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Body Image and Quality of Life: An Exploration Among Individuals with Head and Neck Cancer

Melissa M. Nash, *The University of Western Ontario*

Supervisor: Dr. Philip Doyle, *The University of Western Ontario*
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BODY IMAGE AND QUALITY OF LIFE: AN EXPLORATION AMONG
INDIVIDUALS WITH HEAD AND NECK CANCER

(Thesis Format: Monograph)

by

Melissa M. <u>Nash</u>

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

ABSTRACT

Background: One of the most distressing aspects of head and neck cancer (HNC) is the potential for physical disfigurement. Such changes may impact one's body image (BI) with a secondary potential to impact long-term functioning; hence, changes in perceived BI may be seen as a critical component that influences post-treatment quality of life (QOL).

Methods: Forty participants completed 4 validated questionnaires during regular clinical follow-up visits.

Results: Perception of BI image does influence perception of QOL following HNC treatment(s), yet perceptions are highly individualized. Gender related differences are notable on BI questionnaire scores.

Conclusions: Data suggest that efforts to identify changes in perceived BI may not only be of concern for those with obvious levels of disfigurement. Data also suggest that assessment of BI may reduce the potential for post-treatment distress and decreased QOL, thus, should be included in comprehensive rehabilitation efforts to achieve optimal outcomes in those with HNC.

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CHAPTER 1: INTRODUCTION AND BACKGROUND

Introduction

The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1996, p. 107). This definition recognizes that an individual's health is comprised of multiple and interactive factors that fall within a biopsychosocial framework of functioning. The WHO's definition also highlights the fact that myriad factors work together to influence an individual's perception of their own functional status in both health and disease. However, this definition is not fully reflective of what individuals' value in life; therefore, the definition provided by the WHO may be insufficient when considering the many potential changes when an individual faces illness. Consequently, and given the advances in medical treatment for serious illnesses, it may be essential to examine other factors and interactions beyond the content that forms this simple definition. These medical advances have increased the potential that individuals who previously would have succumbed to disease are often now living longer; however, they also may be living with an extended array of the long-term effects of both the health condition experienced and the associated consequences of treatments for those conditions.

Quality of life (QOL) may be defined as "the perception of individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"((WHOQOL), 1993; WHO, 1997, p. 1). From this definition a number of key concepts can be identified that are inherent to understanding the experience of illness as interpreted by the individual who is

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ill. First, the definition recognizes that one's perceived QOL is highly individualized. Second, it recognizes that QOL is multidimensional in nature and that it may be influenced by multiple domains of functioning; including physical, social and psychological. Thirdly, it explicitly recognizes that QOL is a dynamic concept; which suggests that it will change across the lifespan and may vary across situations and contexts. QOL is in fact an ever changing, dynamic process that is contextually bound. The use of this definition can, however, aid in the understanding of the experiences of those who are diagnosed and treated for serious and life threatening conditions. As a result, the content of this broad definition becomes essential to more fully documenting levels of disability and the subsequent impact on one's QOL. The impact of disease and its associated treatment(s), can impact multiple areas of an individual's life and result in long-lasting and potentially permanent changes that may force alterations to how an individual functions in society.

One health condition that has the potential to impact the person in a highly individualized way and across multiple areas of functioning is head and neck cancer (HNC). HNC refers to any malignancy other than skin cancer "…that lies above the clavicle, but excludes the brain, spinal cord, axial skeleton and vertebrae" (Dropkin, 1999, p. 309). One of the most difficult and often persistent challenges facing this group of cancer survivors may be their (in)ability to cope with the various changes to their physical appearance and not only physical but also social functioning as a result of the disease and its associated treatment(s) (Fingeret et al., 2011). More explicitly, the multi-faceted consequences of HNC and changes secondary to treatment may be quite obvious to others; changes may include both those that are auditory (alterations in the

characteristics of one's voice and speech) and/or visual (alteration in physical features of the head and/or neck). For females there may be particular concern due to the tendency for women to compare their physical appearance with internalized cultural expectations (Boquiren, Esplen, Wong, Toner, & Warner, 2013). Given the dramatic changes in appearance and functioning that commonly result from treatment of HNC, a disturbance in one's "body image" may emerge, develop, and potentially interfere with adjustment, especially with the resumption of previous roles and routines, which subsequently may impede the important task of rebuilding the self (Boquiren et al., 2013).

Additionally, when normal verbal communication is disrupted as a result of treatment, additional disability may occur because of the change in one's voice and/or speech capabilities. Although concerns regarding changes in appearance and self-perception may occur within the context of multiple malignant conditions, these concerns may be of particular significance to those treated for HNC because of the high visibility of the affected area to others. Also, it has been recognized that the need for this clinical population to have multimodal treatment (i.e., surgery, radiation, chemotherapy, and combined modalities) may introduce additional body image changes; as a result of these additional and often extensive treatments, further decreases in QOL may be increased commensurately (Fingeret et al., 2011). Yet one core component of the impact of treatment for HNC centers on changes to one's physical being and the perceptions and attitudes one has toward those changes. For that reason, concerns related to the concept of body image may be raised relative to this unique clinical population.

Defining Body Image

As a concept, "body image" is an incredibly complex entity that requires careful consideration and assessment with all oncology patients, regardless of one's gender. However, given the complexity of concerns specific to body image and due to the fact that its perception and impact are both highly individualized, significant barriers to assessment and identification may emerge. As a direct result, conducting research in the realm of body image poses real and considerable challenges. The most prominent limitation pertains to the fact that operational definitions of what "body image" represents are limited; at times, definitions used tend to be simplistic and are often inconsistent across studies. There is no definitional "gold standard" specific to body image as a measureable entity. For example, White (2000) notes that the term body image is often used interchangeably with aspects of psychological adjustment such as sexuality or stigma. Consequently, this definitional narrowing may neglect to consider the extent to which an individual invests in their own appearance as it relates to one's own cultural characteristics (White, 2000) and potentially, expectations. That is, therefore, an index of the value that a given individual places on their appearance in relation to the perceived expectations that are judged to be of value within the society that they live.

Body image is in fact a multifactorial construct that reflects much more than solely one's view of his or her physical appearance. It can include perceptions, thoughts, and feelings about an individual's entire body and how the person's body functions (Fingeret et al., 2011), as well as our ability to relate to others (Sertoz, Doganavsargil, & Elbi, 2009). Body image is, therefore, dynamic in nature and occurs largely at a subconscious level (Dropkin, 1999) with strong links to the standards of "normal" that

are set by society (Goffman, 1963). Consequently, the idea that body image is reflected in our social interactions should be included in the definition (Dropkin, 1999). Fingeret, Yuan, Urbauer, Weston, Nipomnick and Weber (2011) note that an essential element of the body image experience is that, due to the subjective nature of the construct, the experience "may not reflect the objective reality of the body" (Fingeret et al., 2011, p. 836). Similarly, Boquiren, *et al.* (2013) note that body image represents "a dynamic interaction between the personal expression of being and the social world" and that dissatisfaction with the resultant physical changes might have negative effects on many psychosocial domains (Boquiren et al., 2013, p. 2177). Boquiren *et al.* also suggest that individuals recognize that there exists a "standard", or set of expectations, regarding physical appearance and behavior and that this "standard" will be monitored and evaluated while fulfilling all the roles for a given individual (Boquiren et al., 2013). In recognizing the broad nature of body image as a pertinent concept of recovery, rehabilitation, and survivorship, can be considered the social environment in which the individual interacts as paramount in the development of body image and its associated ideals and requisite perception by each person.

Issues of Survivorship

The National Cancer Institute (NCI) at the National Institutes of Health (NIH) describes "survivorship" as the focus "on the health and life of a person with cancer post treatment until the end of life" (NCI, 2014). The NCI further elaborates that survivorship covers areas that are associated with the physical, psychosocial, and economic issues of cancer, those that extend beyond the diagnosis and treatment phases, as well as the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and

quality of life. The NCI additionally suggests that the survivorship experience includes family members, friends, and caregivers, as well as the individual who has been diagnosed with cancer. This definition of survivorship is highly inclusive; however, the National Coalition for Cancer Survivorship would likely prefer the explicit addition that "survivorship" begins at the point of diagnosis (Ganz, 2011). The use of an all-inclusive definition to guide the survivorship experience has the potential to influence every aspect of care for individuals and their family or caregivers as they manage the challenges associated with a diagnosis and treatment for cancer.

This more inclusive definition of survivorship has the potential to be the guiding framework for which treatments are designed at the inception not only to cure, but also to diminish the long-term side effects and other critical effects of cancer and its associated treatments. Using survivorship as a guide has the potential to encourage the development of less invasive surgical treatments as well as to explore the development of chemotherapeutic approaches that may exist with fewer harmful, toxic side effects. Using this broader definition of survivorship also may advocate for the inclusion of pre-treatment counseling to minimize the potential for distress associated with the disease, its treatments, and the potential accompanying disfigurement (Ganz, 2011; Hausman, Ganz, Sellers, & Rosenquist, 2011). Doing so also may encourage reconstructive therapies that coincide with curative treatment. Additionally, the use of the survivorship definition as a guide may further suggest that there should be long-term strategies for follow-up care, to manage any late effects of treatment and provide recommendations to help re-integrate individuals into life roles following the treatment phase of cancer care. Providing this type of care will help to maximize the health and well-being of all cancer survivors

(Alfano, Ganz, Rowland, & Hahn, 2012). There is tremendous potential to help mitigate potential distress associated with all aspects of the cancer experience when all phases are guided by the concept of survivorship when it is initiated at the point of diagnosis and continued through the treatment and rehabilitation phases of the cancer experience. With the provision of guidance regarding expectations following treatment phases the distress experienced by those individuals who are touched by cancer may be significantly lessened, particularly for those individuals who will experience disfigurement as a result of treatment. Clearly changes in one's body image, real and/or perceived, holds the substantial potential to result in social penalty with its associated negative impact on QOL. Thus, more formal consideration of aspects that comprise the concept of body image would appear to be an important and valuable area of exploration within a clinical context. For this reason, a brief discussion related to the social impact of physical disfigurement secondary to HNC will be presented in the subsequent section of this review.

Social Impact of Disfigurement

There is a large body of research that documents that physical "attractiveness" or "normalness" has a dramatic effect on the social impressions generated by others (Rankin & Borah, 2003; Rumsey & Harcourt, 2004; Tantleff-Dunn & Lindner, 2011). This body of work has generally revealed that individuals who are perceived to have a more "attractive" or "normal" appearance are regarded to have more desirable personal qualities than those deemed "unattractive" or "different" (Levine, Degutis, Pruzinsky, Shin, & Persing, 2005; Rankin & Borah, 2003; Tantleff-Dunn & Lindner, 2011). This perception of attractiveness means that individuals who are considered more physically

attractive are often more popular and are more likely to experience feelings of social

connectedness. This has been demonstrated across the lifespan while beginning in

childhood (Rumsey & Harcourt, 2007; Tantleff-Dunn & Lindner, 2011). It has been

recognized that perceptions of body image begin in childhood and that these perceptions

will continue to influence our social interactions throughout life (Rumsey & Harcourt,

2007). There also exists emerging research which suggests that social functioning is not

only impacted by actual perceived physical "attractiveness", but also by how an

individual perceives his or her own body (Tantleff-Dunn & Lindner, 2011). Individuals

who report more negative perceptions of their body tend to report greater discomfort in

social situations and exhibit and increased level of social avoidance (Tantleff-Dunn &

Lindner, 2011). This social avoidance may subsequently impact interpersonal

relationships, occupational status, and potentially familial relationships. Individuals who

are considered different, or who have a facial disfigurement in particular, often report

perceptions of intrusive staring by others or public avoidance by the individual (Levine et

al., 2005). This intrusion or avoidance may lead to or be the result of increased negative

self-perception and negative body image. This negative body image has the potential to

lead to decreased QOL (Levine et al., 2005; Tantleff-Dunn & Lindner, 2011), in that a

negative self-perception or perceived negative assessment by others is likely to result in a

decrease in perceived self-worth. A lack of self-worth may result in an individual

experiencing a level of social disadvantage that leads to increasing levels of disability.

In the presence of a negative body image, social disadvantages may result due to

perceptions of decreased worth and an unwillingness to interact with others. Regardless

of the presence of actual disfigurement or its degree, individuals who experience negative

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perceptions of body image are also likely to experience poorer social functioning than those individuals who have more positive impressions of one's self. Thus, personal awareness of a physical change and its potential recognition by others may create real and lasting challenges, particularly in those for whom the change has been a consequence of medical care. Lastly, those individuals who present with actual facial "differences" will recognize their difference while also experiencing others' reactions; collectively, this has the potential to decrease one's overall perceived QOL. The interpretation of other's reactions also may lead to different perceptions of one's ability to function and may impact the individuals perceived ability to fulfill previous life roles. When such factors are considered in the context of cancer, the likelihood for changes in one's body image to create substantial downstream negative effects and resultant disability at multiple levels of functioning cannot be disregarded.

Social Consequences of HNC

As noted by Katz and colleagues (2003), it is well recognized that one of the most potentially distressing aspects of HNC is the potential for facial disfigurement and its associated high visibility to others. This challenge is often persistent and difficult for individuals to overcome. The facial region is highly associated with one's self-concept, interpersonal relationships, and is essential in communication (Katz, Irish, Devins, Rodin, & Gullane, 2003). Further, the human face instantly displays aspects of the self to others including one's age, sex, race, health, and mood. Our facial appearance is a primary factor in how we are identified to others as individuals (Borah & Rankin, 2010). It also is well recognized that facial scars can have a significant negative impact on social functioning (Borah & Rankin, 2010; Brown, McKenna, Siddhi, McGrouther, & Bayat,

2008; Rankin & Borah, 2003; Rumsey & Harcourt, 2007). In this regard, changes to the face or neck region that occur due to cancer or its treatment, an especially common occurrence in those with HNC, have the potential to significantly decrease an individual's ability to function socially and ultimately impact broader perceptions of overall functioning and QOL.

The change from a socially accepted appearance to potential disfigurement following treatment for HNC can promote a negative body image. For example, body image disturbances following treatment for cancer may be associated with a variety of changes that can have a significant impact on QOL (e.g., psychological distress, anxiety, reduced physical health, sexual dysfunction) (Boquiren et al., 2013; Dropkin, 1999; Frierson, Thiel, & Andersen, 2006; Katre, Johnson, Humphris, Lowe, & Rogers, 2008). Considering the harmful and broad psychological effects of distress (Bornbaum et al., 2012), an effort to reduce distress is likely the most critical prerequisite component of care in that it may foster active participation by the individual in the rehabilitation process (Doyle, 1994; Doyle & Keith, 2005). Therefore, the importance of explicitly assessing psychological needs at key points in the care pathway, or perhaps better stated as the survivorship trajectory, as well as the ability to provide psychological support as part of routine service provision is now gaining wide acknowledgement in oncology (Cash & Smolak, 2011).

As previously suggested, changes in physical appearance and subsequent influences on perceived body image and/or self-concept following the diagnosis and treatment of HNC may be particularly distressing. A study by Bornbaum, *et al.* (2012) noted that individuals who have untreated distress tend to have poorer medical outcomes.

This study also suggested that visible disfigurement tends to have an impact on social functioning along with other psychosocial consequences and that the associated changes which emerge may lead to increasing levels of distress, which may negatively impact QOL to an even greater extent (Bornbaum et al., 2012).

