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A DESCRIPTIVE ANALYSIS OF THE RELATIONSHIP BETWEEN DISTRESS AND QUALITY OF LIFE IN INDIVIDUALS WITH HEAD AND NECK CANCER

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A DESCRIPTIVE ANALYSIS OF THE RELATIONSHIP BETWEEN DISTRESS AND QUALITY OF LIFE IN INDIVIDUALS WITH HEAD AND NECK CANCER

(Spine title: Distress and QoL in Individuals With Head and Neck Cancer)

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by

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ABSTRACT

Introduction: This study investigated the impact of head and neck cancer on distress and quality of life (QoL). *Method:* Participants were 37 adults (28 men, 9 women) who had been diagnosed with head and neck cancer within the last 12 months. Measurement instruments included: (1) the Brief Symptom Inventory 18 (BSI-18), (2) the European Organisation for Research and Treatment of Cancer (EORTC) general QoL questionnaire (EORTC-QLQ-C30), (3) the EORTC Head and Neck module (EORTC-QLQ-H&N35), and (4) a brief demographic survey. *Results:* A significant inverse relationship was detected between QoL and distress suggesting that as level of distress increases, perceived QoL deteriorates. *Conclusion:* The BSI-18 was found to be an efficient and effective measure of distress. Based on data obtained, distress remains a pervasive problem for individuals with head and neck cancer and affects both global and specific domains of QoL. As a result, routine distress-screening programs may assist in identifying and responding to problematic distress.

Keywords: head and neck cancer, distress, quality of life, gender, psychosocial oncology, BSI-18, EORTC.

DEDICATION

This work is dedicated to the many individuals and families that struggle to cope with distress and the experience of cancer. Particularly to Anne Barbetta and her beloved children Claire and Douglas, who in the face of immense loss and grief managed to find a safe haven of great love.

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CHAPTER 1

Introduction and Review of Literature

Receiving a diagnosis of a life-threatening illness such as cancer is a distressing experience that may profoundly impact multiple areas of an individual's life. In fact, individuals facing a diagnosis of cancer have described the experience as one that is devastating (Sawyer, 2000). In addition to the immediate threat to one's physical health, a diagnosis of cancer has been associated with a significant number of additional changes for the individual. Examples of these changes may include, heightened fear of disease progression or recurrence, fear of death, physical and physiological changes, alteration to social roles and relationships, emotional strain, changes in perceived quality of life (QoL), and a general loss of a sense of control (Aaronson et al., 1991; Parker, Baile, De Moor, & Cohen, 2003; Redd et al., 1991; Spiegel, 1997). Each of these changes has the potential to increase the distress level of a person diagnosed with cancer.

Individuals with cancer frequently report QoL concerns related to physical, psychological, social and spiritual issues with an emphasis on disruptions to psychological well-being including increased levels of distress (Parker et al., 2003). QoL is a multidimensional construct that emerges from a variety of domains including physical and occupational functioning, somatic sensation (e.g., treatment- and disease-related symptoms), psychological status, and social interaction (Myers, 2005; Soni & Cella, 2002). QoL is a personal and subjective evaluation of one's position in life (Myers, 2005; WHO, 1998). While QoL and the factors that influence it are of importance to all, such QoL concerns appear to be heightened among women due to the added familial and societal demands placed on them (Katz, Irish, Devins, Rodin, & Gullane, 2003).

Unfortunately, the frequently late presentation of head and neck cancer is notorious for complicating medical attempts to reduce the dramatic physical, psychological, and social burdens on those diagnosed with head and neck cancer. Further, as a result of the anatomic characteristics of the head and neck region, treatment of head and neck cancer may result in deficits to one's physical appearance that cannot easily be hidden, as well as varying degrees of dysfunction in respiration, swallowing, and speech (Chen et al., 2009; Katz et al., 2003; Katz, Irish, Devins, Rodin, & Gullane, 2000; Koster & Bergsma, 1990; Vartanian et al., 2004). Collectively, these factors may negatively impact the functional outcome and psychosocial adjustment of individuals with head and neck cancer in addition to the documented financial consequences to the health care system (Carlson & Bultz, 2004).

Although extensive research has investigated global QoL among individuals with cancer, limited research has examined the specific factors related to the elevated distress levels found in those receiving a diagnosis of head and neck cancer. In order to appropriately address the psychosocial needs of those with head and neck cancer, it is essential to develop an understanding of the life factors associated with elevated distress. It is only through examination of the relationship between distress, QoL, and the personal factors that exacerbate the ill effects of both, that we may begin to more completely understand the basis of heightened distress levels for individuals with head and neck cancer. As such, the use of validated measures to assess the influence of QoL domains and personal factors on one's perceived level of distress may serve to further elucidate the variables associated with heightened distress among those with head and neck cancer.

Head and Neck Cancer

Cancer of the head and neck 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). These sites include but are not limited to: craniofacial bones, skin, soft tissues, mucosal membranes and salivary glands (Pai & Westra, 2009). Regarding histology, more than 90% of head and neck cancer diagnoses may be histologically classified as squamous cell carcinomas; most of these tumours originate in the nasopharynx, oropharynx, hypopharynx, larynx and oral cavity (Marur & Forastiere, 2008; Ragin, Modugno, & Gollin, 2007). Other less common forms of malignant neoplasms include adenocarcinomas, lymphomas, melanomas and sarcomas (Semple, Sullivan, Dunwoody, & Kernohan, 2004).

According to statistics drawn from the National Cancer Database in 2000-2004 (Cooper et al., 2009), the median age for a diagnosis of head and neck cancer has decreased from 60-69 years of age between 1990-1999 to 50-59 years of age. Head and neck cancer may present as a localized disease without lymph node involvement, or alternatively, it may present with locally or regionally advanced disease with a large primary tumour and/or lymph node involvement, indicating the potential for distant metastases (Fauci et al., 2008). Treatment may consist of surgical excision, radiotherapy, chemotherapy or a combination of these approaches (Fauci et al., 2008; Semple et al., 2004). Irrespective of treatment modality, individuals diagnosed with head and neck cancer face a distinct set of treatment-related challenges related to 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 QoL.

Incidence and Mortality

Currently, head and neck cancer is the eighth most common form of cancer worldwide with 650,000 new cases reported annually (Parkin, Bray, Ferlay, & Pisani, 2002). Within Canada, head and neck cancer (including thyroid cancer) accounts for approximately 6.3% of all cancer diagnoses among men and women each year (Canadian Cancer Society, 2009). Recent statistics project that 10,850 new cases of head and neck cancer (approximately 5,330 males and 5,490 females, a ratio of 1:1 for males-to-females) will be diagnosed in Canada in 2009 (Canadian Cancer Society, 2009). Furthermore, it is estimated that 3,650 individuals (approximately 2,600 males and 1,045 females, a ratio of 2.5:1 for males to females) will die from head and neck cancer, accounting for 4.9% of Canadian cancer deaths in 2009 (Canadian Cancer Society, 2009). While these percentages may appear relatively low compared to other cancer sites (e.g., breast, colon, etc.), they remain worrisome due to the fact that in most countries survival rates have not improved significantly over the past 30 years despite advances in pharmacologic and surgical care (Hunter, Parkinson, & Harrison, 2005; Semple et al., 2004; Wadsworth et al., 2004).

Etiology

The etiology of head and neck cancer stems from a wide 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; Wynder, Bross, & Feldman, 1961; Wynder & Bross 1957). Of these "exposures" tobacco usage is well established as a dominant risk factor for the development of head and neck cancer (Fauci, 2008; Pai & Westra, 2009; Wynder et al., 1961; Wynder & Bross 1957). A recent study conducted by Rodriguez and colleagues (2004) determined that heavy smokers under the age of 46 have a 20-fold increased risk of developing oral and 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). 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). Despite the emphasis on smoking, it is imperative to mention that other forms of tobacco use including smokeless products also pose a significant health threat and as a result, smokeless tobacco has been well established as an etiologic agent for oral cancers (Chen, Katz, & Krutchkoff, 1990; Cogliano et al., 2004; Cullen et al., 1986; Fauci et al., 2008).

In addition to tobacco usage, heavy alcohol consumption is also well recognized as an independent risk factor for head and neck cancer (Sturgis, Wei, & Spitz, 2004). Heavy alcohol consumption has been estimated to increase the risk of developing oral cancer by five-fold (Rodriguez et al., 2004). Though the risk posed by either alcohol or tobacco alone is unquestionably serious and substantial, when the two agents are combined the risk of developing oral or pharyngeal cancer increases 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 to blame for the vast majority of head and neck cancer diagnoses, including those of the larynx, hypopharynx, and oral cavity (Hashibe et al., 2007; Pai & Westra, 2009), their role as an etiologic agent in oropharyngeal tumorigenesis is far less substantial (Pai & Westra, 2009). Instead, the human papillomavirus (HPV) has been recently established as a causative factor in up to 70% of oropharyngeal cancers (Begum, Cao, Gillison, Zahurak, & Westra, 2005; Gillison et al., 2000; Kreimer, Clifford, Boyle, & Franceschi, 2005; Pai & Westra, 2009).

In order to gain a better understanding of the role of HPV in oropharyngeal cancer, it may be important to distinguish the differences between oropharyngeal and hypopharyngeal anatomical regions. The oropharynx consists of four distinct sites: the soft palate, the tonsillar region, the base of the tongue, and the posterior and lateral pharyngeal walls between the nasopharynx and the pharyngoepiglottic fold (Hu, Hahn, & Harrison, 2009; Marur & Forastiere, 2008). In contrast, the hypopharynx is comprised of the post-cricoid area, the pyriform sinuses, and the posterior pharyngeal wall between the nasopharynx and the pharyngoepiglottic fold (Hu et al., 2009; Marur & Forastiere, 2008).

Syrjanen and colleagues (1983) first suggested the role of HPV in head and neck carcinogenesis (Campisi, 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 (Gillison, Koch, & Shah, 1999; Ritchie et al., 2003), namely HPV-16, 18 and 31 (Begum et al., 2005; Gillison et al., 2000; Kreimer et al., 2005; Marur & Forastiere, 2008; Pai & Westra, 2009). In effect, HPV is emerging as a preeminent 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. Fortunately, individuals with HPV-positive head and neck cancer appear to have higher cure rates and better overall survival than individuals with HPV-negative head and neck cancer (Gillison et al., 2000; Marur & Forastiere, 2008). For example, in a study conducted by Gillison and colleagues (2000), it was determined that for individuals with head and neck cancer, the HPV-negative group had a median survival time of only 76 months while the survival of those in the HPV-positive group was estimated to be greater than 91 months. Despite its encouraging survival rates, HPV-positive oropharyngeal cancer is emerging as a dominant form of head and neck cancer as a result of its escalating incidence in the population (Westra, 2009) and subsequent impact on preventative, diagnostic, and therapeutic practices.

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 (Fauci et al., 2008; Freedman et al., 2008; Pai & Westra, 2009), infectious agents such as the Epstein-Barr virus (Fauci et al., 2008), a family history of disease (Pai & Westra, 2009), marijuana smoke (Fauci et al., 2008), and occupational exposures – particularly in nickel refining, textiles, leatherworking, woodworking, metalworking, and any areas with exposure to asbestos, chromium, radiation or mustard gas (Fauci et al., 2008; Marur & Forastiere, 2008). 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.

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 (Semple, 2001). This finding may be related to the fact that communication, emotional expression, social interaction, and other functional capabilities such as eating and swallowing are highly reliant on the structural integrity of this anatomical region. Daily tasks such as eating, breathing and speaking may pose significant difficulty for those treated for head and neck cancer. As a result, individuals may experience substantial problems within the context of social and family settings (Semple et al., 2004).

Often, these challenges are exacerbated by the very visible side effects of head and neck cancer and its treatment including the potential for physical disfigurement and scarring (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). This is understandable because the face is viewed as an important outward expression of one's internalized sense of self (Cash & Pruzinsky, 1990). The emphasis on facial aesthetics and cosmesis may be particularly difficult for those with head and neck cancer owing to the fact that the visible signs of head and neck cancer and its treatment often cannot easily be concealed (Semple et al., 2004). These consequences often prevent individuals 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 (Clarke, 1999). These experiences may result in feelings of stigmatization and consequently cause additional psychological distress. Factors such as these have led researchers to describe head and neck cancer as the most emotionally traumatic form of cancer (Koster & Bergsma, 1990). Considering this finding, it may be beneficial to view health from a more comprehensive and multidimensional perspective in order to account for the physical, psychological, and social factors that contribute to decrements in QoL. Ultimately, perceptions of QoL may be directly impacted by distress and its influence cannot be discounted in determining the larger effects of head and neck cancer on the individual.

Quality of Life

Although the purpose of seeking medical treatment is directed toward identifying and eliminating disease or alleviating pain and suffering, 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' finding points to the potentially overwhelming nature of the treatment and side effects associated with head and neck cancer. Side effects may include substantial changes to one's physical appearance and ability to verbally communicate resulting in changes to perceived body image, self-esteem and self-concept (Doyle, 2005a). 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 QoL and well-being.

Quality of Life Defined

QoL is a multidimensional construct that finds a portion of its conceptual roots in the comprehensive definition of health, originally established by the World Health Organization (WHO) in 1947 (WHO, 1947). The WHO defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1999, p. 100). They go on to further define QoL 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).

Researchers also have suggested that other perceptions such as treatment satisfaction, occupational functioning, coping style, spirituality, sexuality, intimacy and stress-management techniques be considered when evaluating QoL (Chida, Hamer, Wardle, & Steptoe, 2008; Felder, 2004; Gritz et al., 1999).

This expanded definition of QoL proposed by the WHO (1998) highlights the fact that QoL is a subjective and individual evaluation of one's position in life (Myers, 2005). It is a multidimensional construct that emerges from a variety of domains including physical and occupational functioning, somatic sensation (e.g., treatment- and disease-related symptoms), psychological status, and social interaction (Myers, 2005; Soni & Cella, 2002). However, it is important to note that these domains are not mutually exclusive, but rather, overlapping and complementary in nature. Additionally, QoL is a dynamic concept that changes over time and according to the situation (Myers, 2005). Essentially, QoL in a health-related context refers to "patient satisfaction with levels of functioning and the control of disease and/or treatment-related symptoms" (Gotay & Moore, 1992, p.12). One's personal perception of what constitutes "quality" is a key component of this definition and is integral to the description and measurement of QoL. Due to the numerous and multidimensional side effects of treatment for head and neck cancer, it is imperative that ones' perceived QoL be considered and attended to in a meaningful manner. Therefore, descriptions of factors that influence QoL in those diagnosed with and treated for head and neck cancer are required.

Quality of Life in the Head and Neck Cancer Population

In a study conducted by Gritz and colleagues (1999), individuals with head and neck cancer reported lower levels of QoL than those diagnosed with either colon or lung cancer. In order to understand this discrepancy, it may be valuable to address some of the specific physical, psychological and social challenges experienced by those with head and neck cancer. The physical dimension refers to any observed and/or perceived changes in bodily function (Cella & Tulsky, 1993). For those with head and neck cancer, physical concerns extend beyond those generally associated with cancer such as pain, nausea, sleep disturbances and fatigue (Ledeboer, van der Velden, de Boer, Feenstra, & Pruyn, 2005), to include additional challenges such as dysphagia, xerostomia, limited shoulder mobility (a consequence of neck dissection), dental issues, 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; Ledeboer et al., 2005; Owen, Watkinson, Pracy, & Glaholm, 2001). The burden of these added physical challenges may directly influence the psychological and social dimensions of QoL and contribute to increasing levels of overall distress in some individuals.

