Project Title	Total Amount
2012	2013	Bornbaum, C.	Canadian Institutes of Health Research (Priority Area: Patient-Oriented Research)	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$55,417
2012	2013	Bornbaum, C.	Ontario Graduate Scholarship	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$15,000 offered & declined

2012	2013	Bornbaum, C.	The University of Western Ontario – Western Graduate Research Scholarship	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$8,000
2011	2012	Bornbaum, C.	Ontario Graduate Scholarship	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$15,000
2011	2012	Bornbaum, C.	The University of Western Ontario – Western Graduate Research Scholarship	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$8,000
2010	2011	Bornbaum, C.	Ontario Graduate Scholarship in Science and Technology	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$10,000
2010	2010	Bornbaum, C.	The University of Western Ontario – Western Graduate Research Scholarship	Measuring the sixth vital sign: A prospective, longitudinal analysis of distress in head and neck cancer (Doctoral research)	$19,000
2009	2009	Bornbaum, C.	The University of Western Ontario – Western Graduate Research Scholarship	A cross-sectional analysis of distress and quality of life concerns in individuals diagnosed with head and neck cancer	$10,000
2008	2009	Bornbaum, C.	The University of Western Ontario – Western Graduate Research Scholarship	A cross-sectional analysis of distress and quality of life concerns in individuals diagnosed with head and neck cancer	$10,000

i) **PUBLICATIONS**

1) **Life-time summary (count) according to the following categories:**

Books authored: 0
Books edited: 0
Chapters in books: 0
Papers in refereed journals: 4
Papers in refereed conference proceedings: 0
Technical reports: 0
Abstracts and/or papers read: 1
Presentations at professional meetings/workshops and others: 41

Papers in <u>refereed</u> journals:

4. **Bornbaum, C.C.,** Day, A.M.B., & Doyle, P.C. (2013). Examining the construct validity of the Voice-Related Quality of Life (V-RQOL) measure in alaryngeal speakers. *American Journal of Speech-Language Pathology,* [In Press].

3. **Bornbaum C.C.,** Doyle, P.C., Skarakis-Doyle, E., & Theurer, J.A. (2013). A critical exploration of the International Classification of Functioning, Disability and Health (ICF) framework from the perspective of cancer care: Recommendations for revision. *Journal of Multidisciplinary Healthcare, 6,* 75-86.

2. **Bornbaum, C.C.,** Fung, K., Franklin, J.H., Nichols, A., Yoo, J., & Doyle, P.C. (2012). A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Supportive Care in Cancer, 20(9),* 2157-2165. doi: 10.1007/s00520-011-1326-2.

1. Yeung, J.C., Fung, K., **Bornbaum, C.C.,** Day, A.M.B., Dziboa, A., Parsa, V., Levee, T. & Doyle, P.C. (2011). A clinical approach to monitoring variability associated with adductor spasmodic dysphonia. *Journal of Otolaryngology Head and Neck Surgery, 40(4),* 343-349*.*

Abstracts and/or papers read:

1. **Bornbaum, C.C.,** Fung, K., & Doyle, P.C. (2010). Heightened distress and quality of life concerns in individuals with head and neck cancer. *Psycho-Oncology, 19(S2),* S100-S101.

Presentations at professional meetings/workshops:

41. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J., Nichols, A. & Yoo, J. Factors contributing to elevated distress in caregivers of individuals with head and neck cancer. To be presented at the Multinational Association of Supportive Care in Cancer conference, Berlin, Germany, June 27-29, 2013.

40. **Bornbaum, C.C.** A prospective, longitudinal analysis of distress in individuals diagnosed with head and neck cancer. Invited presentation at the Department of Otolaryngology – Head and Neck Surgery Grand Rounds, London, ON, May 22, 2013.

39. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J., Nichols, A. & Yoo, J. Caregiver distress and quality of life in head and neck cancer: A comparison of new (<12 months post-diagnosis) and longer-term caregivers (≥12 months post-diagnosis). Presented at the Canadian Association for Psychosocial Oncology conference, Ottawa, ON, April 24-26, 2013.

38. **Bornbaum, C.C.** Reflections on the graduate school process: Tips and tricks for success and sanity. Invited presentation at the University of Western Ontario, London, ON, March 1, 2013.

37. Doyle, P.C., Scott, G.M., **Bornbaum, C.C.,** & Day, A.M.B. Listener comfort as a clinical metric for tracheoesophageal voice. Presented at the XXI Pacific Voice and Speech Foundation/ECLA Voice Conference: Neoplastic Lesions of the Larynx + Voice & Deglutition – Update in Diagnosis and Treatment, Ronald Reagan Hospital, UCLA Medical Center, Los Angeles, CA, February 22-23, 2013.

36. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J., Nichols, A. & Yoo, J. Factors contributing to elevated distress in caregivers of individuals with head and neck cancer: A preliminary examination. Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 6, 2013.