QOL, as a comprehensive construct, is highly impacted by an individual's perceptions of his or her health. There exist many psychosocial domains that are impacted by an individual's perceived health and, therefore, alterations in these domains can influence QOL. When an individual is diagnosed and treated for a serious health condition, many areas of that individual's life can be significantly impacted. HNC is one condition that has significant life altering implications. These implications may be due to the potential for HNC and its associated treatment(s) to alter perceptions of one's self. Such changes in one's body image can have a significant impact on the ability to fulfill life roles as an individual may interpret the changes in their appearance and ability to physically function as so severely altered that they no longer recognize their self-worth. Further, due to the high potential for facial disfigurement as a result of treatment, the individual's ability to function socially may be altered and the associated negative attention or stigma that is received following treatment may have devastating consequences. Therefore, perception of body image can be seen as a potentially key determinate of QOL. Clearly, HNC and its treatment (regardless of modality) have a high potential to create a negative change in body image. Consequently, body image should be addressed as part of comprehensive treatment beginning with the initial stages of planning for survivorship, throughout treatment and also to end of life. However, as of yet, explorations of body image in those with HNC have been somewhat limited. Based

on the importance of body image on the larger concept of QOL, as well as the dearth of information related to this potential relationship, explorations into changes in perceived body image in those treated for HNC may be of considerable importance as an outcome metric.

Head and Neck Cancer in Canada

In Canada, statistics indicate that 10,850 new cases of HNC were diagnosed in 2013. The anatomical site of malignancies contained in this estimation include the oral cavity, larynx, and thyroid (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). This is an increase of the estimated 10,650 new cases diagnosed in 2012 (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). Approximately, 4910 of these cases were diagnosed in men and 5940 in women (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Men were more likely to be diagnosed with oral cavity or larynx cancers than women, at a rate of less than 3:1 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). However, more women were diagnosed with thyroid cancers than men at a rate of 3.5:1 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). A summary of this data is provided in Table 1. Approximately 15 years ago, statistics would have been substantially different with the overall ratio ranging from approximately 10:1 to 15:1 cases of HNC diagnosed in men compared to women (Woodard, Oplateck, & Petruzzelli, 2007). This change in demographics will have a complex impact on treatment and outcome related variables. The potential variables that may interact to influence treatment decisions include an individual's age or stage of life, the type of familial responsibilities an individual may have, employment, religious beliefs or a combination

of such personal characteristics. These potential influences among other possibilities are essential considerations for an individual to decide what treatments may be best for their life.

Table 1: Estimated new cases of cancer by sex, Canada, 2013.*

Cancer	Total	Male	Female
Thyroid	5,700	1,260	4,440
Oral	4,100	2,800	1,300
Larynx	1,050	850	200
Total	**10,850**	**4,910**	**5,940**

*Adapted from Table 1.2, Canadian Cancer Statistics, 2013.

Treatment choices may reflect life circumstances, in that participants may choose more aggressive life sustaining treatments because of familial responsibilities or look for options that provide a rapid recovery in order to return the ability to fulfill life roles. Alternatively, treatments may be determined by the least invasive option to avoid physical scars. In 2010, Wessels, Graeff, Wynia, De Heus, Kruitwagen, Woltjer, Teunissen and Voest noted that male and female patients with varied sites of cancer differed in their preferences specific to the extent and manner of communication, counseling and rehabilitation, length of consultation, and choices in treatment and care (Wessels et al., 2010). Participants included in this study had diagnoses of breast, gastrointestinal, urogenital, head and neck, lung and skin cancers. The types of treatments chosen may take into consideration the long-term outcomes and the preferences for the new population of HNC patients more so than previously when consideration is given to survivorship from the point of diagnosis. At times, treatments also may be chosen based on the ability to hide physical scars. This may be a particular concern for younger HNC survivors because this group may live longer with the long-term effects of the treatment.

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The influence of treatment related alterations in body image has been recognized through the study of body image in multiple clinical populations; however, the full extent has not been considered within the HNC group. Therefore much of what has been learned about body image for this group has developed from the study of body image within other clinical populations.

Background: Research on Body Image

Body image has profound importance to the full range of the human experience. It has been studied in diverse disciplines and professions including medicine, psychology, anthropology and philosophy and many theories of its significance and development have been constructed. To understand the differing perspectives of body image it is important to first understand the lineage of the construct itself. In order to accomplish this objective it is essential to understand how body image research began, how it expanded, and the focus of body image as a current area of research.

In the early 1900s, research on body image or what was then termed "body schema", began with an attempt to understand the unusual forms of body perception associated with brain injuries. It was also studied in an effort to understand the phenomenon of sensory experiences of "phantom limbs" in those who had limbs amputated. It was then thought to be "a hypothetical neural mechanism whereby changes in body posture and movement were proposed to be centrally coordinated" (Cash & Smolak, 2011, p. 4). However, it was in 1935 that Paul Schilder, a neurologist, was responsible for moving the study of body image beyond the domain of strictly neuropathology. In his book, *The Image and Appearance of the Human Body* (1950), Schilder proposed that the construct would be better understood through a

biopsychosocial paradigm. He emphasized the need to examine not just the neurological

aspects, but to also give consideration to psychological and sociocultural elements

(Schilder, 1950). In psychology, interest in body image was first acknowledged with the

work of Seymour Fisher and Sidney Cleveland (1968) and later by Franklin Shontz

(1969). Beginning in 1958, these early researchers, published theories based on

psychodynamic views (Fisher & Cleveland, 1968), field theory, Gestalt psychology, and

cognitive theory (Shontz, 1969). As a result of this early work, efforts emerged with the

goal of seeking to apply these concepts to the study of disability and health. Of

paramount importance was the work of Shontz who introduced the concept of self-

perception into the study of body image (Cash & Pruzinsky, 1990). The recognition that

an individual's self-perception was essential to understanding the construct of body

image furthered the ability to study it in multiple clinical conditions.

The evolution of scholarship that focused on body image occurred during the

1990s with the work of Thomas Cash, Thomas Pruzinsky and J. Kevin Thompson (Cash

& Pruzinsky, 1990; Thompson, 1990, 1996). Their research stressed the

multidimensionality of body image and expanded research in the fields of disfigurement,

disability, rehabilitation (Cash & Pruzinsky, 1990) and relative to eating disorders

(Thompson, 1990, 1996). Where the concept of body image was previously considered

one-dimensional and perceptual in nature, Cash *et al.* (1990) expanded this concept so

that the multidimensional nature of body image could be pursued. This was accomplished

through the consideration that both perceptual dimensions (i.e., physical appearance,

fitness, and health) and attitudinal dimensions (i.e., affective, cognitive and behavioral

domains) be integrated conceptually (Keeton, Cash, & Brown, 1990). Thus, during the

1990s a surge in both scientific and clinical interest into eating disorders and body dysmorphic disorder incited a tremendous increase in research into the assessment and understanding of these experiences and alterations to perceived body image. Given that the key diagnostic characteristics of these conditions pertain to body image, the study of body image dysfunction has led to an increased understanding of body image development. This understanding relates not only to when significant pathology exists, but also where a positive body image has been developed.

Research into body image has continued and expanded in recent years, with an increasing focus on disfiguring conditions (i.e., breast cancer, dermatological conditions [e.g., psoriasis] or rheumatic conditions [e.g., rheumatoid arthritis]) and the potential for disability that the consequences of these disorders may create. Further expansion has also continued in an effort to understand cosmetic surgery, body altering pharmaceuticals, and the growing popularity of these issues for both genders. Body image assessment has become a priority with a focus on developing better tools to aid in the identification of body image disturbance. A second priority of body image research is the development of effective treatment methodologies for body image disturbance. Ultimately, decades of research on body image has expanded our understanding of this topic within multiple fields of study and countless publications have been constructed to illustrate the multitude of theories about body image that exist (Cash & Smolak, 2011; Grogan, 2008; Rumsey & Harcourt, 2012). Therefore, efforts that seek to more fully understand the potential impact of changes in body image on one's functional status in the context of other health conditions have continued to emerge.

Body image, and appearance in general, are identified as particularly valuable in contemporary Western culture. This emphasis is easily identified through the media's use of images for marketing a variety of products. One perspective on body image development that considers this value is the sociocultural perspective (Tiggemann, 2004, 2011). This perspective holds as a central tenet that sociocultural ideals and pressures are paramount in the manifestation of an individual's body image and specifically body image dissatisfaction or disturbance (Tiggemann, 2011). A basic understanding of this perspective holds four central beliefs. The first is that there exist culturally specific societal ideals of appearance and functioning. For example, in Western culture, the ideal for women is considered to be youthful, with a tall and thin body with moderately large breasts, tanned yet not too tanned, and clear skin. Second, these ideals are transmitted through various sociocultural channels, that is, family, peers and media. A casual glance at the covers of most magazines illustrates how this ideal is exemplified and transmitted in Western culture. Thirdly, individuals are believed to internalize these standards or derive an individual meaning from them with a subsequent level of importance becoming associated with this ideal. And finally, a level of satisfaction (or potentially dissatisfaction) with one's self (appearance and functioning) will develop based on the extent to which that individual fits into the prescribed ideals of the individual's culture (Tiggemann, 2011). This level of satisfaction is created through the internal comparison of the individual to this prescribed ideal based on the amount of value given to the ideal by a given individual. Collectively, these four central beliefs have been utilized to study body image and further the understanding of body image.

The sociocultural perspective has traditionally been applied in the realm of body weight and body shape; however, it could also seemingly be applied to any aspect of body image wherein an individual could potentially deem himself or herself to be different or deficient from "normal" or "expectation". In principle, this theory could be applied equally as well to other body features such as breast size, eye shape, size of scar or facial symmetry (Tiggemann, 2011). The sociocultural theory, however, presents with both limitations and strengths. First, when considered in its simplest form, the theory suggests that everyone would experience extreme body dissatisfaction, particularly in Western culture where the ideal is essentially unreachable for the average person; this is obviously inaccurate. Though all individuals may perceive themselves different at some point in time, not everyone will experience an extreme body image disturbance as a result of the difference they believe exists. Therefore, this theory is missing the identification of potential mediating factors that may protect individuals from this level of distress. Yet this perspective does provide a simple way to understand the importance of body image as it results from interactions with an individual's culture. Research also has demonstrated that societal ideals are passed through media, family and peers to individuals, which leads to a comparison with these ideals (Thompson & Stice, 2001). Though the research by Thompson and Stice provides support for this theory, further research is required to determine the full level of applicability of the sociocultural theory for understanding the complex nature of body image, particularly in situations where treatment of a health conditions increases the likelihood of changes in one's perception of body image.

A second perspective on body image originally introduced by Albert Bandura, recognizes the impact of sociocultural values and is termed the "cognitive-behavioral" perspective. One of the central components of cognitive-behavioral theory is observational learning. "Observational learning occurs when an organism's responding is influenced by the observation of others, who are called models" (Weiten, Dunn, & Yost Hammer, 2012, p. 48). Essentially, this description suggests that we learn what (societal) expectations exist, how to respond to them, and how we should act through watching others who are similar to us; that is, we learn male and female behaviors and expectations. To further understand the cognitive-behavioral perspective as it relates to body image development and functioning it is important to distinguish between factors that can be referred to as "historical" and those that are "proximal". This distinction is critical in that it illustrates how body image is created as well as what factors exist that maintain body image throughout an individual's life.

Historical factors are those events in an individual's life that influence how one comes to think, feel and act with respect to their body. Among these "historical" factors are cultural socialization, family and peer relationships, physical characteristics and the individual's personality (Cash, 2011). These factors create fundamental body image attitudes through social learning and cognitive processing that relate to the level of body image evaluation and investment that an individual will experience. In this context, evaluation refers to the level of satisfaction or relative dissatisfaction that an individual experiences and investment refers to the amount of value that the individual places on this evaluation (Cash, 2011).

In contrast, proximal factors refer to those current influences that either contribute to the maintenance of one's body image or force an alteration to one's previously held perception. A large volume of scientific research relating to body image has foundations in the cognitive-behavioral perspective. Specifically, this perspective has led to a greater understanding of eating disorders, body dysmorphic disorder, and an individual's reactions to appearance altering conditions such as vitiligo, burns or accidents and cancer (Cash, 2011). This perspective, like others, has most frequently been used in the study of body image disturbance; however, it also can be readily applied to the development of a positive body image. Thus, this perspective is understandably considered a tremendous asset to the overall study of body image as a conceptual entity. Given that this perspective has been used to guide body image research, it may be essential to consider the paradigms associated with the cognitive-behavioral perspective when pursuing body image research. Indeed a large body of research has used the cognitive behavioral perspective to guide the study of body image within clinical populations. The perspective has been used particularly to study disordered eating, not only to further the understanding of the how the disorder is developed, but also as a way to guide treatments.

Since eating disorders have been associated with severe medical and psychosocial morbidity and immense health care costs, it is understandable that significant inquiry into understanding this group of conditions as well as their associated treatments and outcomes has developed. Eating disorders are more frequently diagnosed in adolescent and young adult women, with an estimate that up to 90% of diagnosed cases are identified in females. Research associated with eating disorders, including anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise

specified (EDNOS), has had a significant impact on our understanding of body image disturbances. Among these conditions there exist some similar diagnostic criteria that relate to issues of body image including an intense preoccupation and negative feeling with regards to an individual's own body shape, weight and/or size (American Psychological Association, 2000). A further similarity among these eating disorders is that there exists a disturbance in the amount of influence of body weigh or shape has on the individual's evaluation of self-worth (American Psychological Association, 2000). These weight and shape issues are present regardless of the current state of the individual's body. However, a disturbance in body image can be considered not only as a key diagnostic feature, but also as a potential risk factor for the development of an eating disorder. Body image disturbance is also seemingly the most persistent symptom, as it frequently remains after other behavioral symptoms are resolved (Crowther & Williams, 2011; Hrabosky, 2011; Selwyn Delinsky, 2011).

Research and treatment for eating disorders most frequently centers on beliefs associated with the cognitive-behavioral perspective (Crowther & Williams, 2011; Hrabosky, 2011; Selwyn Delinsky, 2011). These treatments may involve a therapy to correct the disordered patterns of cognition associated with body image disturbance. The effectiveness of this type of treatment has furthered the understanding of the concept of body image development and maintenance. This has been accomplished with the success of therapies that help individuals overcome eating disorders and develop a more positive body image. Understanding the role of body image in these conditions has provided a true basis for the understanding of body image as it relates to other conditions, specifically those that result in disfigurement. Such disfigurement may be found to be the

direct result of a condition as it is for many dermatologic conditions or it may be the result of treatment(s) for a condition as it frequently is for cancer.

Another condition, through which the research has helped to guide our understanding of disfiguring conditions, is that of body dysmorphic disorder (BDD) or dysmorphophobia. This condition, which has also been studied through the theoretical framework of the cognitive-behavioral perspective (Phillips, 2011), is the preoccupation with an imagined defect in appearance; or, if a slight "abnormality" does exist, the individual experiences excessive concern relating to that perceived defect (American Psychological Association, 2000). This concern is associated with clinically significant levels of distress and may impair social functioning in all settings (i.e., familial or occupational) (Phillips, 2011). Additionally, this impairment in functioning will frequently result in markedly poor QOL (Phillips, 2011). The prevalence of this condition which reportedly ranges from 0.7% to 53% has been studied within many different populations including high school or college-aged students, general psychiatric in-patients, dermatology patients, and those undergoing cosmetic surgery (Phillips, 2011). The reported prevalence rates of BDD are population specific rather than general and are therefore bound by definition. These highly varied prevalence rates become an issue for the study of this condition as it creates difficulty in determining the actual prevalence among the general population. This variability makes it unclear if higher rates of BDD are present among individuals in any specific group; i.e. individuals who seek cosmetic procedures. The incomplete understanding of the prevalence creates difficulty in determining the existence of a causal relationship that may suggest that BDD is a cause for individuals to seek these procedures. The inability to determine cause and effect

further highlights the necessity to provide special consideration to the population being studied when considering the applicability of body image research to varying populations in that the existence of arbitrating factors may influence an individual's perception of body image. It also illustrates that while concerns of body image are recognized, efforts to understand how it may impact the individual who experiences this problem remain important. In the context of those undergoing ablative procedures for head and neck cancer, such research would appear to be of critical value relative to outcome monitoring.