The second primary dimension of QoL involves psychological or emotional functioning. Psychological functioning represents a broad continuum ranging from positive affect, such as one's self-assessed well-being, to negative effects such as those associated with distress (Cella & Tulsky, 1993; Karnofsky & Burchenal, 1949). In addition to the emotional and psychological challenges associated with all cancer types, such as stress, anxiety, depression, grief, coping style, and locus of control, among others (Brown & Doyle, 1999; Ledeboer et al., 2005; Llewellyn, McGurk, & Weinman, 2005), individuals diagnosed with head and neck cancer must also address issues related to potentially visible disfigurement and altered appearance (Ledeboer et al., 2005; Semple et al., 2004), which may negatively impact self-esteem, self-concept, and body image (Doyle, 2005a). Furthermore, Western society's emphasis on physical attractiveness serves to increase the psychological burden placed on this particular group of individuals

(Doyle, 1994; Owen et al., 2001). Additionally, women with head and neck cancer may experience elevated levels of psychological burden owing to the fact that their physical appearance is highly valued in Western society and any noticeable deviations from the norm may result in social penalty. It is precisely this emphasis on physical attractiveness, in conjunction with the often present scarring and disfigurement that contributes to the feelings of stigmatization reported among those with head and neck cancer (see Devins, Stam, & Koopmans, 1994; Doyle, 1994; Doyle, 2005b; White, 2004). 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).

Social functioning represents the third primary dimension of QoL. It generally includes one's ability to engage in society and maintain gratifying relationships with friends, family members, acquaintances and significant others (Cella & Tulsky, 1993). Following treatment for head and neck cancer, undesirable physical side effects such as facial weakness, drooling, trismus, physical scarring, and poor speech intelligibility may persist. The presence of these side effects may cause embarrassment and significantly impact not only social and family interactions, but also one's internalized feelings of self-esteem and self-concept (Doyle, 2005a; Semple et al., 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. Undoubtedly, these added challenges have an enormous interactive impact on the physical and psychosocial functioning of individuals with head and neck cancer. As a result, it is important to evaluate the physical and psychosocial functioning of individuals with head and neck cancer in order to identify areas where QoL is compromised so that the appropriate resources and interventions can be recommended when required.

Significance of Quality of Life Research

The burden of head and neck cancer is often largely manifested in psychosocial dysfunction, which can negatively impact one's perceived QoL (Semple et al., 2004). As a result, one of the primary benefits to understanding the variation in an individual's QoL is to minimize the negative impact of head and neck cancer on one's life (Llewellyn et al., 2005). Understanding the relationship between QoL and modifiable psychosocial factors may permit tailored interventions to be constructed with the goal of maximizing individual QoL. Objective and ongoing assessment of the dimensions of QoL has the ability to provide valuable information regarding the long-term outcomes of cancer treatment and its associated side effects (Gritz et al., 1999). Information obtained through such assessments can then be utilized to identify areas where rehabilitation and additional psychosocial support may be required and subsequently guide the appropriate psychosocial interventions with the goal of improving QoL.

In addition to identifying the need for psychosocial interventions, a great deal of QoL data have been shown to predict survival in those with head and neck cancer (Blazeby, Brookes, & Alderson, 2001; Chida et al., 2008; de Graeff et al., 2001; de Boer et al, 1998; Fang, Liu, Tang, Wang, & Ko, 2004; Karvonen-Gutierrez et al., 2008; Mehanna, De Boer, & Morton, 2008). For instance, a meta-analysis conducted by Chida and colleagues (2008) demonstrated that stress-related psychosocial factors were associated with poorer head and neck cancer survival – marked by a 58% increase in the hazard ratio[1]. Additionally, Mehanna and colleagues (2008) determined that global, or overall, QoL data obtained 12 months after a diagnosis of head and neck cancer were found to be significantly associated with survival. Further identification of prognostic factors may help to shape the decision-making of both physicians and those with head and neck cancer regarding curative and palliative treatment options. Finally, using QoL data to identify distressing areas in one's life may allow for appropriate assistance and psychosocial intervention when warranted. Through the identification of distress, the potential to improve QoL and positively influence post-treatment outcomes may emerge.

Distress

Normal emotions such as sadness, worry, and fear occur in every person, and are undoubtedly exacerbated with a diagnosis of 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 and psychological reactions (Mohan & Pandey, 2002). The impact of cancer as a disease, both emotionally and physically influences not only those with the diagnosis but also their families and loved ones. Despite significant biomedical progress over the past 50 years, cancer remains synonymous with suffering, pain, and death (Powe & Finnie, 2003).

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[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, 2009).

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 35% to 45% of individuals with cancer in North America (Bjordal, Kaasa, & Mastekaasa, 1995; Carlson et al., 2004; Carlson & Bultz, 2003; Zabora, Britzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Similar rates of distress have been reported in Asia (Fielding, Lam, & Ho, 2004; Kugaya et al., 2000; Shimizu, Akechi, Okamura, Akizuki, & Uchitomi, 2004), South America (Santos, 2004), Europe (Dolbeault et al., 2003; Gil, Travedo, Tomamichel, & Grassi, 2003; Mehnert, 2004), and the Middle East (Isikhan et al., 2001; Montazeri et al., 2004; Sadeh-Tassa, Yagil, & Stadler, 2004). The consistency of distress prevalence is rather surprising given that an individual's perception of their disease varies greatly across cultures (Erbil et al., 1996). For instance, there are a number of documented culture-related variables that may influence distress and perceived QoL levels among individuals with cancer. These include attitudes and adjustment towards health and illness, perceptions regarding the cause of disease, the role of the physician, the interaction style between the practitioner and the individual with cancer, the role of one's family, and the individual's needs and coping mechanisms (Gordon, 1990; Kleinman, 1986). Given the documented cultural differences influencing perception of illness, it is somewhat astounding that the rates of distress among individuals with cancer remain so consistent around the world. Nevertheless, the similar international prevalence rates imply that psychological distress related to cancer is a persistent and universal concern that transcends cultural differences and as a result must be addressed in a clinically meaningful manner.

Furthermore, 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 almost 50% of all patients), depression (24%), anxiety (24%), and pain (26%), in addition to financial hardship and other challenges. Thus, considering the high prevalence of emotional and psychosocial distress in an ever-increasing cancer population, in conjunction with the established benefits of psychosocial intervention, it comes as no surprise that the Canadian Strategy for Cancer Control has supported the proposal for emotional distress to be formally recognized as the "sixth vital sign" (Rebalance Focus Action Group, 2005). The identification of emotional distress as a recognized vital sign implies that the proactive monitoring of emotional distress is critical and that it should be undertaken as frequently and routinely as the monitoring of one's temperature, respiration, blood pressure, heart rate and pain level (Rebalance Focus Action Group, 2005).

Distress Defined

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 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.* (NCCN, 2009, p.6).

While this definition addresses *most* of the factors pertinent to considerations of distress, in order to comprehensively define the concept of distress, physical and somatic factors must also be considered. It would be negligent to disregard the impact of physical and somatic burden on distress levels, particularly for an oncology population where pain has been clearly established as a predictive factor of psychosocial distress (Byrne, Walsh, Farrelly, & O'Driscoll, 1993). The finding that one's pain predicts their distress level is not surprising given that a person's emotional reaction to physical symptoms can be a source of great distress in and of itself. As a result, it is necessary to include both physical and somatic variables into the formal definition of distress in order to comprehensively attend to all significant distress-related factors.

In many ways, distress represents the antithesis of QoL; it acts as an antagonist to the very dimensions valued in QoL. Distress is also an individual and subjective evaluation. Distress, while not mutually exclusive, is a critical concern relative to one's perceived quality of life. When significant distress is present, QoL is likely to be diminished. Much like QoL, distress is a multidimensional construct that incorporates physical, somatic, psychological, social, and spiritual dimensions. Like QoL, distress also is a dynamic concept that changes over time and is contextually dependent. Lastly, similar to QoL, the domains of distress are overlapping and complementary. Therefore, it would not be unreasonable to suggest that anticipatory stress related to the real or anticipated side effects of one's impending treatment may produce a unique source of distress to the individual and result in feelings of fear, anxiety, or even panic.

It is important to note that the experience of distress is a normal part of life for everyone, irrespective of health status. 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 painful treatments (Haman, 2008). Yet, since distress is such a common consequence secondary to diagnosis and treatment, it may be overlooked by many health care providers who assume that intervention is unnecessary (Endicott, 1984). Ultimately, however, distress must be identified and addressed in order to avoid negative outcomes.

In terms of identifying clinical levels of distress, the American Psychiatric Association (DSM-IV, 1994) recommends that distress which "interferes significantly with the person's normal routine, occupational or academic functioning, or social activities or relationships" is to be deemed significant and requires intervention and treatment. When applying this definition to individuals with cancer, one must be mindful of the fact that an individual's normal functioning and activities may be curtailed by the illness itself, and not directly by distress. In this instance, clinical judgment is required to determine whether an individual's decreased functioning can be attributed to distress or merely the symptoms and consequences of the treatment itself (Haman, 2008).

A key indicator of clinically significant distress is the length of time that the individual has been experiencing distress. Distress which leads to psychologic disorders such as depression and anxiety that persist for more than a week are in need of assessment and intervention (Haman, 2008). Since pretreatment distress can predict the persistence of psychologic symptoms long after the completion of treatment (de Leeuw et al., 2001), it is ideal to minimize distress through early identification. Thus, it is important for health care providers to inquire about the persistence of symptoms, the pervasiveness of disruption to one's life, and the severity of distress that the individual is experiencing (Haman, 2008). Addressing negative psychosocial outcomes such as distress is a critical component to delivering comprehensive health care. Without the early identification of problematic distress levels, individuals' may experience innumerable consequences related to physical, psychological and social functioning. These consequences may ultimately result in decreased QoL for those living with head and neck cancer.

Consequences of Untreated Distress

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, Lepper, & Croghan, 2000; Jenkins, Carmody, & Rush, 1998; McDonough, Boyd, Varvares, & Maves, 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 head and neck cancer, contributing to a vicious cycle that may not only worsen depression and overall rates of distress, but also negatively effect disease control through decreased medical compliance (DiMatteo et al., 2000).

Upon consideration of these factors and what is known about QoL in head and neck cancer, it is not surprising that 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 et al., 1995; Dropkin, 1986; Misono et al., 2008). Additionally, several reports have demonstrated that suicide rates may be as much as 10 times greater among individuals with head and neck cancer than for those in the general population (Henderson & Ord, 1997; Kendal, 2007; Zeller, 2006; Zonderman, Costa, & McCrae, 1989). Although no causative factors for the elevated levels were specified, it has historically been hypothesized that those with head and neck cancer, many of whom have a history of alcohol and tobacco use, also have a disproportionate level of psychological distress. Behaviours such as tobacco smoking and alcohol consumption are thought to exacerbate feelings of distress (Breslau, Kilbey, & Andreski, 1991; Grant & Harford 1995; Kendler et al., 1993; Ronis, Duffy, Fowler, Khan, & Terrell, 2008). In addition to tobacco and alcohol use, untreated depression may also play a contributive role in the elevated suicide rates of the head and neck cancer population.

A multitude of variables contribute to the causation of depression within this group. The physical location of head and neck cancer has been hypothesized as a major reason for the elevated rates of depression in this population (Lydiatt, Moran, & Burke, 2009). The most fundamental aspects of one's humanity, including one's ability to breathe, eat, speak, and socialize in public may be affected by the diagnosis and/or treatment of head and neck cancer. Further, facial disfigurement cannot be concealed which may impair emotional expression and social interactions leading to additional social withdrawal and avoidance of potentially beneficial support systems (Lydiatt et al., 2009). The evasion of support systems may increase feelings of isolation and exacerbate the psychological symptoms associated with depression, thus potentially contributing to the elevated depression and suicide rates of the head and neck cancer population.

Untreated psychological conditions in addition to alcohol or tobacco use may have a tremendous impact on the perceived level of distress for individuals with head and neck cancer. McDonough and colleagues (1996) reported that levels of psychological distress related to illness are significantly higher than the physical impact of disease among individuals with head and neck cancer. Given the well-established and significant multifactorial challenges associated with head and neck cancer, the fact that psychological distress may outweigh physical concerns in terms of consequences for the individual highlights the critical need to further understand and elucidate psychosocial distress in those diagnosed with and treated for head and neck cancer.

Benefits of Distress Management

Research suggests high prevalence rates of distress are evident in cancer populations around the globe, with heightened rates among the head and neck cancer population (Bjordal et al., 1995; Carlson et al., 2004; Carlson & Bultz, 2003; Zabora et al., 2001). 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 health care providers. Additionally, a multitude of clinical studies have repeatedly demonstrated that psychosocial intervention is beneficial to individuals with cancer (Cunningham, 2000;

Hammerlid, Persson, Sullivan, & Westin, 1999; Newell, Sanson-Fisher, & Savolainen, 2002). For instance, a systematic review conducted by Newell and colleagues (2002) found that psychosocial interventions involving counseling (either structured or unstructured) and guided imagery have been shown to improve QoL and the general functional ability of individuals with cancer. Furthermore, one of the trials included in the review reported that all participants using psychological therapies asserted that they would use them again and would recommend them to other individuals diagnosed with cancer (Miller et al., 1998).

Several reviews in the literature have noted that psychological therapies may assist individuals in several ways including, improving their QoL, emotional adjustment, and coping skills (Devine & Westlake, 1995; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer, & Mark, 1995; Rimer, Keintz, & Glassman, 1985), increasing their physical health and functional adjustment (Devine & Westlake, 1995; Fawzy et al., 1995; Meyer & Mark, 1995), perceived satisfaction with health care services (Meyer & Mark, 1995; Rimer et al., 1985), and treatment compliance rates (Rimer et al., 1985). Further, such intervention has been reported to reduce disease- and treatment-related symptoms (Devine & Westlake, 1995; Meyers & Mark, 1995; Rimer et al., 1985; Wallace, 1997). Despite the plethora of documented benefits to psychosocial interventions, the psychosocial and emotional needs of individuals with head and neck cancer often remain unmet. When one considers that the psychosocial and emotional burden may be heightened for women due to Western society's emphasis on physical attractiveness, among other factors, considerations of gender may be particularly important in this population.

The Influence of Gender on QoL and Distress

Gender has historically been viewed as an important variable in the psychosocial adjustment to head and neck cancer. Although the side effects of head and neck cancer are difficult for most individuals to cope with, the consequences of treatment may be particularly challenging and highly penalizing for women. Women have traditionally been believed to experience greater difficulty because they not only have to manage the general concerns related to cancer, but also the gender-specific issues that arise. Altered communication and disfigurement are both likely outcomes of treatment for head and neck cancer (Brown & Doyle, 2001; Dibble, Padilla, Dodd, & Miaskowski, 1998; Doyle, 1994). Both factors have the potential to detract from femininity and as a result may influence one's roles and functioning in society. With respect to altered speech, researchers have found that women treated for head and neck cancer were more socially penalized than men for sounding less natural, pleasant, and acceptable (Eadie & Doyle, 2004). With regard to issues of disfigurement, it is well recognized that women's physical appearance continues to be highly valued in Western society and any noticeable deviations from the norm may have devastating psychosocial and emotional implications.