35. **Bornbaum, C.C.** An introduction to caregiver distress and concerns among family members of individuals diagnosed with cancer. Invited presentation at the University of Western Ontario, London, ON, November 27, 2012.

34. Cox, S., Day, A.M.B., **Bornbaum, C.C.** & Doyle, P.C. The impact of the electrolarynx on voice-related quality of life. Paper presented at the Annual American Speech-Language Hearing Association convention, Atlanta, GA, November 15, 2012.

33. **Bornbaum, C.C.** A practical guide to identifying and managing distress in clinical settings. Invited presentation at the Annual Meeting of The International Association of Laryngectomees (Voice Institute), Raleigh, North Carolina, USA, June 2012.

32. Kahlili, S., Doyle, P.C., Franklin, J., Nichols, A., Yoo, J., Sleeth, L., **Bornbaum, C.C.,** & Fung, K. Tracheoesophageal puncture: An initial exploration of factors affecting voice quality. Paper presented at the 66th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Toronto, ON, May 2012.

31. **Bornbaum, C.C.,** & Doyle, P.C. Is the Voice-Related Quality of Life (V-RQOL) valid for postlaryngectomy speakers? Examining the construct validity of the V-RQOL. Paper presented at the 66th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Toronto, ON, May 2012.

30. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J., Nichols, A & Yoo, J. Perceptions of distress and quality of life among caregivers of individuals diagnosed with head and neck cancer. Presented at the Annual Meeting of the Canadian Association for Psychosocial Oncology, Vancouver, BC, April 26, 2012.

29. **Bornbaum, C.C.** & Doyle, P.C. Understanding the benefits of quality of life measures in the alaryngeal population. Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 2012.

28. Cox, S.R., Day, A.M.B., **Bornbaum, C.C.,** Sleeth, L., Dzioba, A. & Doyle, P.C. Electrolaryngeal use on Voice-Related Quality of Life (V-RQOL): Understanding the potential for voice-related disability following total laryngectomy. Presented at the 5th annual Aging, Rehabilitation & Geriatric Care Research Conference, London, ON, February 2012.

27. Cox, S.R., Day, A.M.B., **Bornbaum, C.C.,** Sleeth, L., Dzioba, A. & Doyle, P.C. Voice-related disability: Uncovering the impact of the electrolarynx (EL) on Voice-Related Quality of Life (V-RQOL). Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 8, 2012.

26. **Bornbaum, C.C.,** Day, A.M.B., & Doyle, P.C. Evaluating the validity of the Voice-Related Quality of Life measure: Is it an appropriate measure for the laryngeal cancer population? Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 8, 2012.

25. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J., Nichols, A. & Yoo, J. Factors contributing to elevated distress in caregivers of individuals with head and neck cancer: A preliminary examination. Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 8, 2012.

24. **Bornbaum, C.C.,** Doyle, P.C., Day, A.M.B., Dzioba, A., Sleeth, L. & Fung, K. Construct validation of the V-RQOL in alaryngeal speakers. Paper presented at the Annual American Speech-Language Hearing Association convention, San Diego, CA, November 2011.

23. **Bornbaum, C.C.,** Doyle, P.C., Day, A.M.B., Dzioba, A. & Sleeth, L. Relationships between listener comfort & voice severity in tracheoesophageal speech. Paper presented at the Annual American Speech-Language Hearing Association convention, San Diego, CA, November 2011.

22. **Bornbaum, C.C.** An introduction to the issue of distress in considerations of health-related quality of life. Invited presentation at the University of Western Ontario, London, ON, November 2011.

21. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J.H., Nichols, A., & Yoo, J. Identifying and managing distress in head and neck cancer. Paper presented at the 65th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Victoria, BC, May 2011.

20. Yeung, J., Fung, K., Dzioba, A., Day, A., **Bornbaum, C.C.,** Sleeth, L., Doyle, P.C. Influence of listener experience on perceptual judgments of adductor spasmodic dysphonia. Paper presented at the 65th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Victoria, BC, May 2011.

19. **Bornbaum, C.C.,** Fung, K., & Doyle, P.C. The Influence of Treatment Modality on Reported Distress Levels and Quality of Life Concerns in Individuals with Head and Neck Cancer. Paper presented at the Canadian Association of Psychosocial Oncology conference, Toronto, ON, May 2011.

18. **Bornbaum, C.C.,** Fung, K. & Doyle, P.C. Evaluating psychosocial well-being in individuals with head and neck cancer. Poster presentation at Faculty of Health Sciences Research Day, London ON, March 25, 2011.

17. **Bornbaum, C.C.,** Fung, K., & Doyle, P.C. Assessing the impact of treatment modality on perceived levels of distress and quality of life in individuals diagnosed with head and neck cancer. Poster presented at the 4th annual Aging, Rehabilitation & Geriatric Care Research conference, London, ON, February 2011.