Within body image research it appears crucial that consideration be given to the fact that a large proportion of research has been completed using college-aged participants. However, it is recognized that this experimental group may not provide a sufficient understanding of body image across the lifespan, as college-aged participants may not be representative of the larger adult population, particularly those with health conditions that may result in physical alterations as a consequence of medical treatment. Given that some alterations in physical appearance are expected throughout an individual's lifetime, some of which may be more pronounced in women, it should be expected that body image changes would befall over the course of one's life.

A review of empirical research on body image in adults found that body dissatisfaction, most of which was related to body shape and/or weight, was surprisingly stable across the adult lifespan for women until an elderly age, which was considered individuals aged 65-85 years among the studies found during the review process (Tiggemann, 2004). The Tiggemann study also identified a distinction for older women that highlighted the difference between body image evaluation (dissatisfaction) and investment (importance) (Tiggemann, 2004). Further this study found that the relative

importance of body shape, weight and appearance decreased with increasing age despite the lack in change of dissatisfaction (Tiggemann, 2004). Tiggemann, however, did identify that significant gaps in the literature still exist and this appreciably limits the understanding of body image across the lifespan (Tiggemann, 2004). The study of body image across the lifespan remains an area that requires significant research consideration. Additionally, there should be a specific focus on the potential differences in the perception of body image between genders throughout the lifespan, as currently information is limited.

Special consideration must be given to the differences between how men and women may perceive body image. There exists a cultural emphasis on how women's bodies look and how men's bodies function (Murnen, 2011). Although this gap is slowly diminishing, gender differences likely remain in prevailing Western society. In fact, Rankin and Borah (2003) found that culturally, "white" women with facial abnormalities regardless of cause of "disfigurement", were judged more harshly than women of other ethnicities and were judged significantly more harshly than men. Both men and women are provided with body image ideals based on cultural expectations and gender roles; however, it has been recognized that an emphasis on appearance is considered increasingly important for women which has created the suggestion of a trend for higher levels of body image disturbance in women (Murnen, 2011).This gender difference has been noted through the study of many conditions affecting body image including eating disorders (Crowther & Williams, 2011; Hrabosky, 2011; Selwyn Delinsky, 2011), body dysmorphic disorder (Phillips, 2011), dermatology (A. R. Thompson, 2011) and oncology (Boquiren et al., 2013). This increase in incidence is potentially related to a

heightened level of body image evaluation in combination with the culturally reinforced body image investment that women experience. This trend seemingly exists regardless of culture (Murnen, 2011).

In contemporary Western culture, women often fill multiple roles in society (e.g., mother, employee, and volunteer). However, there is often an expectation that women will have employment outside of the home, are still responsible for raising children, and yet the expectation persists to fulfill these roles while still maintaining a focus on their appearance and potentially even a demand that this be a priority. This experience is often referred to as being the "super woman" who fulfills all obligations with "effortless perfection" (Murnen, 2011, p. 178). However, when a woman, particularly a younger woman is faced with illness, this ability to fulfill all the expected roles may be significantly diminished. Given the expectations of the "super woman" conceptualization, it may then create the potential for significant distress when one is unable to achieve this expectation. This is not to suggest that men will not also experience distress, but simply that women may experience a heightened level with respect to body altering illness due to this perceived increase emphasis on appearance. This emphasis is related to the cultural expectation that women meet a certain appearance ideal. As suggested by the theories of body image development, the extent to which a woman values this expectation may determine how perceptions of body image may relate to perceptions of self-worth (Przezdziecki et al., 2013). This perception of self-worth can influence our patterns of interaction with others (e.g., an individual who has positive perceptions of self-worth, will likely express more confidence during interactions with others). It also may relate to how we perceive others who may or may not meet the "ideal" image.

It has long been recognized that a perceived challenge for those who experience facial disfigurement is a difficulty centered on the patterns of interaction with others (Borah & Rankin, 2010; Macgregor, 1990). These patterns of interaction may serve to reinforce positive or negative perceptions of body image. If an individual has a negative body image, they may experience distress particularly when trying to engage in social interactions. In the face of illness, this negative perception can subsequently influence overall health outcomes, particularly when the illness holds the potential for disfigurement as it does with many oncologic conditions. Therefore, while this concern is of specific concern relative to HNC and its treatment, it has not been fully addressed in the literature.

In the field of oncology, a substantial amount of study has been given to the impact of body image change following breast cancer. In fact, the greatest amount of body image research in oncology has focused on breast cancer. This research focus is understandable given that women are known to experience greater concern than men for body image. Further it is understandable because breast cancer primarily affects women and directly relates to a physical attribute that is considered part of a woman's "ideal" appearance. The breast is recognized as having both social and societal connotations and is attributed to the concept of femininity, motherhood, as well as sexuality (Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Helms, O'Hea, & Corso, 2008). Treatment for breast cancer may be invasive and may result in physical deformity due to lumpectomy or to complete breast removal via mastectomy (Helms et al., 2008; Przezdziecki et al., 2013). Research has illustrated that these surgical procedures can have a negative effect on psychosocial functioning through changes in identity or body

image, confidence or esteem, and/or sexuality and overall QOL (Helms et al., 2008; Rosenberg et al., 2012). The consequences of diagnosis and treatment in this cancer site also have often been linked with substantial distress (Carver et al., 1998). This distress is particularly significant when an individual's self-worth is substantially based on appearance (Boquiren et al., 2013; Carver et al., 1998). Thus, the broader impact of changes in body image on perceived QOL is well documented in the literature.

Research among breast cancer survivors has shown that women who identify less contentment with their body image are more likely to experience greater adjustment problems, higher levels of anxiety and depression, and lower QOL (Begovic-Juhant et al., 2012). The knowledge gained from breast cancer research may help to inform the understanding of the impact of body image on other types of cancer as well. However, despite the breadth of research that has been conducted on the impact of disfigurement on those treated for breast cancer, little research has focused on post-treatment appearance changes in general for other cancers. Further, few studies have evaluated potential influencing factors on perceptions of body image. More specifically, this would include factors such as the site of cancer, patient age, and/or gender on the individual's resultant body image following treatment for cancer (Nozawa et al., 2013). Past research has indicated that individuals who undergo a physical change later in life, rather than those that occur at birth or in childhood will experience greater psychological distress. The suggested reason for this phenomenon that has been posited is that these individuals will grieve for their previous appearance and sense of self while simultaneously dealing with the reactions of others (Begovic-Juhant et al., 2012; Bradbury, 1997). This acknowledgement of the various interactive factors affecting body image is essential to

understanding how body image is influenced following diagnosis and treatment of HNC.

However, information on the presence and simple identification of perceived changes in

body image in those treated for HNC is clearly lacking. The ability to gather such data

would provide the starting point for increased understanding of the multiple issues that

may influence perceptions of body image and its influence on QOL in the post-treatment

period.

In 2013, Rhoten, Murphy, and Ridner reviewed literature on research regarding

body image (as a psychosocial construct) in HNC (Rhoten, Murphy, & Ridner, 2013).

The search yielded only nine studies that were published in English without any date

parameters illustrating the paucity of empirical research on this topic (Rhoten et al.,

2013). Additionally, of these nine publications, the authors found that only five had used

measurement instruments that were specific to body image (Rhoten et al., 2013). The

study specifically found that there is a lack of research pertaining to the relationship

between body image and other psychosocial variables. It also found that there is an

absence of empirical work that considers potential features, like gender, age or the

amount of time since diagnosis that may influence the perception of body image among

HNC survivors. However, despite the relatively small number of studies that have been

conducted in this area, a few commonalities have emerged. Collectively, these studies

reported that 36-77% of participants studied presented with concerns about body image

following treatment for HNC; in at least some instances, participants also reported

associated distress (Rhoten et al., 2013). Most frequently, body image concerns were

correlated with depression and social avoidance (Rhoten et al., 2013). And finally, post-

surgical coping effectiveness was decreased when a concern about body image was

present (Rhoten et al., 2013). It is therefore in the best interest of both the individual and the care providers to identify individuals who are both at risk for and are experiencing body image disturbance in order to achieve optimal rehabilitation.

The 2013 literature review by Rhoten, Murphy and Ridner also presented a model of the primary causal factors associated with body image disturbance for individuals who have been treated for HNC. The authors posit that disfigurement results not only from the resection of tumor and the resultant scars, but also from the impairment in one's ability to produce facial expressions that are necessary for typical non-verbal communication (Rhoten et al., 2013). Secondary to physical disfigurement, HNC is often associated with some level of dysfunction in the ability to speak, eat and swallow. Such dysfunction also may be associated with a change in body image or self-image that will continue to impact an individual's ability to function (Rhoten et al., 2013) and fully participate in a variety of situations. The resultant disfigurement and dysfunction associated with HNC ultimately may then lead to a disturbance in perceived body image and may subsequently increase the likelihood of psychological distress with may further decrease perceived QOL.

In other disease populations, body image disturbances and disfigurement have been shown to result in a profound social disability (Millsopp et al., 2006). Social disability may be associated with stigma surrounding the diagnosis and treatment for HNC, as it has often been attributed to negatively perceived personal behaviors (Lebel et al., 2013). Specifically, stigma may emerge due to the fact that the diagnosis of HNC have been associated historically with excessive alcohol and tobacco use and more recently with the human papillomavirus (HPV) (Kreimer et al., 2013) which can be

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sexually transmitted. Therefore, in some instances, HNC has been viewed as being "self-inflicted" and the associated behavioral traits are viewed negatively by society (Lebel et al., 2013). Due to the changes in perceived body image and the potential for stigma, many individuals with HNC feel unable to return to the previous roles they fulfilled in personal, professional, and social environments (Lebel et al., 2013; Rhoten et al., 2013). When an inability to return to full, pre-diagnosis functioning exists, a lower perceived quality of life will likely result for many. However, this reduction in QOL may be further exacerbated in those individuals who experience a concomitant disturbance in body image. Clearly, concerns related to body image in those with HNC require consideration from the point of diagnosis and continuing throughout survivorship. Based on other data from the broad oncology literature, as well as the limited information on those with HNC, more research is required in order to more fully understand how the concept of body image may be altered in this unique and important clinical population.

Summary

Body image has the potential to influence almost every aspect of an individual's life. Throughout life there are many influences that may alter a given individual's body image, particularly when physical appearance is altered due to illness and/or its treatment. While much of what is acknowledged regarding body image in HNC has been inferred from the study of body image in other populations, the understanding of body image remains somewhat limited. Additionally, and specific to those treated for HNC, there are limited data on how body image may be impacted via HNC. It is recognized that one of the most potentially distressing aspects of HNC is the potential for physical disfigurement and the high potential for its visibility to others. However, there is limited information on

how changes in perceived body image may also influence the individual's broader perceptions of QOL. Through efforts to better understand how the perception of body image and the interpretation of the reactions of others influence an individual's perception of his or her ability to function in life roles, we also may better understand how body image influences QOL.

Physical changes, most particularly those of the face and neck, may directly impact one's body image with secondary potential to impact short- and long-term functioning. It is, therefore, understandable that changes in perceived body image may be seen as a primary factor that influences broader treatment outcomes in association with HNC. Treatment outcomes will influence QOL as the results determine the perception of functional ability. Changes in body image and perceived QOL hold the clear potential to interfere with one's resumption of previous roles and routines after treatment is completed and may consequently impede the rebuilding of one's self and facilitate improved rehabilitation outcomes. Thus, the purpose of the present study sought to identify and describe potential changes in body image in individuals treated for head and neck cancer.

Statement of Problem

Advances in medical technology and treatment have provided those diagnosed with cancer with a greater chance of survival than has been observed previously. These advances in some instances have led to reductions in distress from the physical symptoms that accompany many cancer treatments (Nozawa et al., 2013); yet distress continues to persist for many individuals who are treated for cancer. The distress experienced has been demonstrated to result from multiple psychosocial variables (Nozawa et al., 2013). Body

image can be considered the subjective concept of one's appearance and ability to function based on the individual's thoughts and feelings, as well as perceptions of others' reactions (Dropkin, 1999). Body image can further be thought of as one psychosocial variable that can potentially influence distress that an individual may experience following cancer treatment in general. HNC is a condition with tremendous potential for body image change due to the high visibility to others of the affected and treated area. To date, however, little empirical research has sought to describe and illustrate the manifestation of body image for those with HNC. Further, because body image may play a considerable role in one's self-concept, social re-entry, and rehabilitation during the post-treatment period, body image may have a real and direct impact on QOL. Consequently, this study was designed to identify and describe the presence of changes in perceived body image in those treated for HNC and to address its potential relationship to perceived QOL in this unique clinical population. The specific questions posed in the present study were:

1) Do individuals who have been diagnosed and treated for HNC report concerns regarding perceived body image?

2) Are measures of body image related to overall perceived QOL?

3) Do differences in perceived body image exist between men and women?

CHAPTER 2: METHODS

Participants

The population utilized in this study included men and women between the ages of 31 and 65 years who had been diagnosed with and treated for a head and neck malignancy. The mean age of all participants was 54.9 (SD = 8.14) with the mean age for men being 56.4 years (SD = 5.9, range 45 – 65 years) and the mean age of women being 50.3 years (SD = 12, range 31 - 65 years). The individual site of primary cancer diagnosis was varied among participants; however, the majority of participants had been diagnosed with oral cancer (see Figure 1).

Potential participants were initially identified by their primary otolaryngologist (head and neck surgeon) during regular surgical follow up appointments. The physician briefly outlined the purpose of the study; if the participant was interested in further information and potential participation in the study, then the physician requested that the researcher provide additional information. The primary researcher would then present full details on study involvement. Ethical approval was granted based on these stipulations from Western University's Health Sciences Research Ethics Board and Lawson Health Research Institute.

Seventy individuals were initially identified as potential participants. Once each of them was provided with complete information concerning the study, these individuals were then provided with a package containing a detailed letter of information, a demographic information sheet, four surveys, and a contact list for local and national organizations that provide aid to individuals with cancer. Returning the completed surveys provided formal consent to participate in the project. Of these 70 consented

participants, 30 males and 10 females ultimately completed and returned full packages to the researcher. Of these 40 participants, 16 were treated with surgery alone, six with surgery and radiation therapy, 10 with surgery, radiation and chemotherapy, one with surgery and chemoradiation, two with radiation alone, two with chemoradiation, two with chemotherapy and radiation therapy and one with chemotherapy alone (see Table 1 for complete participant details).