Furthermore, in today's society women often balance multiple roles (e.g., as professionals, wives, mothers, and caregivers), which may be threatened by the diagnosis of cancer (Stahly, 1992). For instance, women may experience changes in physical abilities that may impede their capacity to work, function independently, care for family members, complete household tasks, etc... (Eadie, Doyle, Beaudin, White, & Myers, 2004). Failure to maintain these roles may jeopardize feelings of independence and self-reliance. This would seem to be particularly true for single women who lack external support, but can also be devastating to families in which the woman serves as the principal means of financial support. Since cancer may limit a woman's personal and interpersonal functioning, her support system must adapt and learn to accommodate new routines, redistribute roles, offer emotional support, create a new sense of normalcy, and anticipate future changes (Lewis & Hammond, 1992). Shifting responsibility from one's self to another may prove exceptionally difficult for previously self-sufficient and independent women and consequential stressors may occur. Adjusting to these changes may produce a unique source of distress for some women; particularly single women or women who have served as the primary economic support for their families.

In contrast to their male counterparts, women may also experience additional problems. For example, in a study exploring psychosocial adjustment in individuals treated for head and neck cancer, researchers discovered that women were more vulnerable to the psychosocial impact of head and neck cancer than men (Katz et al., 2003). Specifically, female participants reported more depressive symptoms and decreased "life happiness" (i.e., lessened overall satisfaction with life). Allison, Locker, Wood-Dauphinee, Black, and Feine (1998) reported that being female predicted poorer health-related QoL (i.e., poorer physical, role, cognitive, emotional, and social functioning) in this same population. These findings are consistent with the work of Parker and colleagues (2003) who found that women with cancer tend to experience greater levels of anxiety, depression and poorer QoL than their male counterparts. However, while the aforementioned investigations provide evidence that head and neck cancer and its treatment may affect women differently and potentially more severely than men, no studies have explicitly examined women's personal experiences specific to distress, QoL and head and neck cancer. In an effort to gain insight into the nature of these experiences, it may be valuable to descriptively analyze the role of distress in relation to decreased QoL within men and women diagnosed with head and neck cancer. Thus, in order to effectively explore the influence of distress on QoL, it is imperative to utilize psychometrically sound measurement instruments capable of detecting the presence of clinically significant levels of distress.

Measurement Instruments

The measurement instruments utilized in the present study included: (1) the Brief Symptom Inventory 18 (BSI-18) to measure distress, (2) the EORTC QoL Questionnaire (EORTC-QLQ-C30), and (3) the EORTC Head and Neck module (EORTC-QLQ-H&N35), which measure the participant's global and head and neck cancer-specific QoL.

Brief Symptom Inventory 18 (BSI-18). The BSI-18 is an 18-item measure of psychological distress that contains three symptom dimensions (e.g., Somatization, Depression, and Anxiety) and a Global Severity Index. It is a brief and highly sensitive symptom inventory designed to screen for psychological distress and psychiatric disorders within oncology and community populations (Derogatis, 2000). The BSI-18 is an abbreviated version of its parent version, the BSI, which is an abbreviated version of the Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 2000). The BSI is a 53-item questionnaire designed to be a multidimensional treatment outcome and monitoring measure, while the SCL-90-R is a 90-item questionnaire originally designed for this same purpose (Derogatis, 2000). However due to their length, the BSI and the SCL-90-R do not serve as appropriate screening tools and as a result were not utilized for this particular study. In an attempt to address this shortcoming, the BSI-18 was developed by Derogatis (2000) primarily to serve as a highly sensitive screening tool to be used in clinical settings. In spite of its brevity, it may also be utilized to measure treatment outcomes (Derogatis, 2000). Administration time for the BSI-18 is estimated to take no longer than 4-5 minutes, and its scoring procedures are equally brief (Derogatis, 2000).

Each item included on the BSI-18 is rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (always). Respondents are asked to answer each item based on 'how they have been feeling during the past seven days'. Based on experimental evaluation (Derogatis, 2000), positive cases of distress can be identified by a Global Severity Index score of ≥ 63 or when the T-score for any two subscales is ≥ 63.

In order to verify the dimensions of the BSI-18, a factor analysis was performed on all 18 items within a community sample (N = 1,134) (Derogatis, 2000). A principal components analysis was conducted with a Kaiser Varimax rotation. From this analysis, four factors were identified that had eigenvalues[2] greater than 1.0 and were consistent with the scree plot test for retention. After conducting the confirmatory factor analysis, Derogatis (2000) was able to clearly confirm the depression dimension, with all six hypothesized items demonstrating high loadings for factor I. Similarly, the somatization dimension displayed saturated loadings for all six hypothesized loadings on factor II. Factor III displayed high loading coefficients for four out of the six items from the anxiety dimension; however the remaining two items (3 and 18) have split loadings on

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[2] An eigenvalue is a "measure of the proportion of the total variance accounted for by a factor in discriminant analysis or factor analysis" (Portney & Watkins, 2000, p. 743).

factor IV as well. Additionally, the items loading on factor IV appear to measure panic: "suddenly scared for no reason" (item 9), "spells of terror or panic" (item 12), and "feeling fearful" (item 18). The American Psychiatric Association (1994) classifies symptoms of panic under the general rubric of anxiety disorders in the DSM-IV. Additionally, symptoms of panic represent an acute and distinct expression of the anxiety phenomenon. Furthermore, when examining the correlations between items loading onto factor III and factor IV, items representing panic-related events are correlated very highly with each other (i.e., the eigenvalue for factor IV was precisely 1.00). For diagnostic purposes, therefore, the presence or absence of panic symptoms may be highly discriminative and signal specific diagnostic pathways. However, for the purposes of screening for distress and measuring outcomes, the significance of panic symptoms resides in their overall contribution to the anxiety dimension and subsequent Global Severity Index scores, which indicate the presence of distress when greater than or equal to 63.

With respect to reliability, the three proposed dimensions were determined to have acceptable internal consistency within the community population (N = 1,134), evident through the following alpha coefficients: depression – 0.84, anxiety – 0.79, somatization – 0.74, and Global Severity Index – 0.89 (Derogatis, 2000). When the dimensions were tested with psychiatric outpatients (N = 719), the coefficient alpha values were higher in each category: depression – 0.85, anxiety – 0.81, somatization – 0.80, and Global Severity Index – 0.90. Although test-retest reliability was not conducted specifically for the BSI-18, reasonable estimates may be obtained from the corresponding BSI scale. The BSI test-retest reliability values are well within the acceptable range with values ranging from 0.68 to 0.90 ($p < 0.05$). The specifics for each dimension are as follows: depression – 0.84, anxiety – 0.79, somatization – 0.68, and Global Severity Index – 0.90. Thus, these dimensions were deemed appropriate for inclusion in the BSI-18.

European Organisation for Research and Treatment of Cancer (EORTC) QoL measurement instruments. The EORTC is a series of self-administered cancer-specific measurement instruments that are designed to assess QoL within oncology populations (Sherman et al., 2000). The core questionnaire, the EORTC-QLQ-C30 (version 3.0) (Aaronson et al., 1993), 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 QoL (Fayers, Aaronson, Bjordal, Curran, & Groenvold, 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 QoL (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 QoL and 7 indicates excellent health or QoL. 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 (Bjordal et al., 2000). 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 QoL, 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 test validity and reliability have determined that all scales consistently show Cronbach's alpha coefficients of > 0.70 (Bjordal et al., 2000). Consequently, the EORTC-QLQ-C30 is a suitable measurement instrument for use in the current research project.

While it is important to address general QoL issues that may be relevant to most individuals diagnosed with cancer, there are a number of disease-specific issues that arise and need to be addressed. This is particularly significant when assessing QoL issues among those with head and neck cancer. 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 individual's difficulties (Sherman et al., 2000). Studies confirm that both general and site-specific measure each contribute unique and important information regarding QoL (D'Antonio, Zimmerman, Cella, & Long, 1996; Gliklich, Goldsmith, & Funk, 1997).

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 (Aaronson et al., 1993; Bjordal & Kaasa, 1992). It is currently one of the most widely tested disease-specific QoL measures for oncology populations (Bjordal et al., 2000). 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. The module also contains eleven single items (Aaronson et al., 1993). 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, 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 QoL, depending on which subscale is being evaluated (Bjordal et al., 2000). The EORTC-QLQ-H&N35 module has been validated in diverse samples of oncology populations within North America and Western Europe (Aaronson et al., 1993; Bjordal & Kaasa, 1992; Sherman et al., 2000). 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). 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) and 0.68 in another (Bjordal et al., 2000). Nevertheless, despite the lower reliability for the senses scale, the EORTC core questionnaire and accompanying head and neck cancer module are reported to be excellent measures with good psychometric properties; as a result, these instruments were selected to assess QoL among the individuals diagnosed with head and neck cancer taking part in this investigation.

Questionnaire rationale. Self-report measurement was selected for the present investigation because when preformed in a standardized manner, this form of measurement can be quite sophisticated and tremendously cost efficient (Derogatis, 2000). Additionally, self-report techniques have the advantage of deriving data from the individual centrally involved in the phenomena, also referred to as the "experiential self" (Derogatis, 2000). Clinical observers are only privy to the shared and visible manifestations and are limited to reporting perceived versions of the participant's experience based on verbal reports and perceptible behaviour (Derogatis, 2000). It is the individual's perception of their experience that defines them in the most effective and meaningful manner. Additionally, in an effort to minimize the potential for recall bias, all measurement instruments ask individuals to report their experiences based on how they have been feeling over a fixed period of time; in the present case, that period is the past seven days. The relatively short time frame may help to minimize inaccuracies in the reports. Furthermore, research has shown that self-report measures are generally valid, despite the potential for recall bias (Portney & Watkins, 2000). Ultimately, the use of self-report measures may be particularly beneficial with respect to evaluations of QoL and distress, where individuals may be hesitant to reveal sensitive mental health concerns.

In addition to utilizing self-report measures, given the potentially sensitive nature of probing an individual's mental health status, mail-administered questionnaires were selected as the method of data collection. Mail-administered surveys provide a sense of anonymity for participants, which may help to encourage candid and honest answers (Portney & Watkins, 2000), particularly when investigating issues related to mental health. Revealing challenges related to mental health status may result in stigmatization (Wahl, 1999), which may have led to falsified participant responses due to a social desirability bias. In contrast to other common methods of data acquisition, such as formal interviews, focus groups, or interviewer-administered surveys, the anonymity afforded to participants through the self-report method was anticipated to decrease the potential for social desirability bias (Presser & Stinson, 1998). Consequently, relative to other methods, completing written questionnaires allows for less participant discomfort when providing responses. As a result, the authenticity of the data obtained through self-report, mail-administered questionnaires may be more reflective of the actual experiences of participants.

In sum, the BSI-18 and EORTC QoL assessment tools are psychometrically sound measurement instruments capable of detecting levels of QoL and the presence of clinically significant distress among individuals diagnosed with head and neck cancer. The use of mail-administered measures has the potential to facilitate candid participant data that is reflective of the personal experiences of participants. 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 QoL 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 QoL and positively influence post-treatment outcomes may emerge.

Statement 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). Often, these problems are exacerbated by the very visible side effects of head and neck cancer, namely, physical disfigurement and scarring. This is particularly troubling given that society places more importance on the head and neck region than any other area of the body (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 et al., 1995; Dropkin, 1986; Misono et al., 2008). These findings suggest that head and neck cancer is highly traumatic psychosocially with a multitude of complex patient concerns emerging.

Psychological distress related to cancer is a persistent and universal concern that transcends cultural differences and as a result must be addressed in a clinically meaningful manner. The problem has become so pervasive that the Canadian Strategy for Cancer Control has officially supported the proposal for emotional distress to be formally recognized as the sixth vital sign (Rebalance Focus Action Group, 2005). In order to minimize the overall negative impact of head and neck cancer and address the consequences resulting from decreased QoL and distress, efforts must be made to understand the presence of and variation in distress and QoL across individuals.

Acknowledgement of the "human side" of cancer care is essential to a compassionate and well-managed cancer care program. The time has come for health care providers, and the health care system at large, to recognize the roles of distress and QoL as fundamental components of health care. Through understanding the relationship between QoL and modifiable psychosocial factors, tailored interventions may be constructed with the goal of maximizing individual QoL and reducing personal distress. Moreover, understanding the influence of head and neck cancer on QoL and distress levels in both men and women is a particularly timely pursuit given that the incidence of head and neck cancer in women is increasing worldwide (Curado & Hasibe, 2009). Given the well-established and significant multidimensional challenges associated with head and neck cancer, the aforementioned findings highlight the critical need to further understand and elucidate psychosocial distress in those diagnosed with and treated for head and neck cancer.

Although extensive research has investigated global or overall, QoL among individuals with cancer, limited research has examined the specific domains of QoL associated with the elevated rates of distress found in the head and neck cancer population (e.g. physical functioning, emotional functioning, social functioning, etc.) The identification of distress and its potentially negative influence on QoL 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 QoL 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, 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 QoL will be correlated with validated measures of distress and demographic information in an effort to identify and characterize the relationship between distress and QoL in individuals with head and neck cancer. With this information, health care practitioners will 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. Determine the presence of psychological distress in a sample of individuals diagnosed with head and neck cancer and compare this rate to previous findings in the literature.
2. Assess whether gender influences perceived QoL and/or distress level among individuals with head and neck cancer.
3. Describe the relationship between distress level (as measured by the Brief Symptom Inventory-18) and *overall* QoL (as measured by the EORTC-QLQ-C30) among individuals diagnosed with head and neck cancer.
4. Describe the relationship between distress level (as measured by the Brief Symptom Inventory-18) and *specific domains* of QoL (e.g., physical, emotional, cognitive, role, and social functioning) as measured by the EORTC-QLQ-C30 among individuals diagnosed with head and neck cancer.

CHAPTER 2

Method

Participants

All participants involved in this research protocol were initially recruited by their physician and/or surgeon at the Otolaryngology and Head and Neck Oncology Clinic and/or 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 the primary investigator. Prior to undertaking this study, the Ethics Review Board at The University of Western Ontario approved this protocol; ERB Approval # 16392E (see Appendix A).

Inclusion Criteria. In order to be included in this study, participants had to be between 40 and 80 years of age. They also must have received a diagnosis for a primary malignancy of the head and neck region (excluding skin cancer, i.e., basal cell carcinoma, squamous cell carcinoma or melanoma). At the time of participation, individuals were required to be within zero and 12 months post-diagnosis.

Exclusion Criteria. Individuals less than 40 years of age or greater than 80 years of age were excluded. This exclusion criterion was based on the judgment that they may have represented a cohort that is too different as a result of life influences which may impact treatment and subsequent QoL and/or perceived distress levels. Individuals with recurrences of their cancer or with cancer in any other anatomical site(s) beyond the head and neck region (due to a new primary tumour or distant metastasis) were excluded since these factors may have influenced their current perceptions of QoL and/or distress level. If individuals were unable to read and speak English or 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.