16. Sleeth, L., Skidmore, E., Elliot, H.C., **Bornbaum, C.C.,** & Doyle, P.C. Comprehensive evaluation of voice severity and listener comfort in postlaryngectomy tracheoesophageal speakers. Poster presented at the 4th annual Aging, Rehabilitation & Geriatric Care Research conference, London, ON, February 2011.

15. **Bornbaum, C.C.** & Doyle, P.C. Distress in head and neck cancer: An important factor influencing perceived quality of life. Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 2011.

14. Sleeth, L., Skidmore, E., Elliot, H.C., **Bornbaum, C.C.,** & Doyle, P.C. Auditory-perceptual assessments of voice severity and listener comfort in postlaryngectomy tracheoesophageal speakers. Presented at the 23rd annual Western Research Forum, London, ON, February 2011.

13. **Bornbaum, C.C.** & Doyle, P.C. Multidimensional concerns in individuals with head and neck cancer. Presented at the 23rd annual Western Research Forum, London, ON, February 2011.

12. Doyle, P.C., Skidmore, E., Seuchuk, C., **Bornbaum, C.C.,** Day, A.M.B., Caty, M.-E., & Levee, T. Evaluation of Listener Comfort and Voice Severity in Tracheoesophageal Speech. Paper presented at the annual American Speech Language & Hearing Association conference, Philadelphia, USA, November, 2010.

11. **Bornbaum, C.C.,** Fung, K., & Doyle, P.C. Heightened distress and quality of life concerns in individuals with head and neck cancer. Paper presented at the 12th world congress of psycho-social oncology hosted jointly by the International Psycho-Oncology Society and the Canadian Association of Psychosocial Oncology, Quebec City, QC, May 2010.

10. **Bornbaum, C.C.,** Doyle, P.C., Fung, K., Franklin, J.H., Nichols, A., & Yoo, J. Distress and quality of life in head and neck cancer. Poster presented at the 64th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Niagara Falls, ON, May 2010.

9. Yeung, J.C., Fung, K., Day, A.M.B., Dzioba, A., **Bornbaum, C.C.,** Levee, T., & Doyle, P.C. (2010). Longitudinal evaluations of laryngeal overpressure and Voice-Related Quality of Life in adductor spasmodic dysphonia. Paper presented at the 64th Annual Canadian Society of Otolaryngology – Head & Neck Surgery conference, Niagara Falls, ON, May 2010.

8. **Bornbaum, C.C.** & Doyle, P.C. Relationships between distress and quality of life in individuals with head and neck cancer. Invited presentation at Wellspring-Sunnybrook Cancer Centre, Toronto, ON. April 1, 2010.

7. **Bornbaum, C.C.** & Doyle, P.C. The role of distress screening in assessments of quality of life among individuals with head and neck cancer. Poster presentation at Faculty of Health Sciences Research Day, London ON, March 22, 2010.

6. **Bornbaum, C.C.,** Fung, K., & Doyle, P.C. Identification of distress in individuals with head and neck cancer in the early post-diagnostic period. Poster presented at the 3rd annual Aging, Rehabilitation & Geriatric Care Research conference, London, ON, February 2010.

5. Eadie, T.L., Nevdahl, M.T., **Bornbaum, C.C.,** Day, A.M.B., & Doyle, P.C. Voice Disability in Laryngectomized Women: Esophageal, Tracheoesophageal, & Electrolaryngeal Speech. Paper presented at the annual American Speech Language & Hearing Association conference, New Orleans, USA, November 2009.

4. **Bornbaum, C.C.** Understanding personal determinants of health: A comprehensive perspective. Invited presentation at Six Nations Polytechnic Institute, Brantford, ON. November 5, 2009.

3. **Bornbaum, C.C.,** Sillick, J., & Doyle, P.C. Vocal communication disability among electrolaryngeal speakers. Poster presented at the 2nd annual Aging, Rehabilitation & Geriatric Care Research conference, London, ON, February 2009. *First two authors had equal contribution.

2. **Bornbaum, C.C.** & Doyle, P.C. The impact of stigmatization and judgments of responsibility on individuals diagnosed with lung cancer. Presented at the Health and Rehabilitation Sciences Research Forum, London, ON, February 2009.

1**. Bornbaum, C.C.** & Doyle, P.C. Stigma, shame, and judgments of responsibility: Factors influencing quality of life in individuals diagnosed with lung cancer. Presented at the 21st annual Western Research Forum, London, ON, February 2009.

Manuscripts under review

2. **Bornbaum, C.C.,** Day, A.M.B., Izaryk, K., Morrison, S., Ravenek, M., Skarakis-Doyle, E., & Sleeth, L. (2013). Exploring the use of the ICF in education: A scoping review. Manuscript submitted to *Disability & Rehabilitation.*

1. Brandt, M.G., Rotenberg, B.W., Moore, C.C., **Bornbaum, C.C.,** & Doyle, P.C. (2013). A prospective evaluation of the impact of nasal surgery on voice. Manuscript submitted to *Journal of Voice.*