Figure 1: Participant Site of Cancer Origin
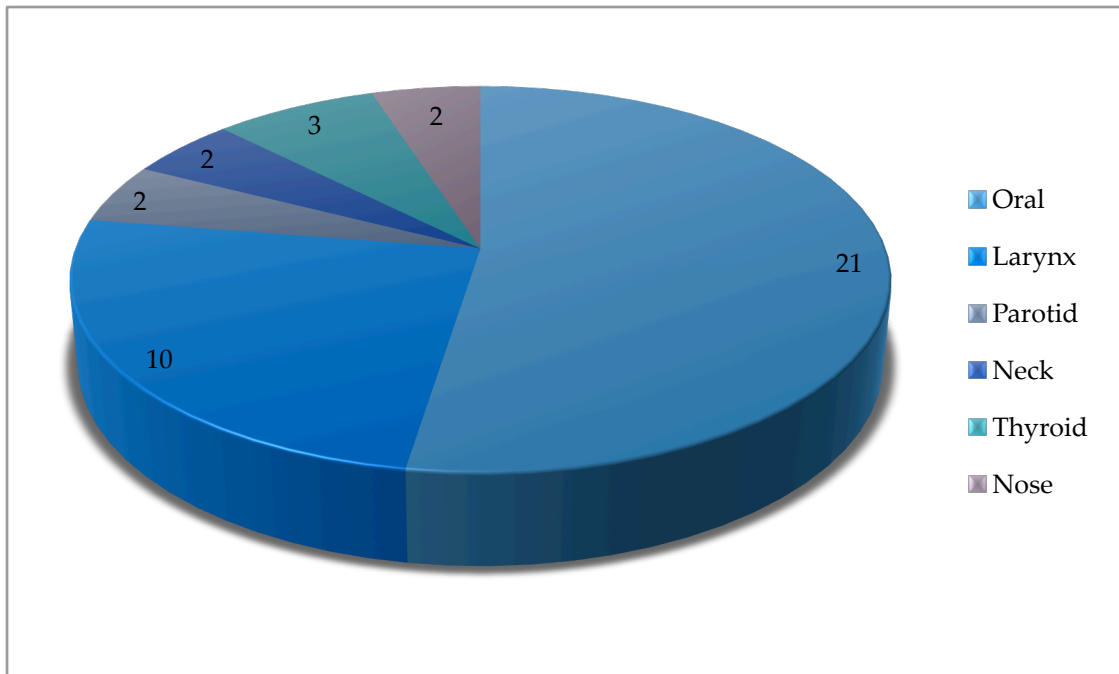
Table 2: Participant Demographic Information

Demographics			Disease/ Treatment Characteristics		
Gender			**Cancer Site**		
Male	30		Oral	21	
Female	10		Larynx	10	
Age – mean + SD	54.9 (8.14)		Other	9	
Range	(31-65)				
Partnered			**Time since diagnosis**		
Yes	34		Within last year	9	
No	6		Within last 5 years	24	
			Within last 10 years	7	
Education Level			**Treatment Modality**		
Completed High school	19		Surgery alone	16	
Completed College	9		Surgery, radiation and chemotherapy	10	
Completed Undergraduate Degree	4		Surgery and radiation	6	
Completed Post-Graduate Degree	7		Other	8	
Other	1				

Inclusion Criteria

All participants were required to meet the following criteria for inclusion in the

study: were between the ages of 18 and 65 years of age, had been diagnosed and treated

for HNC, and had not had a previous diagnosis of cancer (regardless of site within the

body). All participants were required to present with a self-report of good general health

outside of their cancer diagnosis. Additionally, participants had to be a minimum of three

months but not greater than 10 years post treatment. The nature of the project also required inclusion criteria that stipulated participants be able to read, write, and understand English in order to provide informed consent and complete the research tasks that were involved in the study.

Exclusion Criteria

Participants with skin cancers (basal cell, squamous cell, or melanoma) were excluded from the study, in addition to those who reported a previous diagnosis of another cancer regardless of primary site. Participants also were excluded from participating in the study if their age fell outside the required range (18-65), if the individual had experienced a recurrence of cancer, if they had completed treatment less than three months at the time of contact, or more than 10 years ago. Finally, potential participants were excluded if they did not read/speak English, or if their vision did not permit them to see the questionnaires.

Data Acquisition Procedure

This study used four previously validated, self-rated, written measurement questionnaires. Two of the questionnaires were designed in an effort to specifically address each participant's self-perceptions of his/her body image and two were designed to address issues relating specifically to quality of life. As part of the package provided to participants, demographic information was also obtained. Upon receiving the package, participants were provided with the option to complete the survey package on site or take the package and return it by mail with prepaid postage. The entire package included a demographic information survey, the Body Image Scale, the Body Image Disturbance Questionnaire, the European Organization for the Research and Treatment of Cancer

Quality of Life Questionnaire, as well as their site-specific module for head and neck cancer. The package also contained a contact list for local and national organizations that provide assistance to individuals who have been treated for cancer.

Measurement Instruments

The *Body Image Scale* (BIS). The BIS is a 10-item self-report questionnaire, which utilizes a scaled response format that ranges from "Not at all" to "Very much". Responses to questions seek to ascertain information on each individual's self-perceptions of their physical appearance and any changes that may have resulted from their illness/disease and/or associated treatments. The BIS was explicitly designed for use with oncology populations; however, it was not specifically developed for application for those with head and neck cancer. The validation of the BIS was conducted with both male and female participants, however, the age range was not reported in the study (Hopwood, Fletcher, Lee, & Al Ghazal, 2001). Validation participants had been diagnosed and treated for a range of cancer sites including breast, large bowel, testis, gynecological cancer, or lymphoma. Thus, this group comprised participants with both visible and non-visible alterations in appearance. While not previously validated for those with head and neck cancer, the BIS has previously been used with this clinical population (Fingeret et al., 2012; Fingeret et al., 2011). The results from these studies collectively indicate that the BIS is a reliable and valid tool for use in this unique cancer population. Each question included on the measures provides a score from zero to three. Once completed, the 10 item scores are then summed to provide an overall summary score for the respondent, with this score ranging from zero to 30. Zero scores represent no perceived symptoms/distress and higher scores represent one's perception of an

increasing level of symptoms/distress. It should further be noted that the existence of a clinically significant score has yet to be determined and therefore the interpretation of all scores continues to be highly subjective. However, inferentially a score close to the maximum score of 30 may suggest that an individual is experiencing significant concern.

The *Body Image Disturbance Questionnaire* (BIDQ). The BIDQ is a seven-item self-report questionnaire which utilizes scaled response questions, as well as open-ended questions to elicit additional information on each individual's perception of themselves or their body image. This measurement instrument has been shown to be reliable and valid within a non-clinical sample of male and female college/university-aged participants. Although this instrument has not been used previously within an oncology population, it does demonstrate significant face validity for use within those diagnosed and treated for a malignancy.

The language used throughout the BIDQ questionnaire is neutral and not specific to any type of health condition. This use of neutral language illustrates the usability of this questionnaire within any clinical population that could perceive themselves as exhibiting a deficiency in any aspect of body image (Cash, Phillips, Santos, & Hrabosky, 2004). Each question is rated using a scoring from one to five. A score of one suggests the individual is "Not at all concerned or preoccupied" and a score of five suggests the individual is "Extremely concerned or preoccupied" with issues related to the concept of body image. The measure is ultimately scored as a single mean value of the seven items, which similar to each question, ranges from one to five. If there are missing data on no more than a single item of the instrument, the BIDQ score may be calculated by substituting the respondent's mean overall score for the missing item. Once scoring is

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completed, a greater mean score on the BIDQ suggests a greater perceived disturbance in body image and/or one's preoccupation with a perceived physical defect that results in one's altered perception(s) of body image. In addition to the scaled response questions, this questionnaire utilizes five open-ended questions for participants to elaborate on their response and to provide additional information regarding the individual's specific concerns regarding their body.

This instrument was validated using college-aged individuals and has not previously been used within a clinical oncology population. The validation using college-aged individuals may create a concern with the interpretation of scores for those individuals who have experienced a cancer diagnosis and its associated treatments. Further differences in age may impact the score as well as the inclusion in a clinical population. It should also be noted that a clinically significant score has not been determined at present and therefore the interpretation of scores is considered subjective.

The European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). The EORTC QLQ-C30 is a 30-item self-report questionnaire, which utilizes a scaled response to ascertain an individual's perception of his or her quality of life. The first 28 questions require scaled responses that range from a score of "1" (not at all) to a score of "4" (very much). These questions are related to specific symptoms and types of functioning. The final two questions are scaled that ranges from "1" (very poor) to "7" (excellent) with these scores related to global perceptions of the individual's health and quality of life. This questionnaire was designed specifically for use with oncology populations with any site of origin (Niezgoda & Pater, 1993). The questionnaire has been validated with individuals who have been diagnosed

with a multitude of different cancers including the following sites: lung, breast, ovarian, and head and neck; validation has also been conducted using both male and female participants with exception of those cancer sites that are specific to sex (Osoba, Zee, Pater, Kaizer, & Latreille, 1994).

By design, the EORTC QLQ-C30 provides a variety of scoring options and areas to consider. More specifically, it provides a global quality of life score, a score for each of five scales of "functioning" including physical, role, emotional, cognitive and social, as well as nine symptom or item scales that are quantified using both a raw score and a transformed score. A linear transformation is used to standardize the raw score so that scores from each scale will have the same range. Transformed scores are designed to range from zero to 100. When scores are transformed, a higher score is representative of a higher response level; that is, a high score for the global health status suggests a high perceived quality of life and high score for a functional scale represents a high (or healthy) level of functioning. This is in contrast to a high transformed score on a symptom scale, which represents a high level of symptomatology or problems being experienced. This interpretation highlights a potential complication with the use of the transformed score, in that the different categories are interpreted differently while still using the same scale. This transformation may further complicate interpretations as the numeric value between scores is not representative of any specific difference between levels of functioning or the experience of symptoms (Fayers et al., 2001). It should also be noted that the presence of statistically significant difference between scores for any comparison group may not reflect a clinically significant difference (Fayers et al., 2001).

This scoring transformation and interpretation is the same that is used for each of the site-specific modules created to complement the use of the core EORTC questionnaire.

The European Organization for the Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ- H&N35). In addition to the core EORTC QLQ - C30 questionnaire participants were also asked to complete the EORTC Head & Neck cancer module (EORTC QLQ-H&N35). This site-specific measure is a 35-item self-report questionnaire. This supplemental module addresses concerns that may be commonly reported for those who are being treated for head and neck cancer. According to the recommendation of the EORTC working group (Aaronson et al., 1993), site specific modules such as the H&N35 are to be used in combination with the EORTC QLQ-C30 to assess symptoms and side effects of treatments, social functioning and body image/sexuality. The first 30 questions of the module are scored from "1" (not at all) to "4" (very much) and the final five questions are scored in a binary fashion as either "1" (no) or "2" (yes). Similar to the generic measurement tool that is common to all cancers, scoring the module also produces both a raw and transformed score in the same format as the QLQ-C30 and results in 18 domains/items. For all domains/items, higher scores are suggestive of the participant's perception that they experience greater problems in a given area of functioning.

Data Collection

The population studied in the present investigation was considered a sample of convenience. Consecutive selection was utilized and 70 potential participants who met all inclusion and exclusion criteria were identified. Data collection occurred within a single outpatient, tertiary care site at London Health Sciences Center, Victoria Campus,

London, Ontario, Canada. Participants were recruited between November 2013 and

February 2014.

Data Analysis

Once completed packages were received, each participant's scores were

calculated, according to the recommended guidelines for each measure (e.g., a calculation

of the sum of all scores for the BIS). The global quality of life, five functioning scales

and the nine symptom scales from the EORTC QLQ-C30, and the 18 symptom scales

from the QLQ-H&N35 were recorded. The single BIS and the single BIDQ scores were

also obtained. Statistical analysis included descriptive statistics, parametric statistics

including t-tests and Pearson correlation coefficients and nonparametric Mann-Whitney

U-tests when deemed appropriate because of distributional concern. Supplemental

observational assessments also were undertaken to compare other factors including age,

time since diagnosis, treatment modality, and site of cancer origin.

CHAPTER 3: RESULTS

Initially, descriptive statistics including measures of central tendency were identified for all questionnaire packages returned by participants. Second, t-tests and Mann-Whitney U-tests comparing genders were completed for three scores (the BIS, BIDQ and Global QOL). A t-test and Mann-Whitney U-test were also performed comparing scores between the BIS and BIDQ. Finally, a Pearson correlation matrix was completed using all domain scores determined to have face validity related to the concept of body image.

The comments provided by participants through the open-ended questions included on the BIDQ were read to identify any additional topics that participants felt were not addressed through the instruments that related to perceptions of body image. This was done in an effort to further understand the experiences of individuals who participated.

Following the a priori plan for evaluation of the data, supplemental analyses were also completed. This included observational comparisons for scores from the BIS, BIDQ and Global QOL with specific attention directed to participant age, time since diagnosis, cancer site, and treatment modality and the potential influence these factors may have on perceived body image and QOL.

Descriptive Statistics

Forty of 70 packages (59%) were completed and returned for analysis; 10% were completed on site with all others returned by mail. Measures of central tendency were calculated for the participants' responses to each question as raw scores, and each domain score as transformed scores, for each of the four instruments.

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Body Image Scale (BIS)

Mean, mode and median scores were calculated for each question contained in the BIS instrument and these scores are presented in Table 3. Interestingly, Question 2 (*"Have you felt less physically attractive as a result of your disease or treatment?"*) had the highest mean, while Questions 4 and 5 (*"Have you felt less feminine/masculine as a result of your disease or treatment?"* and *"Did you find it difficult to look at yourself naked?"*, respectively) had the lowest mean. However, even though the scores could only range from 0 - 3, the range in mean scores for each question was small at 0.33-0.63. The mode and median scores also illustrate that the majority of participants do not experience the concerns that are addressed and potentially captured on the BIS questionnaire.

Table 3: BIS: Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Q1	40	0-3	0.48	0	0	0.68
Q2	40	0-3	0.63	0	0	0.81
Q3	40	0-3	0.4	0	0	0.71
Q4	40	0-3	0.33	0	0	0.69
Q5	40	0-3	0.33	0	0	0.69
Q6	40	0-3	0.53	0	0	0.78
Q7	40	0-3	0.35	0	0	0.8
Q8	40	0-3	0.45	0	0	0.75
Q9	40	0-3	0.43	0	0	0.81
Q10	40	0-3	0.43	0	0	0.71

Body Image Disturbance Questionnaire (BIDQ)

Table 4 presents the mean, mode and median scores for each of the seven questions posed in the BIDQ. It should be noted that Question 6, (*"Has your physical "defect" significantly interfered with your schoolwork, your job, or your ability to function in your role? How much?"*), revealed the highest mean, while Question 2, (*"If*

you are at least somewhat concerned [about the appearance of some part of your body],

do these concerns preoccupy you? That is do you think about them a lot and they're hard

to stop thinking about?"), had the lowest mean among participants. However, similar to

the difference among scores on the BIS, and with a scoring range of 1 – 5 for each

question, there was only a small range in mean scores observed (i.e., 1.4 - 1.83). The

mode and median scores further illustrate that few participants indicated that they

experienced any concern or preoccupation with the concepts captured in the BIDQ.

Table 4: BIDQ: Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Q1	40	1-5	1.7	1	1	1.07
Q2	40	1-5	1.4	1	1	0.81
Q3	40	1-5	1.65	1	1	0.98
Q4	40	1-5	1.73	1	1	1.01
Q5	40	1-5	1.7	1	1	0.97
Q6	40	1-5	1.83	1	1	1.28
Q7	40	1-5	1.73	1	1	1.06

European Organization for the Research and Treatment of Cancer Quality of Life

Questionnaire (EORTC QLQ-C30)

The mean, standard deviation, and range of scores for each of the 30 questions on

the EORTC QLQ-C30 are shown in Table 5. Responses to Questions 18 ("*Were you*

tired?") and 22 ("*Did you worry?*"), which were both related to self-ratings in the

previous week, were shown to have the highest mean values indicating that this group of

participants experienced at least "a little" fatigue and worry. It should be noted that this

analysis excluded Questions 29 and 30 because they were scored using a different scale.

Conversely, Question 5 ("*Do you need help with eating, dressing, washing yourself or*

using the toilet?") exhibited the lowest mean. Measures of central tendency for each of

the domains (Global QOL, physical, role, emotional, cognitive and social functioning,

fatigue, nausea, pain, dysponea, insomnia, appetite loss, constipation, diarrhea and

financial difficulties) were calculated for this instrument and are presented in Table 6. Of

the functional domains, the physical domain was shown to have the highest mean value,

while global QOL was shown to have the lowest mean value. This indicates that

individuals who participated in this study perceived that their physical functioning is at a

more optimal level, while they perceive their global QOL to be less optimal. Review of

the symptom domain showed "insomnia" to have the highest mean, while "nausea" was

shown to have the lowest mean. This suggests that greater symptomatology could be

attributed to more psychological aspects of functioning while physical functioning would

seemingly be perceived as generally good.