In total, 133 individuals identified as potential participants based on their congruence with the proposed inclusion criteria were contacted. Of these potential participants, 33 individuals could not be contacted. Ultimately, 69 individuals expressed an interest in participating. Reasons identified for those who did not desire to participate included: too ill/hospitalized (n = 6), too fatigued (n = 3), too busy (n = 2), research topic too upsetting (n = 1), not interested (n = 15), does not speak/read English well enough (n = 3), already enrolled in a study (n = 1), contact information not up to date (n = 3) and participant could not be reached (n = 30). Sixty-nine packages containing the demographic questionnaire, EORTC general QoL assessment tool (EORTC-QLQ-C30), EORTC head and neck cancer specific tool (EORTC-QLQ-H&N35) and the BSI-18 were sent to individuals diagnosed with head and neck cancer across Ontario, Canada.

Participants were 37 adult Canadians (28 males, 9 females). Participant ages ranged from 43 to 78 years of age (mean = 59.42 years of age). Women were slightly older with a mean age of 61.55 (range = 43-78 years of age) when compared to their male counterparts who had a mean age of 58.75 (range = 45-76 years of age). All participants had received a diagnosis of head and neck cancer within the 12 months prior to their participation in this study. This timeline was selected because the first 12 months after receiving a diagnosis for head and neck cancer involves a number of potentially distressing changes in the life of the individual as they attempt to cope with their diagnosis, active treatment and the subsequent challenges that follow.

Procedure

The study consisted of a cross-sectional, self-report, survey design. Research conducted through use of surveys provides a numeric or quantitative description of trends, opinions, or attitudes of a population by studying a specific sample of that population (Creswell, 2008). For this investigation, the questionnaires were utilized for data collection purposes with the intent of describing and relating the characteristics of this sample to the head and neck cancer population at large.

All individuals who consented to participate were mailed a package containing a letter of information (see Appendix B), a demographic questionnaire (see Appendix C), EORTC general QoL assessment tool (EORTC-QLQ-C30) (see Appendix D), the EORTC head and neck cancer specific QoL assessment tool (EORTC-QLQ-H&N35) (see Appendix E), the Brief Symptom Inventory 18 (BSI-18) (see Appendix F) to assess distress, a list with the contact information for local psychological support services (see Appendix G), and a self-addressed and 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 that they were under no obligation to complete the questionnaire and would not 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 and her supervisor.

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.

Measurement Instruments

As indicated previously, the measurement instruments utilized in this study included: (1) the Brief Symptom Inventory 18 (BSI-18) to measure distress, (2) the EORTC QoL Questionnaire (EORTC-QLQ-C30) and (3) the EORTC Head and Neck module (EORTC-QLQ-H&N35), which measure the participant's global and head and neck cancer-specific QoL, respectively. The order of these questionnaires was randomly assigned, and participants were instructed to complete each questionnaire as per the enclosed instructions 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. It was anticipated that completion of all tasks would take approximately 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, and potentially distressing items that followed in the accompanying questionnaires (Portney & Watkins, 2000).

Demographic information. Demographic items consisted of the participant's age, sex, marital status, length of time since diagnosis, and the specific site of the malignancy (e.g., larynx, oral cavity, etc.). All sites of malignancy were classified according to the standard coding system used by the LRCP. Following completion of the demographic items, participants were asked to complete each of the three questionnaires. The order of questionnaires was randomly assigned to individuals in an effort to eliminate any response bias due to the influence of exposure to the preceding measure.

Data Analysis

Raw data from the current study were analyzed using SPSS 16.0 for Windows (SPSS Inc., 2008); Horatio (V. 3.0a) was used for power analysis (Lee, 2004). Initially, descriptive statistics (means, standard deviations, frequency distributions, etc.) were calculated for the demographic data, the individual items, and the global and specific domains of each questionnaire (e.g., BSI-18, EORTC-QLQ-C30, EORTC-QLQ-H&N35). The Pearson product-moment coefficient of correlation was used to assess correlation between the parametric independent and dependent variables.

Power calculation. Power calculations were conducted using Horatio (Version 3.0a) (Lee, 2004) to identify the necessary sample size. In order to detect a medium sized effect ($r^2 = 0.12$) at an alpha level of 0.5 with two levels of the independent variable 'gender' (between-groups), at 80% power, a sample of 60 participants was required, with 30 participants at each level. A total of 69 questionnaires were mailed to potential participants to ensure we met the minimum required number of participants.

Parameter estimation. Parameter estimates were used in order to estimate population characteristics. In this case, they were used to assess whether the study sample would be representative of the same population of individuals with head and neck cancer. Parameter estimates were assessed through the use of ratios and histograms. Moreover, ratios of male-to-female participants were compared to the most recent gender-based head and neck cancer ratios available.

Presence of distress. The presence of clinically significant distress was identified based on a GSI score of ≥ 63 on the BSI-18 measurement instrument. The presence of significant distress was then examined specific to participant gender and to the sample as a whole. Rates of distress present in this sample could subsequently be compared to previous findings in the literature.

Effect of Gender. Since the final number of male and female participants differed substantially (i.e., 28 males vs. 9 females), nonparametric statistics were used to assess potential differences. The Mann-Whitney U-test is one of the most statistically powerful nonparametric procedures available (Portney & Watkins, 2000). The Mann-Whitney U-test is analogous to the parametric *t*-test for independent samples and much like the *t*-test, the U-test does not require that groups be the same size (Portney & Watkins, 2000). As a result, it serves as an excellent alternative to the *t*-test when parametric assumptions (i.e., normal distributions) are not met.

As a result, the Mann-Whitney U-test for two independent samples was employed to address the second research objective, which was to 'assess whether the gender of an individual influences their perceived QoL and/or distress level'. Specifically, the Mann-Whitney U-test was utilized to examine the effect of the independent variable, gender, on the first dependent variable, global QoL as measured by the EORTC general questionnaire. The same procedure was repeated to evaluate the effect of the independent variable, gender, on the dependent variable, distress (measured according to the GSI score on the BSI-18).

Correlational Assessment of Measures. In an effort to address the third research objective, 'determine the relationship between distress level and *overall* QoL among individuals diagnosed with head and neck cancer' and the fourth research objective, 'determine the relationship between distress level and *specific domains* of QoL among individuals diagnosed with head and neck cancer', correlations between the parametric dependent variables: distress, global QoL, and the specific domains of QoL (e.g., physical, emotional, cognitive, role, and social functioning) were assessed using the Pearson product-moment correlation. Interpretation of the correlations will be based on the criteria for evaluating correlation coefficients cited in Portney and Watkins (2000). Correlations ranging in value from 0.00 to .25 denote little or no relationship; values from .25 to .50 indicate a fair degree of relationship; those from .50 to .75 suggest a moderate to good relationship; while values above .75 are considered to be good to excellent (Portney & Watkins, 2000). Moreover, an a priori alpha level of .05 was used for all statistical tests.

Test-retest reliability. In order to assess participant agreement, three weeks following the completion and return of the study packages, 10 randomly selected participants (six men and four women) received a second copy of the same questionnaire package they completed at first administration. The data obtained on the second administration was compared to the first, and agreement was assessed for each item of each measurement instrument (e.g., BSI-18, EORTC-QLQ-C30, EORTC-QLQ-H&N35). In order to determine who was invited to repeat the experiment, a coin was flipped for each enrolled participant with the “head” side of the coin indicating that the individual would be invited to participate in this portion of the experiment. This procedure of coin flipping was repeated until six male and four female names were collected.

Participant agreement was evaluated for each of the measurement instruments (e.g., BSI-18, EORTC-QLQ-C30, EORTC-QLQ-H&N35) by summing the number of exact item matches from the first and second administrations, summing the number of items within +/- one scaled response point from each other, and finally summing the number of questions that were within +/- two scaled points from each other. Exact matches, and +/- one totals were added together and divided by the total number of items to give a percent agreement score for each participant. This procedure was repeated for each measurement instrument.

CHAPTER 3

Results

Response Rates

Overall 39 individuals (30 males, 9 females) returned the completed questionnaire package. The overall response rate was 56.52%, and individual group response rates were as follows: men = 63.83% and women = 40.91%. Prior to formal data analysis two male participants were excluded because their questionnaires were not completed in entirety and, consequently their data were excluded from data analysis. Ultimately, 37 participants (28 males, 9 females) were formally registered in the study. Comprehensive demographic data for these participants can be found in Table 1.

Demographic Information

Gender. In total, the 28 male (mean age = 59.03 years) and 9 female participants (mean age = 61.56 years) resulted in a male-to-female ratio of 3.1:1. Unfortunately this ratio was not consistent with the current sex-based incidence ratio of 1:1 for head and neck cancer in Canada (Canadian Cancer Society, 2009).

Time since diagnosis. The length of time since a participant had received their diagnosis ranged from 3 to 12 months (mean = 7.92). On average, male participants had lived with their cancer for approximately one additional month (mean = 8.16, range 3-12 months) when compared to the female participants (mean = 7.17, range 4-12 months). Comprehensive data pertaining to the distribution of time since diagnosis for participants can be found in Figure 1.

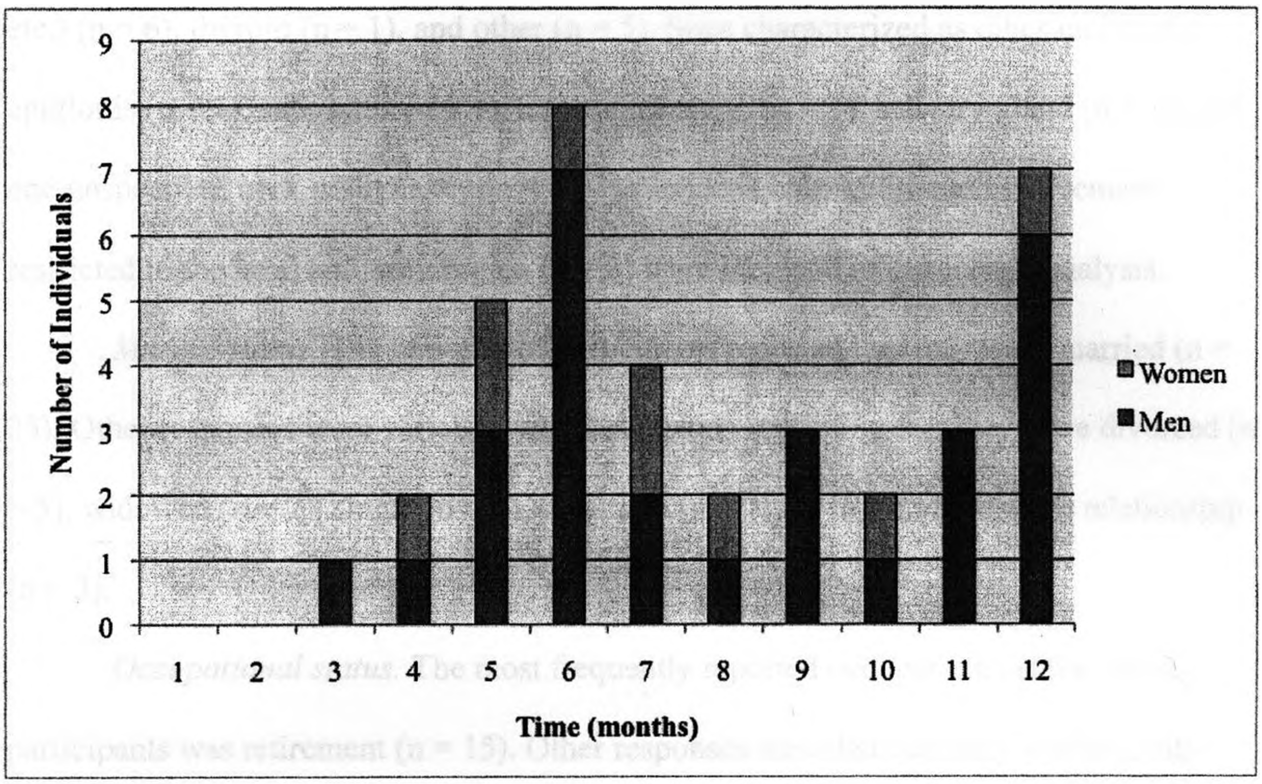
Cancer site. Distribution of cancer sites was rather variable yet characteristic of a participant sample of convenience drawn from a large regional cancer centre. The most

Table 1 *Demographic Data of Participants*

Variable	Men (n)	Women (n)	Total
Number of Participants	28	9	37
Age (years)	Mean 58.75 (45-76)	Mean 61.55 (43-78)	Mean 59.43 (43-78)
Number of Months Since Diagnosis	Mean 8.16 (3-12)	Mean 7.17 (4-12)	Mean 7.92 (3-12)
Cancer Site			
Oral Cavity (e.g., lip, tongue, tonsil, etc.)	10	5	15
Larynx	7	0	7
Throat (e.g., pharynx, oropharynx, etc.)	5	1	6
Thyroid	0	1	1
Multi-Site Involvement	2	1	3
Other	4	1	5
Marital Status			
Married	18	7	25
Separated	1	0	1
Divorced	4	1	5
Widowed	1	1	2
Common-Law	3	0	3
Single	1	0	1
Occupational Status			
Currently Working Full-Time	5	0	5
Currently Working Part-Time	6	1	7
On Sick Leave/Disability	4	3	7
Retired	11	4	15
Other	2	1	3

*Values in brackets represent the range of data.

Figure 1. Distribution of time since diagnosis for participants differentiated according to sex.



frequently reported site of cancer among participants was of the oral cavity (n = 15). Other sites included the larynx (n = 7), throat (e.g., pharynx, oropharynx, hypopharynx, etc.) (n = 6), thyroid (n = 1), and other (n = 5). Sites characterized as other included the epiglottis (n = 1), subglottis (n = 1), mucoepidermoid (n = 1), salivary gland (n = 1), and one unspecified neck malignancy (n = 1). Participants with multi-site involvement restricted to the head and neck region (n = 3) were included in the current analysis.

Marital status. The majority of participants reported that they were married (n = 25). Other responses were variable with participants indicating that they were divorced (n = 5), widowed (n = 2), single (n = 1), separated (n = 1), or in a common-law relationship (n = 3).

Occupational status. The most frequently reported occupational status among participants was retirement (n = 15). Other responses included currently working full-time (n = 5) or part-time (n = 7) while others noted that they were currently on sick leave and/or disability due to illness or injury (n = 6). In addition, one individual noted that he was not presently working, while two other participants reported that they were currently unemployed but actively seeking full-time employment.

Parameter Estimation

Parameter estimates were used in order to estimate population characteristics. In this case, they were used to assess whether the study sample would be similar to the population of individuals with head and neck cancer. With respect to gender, the 28 male participants and 9 female participants resulted in a male-to-female ratio of 3.1:1. Since this ratio was not even (e.g., 1:1) and the female sample was relatively small, non-parametric statistics were utilized throughout gender-based data analysis.

Presence of Distress

From the sample of 37 participants, clinically significant distress (i.e., a GSI score of ≥ 63) was detected in nine participants (24.32%). Specifically, eight of the 28 male participants (28.57%) reported significant distress, while only one of the nine female participants (11.11%) reported significant distress. The mean age of distressed individuals was 57.89 years (range 45-72 years), while the average time since diagnosis was 7.89 months (range 3-12).

The mean GSI score for individuals *with* significant distress was 67.56 (range 63-72), while the mean EORTC global QoL was 58.26 (range 33.33-100.00). Specifically, the mean EORTC general QoL functional scale scores for distressed individuals was 67.91 (range 46.00-91.93), with a higher number indicating better functioning. In contrast, the mean GSI score for participants *without* distress was 49.24 (range 31-62), while the mean EORTC global QoL was 67.76 (range 33.33-100.00). Additionally, the mean EORTC general QoL functional scale scores for distressed individuals was 80.87 (range 52.00-100.00).

With respect to symptom scales, for which lower scores indicate fewer symptoms, the EORTC general QoL symptom scale revealed a mean score of 28.40 (range 12.33-55.56) for distressed participants, while the EORTC head and neck-specific symptom scale generated a mean score of 35.93 (range 18.06-49.17). Conversely, for participants *without* distress the EORTC general QoL symptom scale indicated a mean score of 19.65 (range 0.00-59.89) for distressed participants, while the EORTC head and neck-specific symptom scale produced a mean score of 25.62 (range 0.00-58.43).

The site of cancer for participants with clinically significant distress was highly variable and included the oral cavity (n = 3), throat (n = 2), multi-site (restricted to the head and neck region) involvement (n = 2), mucoepidermoid (n = 1), and an unspecified neck malignancy (n = 1). Finally, while a number of distressed participants reported that they were currently retired (n = 4), the occupational status for distressed participants was also variable and included, currently working full-time (n = 1), currently on disability/sick leave (n = 3), and unemployed (n=1). Comprehensive data pertaining to the frequency of distress scores among participants can be found in Figure 2. Furthermore, comprehensive data on measures of distress and QoL scores of participants with clinically significant distress as defined by a GSI score of ≥ 63 can be found in Table 2.

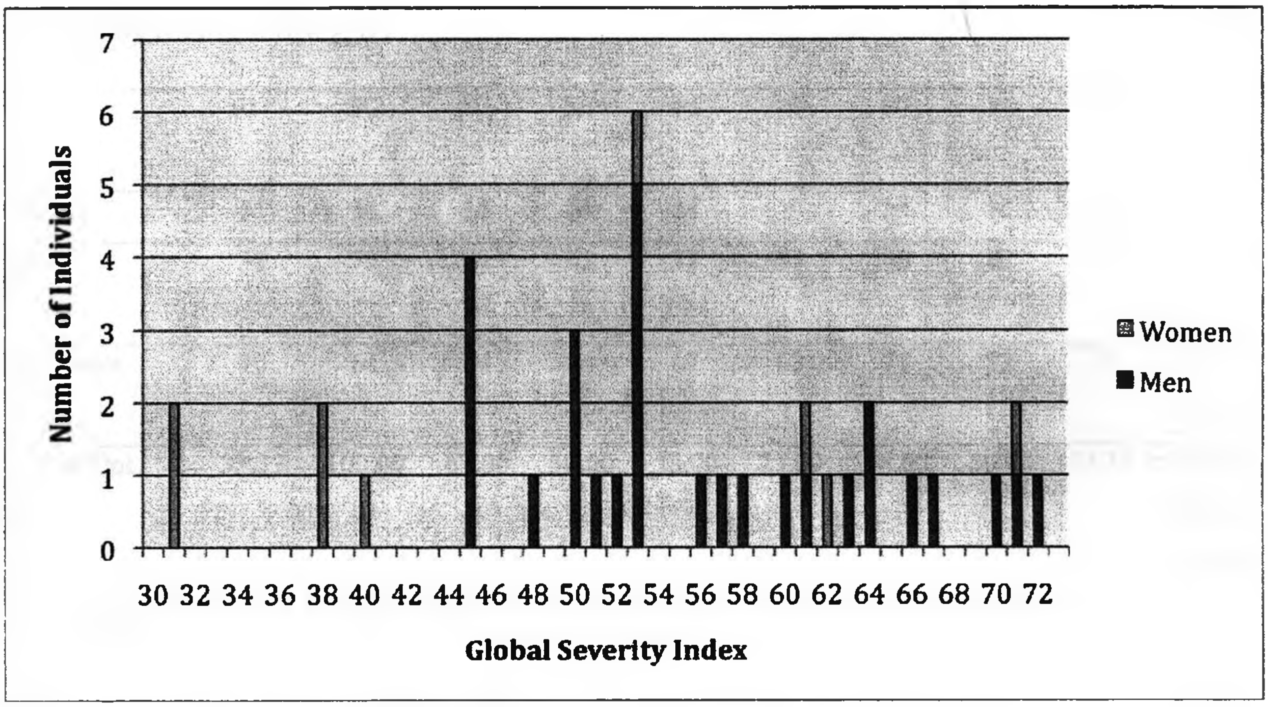
Effects of Gender

When the independent variable (gender) and the dependent variable (global QoL) were evaluated, it was determined that the effect of gender on global QoL was not statistically significant (U = 124.00, p = .943). Furthermore, when gender and distress were evaluated, it was found that gender also was not statistically significant (U = 82.50, p = .122). Hence, for all other data analyses male and female data were pooled.

Correlational Assessment of Measures

Correlations between the dependent variables: distress, global QoL, and the specific domains of QoL (e.g., physical, emotional, cognitive, role, and social functioning) were assessed using the Pearson product-moment correlation. There was a moderate-to-good correlation between distress and global QoL and this correlation was found to be statistically significant (*r* = -.589, p = .000). Significant correlations were

Figure 2. Frequency of BSI-18 Global Severity Index distress scores among participants.



*GSI scores ≥ 63 indicate the presence of clinically meaningful distress levels.

Table 2 *Distress and QoL Scores of Participants with Clinically Significant Distress as defined by a GSI score ≥ 63*

	P1*	P2	P3	P4	P5	P6	P7	P8	P9	Mean (Range)
Gender	M	M	M	M	M	F	M	M	M	N/A
Age	58	71	48	62	57	45	46	62	72	57.89 (45-72)
GSI Score	70	64	64	66	67	63	71	72	71	67.56 (63-72)
Global QoL Score	33.33	100.00	67.00	50.00	58.00	75.00	58.00	50.00	33.33	58.26 (33.33-100.00)
Physical QoL	80.00	93.00	66.67	60.00	86.67	100.0	80.00	86.67	93.00	82.89 (60.00-100.00)
Role QoL	66.67	83.33	66.67	66.67	66.67	100.0	50.00	83.33	66.67	72.22 (50.00-100.00)
Emotional QoL	50.00	83.33	75.00	75.00	66.67	33.33	0.00	33.33	33.33	50.00 (0.00-83.33
Cognitive QoL	83.33	100.00	83.33	50.00	66.67	60.00	33.33	33.33	66.67	64.07 (33.33-100.00)
Social QoL	66.67	100.00	50.00	33.33	33.33	100.0	66.67	100.0	83.33	70.37 (33.33-100.00)

* P# indicates the distressed participant's identification number.

detected between distress and each of the specific domains of QoL (e.g., physical, role, emotional, cognitive and social functioning). According to Cohen's measure, the domains of physical functioning ($r = -.388$, $p \leq .018$), role functioning ($r = -.416$, $p \leq .011$), and social functioning ($r = -.344$, $p \leq .037$) all demonstrated a fair relationship, while both emotional ($r = -.691$, $p \leq .000$) and cognitive ($r = -.697$, $p \leq .000$) functioning demonstrated a moderate- to-good relationship. The negative correlations indicate that there is an inverse relationship between distress and measures of QoL implying that as distress increases, one's perceived QoL decreases. Comprehensive data pertaining to the correlations between distress and QoL scores among participants can be found in Table 3. Further evidence of the inverse relationship between distress and global QoL is presented in the scatter plot analysis in Figure 3.

Test-Retest Reliability

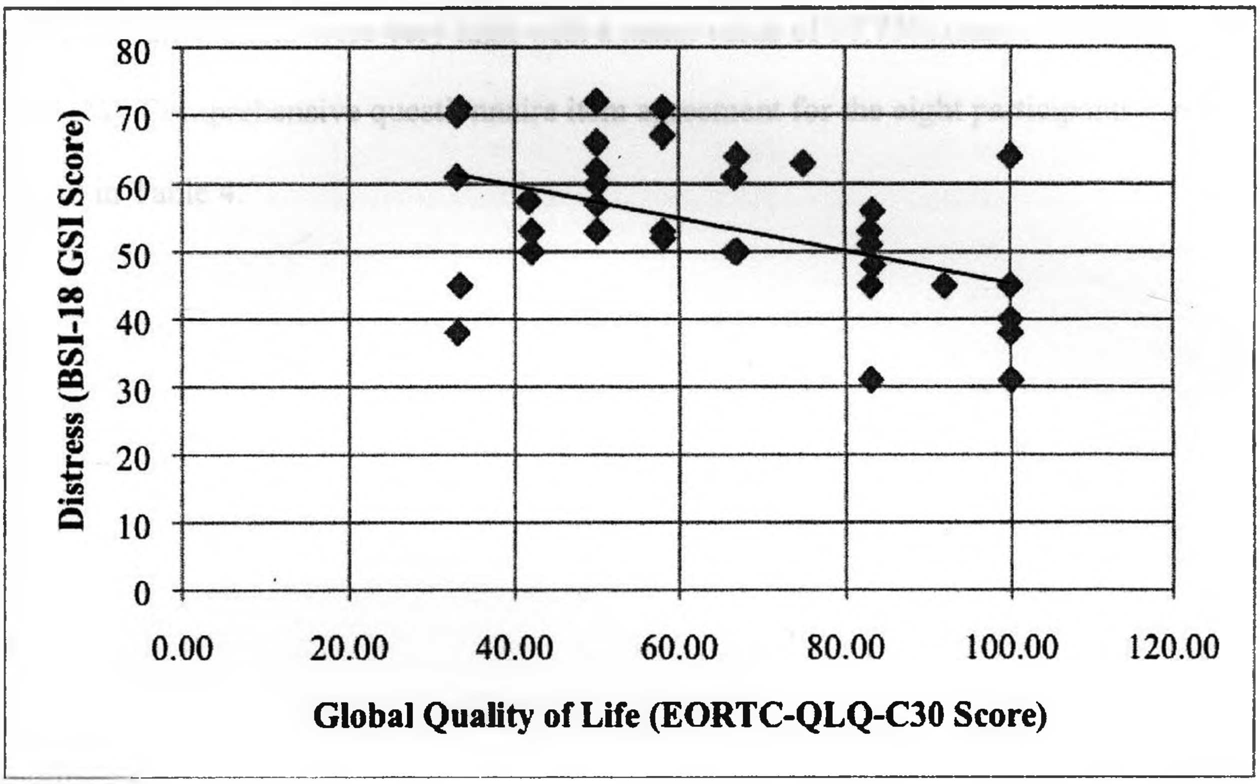
In order to assess participant agreement, three weeks following the completion and return of the study packages, 10 randomly selected participants (six men and four women) received a second copy of the same questionnaire package they completed at first administration. In total, all 10 individuals (males: $n = 6$; females: $n = 4$) returned the completed questionnaire package. Prior to formal reliability analysis two female participants were excluded because the returned questionnaires were not completed in entirety. Thus, eight participants (males: $n = 6$; females: $n = 2$) returned the completed reliability questionnaire packages and were included in the reliability portion of the study. The purpose of re-administration was to assess whether participant responses to each questionnaire on the second administration of the questionnaire agreed with their

Table 3 *Correlations Between Distress and QoL (N = 37)*

		Phys.	Role	Emot.	Cog.	Social	Global QOL	Distress
Physical Functioning	Pearson Correlation	1	.688*	.067	.267	.587*	.480*	-.388*
	p level		.000	.694	.110	.000	.003	.018
Role Functioning	Pearson Correlation		1	.186	.337*	.631*	.492*	-.416*
	p level			.270	.041	.000	.002	.011
Emotional Functioning	Pearson Correlation			1	.678*	.096	.486*	-.691*
	p level				.000	.574	.002	.000
Cognitive Functioning	Pearson Correlation				1	.246	.506*	-.697*
	p level					.142	.001	.000
Social Functioning	Pearson Correlation					1	.499*	-.344*
	p level						.002	.037
Global QOL	Pearson Correlation						1	-.589*
	p level							.000
Distress (GSI Score)	Pearson Correlation							1
	p level							

* Correlation is significant at the minimum level of $p \leq 0.05$ level (2-tailed).

Figure 3. Scatter plot analysis of the inverse relationship between distress (as measured by the BSI-18 GSI score) and global QoL (as measured by the EORTC-QLQ-C30 score) – N = 37



*Note: Higher EORTC-QLQ-C30 scores indicate better QoL, while higher BSI-18 scores indicate higher levels of distress.

responses on the first. Assessment of test-retest reliability indicated high levels of exact agreement for all measurement instruments with a mean value of 77.86% (range 74.19% - 82.99%). Moreover, the reliability assessment for items with either exact agreement or a one point differential were very high with a mean value of 97.75% (range 97.50% - 98.61%). Comprehensive questionnaire item agreement for the eight participants can be found in Table 4.

Table 4 *Item Agreement Between Administration One and Administration Two of the BSI-18, EORTC-QLQ-C30, and EORTC-QLQ-H&N35 Questionnaires*

Questionnaire	Reliability Participant	Exact Agreement (%)	+/- 1 Agreement (%)	Exact and +/- 1 Agreement (%)	> +/- 1 Agreement (%)
BSI-18	1	88.89	11.11	100.00	0.00
	2	94.45	5.55	100.00	0.00
	3	69.45	30.55	100.00	0.00
	4	72.22	27.78	100.00	0.00
	5	88.89	11.11	100.00	0.00
	6	83.34	11.11	94.45	5.55
	7	94.45	5.55	100.00	0.00
	8	72.23	22.22	94.45	5.55
Mean BSI-18 Values		82.99	15.62	98.61	1.39
EORTC- C30	1	100.00	0.00	100.00	0.00
	2	76.67	23.33	100.00	0.00
	3	70.00	30.00	100.00	0.00
	4	63.33	36.67	100.00	0.00
	5	90.00	10.00	100.00	0.00
	6	43.33	43.33	86.67	13.33
	7	83.33	16.67	100.00	0.00
	8	66.67	26.66	93.33	6.67
Mean EORTC- C30 Values		74.17	23.33	97.50	2.50
EORTC-H&N35	1	94.29	5.71	100.00	0.00
	2	88.57	11.43	100.00	0.00
	3	65.71	34.29	100.00	0.00
	4	65.71	34.29	100.00	0.00
	5	94.29	5.71	100.00	0.00
	6	42.86	42.86	85.72	14.28
	7	77.14	22.86	100.00	0.00
	8	82.86	14.29	97.15	2.85
Mean EORTC-H&N35 Values		76.43	21.43	97.86	2.14

Note. Exact agreement indicates the percentage of scores that exactly agreed across administrations

+/- 1 agreement indicates the percentage of scores that were within +/-1 scaled value across administrations.

Exact and +/- 1 agreement total is the combined total of exact agreement scores and those that were +/- 1 scaled value across administrations.

> +/- 1 agreement indicates the percentage of scores that were greater than +/- 1scaled value across administrations.