Table 5: EORTC QLQ-C30 Question-Based Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Q1	40	1-4	1.65	1	1	0.92
Q2	40	1-4	1.6	1	1	1.01
Q3	40	1-4	1.28	1	1	0.75
Q4	40	1-4	1.1	1	1	0.3
Q5	40	1-4	1.03	1	1	0.16
Q6	39	1-4	1.5	1	1	0.91
Q7	40	1-4	1.53	1	1	0.82
Q8	40	1-4	1.5	1	1	0.96
Q9	40	1-4	1.6	1	1	0.78
Q10	40	1-4	1.73	1	2	0.85
Q11	40	1-4	1.88	1	2	0.94
Q12	40	1-4	1.55	1	1	0.71
Q13	40	1-4	1.43	1	1	0.78
Q14	40	1-4	1.15	1	1	0.36
Q15	40	1-4	1.05	1	1	0.22
Q16	40	1-4	1.25	1	1	0.59
Q17	40	1-4	1.13	1	1	0.33
Q18	40	1-4	1.9	2	2	0.71
Q19	40	1-4	1.38	1	1	0.74
Q20	40	1-4	1.35	1	1	0.53
Q21	40	1-4	1.68	1	1.5	0.8
Q22	40	1-4	1.9	2	2	0.87
Q23	40	1-4	1.45	1	1	0.64
Q24	40	1-4	1.55	1	1.5	0.6
Q25	40	1-4	1.75	2	2	0.74
Q26	40	1-4	1.48	1	1	0.75
Q27	40	1-4	1.73	1	1	0.91
Q28	40	1-4	1.55	1	2	0.9
Q29	40	1-7	5.5	6	6	0.99
Q30	40	1-7	5.65	6	6	1.21

Table 6: EORTC QLQ-C30 Domain-Based Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Global Health Status						
G-QOL	40	0-100	75.78	83	79	17.26
Functioning Scales						
Physical	40	0-100	88.83	100	100	18.37
Role	40	0-100	82.43	100	100	26.13
Emotional	40	0-100	79.15	100	83	20.17
Cognitive	40	0-100	81.65	100	83	18.75
Social	40	0-100	80	100	100	25.94
Symptoms						
Fatigue	40	0-100	24.03	0	22	23.21
Nausea	40	0-100	3.35	0	0	8.6
Pain	40	0-100	18.88	0	8.5	29.91
Dyspnea	40	0-100	16.63	0	0	32.01
Insomnia	40	0-100	29.1	0	33	31.94
Appetite loss	40	0-100	14.1	0	0	25.99
Constipation	40	0-100	8.33	0	0	19.64
Diarrhea	40	0-100	4.13	0	0	11.05
Financial Difficulties	40	0-100	18.33	0	0	30.19

European Organization for the Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35)

Table 7 summarizes findings for all of the QLQ-H&N35 questions, which were scaled based on the individual's experiences in the past week. Question 41 ("*Have you had a dry mouth?*") exhibited the highest mean score. Also of note are the questions reporting the lowest mean scores; specifically Questions 36 ("*Have you had problems swallowing pureed food?*") and 64 ("*Have you lost weight?*"). Two participants each

failed to respond to a single question, hence, the data presented are reduced accordingly. The range, mean, mode, median and standard deviation scores for each domain from the QLQ-H&N35 are shown in Table 8. Of these symptom domains, use of "nutritional supplements" and experiencing "dry mouth" were shown to have the highest mean, while reliance on a "feeding tube" was shown to have the lowest mean. This result suggests that, of the symptoms captured in the H&N35, "dry mouth" was most often experienced by participants in this study, but reliance on a feeding tube for nutrition was a seemingly rare occurrence.

Consistency of Responses

The responses provided by participants illustrate consistency or seeming intra-rater reliability in their perceptions of both QOL and body image. In instances where individuals provided a better score on perceived global QOL from the EORTC QLQ-C30, the other functional domains were also assessed in a similarly high manner, which suggests more positive perceived functioning. Similarly, when individuals identified a worse score for perceived global QOL, they also reported worse scores on perceptions of functioning across the domains from the EORTC questionnaires, as well as perceptions of increasing symptomatology on the symptom domains and items. Also, participants with a high score on the BIS exhibited similar high scores on the BIDQ. Recall that for these scales, a higher number score is indicative of heightened body image concerns or increasing likelihood of body image disturbance. Interestingly, participants who reported a poor score for global QOL also reported worse scores on each the BIS and BIDQ. This suggests those participants who are experiencing greater perceived concern with aspects of body image also experience worse perceived QOL.

Table 7: EORTC QLQ-H&N35 Question-Based Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Q1	40	1-4	1.4	1	1	0.67
Q2	40	1-4	1.38	1	1	0.63
Q3	40	1-4	1.35	1	1	0.58
Q4	40	1-4	1.25	1	1	0.49
Q5	40	1-4	1.2	1	1	0.51
Q6	40	1-4	1.1	1	1	0.3
Q7	39	1-4	1.68	1	1	0.95
Q8	40	1-4	1.48	1	1	0.75
Q9	39	1-4	1.47	1	1	1.03
Q10	40	1-4	1.55	2	2	1.01
Q11	40	1-4	2.3	1	2	0.95
Q12	40	1-4	1.85	1	1	0.75
Q13	40	1-4	1.23	1	1	0.87
Q14	40	1-4	1.6	1	2	0.9
Q15	40	1-4	1.85	1	1	0.94
Q16	40	1-4	1.7	1	1	0.36
Q17	40	1-4	1.15	1	1	0.36
Q18	40	1-4	1.53	1	1	0.88
Q19	40	1-4	1.6	1	1	0.84
Q20	40	1-4	1.2	1	1	0.65
Q21	40	1-4	1.5	1	1	0.88
Q22	40	1-4	1.65	1	1	1.03
Q23	40	1-4	1.55	1	1	0.91
Q24	40	1-4	1.45	1	1	0.81
Q25	40	1-4	1.2	1	1	0.52
Q26	40	1-4	1.45	1	1	0.75
Q27	40	1-4	1.33	1	1	0.8
Q28	40	1-4	1.18	1	1	0.59
Q29	40	1-4	1.63	1	1	0.84
Q30	40	1-4	1.68	1	1	0.89
Q31	40	1-4	1.28	1	1	0.45
Q32	40	1-4	1.45	1	1	0.5
Q33	40	1-4	1.03	1	1	0.16
Q34	40	1-4	1.1	1	1	0.3
Q35	40	1-4	1.15	1	1	0.36

Table 8: EORTC QLQ-H&N35 Domain-Based Measures of Central Tendency

	N	Range	Mean	Mode	Median	SD
Symptoms						
Pain	40	0-100	10.59	0	8	14.02
Swallowing	39	0-100	12.26	0	0	17.67
Senses Problems	40	0-100	14.65	0	0	23.96
Speech Problems	40	0-100	18.55	0	11	23.96
Trouble w/ Social Eating	40	0-100	16.25	0	0	25.67
Trouble w/ Social Contact	40	0-100	10.93	0	7	19.66
Less Sexuality	40	0-100	23.35	0	8.5	24.46
Teeth	39	0-100	15.71	0	0	23.96
Opening mouth	40	0-100	18.3	0	0	34.54
Dry mouth	40	0-100	43.3	33	33	34.02
Sticky Saliva	40	0-100	28.28	0	33	31.67
Coughing	40	0-100	27.4	0	33	30.11
Felt ill	40	0-100	4.95	0	0	11.93
Pain Killers	40	0-100	27.5	0	0	45.22
Nutritional Supplements	40	0-100	45	0	0	50.38
Feeding Tube	40	0-100	2.5	0	0	15.81
Weight Loss	40	0-100	10	0	0	30.38
Weight Gain	40	0-100	15	0	0	36.16

Gender Comparisons

A t-test was performed to compare scores between women and men for the Global QOL, BIS and BIDQ scores (see Figures 2, 3 and 4 for visual comparison). A statistically significant difference between genders was found only on the BIS score ($t = 2.128$; $df = 38.2$, $p < 0.04$). Because of concern regarding the uneven sample sizes across gender and the potential that data were not normally distributed, a Mann-Whitney U-test was also preformed for these comparisons. In this case, a statistically significant difference was found for both the BIS and BIDQ scores ($U=83.5$, $p=0.036$ and $U=87.5$, $p=0.050$).

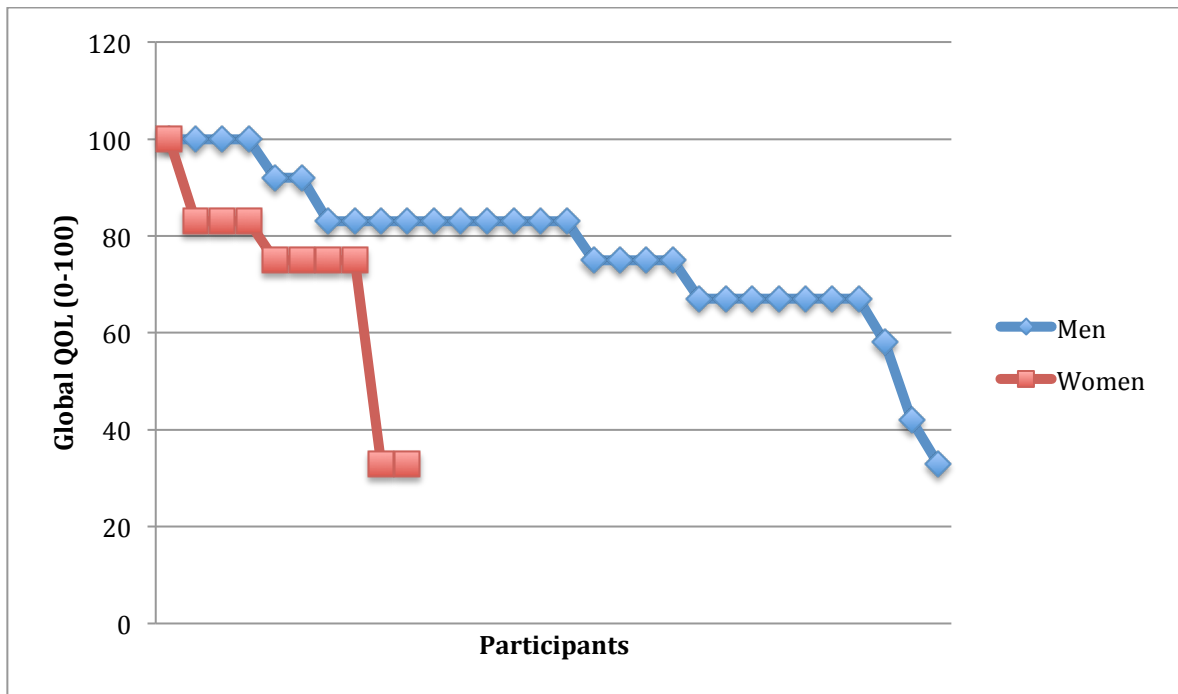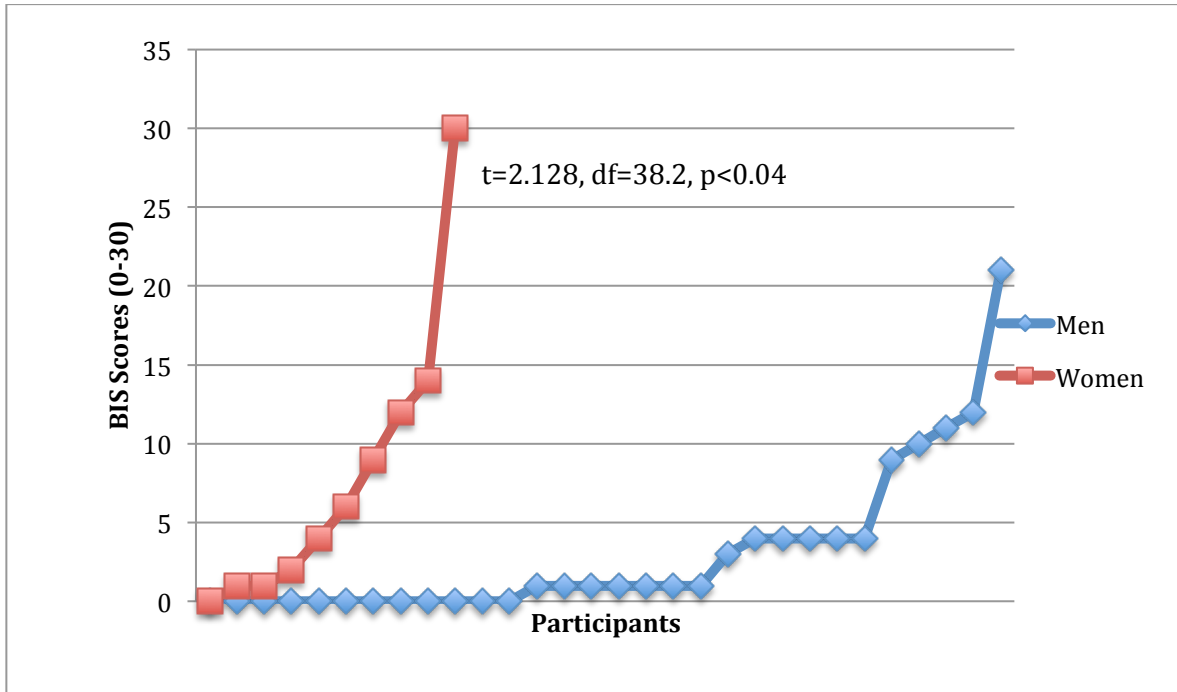Figure 2: Comparison of Global QOL Scores by Gender

Figure 3: Comparison of BIS Scores by Gender

Figure 4: Comparison of BIDQ Scores by Gender

Comparison of BIS and BIDQ

A t-test was performed to compare the pooled scores on the BIS and BIDQ across the 40 participants was also conducted. A statistically significant difference was found between the two measures (t=2.55, df=78, p=0.013).

Correlation Analysis

The scores for global QOL, each functioning domain, and 10 of 27 symptom scales from the EORTC QLQ-C30 and H&N35; as well as the scores from the BIS and BIDQ, were compared to determine any potential relationships between items for all 40 participants. Scores included in this analysis were determined based on the level of face validity of each domain to the concept of body image. This correlation analysis revealed moderate-to-strong relationships across several measures obtained; the correlation matrix can be found in Table 9.

First, a strong correlation was identified between the two body image questionnaires (r=0.87). Next, a moderate inverse relationship between both the BIS and BIDQ scores and the Global QOL score were found (r=-0.63 and r=-0.64, respectively). Strong relationships were identified among the BIS and BIDQ with the social functioning or item domains from the EORTC QLQ-C30 and H&N35 (see Table 8 for each r value). Also, a strong correlation was found between the BIS and the financial difficulties domain from the EORTC QLQ-C30 (r=0.7723), while a moderate relationship was identified among the financial difficulties domain and both the BIDQ and Global QOL scores (r=0.69 and r=0.54 respectively). A moderate relationship was also found among the fatigue domain from the EORTC QLQ-C30 and both the BIS and BIDQ (r=0.62 and r=0.54, respectfully), while strong correlations can be noted between the fatigue domain

and the global-QOL and functioning domains (see Table 9). Finally, both strong and moderate and significant relationships were found between the weight loss domain from the H&N35 and the BIS, BIDQ, Global QOL and social functioning and items domains. All correlations were significant at the level of $p < 0.01$.

Participant Comments from BIDQ

As noted, the BIDQ has 5 open-ended questions, which provide individuals with an opportunity to elaborate on their responses to scaled-response questions. The open-ended questions are associated with Questions 1, 2, 5, 6, and 7. Of the 40 participants, 21 provided additional comments for both Questions 1 and 7, 11 provided comments for Question 2, 19 comments were provided for Question 5 and, finally, 20 responses were provided for question for Question 6. These comments further elaborate our understanding of the individual's experience following treatment for HNC and the perceived impact the experience has had on his or her life.

Table 9: Correlation Matrix

	BIS	BIDQ	G-QOL	P-Func	R-Func	E-Func	C-Func	S-Func	FA	FI	HNSP	HNSO	HNSC	HNSX	HNFI	HNFE	HNWL	HNWG
BIS	1	*0.87293	*-0.63917	*-0.54077	*-0.45112	*-0.64304	*-0.50945	*-0.71658	*0.62862	*0.77232	*0.48612	*0.72980	*0.77903	*0.52351	*0.24406	*0.64406	*0.71705	*0.04617
BIDQ		1	*-0.64687	*-0.49518	*-0.49249	*-0.62762	*-0.45628	*-0.72824	*0.54700	*0.69892	*0.57857	*0.61856	*0.84358	0.39070	*0.13613	0.46852	*0.70741	*-0.07982
G-QOL			1	*0.63212	*0.66493	0.73726	*0.72921	*0.68132	*0.69996	*0.54015	*0.63003	*0.58647	*0.64901	*0.34163	*0.29421	*0.40171	*-0.63096	*0.21907
P-Func				1	*0.69489	*0.27491	0.41147	*0.50274	*0.73352	*0.40405	*0.50043	*0.49904	*0.49904	*0.26581	*0.43982	*0.49280	*0.46997	*0.13142
R-Func					1	*0.32557	*0.60651	*0.56370	*0.72603	*0.38051	*-0.46604	*-0.53899	*-0.43574	*-0.33798	*-0.34612	*-0.30674	*-0.52873	*0.24002
E-Func						1	*0.64811	*0.59427	*-0.50257	*-0.50925	*-0.53113	*-0.33686	*-0.59850	*-0.34623	*-0.15080	*-0.23435	*-0.45436	0.00035
C-Func							1	*0.62836	*-0.66618	*-0.39682	*-0.39915	*-0.44581	*-0.33886	*-0.37680	*-0.21896	*-0.42077	*-0.34478	*0.04198
S-Func								1	*-0.72633	*-0.68320	*-0.60918	*-0.70389	*-0.73682	*-0.56814	*-0.17220	*-0.50010	-0.55305	*0.19133
FA									1	*0.54420	*0.42963	*0.59194	*0.47633	*0.40599	*0.30193	*0.53074	*0.45407	*-0.17151
FI										1	*0.42421	*0.61918	*0.53231	*0.35677	*0.29135	*0.43872	*0.63652	*0.05414
HNSP											1	*0.50588	*0.73288	*0.31011	*0.16184	*0.17222	*0.59797	*-0.13403
HNSO												1	*0.65536	*0.52934	*0.23890	*0.52902	*0.58185	*-0.10909
HNSC													1	*0.45873	*0.02687	*0.34703	*0.67089	*0.11017
HNSX														1	*0.06475	*0.42200	*0.21088	*0.10327
HNFI															1	*0.38118	*0.32673	*-0.17647
HNFE																1	*0.48038	*-0.06727
HNWL																	1	*-0.14003
HNWG																		1

*p<0.01

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Supplemental Observational Analysis of Data

Age

Observational analysis of graphical trend-lines of increasing age, including both male and female participants, in relation to the global QOL scores suggests a slight perceived decrease in global quality of life for younger participants; younger participants were arbitrarily considered those under age 55. This trend is illustrated in Figure 5. Similar analysis of age relative to the BIS and BIDQ scores suggests that younger participants also reported greater concern with perceived body image. Figures 6 and 7 illustrate, using a trend line, the graphical comparison of scores between the BIS and BIDQ by increasing age.

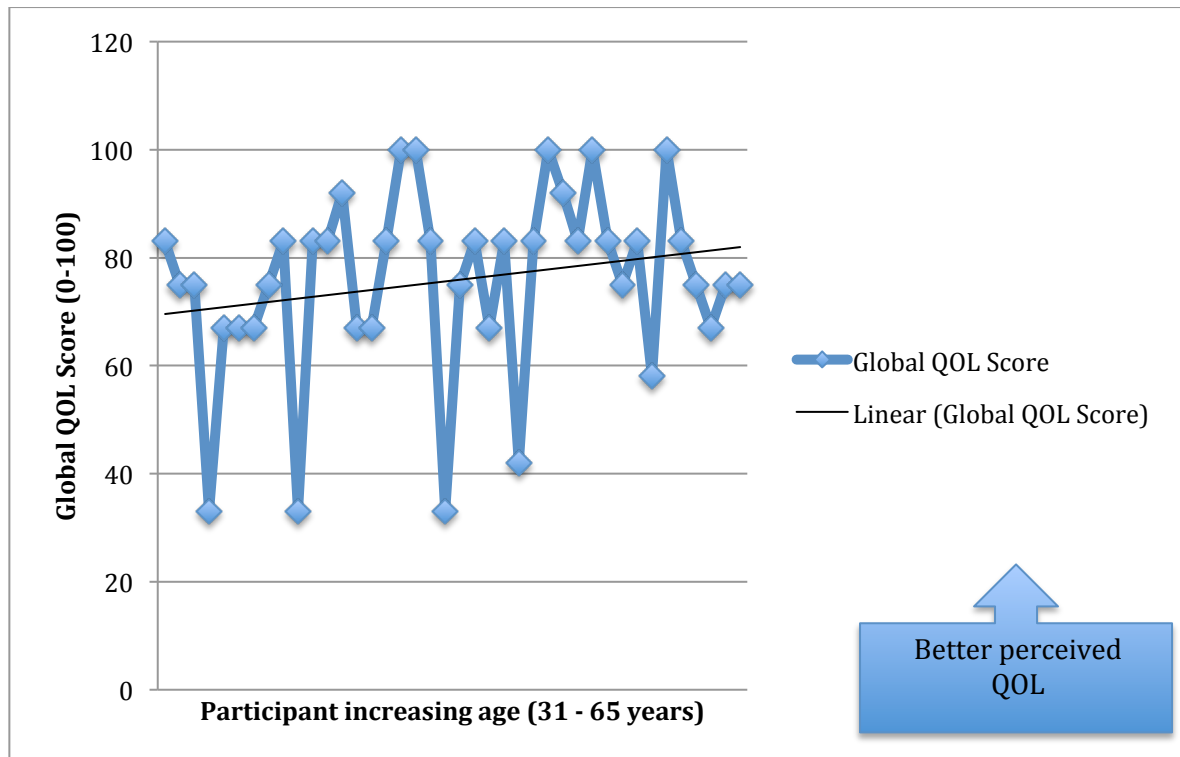Figure 5: Comparison of Global QOL Scores by Increasing Age

Figure 6: Comparison of BIS Scores by Increasing Age
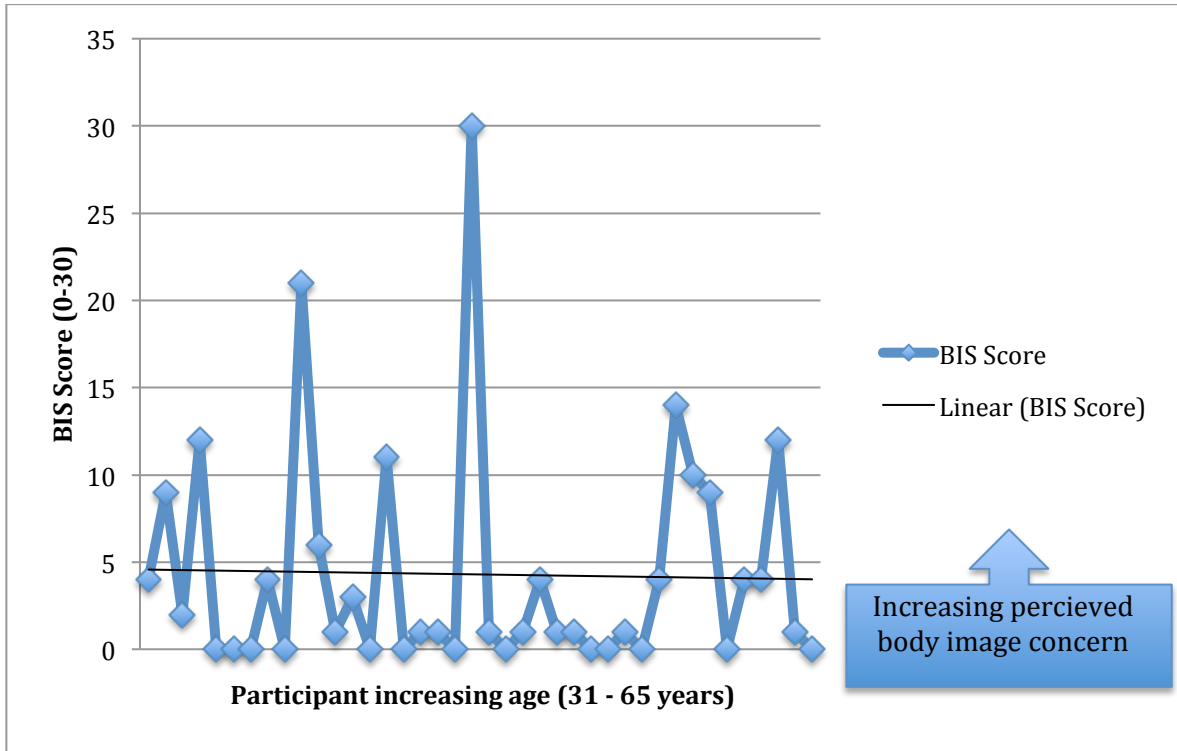
Figure 7: Comparison of BIDQ Scores by Increasing Age
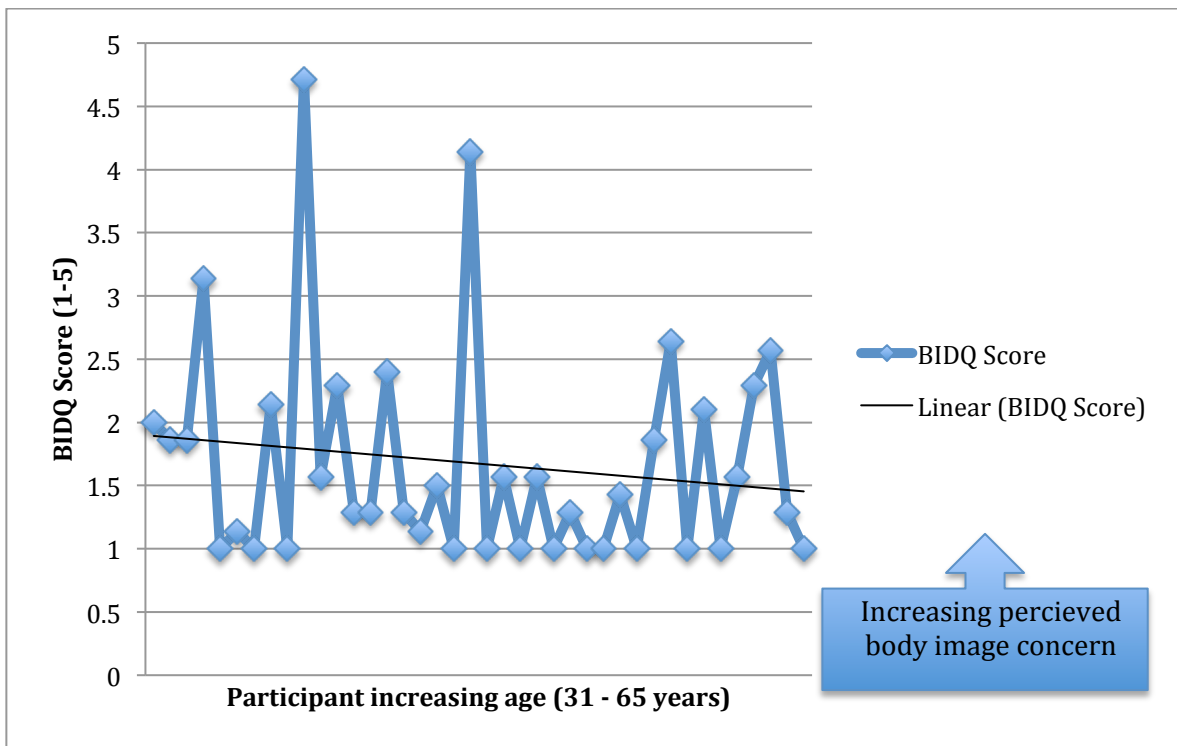
Time Since Diagnosis

The mean time since diagnosis for this group of participants was 33 months. Observational analysis of the line of best fit for time since diagnosis (in months) in relation to participant scores for Global QOL suggests an increase in QOL with increasing time since diagnosis (see Figure 8). Similar analysis of time since diagnosis in relation to participant scores on the BIS and BIDQ suggest a decrease in scores as post-treatment time increases (see Figures 9 and 10). These changes suggest that with increasing time since diagnosis, perceived QOL will improve and body image concerns will decrease which may subsequently suggest improved functioning.