Table 4 *Item Agreement Between Administration One and Administration Two of the BSI-18, EORTC-QLQ-C30, and EORTC-QLQ-H&N35 Questionnaires*

Questionnaire	Reliability Participant	Exact Agreement (%)	+/- 1 Agreement (%)	Exact and +/- 1 Agreement (%)	> +/- 1 Agreement (%)
BSI-18	1	88.89	11.11	100.00	0.00
	2	94.45	5.55	100.00	0.00
	3	69.45	30.55	100.00	0.00
	4	72.22	27.78	100.00	0.00
	5	88.89	11.11	100.00	0.00
	6	83.34	11.11	94.45	5.55
	7	94.45	5.55	100.00	0.00
	8	72.23	22.22	94.45	5.55
Mean BSI-18 Values		82.99	15.62	98.61	1.39
EORTC- C30	1	100.00	0.00	100.00	0.00
	2	76.67	23.33	100.00	0.00
	3	70.00	30.00	100.00	0.00
	4	63.33	36.67	100.00	0.00
	5	90.00	10.00	100.00	0.00
	6	43.33	43.33	86.67	13.33
	7	83.33	16.67	100.00	0.00
	8	66.67	26.66	93.33	6.67
Mean EORTC- C30 Values		74.17	23.33	97.50	2.50
EORTC-H&N35	1	94.29	5.71	100.00	0.00
	2	88.57	11.43	100.00	0.00
	3	65.71	34.29	100.00	0.00
	4	65.71	34.29	100.00	0.00
	5	94.29	5.71	100.00	0.00
	6	42.86	42.86	85.72	14.28
	7	77.14	22.86	100.00	0.00
	8	82.86	14.29	97.15	2.85
Mean EORTC-H&N35 Values		76.43	21.43	97.86	2.14

Note. Exact agreement indicates the percentage of scores that exactly agreed across administrations

+/- 1 agreement indicates the percentage of scores that were within +/-1 scaled value across administrations.

Exact and +/- 1 agreement total is the combined total of exact agreement scores and those that were +/- 1 scaled value across administrations.

> +/- 1 agreement indicates the percentage of scores that were greater than +/- 1scaled value across administrations.

CHAPTER 4

Discussion

The present study was designed to assess four specific research objectives related to distress in those diagnosed with head and neck cancer. Those objectives were to: (1) determine the presence of psychological distress in a sample of individuals diagnosed with head and neck cancer and compare this rate to previous findings in the literature, (2) assess whether gender influences the perceived QoL and/or distress level of individuals with head and neck cancer, (3) describe the relationship between distress level (as measured by the Brief Symptom Inventory-18) and *overall* QoL (as measured by the EORTC-QLQ-C30) among individuals diagnosed with head and neck cancer, and (4) describe the relationship between distress level (as measured by the Brief Symptom Inventory-18) and *specific domains* of QoL (e.g., physical, emotional, cognitive, role, and social functioning) as measured by the EORTC-QLQ-C30.

In an effort to address a variety of issues emerging from the study, several areas will be addressed independently in the discussion to follow. The discussion will commence by addressing the outcome of each of the four research objectives. Since the results of this study were elicited using the BSI-18, EORTC-QLQ-C30, and EORTC-QLQ-H&N35, response rates and participant demographics (e.g., time since diagnosis, marital status, occupational status) will be discussed next. Following this, a discussion of the results of statistical analysis tests (i.e., presence of distress, effects of gender, correlational assessment of measures) and reliability analysis will be addressed. Factors that influence distress in the head and neck cancer population and the clinical implications related to the identification of heightened distress will also be explored.

Finally, the limitations of the present study will be outlined and followed by directions for future research and overall conclusions.

Findings Specific to Research Objectives

With respect to the first research objective concerning the presence of psychological distress in a sample of individuals with head and neck cancer, results indicated that clinically significant distress (defined by a GSI score of ≥ 63) was present in 24.32% ($n = 9$) of the 37 participants. Moreover, clinically significant distress was detected in 28.57% ($n = 8$) of male participants, while only 11.11% ($n = 1$) of female participants reported distress levels that exceeded the defined GSI cutoff score. When these rates are compared to previous findings in the literature, it appears that the presence of distress in this sample is approximately 10-20% lower than the reported 35-45% prevalence rates of distress in oncology populations; however, it must be noted that the present sample was considerably smaller than those previously cited in the literature (Bjordal & Kaasa, 1995; Carlson et al., 2004; Carlson & Bultz, 2003; Sellick & Crooks, 1999; Stefanek, Derogatis, & Shaw, 1987; Zabora et al., 2001). Despite this discrepancy, the overall rate of distress detected in this study was consistent with findings (e.g., depression and anxiety prevalence rates of 24%) from large-scale distress studies conducted by Zabora et al. (2001) and Carlson et al. (2004). Interestingly, the mean GSI score from the present study (GSI = 54.04) was exactly the same as the value reported in Zabora et al.'s (2001) study of 396 individuals with head and neck cancer; this finding suggests that even though we detected a lower percentage of distress, the current findings related to potential severity are still consistent with past literature.

Relative to the second research objective that assessed whether the gender of an individual influences their perceived QoL and/or distress level, it was determined that despite the potential for an added burden on women, gender did not appear to have a significant effect on either global QoL or distress. However, the lack of detectable difference between gender on QoL and distress may be related to the limited sample size of the present study. Additionally, the number of female participants may not have been sufficient enough to detect an effect. Consequently, further research into the important factor of gender remains an important area of inquiry in the future.

Finally, relative to the third and fourth research objectives which assessed the relationship between distress (as measured by the BSI-18) and both *global* and *specific* domains of QoL (as measured by the EORTC-QLQ-C30), results indicated that there is indeed a significant inverse relationship between distress scores and both *global* and *specific* domains scores for QoL. This finding clearly reveals that as the distress level of an individual increases, the perceived QoL of the same individual decreases. Interestingly, when the specific domains of QoL were examined, both emotional and cognitive functioning demonstrated a moderate relationship with distress, while social, role and physical functioning showed more fair relationships with distress. The strong relationship between distress and the psychological facets of QoL, represented by emotional and cognitive functioning, is not surprising given that levels of psychological distress related to head and neck cancer have been reported to be significantly higher than the physical impact of disease (McDonough et al., 1996).

A number of factors may contribute to the elevated level of psychological burden within this population. First and foremost, the most fundamental components of one's humanity, including the ability to breathe, eat, speak and appear in public, may be directly impacted by the diagnosis and/or treatment of head and neck cancer. Further, physical consequences such as facial disfigurement cannot easily be concealed which may impair emotional expression and social interactions leading to additional social withdrawal and the possible avoidance of potentially beneficial support systems (Lydiatt et al., 2009). The avoidance of support systems may increase feelings of isolation and exacerbate the psychological symptoms associated with distress. This in turn may potentially contribute to elevated distress levels among individuals with head and neck cancer with a simultaneous impact on perceived QoL. The present findings and their interpretation indicate that addressing negative psychosocial outcomes such as distress should be identified as an essential component of comprehensive health care. Early identification of problematic distress levels may subsequently help to reduce the potentially negative consequences of distress that may cross physical, psychological and social domains of functioning. These consequences may ultimately contribute to decreased QoL for those living with head and neck cancer.

Response Rates

The overall participant response rate (39.00%) for this study was markedly below the expected rate of 60% (Asch, Jedrziewski, & Christakis, 1997). This anticipated response rate was drawn from a meta-analysis of 178 studies published in scientific journals in 1991 that utilized mail-administered questionnaires for data collection (Asch et al., 1997). Possible factors that may account for the 21% differential between actual and expected response rates will be addressed in the discussion to follow.

In order to ensure that the response rate obtained was large enough to conduct data analysis, the number of questionnaires required for adequate power was calculated a priori (Asch et al., 1997). Formal power analysis indicated that data from at least 60 participants would be required to reliably conduct formal data analysis. As a result, 69 surveys were distributed to potential participants to increase the likelihood that the number of data sets returned would exceed the required minimum number of participants. Additionally, in an effort to increase response rates, follow-up telephone reminders were conducted for individuals who had not returned their data within three weeks of initial distribution. Despite suggestions by Asch et al. (1997) that telephone reminders were associated with a 13% increase in response rate, unfortunately rates for the present study did not increase.

One reason for the discrepancy in response rate for the present study may be attributable to a potential selection bias. To further explore this notion, it is important to examine the specific reasons provided by participants for choosing not to take part in the present study. Some reasons provided for declining participation included, finding the research topic “too upsetting”, or being “too fatigued”, “too ill”, or “currently hospitalized”. These reasons may be associated with an increased probability that such individuals would have demonstrated higher rates of distress and compromised QoL had they chosen to take part in the present study. In contrast, participant responses such as “too busy” and “not interested” may represent individuals who may have felt that the research topic was not relevant to their experience of cancer. If this was in fact the case, these individuals might have demonstrated lower rates of distress and the associated compromise in QoL. Thus, these potential sources of selection bias may have contributed to the slightly lower than anticipated response rates.

Participant Demographics

Participants in this study consisted of men and women between the ages of 43 and 78 who had received a diagnosis of head and neck cancer within the previous 12 months. This sample was selected because the diagnosis and treatment of head and neck cancer have been associated with some of the highest rates of anxiety, depression and suicide when compared with other cancer sites (Bjordal et al., 1995; Dropkin, 1986; Misono et al, 2008), suggesting that head and neck cancer is a highly traumatic form of illness with a multitude of complex psychosocial concerns. Consequently, this group was believed to be an appropriate target population for the objectives of this study.

Time since diagnosis. The mean length of time since diagnosis for participants was approximately 8 months, however, values ranged from three to 12 months. The lack of recently diagnosed participants may have under-identified the overall presence of distress given that 25-66% of all newly diagnosed individuals experience significantly elevated levels of distress, while as many as 47% have been reported to exhibit a verified psychiatric diagnosis (Derogatis et al., 1983; Kugaya et al., 2000; Stefanek et al., 1987; Zabora, Brintzenhofeszoc, & Smith, 1996; Zabora et al., 1997; Zabora et al., 2001). The 'within 12-months of diagnosis' timeline criterion was selected since the first year after receiving a diagnosis for head and neck cancer may involve a number of potentially distressing changes. It is during this period that individuals may be faced with myriad challenges as they attempt to cope with their diagnosis, active treatment and the subsequent challenges that follow (Mehanna et al., 2008). Additionally, a number of studies have demonstrated that along the continuum of illness, individuals' QoL declines significantly during treatment and begins to increase again around the period of three to six months post-diagnosis (Mehanna et al., 2008). It has also been reported that approximately 12 months after diagnosis, individuals' QoL typically returns to pre-treatment levels (Hammerlid, Silander, Hornestam & Sullivan, 2001; Mehanna et al., 2008; Mehanna & Morton, 2006; Morton, 2003; Nordgren et al., 2006), where it remains for at least the next two years (Mehanna et al., 2008). Thus, the absence of participants representing the newly diagnosed phase of illness (e.g. 0-3 months) may certainly have contributed to the lower presence of distress detected in the present study. It would appear reasonable to anticipate that "stages" of an early post-diagnosis response may exist in that first year. Consequently, additional exploration of this important topic in future work may shed considerable light on a critically important factor relative to distress, rehabilitation, and long-term outcome.

Marital status. Regarding marital status, the majority of participants in the present study reported that they were currently married. The importance of the marital status of participants is related to the contribution of a potentially supportive relationship to levels of perceived and actual social support. Married individuals have been found to report less distress and show better overall adjustment when compared to unmarried individuals (Boeckel, Jacobson, Balducci, Horton & Lyman, 2000; Kugaya et al., 1999). Although certain social interactions (e.g., an unhealthy and/or unsatisfying relationships) have been found to exert a negative psychosocial effect (Baker, 1992; de Leeuw et al., 2000), numerous studies have demonstrated the positive relationship between the degree of one's social support and the extent of QoL and emotional well-being (Cohen & Wills, 1985; de Leeuw et al., 2000; Katz et al., 2003; Krishnasamy, 1996). Indeed, perceived social support has been demonstrated to facilitate positive adjustment to head and neck cancer (Baker, 1992; de Leeuw et al., 2000; Katz et al., 2003).

Relative to the role of gender and its influence on social support, several studies have demonstrated that social support systems provide a greater protective role[3] for women (Fife et al., 1994; Katz et al., 2003; Manne, Taylor, Doughertry, & Kemeny, 1997). Additionally, Fife and colleagues (1994) determined that the perceived social support of professionals was an important factor in explaining positive psychosocial adjustment among men with cancer. Collectively, these conclusions may indicate that the presence of positive social support facilitates adjustment to cancer differently among men and women. Ultimately, women may derive greater benefits from a supportive relationship, whereas men may prefer professional means of psychosocial support, such as individual counseling with a qualified professional. The fact that most female participants were married, in conjunction with the finding that women typically derive the greatest benefit from supportive relationships, may help to account for the lower rates of distress detected among female participants in the present study. However, the limited sample size and number of female participants in the present study prevent any conclusive deductions from being drawn and the external validity of this suggestion deserves direct validation.

Occupational status. With respect to occupational status, a number of participants indicated that they were presently retired. This finding may be related to lower levels of

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[3] The protective role of social support for women is determined by their positive adjustment to illness (Fife, Kennedy & Robinson, 1994).

perceived distress among participants due to the potentially decreased competing demands on one's time and energy. Conversely, while one report noted that retirement had no bearing on the treatment of individuals with head and neck cancer (Rogers, Hanna, Lowe & Magennis, 1999), a number of studies have documented the added burden of receiving a diagnosis of cancer prior to or shortly after retirement (Ganz et al., 2002; Relic, Mazemda, Arena, Koller, & Glanz, 2001). This burden may be related to unanticipated financial costs incurred with treatment, such as those associated with transportation, uninsured pharmaceuticals, and peripheral comfort items, among others. Ultimately, the secondary costs associated with treatment for head and neck cancer has the potential to negatively impact not only the financial stability, but also the QoL and distress levels of retired individuals with head and neck cancer.

Presence of Distress

The presence of distress detected in the current study (24.32%) was approximately 10-20% lower than the 35-45% reported in distress literature around the world (Bjordal & Kaasa, 1995; Carlson et al., 2004; Carlson & Bultz, 2003; Fielding et al., 2004; Isikhan et al., 2001; Kugaya et al., 2000; Montazeri et al., 2004; Sadeh-Tassa et al., 2004; Santos, 2004; Shimizu et al., 2004; Zabora et al., 2001). This disagreement in rates of distress may be attributable to a number of factors including the limited sample size and limited number of female participants in the present investigation.

In an effort to explore the characteristics of distress in the present sample of participants, the demographic variables of the nine individuals who reported significant distress levels were examined in greater detail. Upon assessment of the demographic variables of the distressed individuals, it appears that there were no clear trends related to demographic factors. This finding is consistent with previous research into factors predicting distress among individuals with head and neck cancer (Kugaya et al., 2000). Given the high degree in variability of the sample in conjunction with the limited number of distressed participants, no formal conclusions regarding the demographic characteristics of distressed individuals can be drawn at this time. However, the heterogeneous nature of the demographic data suggest that screening for distress cannot be isolated to one specific sub-group of individuals with head and neck cancer. Rather, routine screening for distress must be employed for all individuals with head and neck cancer, irrespective of demographic characteristics.