Figure 8: Comparison of Global QOL Scores by Time Post-Diagnosis
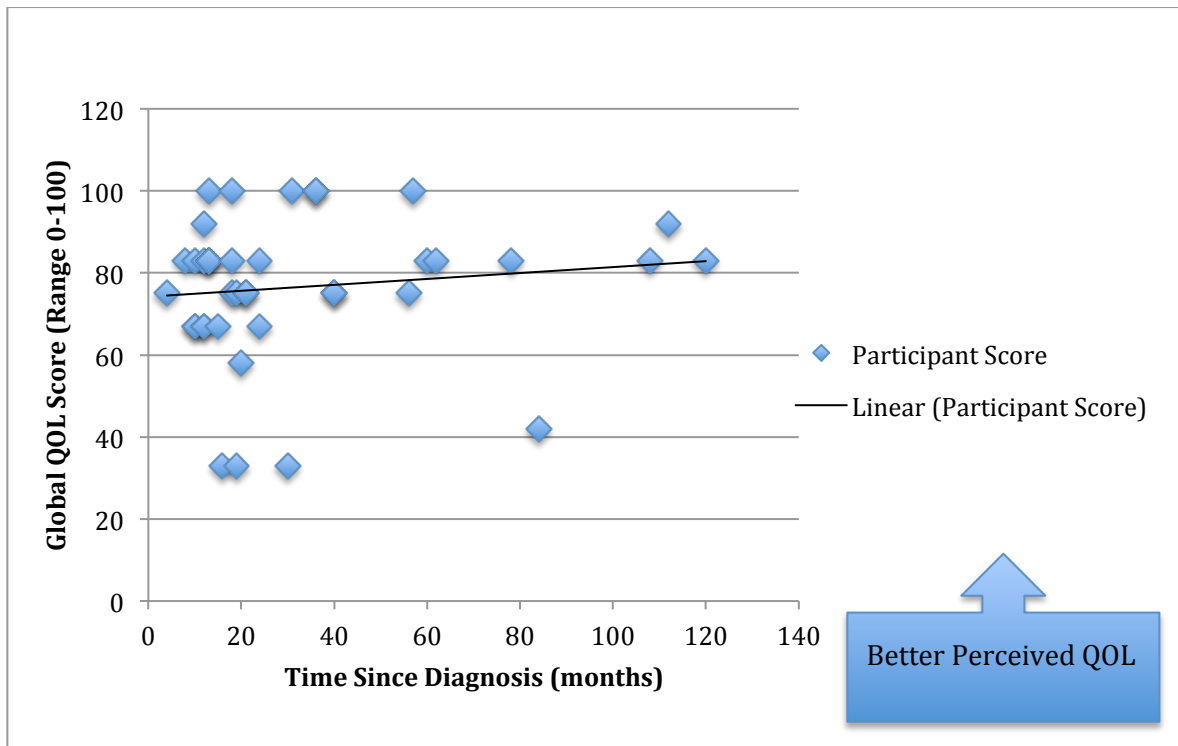
Figure 9: Comparison of BIS Scores by Time Post-Diagnosis
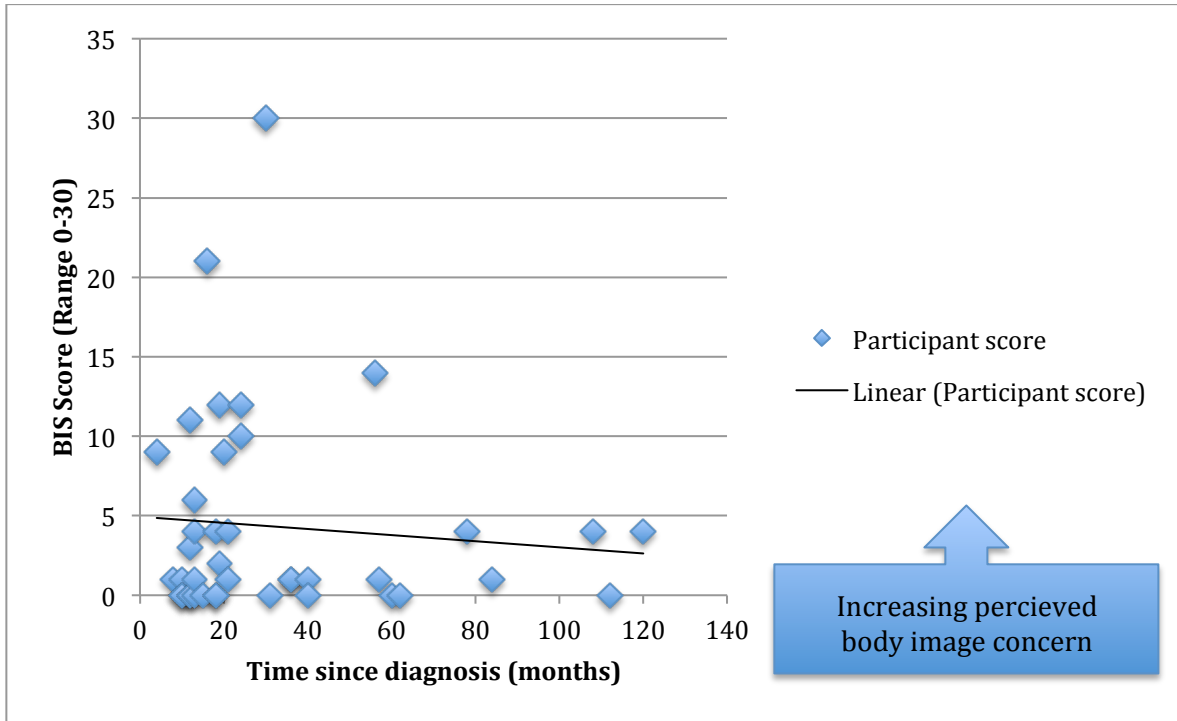
Figure 10: Comparison of BIDQ Scores by Time Post-Diagnosis
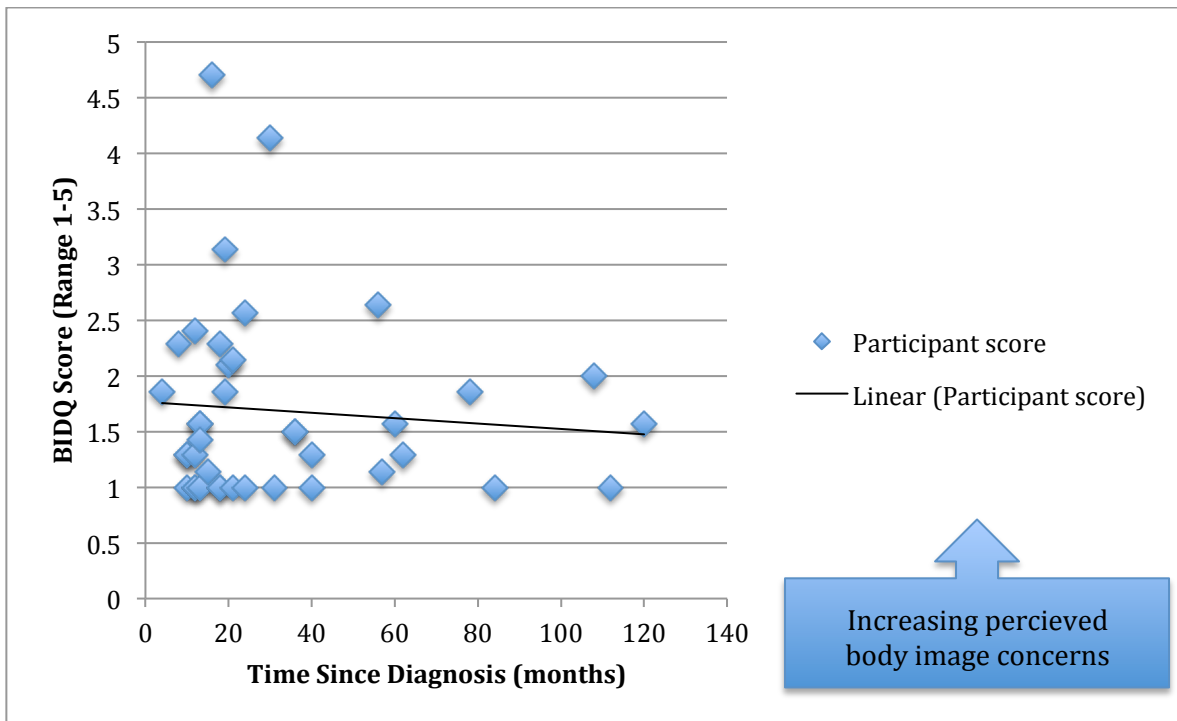
Site of Cancer Origin

An observational comparison of three sites of cancer origin was completed in relation to the Global QOL, BIS and BIDQ scores. These sites arbitrarily included oral, larynx and other. The "other" group included parotid, nose, neck and thyroid (see Figure 1 in Chapter 2 for full description of sites). These sites were grouped together based on the small number from each site. An examination of trend lines and mean scores for each of the three groups for the three measures reveals a mild decrease in the mean score on the BIS for the "larynx" group in comparison to the other two groups while no visual trends are apparent (see Figures 11, 12, and 13).

Figure 11: Comparison of Global QOL Scores by Tumor Site
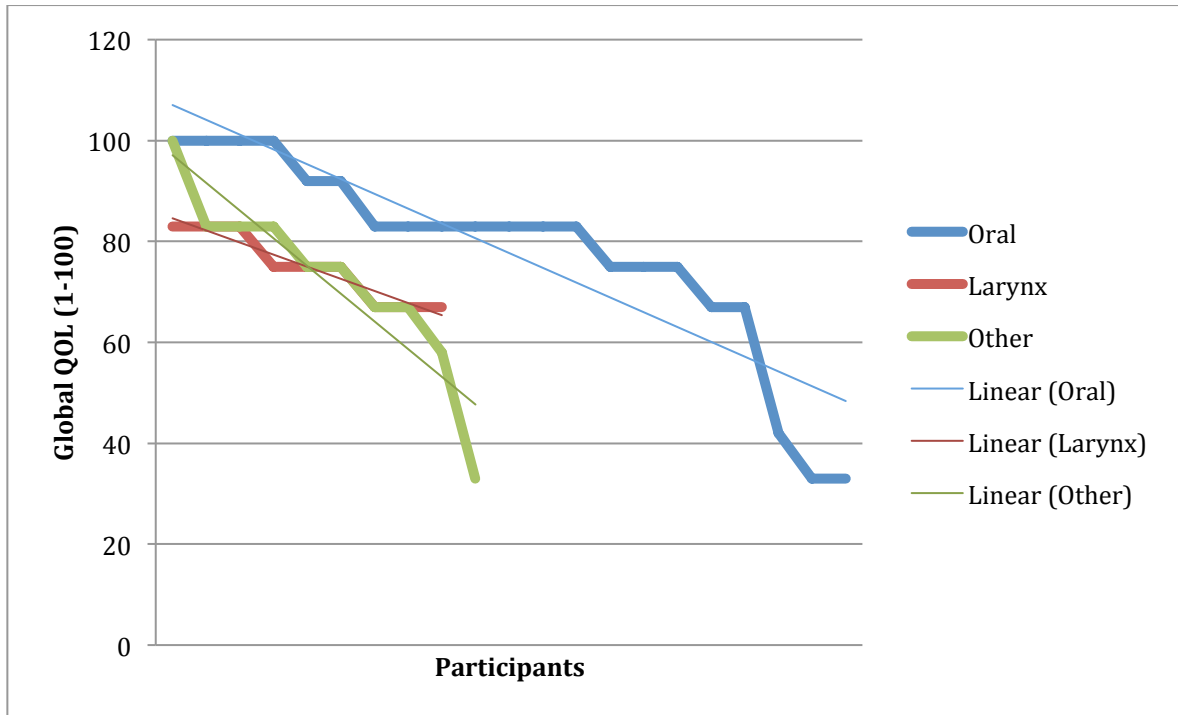
Figure 12: Comparison of BIS Scores by Tumor Site

Figure 13: Comparison of BIDQ Scores by Tumor Site
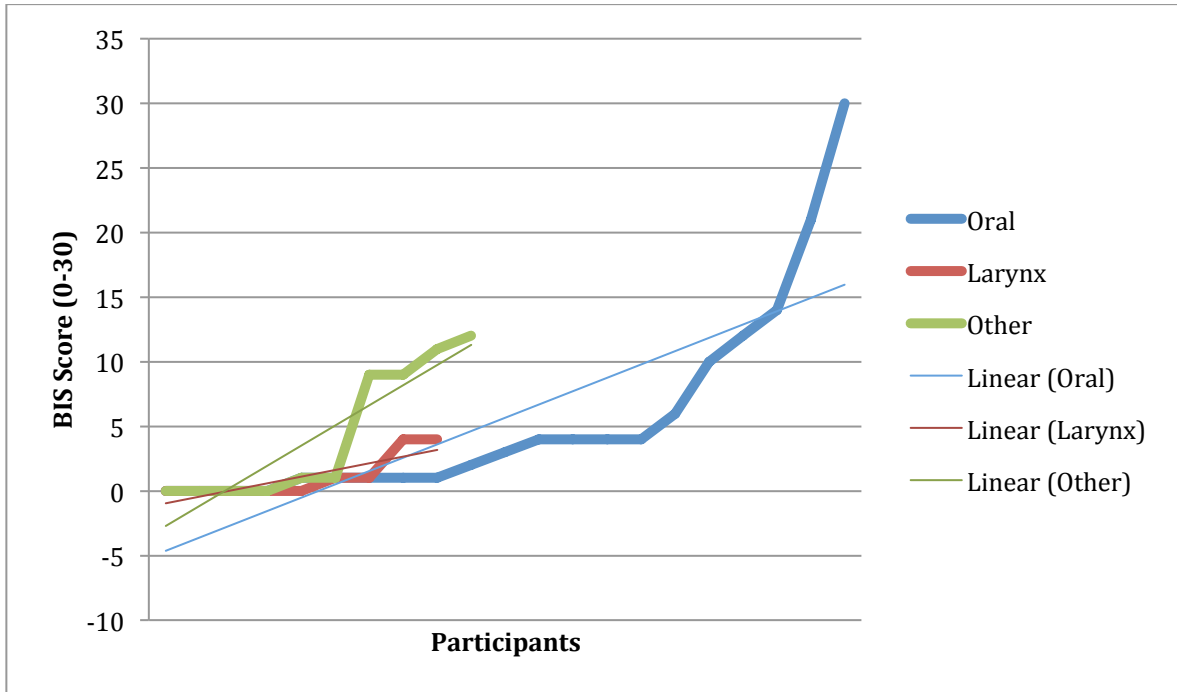
Treatment Modality

Lastly, an observational comparison of three treatment modalities relative to participant scores for each Global QOL, BIS and BIDQ also was performed. The three treatment modalities included (1) surgery alone, (2) combination treatments which included surgery and radiation, surgery, radiation and chemotherapy, or surgery and chemoradiation, and (3) non-surgical treatment which included radiation alone, radiation and chemotherapy or chemoradiation. Trends for the Global QOL, BIS and BIDQ measures, in addition to a comparison of the mean score for each, suggests that there are no notable trends for any treatment group. However, for these participants, the group with non-surgical treatment did have a higher mean score on the BIS (see Figures 14, 15 and 16).