In regard to identified distress, it is important to note that one of the individuals who exhibited elevated distress levels on the GSI score voluntarily indicated a second significant traumatic event in his life that closely coincided with his diagnosis. The significance of this disclosure pertains to the fact that some individuals may have been experiencing distress prior to receiving a diagnosis of cancer. As a result, some may question whether screening for distress in oncology populations will, in fact, serve to identify and address distress that stems directly from oncology-related concerns. For those that may question the point of origin of the distress, it is important to emphasize that it is not the causative circumstance(s) of distress that is/are most important, but rather the consequences that stem from the manifestations of distress that is/are of paramount concern. The specific reason *why* a person is distressed is not as relevant in a clinical oncology context as the mere fact that they *are in fact* distressed. Of course the reasons behind the distress are important and absolutely need to be addressed in an appropriate setting. However, the mere presence of distress may result in a multitude of physical, psychological, and social consequences for the individual, thus necessitating its proper identification. Consequently, researchers and clinicians must understand the primary value of conducting regular screening for distress in this sample population. The identification of clinically significant distress in one-quarter of the present participants minimally demands that clinical attention be paid to this important clinical finding. Attention must then be directed towards offering a referral to psychological services or arranging the provision of appropriate psychosocial intervention for the distressed individual.

Effects of Gender

Relative to the second research objective, which assessed whether the gender of an individual influenced their perceived QoL and/or distress level, the present study found that despite the theoretical potential for an added burden on women, gender did not appear to significantly influence either QoL or distress. Regarding the relationship between gender and QoL, current data from studies investigating the influence of gender on QoL in oncology populations remain conflicting. Similar to the results of the present investigation, a number of studies have reported that gender has no significant influence on QoL (Greimel, Padilla, & Grant, 1998; Rogers, Humphris, Lowe, Brown, & Vaughan, 1998), whereas others have reported lower levels of QoL for women (Allison et al., 1998; De Boer et al., 1995; Langius, Bjorvell, & Lind, 1994).

Similar to the conflicting data on gender and QoL, research pertaining to the influence of gender on distress in oncology populations is also inconsistent. For instance, similar to the results of the present investigation, a number of studies have reported that gender has no significant influence on distress (Chen et al., 2009; Pandey et al., 2007), while others have detected higher rates of distress among women (Hagedoorn, Sanderman, Bolks, Tuinistra, & Coyne, 2008; Strong et al., 2007). Based on these conflicting results, no definite conclusions may be drawn regarding the influence of gender on QoL or distress. A number of sources suggest that there may be heightened QoL and distress-related penalties for women, however, the results of the present study do not confirm this theory. As a result of the statistically non-significant results related to gender, male and female data were pooled for all subsequent data analyses.

Correlational Assessment of Measures

Correlations between distress, global QoL, and the specific domains of QoL (e.g., physical, emotional, cognitive, role, and social functioning) were found to be statistically significant in the present study. Specifically, both the physical and social domains of QoL (e.g., physical, role and social functioning) were fairly well related with distress, while the psychological domain of QoL (e.g., emotional and cognitive functioning) was related to a greater extent by distress. Moreover, it was determined that there is an inverse relationship between distress and QoL, which implies that as one's level of distress increases, their perceived QoL deteriorates.

The inverse relationship between distress and QoL highlights the parallels drawn between the distress and QoL earlier in this paper. Both distress and QoL are individual and subjective evaluations that are dynamic in nature and, consequently, capable of changing over time. Both QoL and distress represent multidimensional constructs that incorporate physical, psychological and social domains. Further, these physical, psychological and social domains are ultimately overlapped and complementary for both distress and perceptions of QoL. Theoretically, distress epitomizes the antithesis of QoL and by definition, acts as an antagonist to the very dimensions that are valued in QoL. In the literature review it was suggested that in principle, when significant distress was present, QoL was likely to be diminished. Consequently, the significant inverse relationship between distress and QoL in the present study has demonstrated that distress and QoL contrast not only in principle, but also in practice.

Reliability Analysis

Three weeks following the completion and return of the study packages, 10 randomly selected participants were mailed a second package of questionnaires they completed at first administration. In total eight individuals fully completed and returned the survey package. The purpose of re-administration was to evaluate the consistency of participant responses between first and second administration of the questionnaires. General consistency between scores across both administrations was anticipated, although some deviation between scores would be deemed acceptable given the variable and dynamic nature of distress.

The findings from this reliability analysis indicated high levels of agreement on all instruments between first and second administrations. Specifically, ratings of distress were highest in agreement, followed by the EORTC global QoL measure and finally, the head and neck specific QoL instrument. Ratings of distress according to the BSI-18 were highest in agreement when compared to the EORTC QoL measures. On examination of individual responses to the BSI-18, GSI scores of distress for each participant ranged from no change in score (as depicted by two participants) to highly variable scores, marked by both increases (n = 3) and decreases (n = 3) in GSI scores. This variable pattern is evident across most test-retest participants, with score differences ranging from two to 16 points.

The most dramatic change was evident in one participant whose reported level of distress increased from 40 to 56 in only three weeks (an increase in GSI score indicates worsened distress). When one considers that the GSI scores range from between approximately 30 to 80[4], a 16-point increased difference is substantial from a clinical perspective. This change is noteworthy when this information is considered in conjunction with the fact that this participant also reported a decline (from five to four on a 7-point scale) in global QoL in spite of a moderate increase in reported overall health (from four to six on a 7-point scale). Despite the fact that this individual's second (reliability) score was below the minimum 63 points required for a defined "case" of distress according to the scoring criteria of the BSI-18 (Derogatis, 2000), such a dramatic increase in a distress score is likely reflective of a negative shift in this individual's perspective and warrants further investigation. From a clinical perspective, one might also suggest that this change warrants some level of intervention to reduce escalation of the perceived distress.

In addition to this remarkable increase in distress score, it is important to note that two of the individuals randomly selected to participate in the test-retest reliability portion of the present study had reported clinically significant distress in their primary data sets. Interestingly, despite the three-week time discrepancy, both participants consistently indicated clinically significant distress levels in both administrations of the

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[4] Scores on the BSI-18 measurement instrument are transformed based on normative oncology samples.

questionnaires, suggesting that their clinically significant distress is a persistent and ongoing phenomenon.

In general, the test-retest reliability data indicate that over a three-week time period participant responses were relatively stable. This finding likely indicates a fair reflection of the rater's internal psychological state and perspectives relative to the BSI-18 survey items given that raters are asked to make assessments based on how they have been feeling throughout the past seven days. Although these preliminary reliability data provide insights into the overall stability of responses, upon closer inspection, some participants' individual experiences of distress and QoL appear quite variable within the first year of living with head and neck cancer. As a result, further evaluation must take place in the future in order to better assess the individual fluctuations in reported distress level, particularly within the first year following a diagnosis of head and neck cancer.

Distress in the Head and Neck Cancer Population

Relative to the prevalence of distress in oncology populations, numerous studies have confirmed that approximately one-third of all oncology patients will experience significant levels of distress warranting psychosocial intervention (Bjordal & Kaasa, 1995; Carlson et al., 2004; Carlson & Bultz, 2003; Sellick & Crooks, 1999; Stefanek et al., 1987; Zabora et al., 2001). Similar and heightened rates of distress ranging from one-third to two-thirds of those with head and neck cancer have been documented (Hutton & Williams, 2001; Kugaya et al., 2000; Sollner et al., 20001; Zabora et al., 2001). In fact, several researchers have identified the diagnosis of head and neck cancer as an actual and potential source of considerable emotional distress (D'Antonio, Zimmerman, Cella & Long, 1996; Devins et al., 1994; Semple et al., 2004; Wadsworth et al., 2004). These findings are not particularly surprising when one considers the whole host of added challenges that plague the head and neck cancer population. Although the presence of distress detected in the current study was slightly lower than rates reported in the literature, the importance of distress identification, monitoring and alleviation remains essential.

Much like decrements to QoL, factors increasing the level of distress among individuals with head and neck cancer stem from numerous interrelated and multidimensional factors. Sources of physical distress for individuals with head and neck cancer may include challenges related to stoma maintenance, dysphagia, xerostomia, limited shoulder mobility, oral care issues, altered voice and speech quality, and difficulties with fundamental daily tasks such as eating, breathing, laughing and crying (Doyle, 1994; Eadie, 2007; Gritz et al., 1999; Ledeboer et al., 2005; Owen et al., 2001). Factors that are physically distressing may also be a source of psychological distress. For instance, the side effects of head and neck cancer treatment may include considerable changes to one's physical appearance and ability to communicate verbally, which may result in changes to one's perceived body image and confidence level (Doyle, 2005a). Upon completion of treatment, many individuals with head and neck cancer may experience a number of undesirable side effects including pain, poorly intelligible speech, facial paralysis, drooling and physical scarring which may cause embarrassment and significantly impact social and family interactions (Semple et al., 2004). The consequences of these distressing physical and social side effects of treatment may contribute to negative psychological outcomes as individuals attempt to cope and adjust to treatment-related changes. Ultimately, Doyle (2005) has suggested that individuals diagnosed with head and neck cancer are particularly vulnerable in the early period post-diagnosis. The present findings support the notion that such concerns are real and must be carefully considered and addressed as part of the clinical care process.

Identifying and Responding to Psychological Distress – Implications for Clinical Practice

In order to respond to the consequences of distress among individuals with head and neck cancer, it is imperative to first and foremost recognize the presence of distress. Despite the fact that distress may be causing disruptions in daily functioning, many individuals may conceal their distress from their primary physician and health care team (Weisman, 1976). Individuals displaying such behaviour may rationalize their secretive response as an appropriate one because they believe that their physician and health care team need to focus their energy on the treatment of their disease. Conversely, oncologists and health care 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 et al., 2001; Zabora et al., 2003). The outcome of these combined evasive 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.

Undetected and untreated distress has been associated with poorer medical outcomes, decreased patient satisfaction and increased health care costs (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, & Britzenhofszoc, 2001). In an effort to avoid the unnecessary use of scarce resources, distress levels must be measured routinely at the time of diagnosis and with each subsequent follow-up. Problems that are identified early may be addressed in a timely manner; thus, decreasing the likelihood that such problems will become amplified.

In order to facilitate the identification of distress, the routine use of questionnaires designed to screen for distress, such as the BSI-18, may prove valuable. Distress screening provides a reliable method of identifying individuals who are experiencing problematic levels of distress. The use of surveys may be particularly useful for individuals who do not openly reveal their distress when speaking with physicians and health care professionals (Zabora et al., 2003). Moreover, the use of distress-screening tools may communicate to individuals that their health care team is concerned about their QoL and psychological well-being. Minimally, it is important to incorporate systematic distress screening into patient intake interviews and history taking. Based on its potential for quick scoring and information transfer, the BSI-18 measurement instrument may be an appropriate distress-screening tool for clinical use. Additionally, the BSI-18 is quick to use, time-efficient to administer and most importantly it is a statistically valid tool. Ultimately the routine use of distress-screening tools may provide a cost-effective means of identifying clinically significant distress for individuals with head and neck cancer.

Economic Implications

Despite acknowledgement by the medical community of the significant psychological burden and distress associated with a cancer diagnosis and 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 health care (Bultz & Carlson, 2005). Within Canada where the provision of health care is both publicly funded and delivered, a 1999 survey of provincial cancer centers found that less than three percent of cancer agency operating dollars were directed towards psychosocial care (Bultz, 2002). Although health care administrators in Canada and insurance companies in the United States claim that the system cannot afford to invest more dollars in health care, researchers have countered that we cannot afford to neglect this problem any longer (Bultz & Carlson, 2005).

Indeed, many forms of psychosocial intervention, such as peer-counseling or support groups, place little to no economic burden on the health care system and have been shown to be effective means of decreasing distress (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1995). Additionally, a preoperative visit from an individual who had recovered from head and neck cancer has been reported to be helpful in reducing psychological distress among those with some specific types of head and neck cancer (Pruyn et al., 1986). This may prove to be a more cost-effective and feasible solution for oncology departments cognizant of cost-containment issues. Furthermore, the importance of spiritual support must not be neglected in the larger context of care (Frampton, 2001). For some individuals, spiritual support may serve multiple functions in the long-term adjustment to cancer such as providing a sense of meaning and purpose, giving emotional comfort, maintaining self-esteem, and providing a sense of hope (Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). In order to assist in the provision of spiritual support, hospital chaplains or other clergy should be referred to patients upon request. This may also provide a cost-effective and meaningful source of support for many individuals experiencing distress. It would appear to be clear that investing in psychosocial interventions now is not only the ethically sound choice, but also one that has the potential to result in significant long-term savings to the health care system.

If the well documented benefits of psychosocial interventions and the pervasiveness of distress do not provide a compelling enough argument for addressing the psychosocial needs of individuals with head and neck cancer, perhaps the economic evidence might. For instance, Koocher, Curtiss, Pollin, and Patton (2001) demonstrated marked benefits derived from psychosocial care with no added cost to the health care system. Similarly, Simpson, Carlson, and Trew (2001) were able to show a 25% decrease in medical system billings as a result of a group psychosocial intervention in a sample of women with breast cancer compared with a randomized control group. Perhaps most telling, 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. Thus, through reduction of the emotional burden of cancer, it may also be possible to reduce its associated economic burden. Yet in order to place the needs of individuals with head and neck cancer at the center of the healthcare model, there must be a fundamental shift towards a multidimensional and comprehensive approach to health care. Full recognition of the "human side" of cancer care is essential to a compassionate and well-managed care program. The time has come for health care providers, and the health care system at large, to recognize the role of distress as a fundamental component of health care.

Limitations to the Present Study

As with any research project, certain limitations to the present study must be considered. First, since the study sample was composed of 28 men and 9 women, the ratio of men-to-women (e.g., 3.1:1) was not representative of current Canadian statistics related to the incidence rates of head and neck cancer (e.g., 1:1). This finding, in conjunction with the limited number of female participants limited the generalizability of any gender-specific findings. Additionally, the limited sample size obtained in the present study prohibited the generalization of findings from the present sample to the head and neck cancer population at large.

Second, the lack of participants in the newly diagnosed phase of illness (e.g. 0-3 months) may have contributed the lower presence of distress detected in this study when compared with rates in the literature. Previous studies have indicated that between 25-66% of individuals who have been recently diagnosed with various forms of cancer experience significantly elevated levels of distress (Kugaya et al., 2000; Zabora et al., 1997; Zabora et al., 2001). The high prevalence of distress identified immediately after a diagnosis is not surprising given that a diagnosis of cancer may produce a sense of dread greater than that caused by other serious illnesses which may have a poorer prognosis (Edlund & Sneed, 1989). As time progresses after receiving a diagnosis of cancer, individuals typically mobilize their coping strategies and begin to adjust to the impact of the diagnosis and treatment (Babin et al., 2008) which may consequently contribute to decreasing levels of distress. Generally, the longer the lapse in time from diagnosis and treatment, the better the QoL of the individual (Terrell et al., 2004); thus, the absence of participants representing this critical stage along the continuum of illness, may certainly have contributed to the lower presence of distress detected in the present study.

Third, the demographic measure used in the present study did not contain a measure of illness severity or stage of disease. In retrospect, data of this type may have provided valuable information relative to one's perceived QoL and distress levels throughout the course of illness. Future research regarding distress should ensure to take measures of illness severity and stage of disease into consideration in order to comprehensively address the multidimensional issues related to distress in oncology populations.

Nevertheless, and given the study limitations noted, the present study has provided valuable insights into the issues related to distress and QoL in head and neck cancer. First, the proposed and statistically supported dynamic relationship between distress and QoL has been established within the present study of individuals with head and neck cancer. Further, the use of the abbreviated BSI-18 was determined to be a very efficient and effective screening tool for distress among individuals with head and neck cancer. The BSI-18 was time-efficient and easy to administer and score making it a convenient and practical tool for use in busy clinical environments. Based on these insights, some directions for future research into the identification and management of distress among individuals with head and neck cancer are offered.

Directions for Future Research

The present study demonstrated both that there is a relationship between distress and QoL and also that an individual's psychological functioning (e.g., emotional and cognitive functioning) represents the facet of QoL that is most significantly and negatively influenced by distress among individuals with head and neck cancer. The BSI-18 measure of distress proved to be a valuable screening tool for distress within the present study. As a result of these collective findings, a number of specific recommendations for future research are proposed.

First, since the presence of distress in head and neck cancer populations has been established, it may be valuable to pilot test and subsequently implement a screening program for distress within clinical oncology settings. Since research has determined that many individuals do not openly reveal their distress to health care practitioners (Zabora et al., 2003), the identification of distress without a standardized protocol may prove very difficult. However, the routine measurement of distress at the time of diagnosis and during regular follow-up appointments with health professionals may prove beneficial in the identification of clinically significant distress.

Second, the feasibility of implementing and utilizing electronic surveys or computerized screening for distress should be analyzed. With the impending shift to the usage of electronic health records, it may be valuable to investigate the technological options for distress screening in order to determine ways to seamlessly transfer information from the computerized screening tool to an individual's electronic health record. The use of computerized distress screening through either on-site computerized surveys or regular e-mail survey follow-up may help to facilitate the routine and universal screening of distress in oncology populations.

Finally, the practicality and feasibility of utilizing Telehealth services as a means of distress monitoring should be explored in a research setting. Telehealth infrastructure is already in place in Ontario and is led by trained nurses to provide health counseling free of charge to Ontario citizens. It may, therefore, be valuable for future research to determine the feasibility of Telehealth services incorporating trained social workers and psychiatric nurses to provide psychosocial support and distress monitoring to individuals with identified clinically significant distress. With the noted limitations considered, future research into the identification, monitoring, and alleviation of distress in individuals with head and neck cancer has great potential for success through the provision of important information to improve patient care.

Summary and Conclusion

This research project was designed to investigate and describe levels of distress and QoL in individuals diagnosed with head and neck cancer. Correlations and tests of statistical significance were conducted using data derived from 37 adult participants living with head and neck cancer. Each participant completed a demographic questionnaire in addition to a measure of distress (BSI-18), a global QoL questionnaire (EORTC-QLQ-C30), and head and neck cancer-specific QoL questionnaire (EORTC-QLQ-H&N35). Both *gender* and *distress* served as independent variables for data analysis purposes.

Data indicate that distress was present in approximately one-fourth of all participants and that gender did not significantly influence distress or QoL for the individuals in this study. Additionally, the relationship between QoL and distress was established, suggesting that as one's level of distress increases, their perceived QoL may consequently decrease. The psychological dimension of QoL was identified as the area most significantly impacted by heightened levels of distress.

Through reduction of the psychosocial burden of cancer, it may also be possible to reduce the associated economic burden. Unidentified and untreated distress has been associated with poorer medical outcomes, decreased patient satisfaction and increased health care costs (Zabora et al., 2000). In order to facilitate the identification of distress, routine screening must be employed. Ultimately, the regular use of distress-screening tools may provide a time- and cost-effective means of identifying clinically significant distress for individuals with head and neck cancer. The time has come for health care providers, and the health care system at large, to not only recognize but also respond to the consequences of distress in an efficient and effective manner that optimizes QoL. Attending to the psychosocial needs of individuals with head and neck cancer is an essential component of compassionate and comprehensive health care; it also makes ethical, economic and emotional sense. The use of screening tools to evaluate distress and QoL offers considerable advantages toward the goal of providing the most comprehensive and most compassionate level of care possible. By doing so, care may be enhanced and long-term outcomes may be optimized.

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APPENDIX A

Western

Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. P.C. Doyle
Review Number: 16392E **Review Level:** Expedited
Review Date: August 12, 2009
Protocol Title: A Descriptive Analysis of the Relationship between Distress Level and Quality of Life Among Individuals with Head and Neck Cancer
Department and Institution: Communication Sciences & Disorders, University of Western Ontario
Sponsor:
Ethics Approval Date: August 13, 2009 **Expiry Date:** August 31, 2010
Documents Reviewed and Approved: UWO Protocol, Letter of Information, Telephone Recruitment Script.
Documents Received for Information:

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 study 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 UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

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.

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information

☐ Janice Sutherland	☐ Elizabeth Wambolt	☑ Grace Kelly	☐ Denise Grafton

This is an official document. Please retain the original in your files.

cc: ORE File
LHRI

APPENDIX B

Voice Production and Perception Laboratory
School of Communication Sciences and Disorders
University of Western Ontario

Letter of Information

Title: A Descriptive Analysis of the Relationship Between Distress Level and QoL Among Individuals with Head and Neck Cancer

Study Investigators: Dr. Philip Doyle, Ph.D., Kevin Fung, B.Sc., M.D., Catherine Bornbaum B.H.Sc., M.Sc.(Candidate)

1. Introduction

You are being invited to participate in a research project investigating issues related to distress level and QoL among individuals diagnosed with 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 QoL 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 QoL and level of distress. 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 side effects, emotional strain, social isolation). We are specifically interested in understanding the areas that you find distressing and how these areas influence your QoL. This study will examine areas of concern affecting QoL in 60 individuals who have been diagnosed 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 individuals diagnosed 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 *overall* QoL among individuals diagnosed with head and neck cancer?
c.) Is there a relationship between distress level and *specific domains* of QoL (e.g., physical, psychological, social) among individuals diagnosed with head and neck cancer?

This study represents a M.Sc. thesis project for one of the investigators (C.B.).

3. Activities Participants Will Take Part In
If you agree to participate, you will be sent 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 QoL and distress level in relation to your cancer. The questionnaires have been used before in research and include the Brief Symptom Inventory 18 (BSI-18) to measure distress, the European Organization for Research and Treatment of Cancer (EORTC) QoL Questionnaire (EORTC-QLQ-C30), and the EORTC Head and Neck module (EORTC-QLQ-H&N35), which measure your QoL. 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 15-20 minutes to complete these tasks.

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 Catherine Bornbaum or Dr. Philip Doyle at (519) 661-2111, extension 80583 (cbornba@uwo.ca/pdoyle@uwo.ca).

Twenty (20) individuals (10 men and 10 women) will be requested to repeat this experiment at a later date. In order to determine who will be invited to repeat the experiment, a coin will be flipped for each enrolled participant with the "head" side of the coin indicating that the individual will be invited to participate in this section of the experiment. This procedure of coin flipping will be repeated until 10 male and 10 female names have been collected. The second portion of this experiment will involve completing the same questionnaires as listed above approximately one month after your initial participation. Not everyone will be required to complete the questionnaires twice. Only the 20 individuals determined through the random selection procedure will be invited to complete the questionnaires twice. Once again, all envelopes will be sent with self-addressed stamped envelopes for your convenience. If you are one of the individuals randomly selected for this portion of the study, we ask that you complete the new questionnaires and mail them back once completed. Please note that participation in this additional portion of the study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your current or future medical care.

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 40 or older than 80 years of age, if you have recurrence of your cancer, if you received your diagnosis more than 12 months ago, if you have cancer in any other areas of your body, if you do not read/speak English, or if you are unable to see the questionnaires. These criteria are set because the investigators are trying to obtain information regarding the QoL in individuals who are between 40 and 80 years of age and whose QoL may have been affected by head and neck cancer, and who are not currently being treated for a recurrence or other cancers (as this may influence one's current QoL and/or distress level). 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. If you are participating in another study at this time, please inform the researchers right away to determine if it is appropriate for you to participate in this study.

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 QoL 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, 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 local 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 individuals living with head and neck cancer. This information will have direct implications on future psychosocial patient care and may assist health care practitioners in identifying those individuals who are most likely to experience high distress levels within the first year of treatment for head and neck cancer. Also, the results will give 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 effect on your current or future medical care. You do not waive any legal rights by signing the consent form.

8. Confidentiality

All data collected will remain confidential. All personal identifying information will be removed from the data and your data will be identified by a code known only to the investigators. 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

If you require any further information regarding this research project or your participation in the study please feel free to contact: Dr. Philip Doyle, Ph.D. and/or Catherine Bornbaum B.H.Sc., M.Sc.(Candidate) c/o Voice Production and Perception Laboratory, School of Communication Sciences and Disorders, Elborn College, University of Western Ontario, London, Ontario, Canada N6G 1H1 (XXX) XXX-XXXX, (XXXXX@uwo.ca / XXXXX@uwo.ca).

If you have any questions about your rights as a research participant or the conduct of the study, you may contact: Dr. David Hill, Scientific Director, Lawson Health Research Institute, (XXX) XXX-XXXX.

By completing and returning the questionnaires, you indicate your consent to participate in the study

This letter is for you to keep.

[redacted]

APPENDIX C

Demographic Information Survey

Title: A Descriptive Analysis of the Relationship Between Distress Level and QoL Among Individuals with Head and Neck Cancer

Study Investigators: Dr. Philip Doyle, Ph.D., Kevin Fung, B.Sc., M.D., Catherine Bornbaum B.H.Sc., M.Sc.(Candidate)

Please read the following questions carefully and provide answers as accurately as possible. For multiple choice options, please circle all choices that apply to you. If no suitable options exist, please use the space provided to explain. Also, if there is any additional information that you feel is important to report regarding your level of distress or QoL, please use the back of these pages to include it.

Age:________

Sex: M / F / Other

Number of <u>months</u> since diagnosed: __________

Site of cancer:

a. Oral cavity (e.g., lip, tongue, cheek, tonsil, etc.)
b. Larynx (voice box)
c. Throat (e.g., pharynx, hypopharynx, oropharynx)
d. Thyroid
e. Sinuses/Paranasal sinuses
f. Other

If "other", please specify:____

Marital status:

a. Married
b. Separated
c. Divorced
d. Widowed
e. Common-law
f. Engaged
g. Single
h. Other

If "other", please specify: ____

Occupational status:

a. Currently working – Full-time
b. Currently working – Part-time
c. Volunteer
d. Retired
e. Other

If "other", please specify: ______________________________

Please include any additional information in the space provided below or on the opposite side of this document.

APPENDIX D

[illegible]

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ☐☐☐☐
Your birthdate (Day, Month, Year): ☐☐☐☐☐☐☐☐
Today's date (Day, Month, Year): 31 ☐☐☐☐☐☐☐☐

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

[illegible]

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

APPENDIX E

EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at all	A little	Quite a bit	Very much
31. Have you had pain in your mouth?	1	2	3	4
32. Have you had pain in your jaw?	1	2	3	4
33. Have you had soreness in your mouth?	1	2	3	4
34. Have you had a painful throat?	1	2	3	4
35. Have you had problems swallowing liquids?	1	2	3	4
36. Have you had problems swallowing pureed food?	1	2	3	4
37. Have you had problems swallowing solid food?	1	2	3	4
38. Have you choked when swallowing?	1	2	3	4
39. Have you had problems with your teeth?	1	2	3	4
40. Have you had problems opening your mouth wide?	1	2	3	4
41. Have you had a dry mouth?	1	2	3	4
42. Have you had sticky saliva?	1	2	3	4
43. Have you had problems with your sense of smell?	1	2	3	4
44. Have you had problems with your sense of taste?	1	2	3	4
45. Have you coughed?	1	2	3	4
46. Have you been hoarse?	1	2	3	4
47. Have you felt ill?	1	2	3	4
48. Has your appearance bothered you?	1	2	3	4

Please go on to the next page

During the past week:		**Not at all**	**A little**	**Quite a bit**	**Very much**
49.	Have you had trouble eating?	1	2	3	4
50.	Have you had trouble eating in front of your family?	1	2	3	4
51.	Have you had trouble eating in front of other people?	1	2	3	4
52.	Have you had trouble enjoying your meals?	1	2	3	4
53.	Have you had trouble talking to other people?	1	2	3	4
54.	Have you had trouble talking on the telephone?	1	2	3	4
55.	Have you had trouble having social contact with your family?	1	2	3	4
56.	Have you had trouble having social contact with friends?	1	2	3	4
57.	Have you had trouble going out in public?	1	2	3	4
58.	Have you had trouble having physical contact with family or friends?	1	2	3	4
59.	Have you felt less interest in sex?	1	2	3	4
60.	Have you felt less sexual enjoyment?	1	2	3	4

During the past week:		**No**	**Yes**
61.	Have you used pain-killers?	1	2
62.	Have you taken any nutritional supplements (excluding vitamins)?	1	2
63.	Have you used a feeding tube?	1	2
64.	Have you lost weight?	1	2
65.	Have you gained weight?	1	2

APPENDIX F

Brief Symptom Inventory 18

Instructions:

The Brief Symptom Inventory 18 (BSI-18) test consists of a list of problems people sometimes have. Read each one carefully and circle the number of the response that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem. Do not skip any items. If you change your mind, please draw an X through your original answer and then circle your new answer.

Please answer the following questions according to this scale:

0 = Not at all 1 = A little bit 2 = Moderately 3 = Quite a bit 4 = Extremely

HOW MUCH WERE YOU DISTRESSED BY:

1. Faintness or dizziness	**0**	**1**	**2**	**3**	**4**
2. Feeling no interest in things	**0**	**1**	**2**	**3**	**4**
3. Nervousness or shakiness inside	**0**	**1**	**2**	**3**	**4**
4. Pains in heart or chest	**0**	**1**	**2**	**3**	**4**
5. Feeling lonely	**0**	**1**	**2**	**3**	**4**
6. Feeling tense or keyed up	**0**	**1**	**2**	**3**	**4**
7. Nausea or upset stomach	**0**	**1**	**2**	**3**	**4**
8. Feeling blue	**0**	**1**	**2**	**3**	**4**
9. Suddenly scared for no reason	**0**	**1**	**2**	**3**	**4**
10. Trouble getting your breath	**0**	**1**	**2**	**3**	**4**
11. Feelings of worthlessness	**0**	**1**	**2**	**3**	**4**
12. Spells of terror or panic	**0**	**1**	**2**	**3**	**4**
13. Numbness or tingling in parts of your body	**0**	**1**	**2**	**3**	**4**
14. Feeling hopeless about the future	**0**	**1**	**2**	**3**	**4**
15. Feeling so restless you couldn't sit still	**0**	**1**	**2**	**3**	**4**
16. Feeling weak in parts of your body	**0**	**1**	**2**	**3**	**4**
17. Thoughts of ending your life	**0**	**1**	**2**	**3**	**4**
18. Feeling fearful	**0**	**1**	**2**	**3**	**4**

APPENDIX G

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.)
London Mental Health Crisis Service	Phone: 1-866-933-2023 (Available 24 hours a day, 7 days a week)
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