Figure 14: Comparison of Global QOL Scores based on Treatment Modality
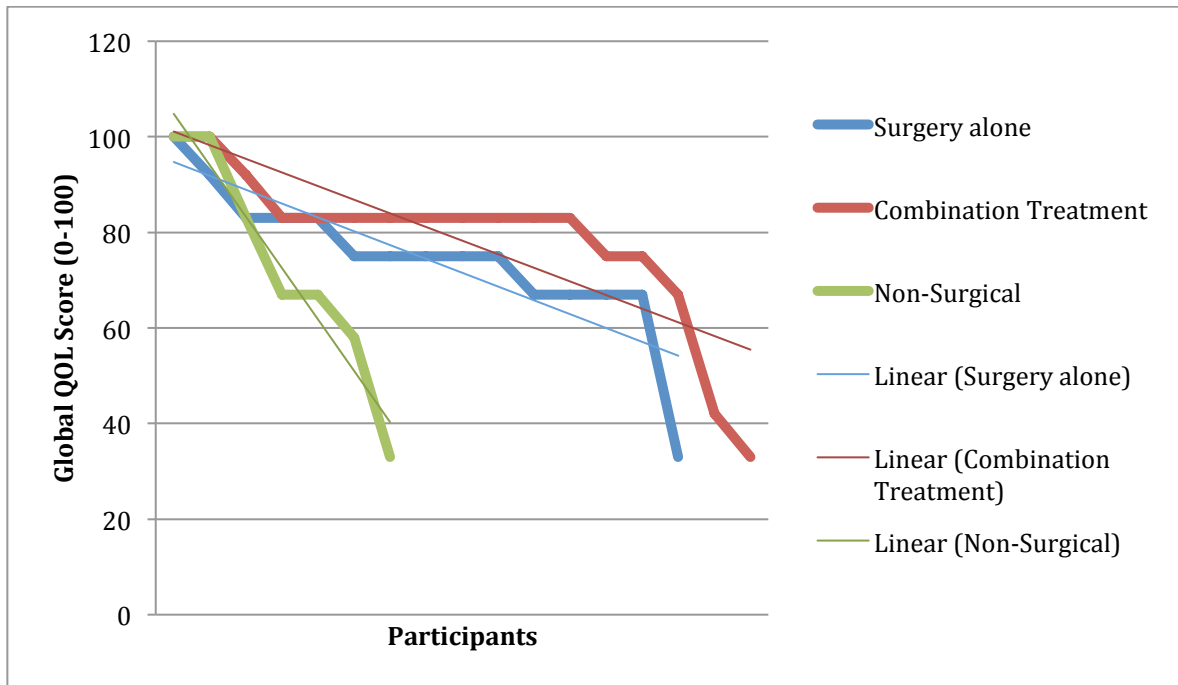
Figure 15: Comparison of BIS Scores based on Treatment Modality
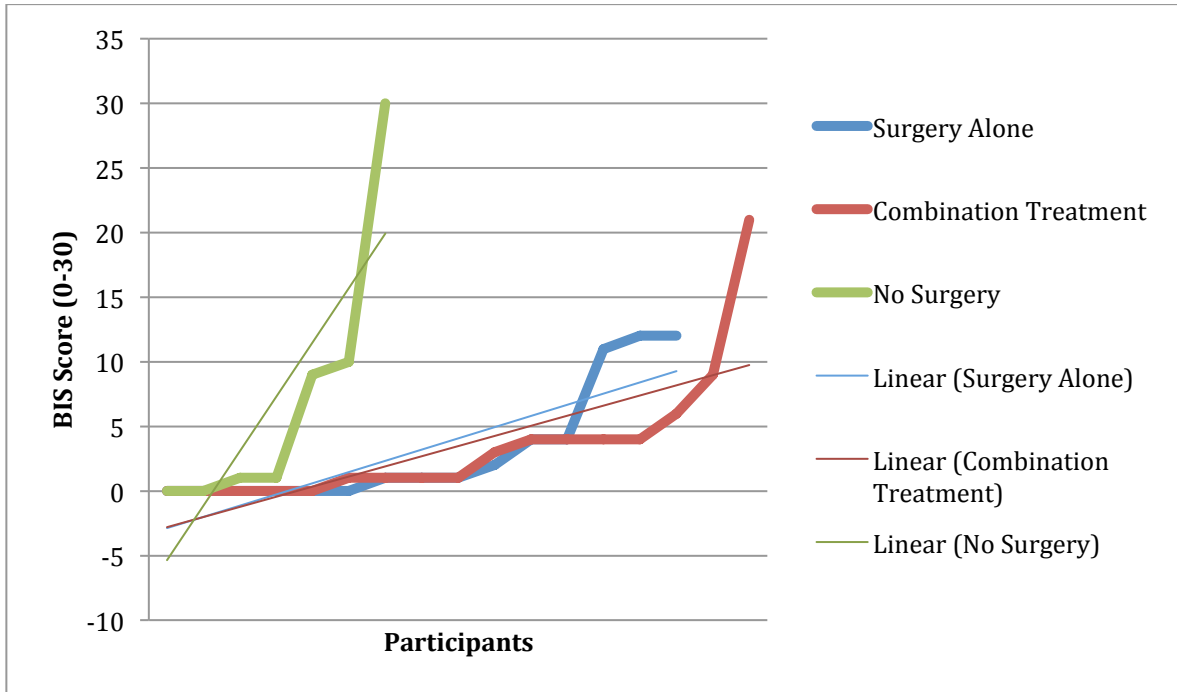
Figure 16: Comparison of BIDQ Scores based on Treatment Modality
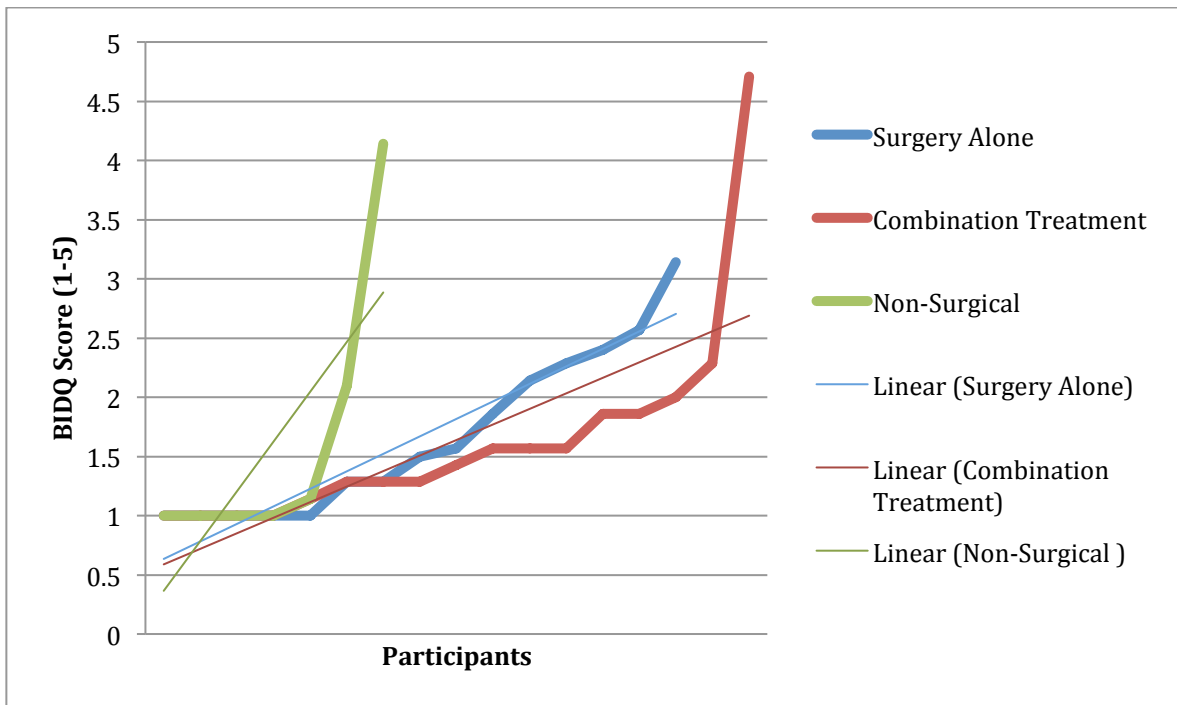
CHAPTER 4: DISCUSSION

The purpose of this study was to identify the presence of changes in body image and to explore the potential impact of perceived body image on QOL for individuals who had been diagnosed and treated for HNC. The intent of this project, while exploratory in nature, was also focused on identifying the potential effect of gender as it influences perceptions of both body image and QOL. In doing so, relationships among perceptions of body image and QOL, domains of life functioning, and specific symptoms commonly associated with HNC and its treatments were also explored. Specific questions addressed included:

1) Do individuals who have been diagnosed and treated for HNC report perceived changes in body image?

2) Are measures of body image related to overall perceived QOL?

3) Do differences in perceived body image exist between men and women?

By addressing these questions, the understanding of the experience of individuals following the diagnosis and treatment of HNC may be expanded. Thus, in sections to follow, specific issues that arose from the data obtained will be addressed. These issues include global descriptions of the findings from both body image and QOL measures and their relationship to one another, the influence of gender on measures obtained, as well as a presentation of limitations of the study, potential clinical implications, and directions for future research with this unique and important clinical population.

Body Image Scale (BIS)

The BIS instrument was designed for use in any oncology population. More specifically, this measure was developed to address general aspects of one's perceived

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appearance and the impact that this perception has on the individual's willingness to interact with others. Thus, perception of body image is extended beyond judgments of solely perceived "physical" changes to include and contextualize its impact on larger issues of social functioning. The BIS may be helpful in efforts to identify individuals who are experiencing increased concern or preoccupation with body image following a cancer diagnosis and treatment. Based on the data obtained in the present study, the majority of participants did not rate any individual questions contained within the BIS as being of concern. While there were differences among the individual participant responses to each question posed, the majority of individuals seemingly are not concerned about their appearance or the impact that those concerns can potentially have on social interactions. Yet, it is also important to acknowledge that this pattern of response was not uniformly observed across the participants studied. There was variability among the participants' responses on the BIS that resulted in summed scores that ranged from 0 to 30. This range suggests that the perception of body image is in fact highly individualized. Consequently, individual perceptions of body image should be evaluated as part of regular clinical follow up in those treated for HNC. While only a few may experience substantial problems, to not address such issues in the larger context of rehabilitation would almost certainly impact functioning at some level. Thus, clinical screening of body image is recommended.

The variability in the scoring from both the individual questions and the overall score from the BIS imply that there potentially exist participant characteristics that influence individuals' perception of body image. Given what has been previously recognized in the study of body image, it may be that differences in gender, age, or

potentially the visibility of physical changes (as determined by the specific site of the cancer) may differentially influence the perception of body image following diagnosis and treatment for HNC (Hagedoorn & Molleman, 2006; Katre, Johnson, Humphris, Lowe, & Rogers, 2008; Murnen, 2011; Pandey, Devi, Ramdas, Krishnan, & Kumar, 2009; Taylor et al., 2004). However, the findings from this questionnaire may not fully inform an understanding of all of the concerns related to body image. Therefore, utilization of an instrument that was designed for use in multiple clinical populations may provide further information that may not be captured with an oncology specific instrument.

Body Image Disturbance Questionnaire (BIDQ)

The BIDQ instrument was designed to identify individuals who are experiencing not only body image dissatisfaction, but also the distress and dysfunction or impairment that results from this dissatisfaction. Thus, the BIDQ seeks to index the impact that one's dissatisfaction with his or her body image has in the larger context of its resultant limitations and/or disability. The BIDQ is reported to be appropriate for use among both men and women beginning in late adolescence through adulthood. Therefore, the application of this instrument in the present study offers a unique means of further understanding the potential for changes in perceived body image that may impact the lives of those with HNC. The current normative comparative samples for the BIDQ were developed with college-aged individuals and provide an average score for men (1.57, SD=0.60) and women (1.81, SD=0.67) that can be used as a comparison with other populations (Cash & Grasso, 2005). However, this limited age range (18-57 years; median = 21 years) for the normative sample may limit the ability to fully generalize the

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scores to older individuals. The primary reason for this inability to compare the

normative sample with the present data may be found in the potential for older

individuals to perceive body image differently than they would have at a younger age.

That is, older individuals tend to place less value on appearance than younger individuals

(Tiggemann, 2004). Similar to data obtained on other measures included in this study, the

majority of participants did not rate any individual question as being of substantial

concern; however, some individuals did rate perceptions of their "defect" as being

"extremely concerning" or "extremely disabling". This variation once again illustrates

that perceptions of body image are highly individualized and must be considered

accordingly. A comparison of the average score among the present male participants that

yielded a score of 1.54 (SD=0.78) is close to the current normative value for the BIDQ. A

comparison with the current average of female participant scores of 2.08 (SD=0.97)

suggests a slight increase in concern or more preoccupation with body image in

comparison to the BIDQ normative group (Cash, Phillips, Santos, & Hrabosky, 2004).

The female participants had overall scores that ranged from $1 - 4.14$ (out of a possible 1-

5 scaled score) and the median was 1.86. The male participants had overall scores that

ranged from 1- 4.71; however, the median was 1.29. These data illustrate the varied

perceptions of body image and concern among the group involved with this study. There

are no obvious discernable trends in demographic variables that would appear to suggest

homogeneity among the participants; therefore, future study to consider discerning

potential influences on body image perception is encouraged.

 Further to the scaled response questions, the BIDQ instrument also utilizes open-

ended questions that allow participants to provide additional comments regarding their

experiences and perceptions. These comments have the potential to provide valuable information in a clinical context in that scaled-response questions may not always "tap" a broader area of concern specific to perceived body image. In the present context, these comments offered insight into specific individual body concerns. For example, one participant shared "[the] scars on my neck and forearm bother me. I had plastic and cosmetic surgery but it didn't help too much … it feels awkward that it doesn't look the way it did before." The participant comments also illuminated individuals' perceptions of themselves and the perceived reaction of others to treatment related changes - "I feel deformed", "[I] don't go for meals with others" and "I don't think about it a lot – only if I meet someone for the first time". These comments further highlight the impact that the disease and associated treatment(s) had on individuals' ability to function in life roles; as one female participant shared, she felt unable to function "due to anxiety, not the physical defect". Similarly, a male participant stated that he "does not want to socialize" due to his physical "defect". These supplementary comments also illustrate the variability in participant concerns. One participant who had elected to have plastic and cosmetic surgery since being diagnosed and treated for HNC noted, "I am 9 years post-op and fairly more confident. Had I completed this survey 6-7 years ago, I would have been extremely preoccupied with my appearance. I find that I have accepted the changes to my body and it gets easier with time". The additional comments gathered as part of the BIDQ may provide valuable guidance for future research and clinical interventions as they may illustrate needs at specific times, for specific sub-groups of individuals or for specific types of functioning in the course of survivorship.

In summary, the body image related questionnaires revealed clear variability among the participants involved in this study. However, the open-ended questions provided potential factors to consider for further study to determine trends among HNC patients. One such factor to consider is the amount of time since the diagnosis, a variable that has previously been shown to decrease the potential for disability as time since diagnosis increases (Taylor et al., 2004). Another consideration is the presence of visible scars to others; yet the current understanding is that body image concern is not always consistent with the extent of visible difference (Hagedoorn & Molleman, 2006; Vickery, Latchford, Hewison, Bellew, & Feber, 2003). When considered together, it would appear that a combination of factors would contribute to each individual's perception of body image and ultimately how body image will influence one's perceived QOL over the short- and long-term post-treatment period.

European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)

Responses to individual questions from the EORTC QLQ-C30 for the group of participants illustrate that the majority are experiencing very few, if any, of the symptoms or concerns that are covered on this instrument. However, three questions (i.e., Questions 18 "*Were you tired?*", 22 "*Did you worry?*" and 25 "*Did you have trouble remembering things?*") did reveal that a majority of participants (n = 29, 26 and 24 out of 40 participants, respectively) felt that they experienced these symptoms at least "A little". While the majority of participants may not have experienced the symptoms that are addressed in this questionnaire, some individuals indicated that they experienced these symptoms "Very much" (n = 1, 4 and 1, for questions 18, 22, 25, respectively). Although

these represent a very small proportion of participants (2.5 – 10%), the influence of such perceived changes cannot be ignored. While the present data are exploratory in seeking to identify problems associated with body image, this finding also illustrates that other potential variables may exist that influence a given individual's perception of their experience of HNC.

Another interesting finding from the present study was the observation that despite the fact that the majority of individuals (n = 24) indicated that they experienced few symptoms explored using the instrument (as determined by a sum of 42 or less out of a possible range of scores from 28 -112 for responses to Questions 1-28), only eight individuals (20%) rated their current perceptions of health or QOL as "excellent". The finding again illustrates the need to consider the presence of other potential factors that may influence a given individual's perception of health and QOL. Yet at present, additional research is necessary in order to identify such factors and their interactions.

A similar pattern is apparent when considering the participant scores for the domains elucidated from the EORTC QLQ-C30. While the majority of participants rated their Global QOL and their various areas of functioning as being very good, there were eight participants who clearly indicated perceived deficits in these areas. This was delineated as a score of 50 or less out of a possible range of scores from 0-100. For example, one 56-year-old female participant scored a 33 for each Global QOL, role, cognitive and physical functioning, a score of 50 for emotional functioning, and a score of 0 for social functioning. As far as the symptom domains, it becomes further apparent that while few individuals report being significantly impacted by individual symptoms, a collection of symptoms may create levels of disability that are not simple additive events.

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Further, some individuals reported symptoms that persisted beyond three months following treatment completion. Thus, the collective data would support the notion that ongoing efforts to monitor symptoms over time may offer important information relative to indexing both short- and long-term outcomes. The ability to identify problems early in their development may then serve to decrease the magnitude of their impact on the individual. This finding continues to suggest that potential mediating variables, such as gender, age or specific site of cancer diagnosis, may exist and influence the individual's perceptions following HNC.

European Organization for the Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35)

The use of a QOL measurement instrument that is designed specifically for individuals with HNC suggests that the symptoms listed are those that are most frequently experienced by those individuals. However, with the exception of Question 10 "Have you had problems opening your mouth wide?", the participants in this study most frequently reported that they did not in any manner experience the symptoms addressed using the EORTC module. In regard to Question 10, the majority of individuals indicated at least "A little" difficulty performing that task. This observation supports the continued importance of monitoring gross oral functioning and associated trismus in those with HNC. Additionally, given that a majority of participants indicated some level of challenge related to opening their mouth widely, efforts that are directed toward objectively measuring such changes (Cox, Jeremic, Fung, & Doyle, 2013), and further, efforts that seek to decrease this limitation via direct therapeutic intervention is supported (Jeremic et al., 2011; Kamstra, Roodenburg, Beurskens, Reintsema, & Dijkstra, 2013;

Stubblefield, Manfield, & Riedel, 2010). Nevertheless, similar to the findings from the EORTC QLQ-C30, the majority of individuals (n=30) reported experiencing minimal symptoms as determined by a sum score of 52 or less out of a possible range of scores of 35-140; however, a few individuals continue to experience considerable specific symptoms. For example, six individuals indicated a score of "4" ("very much") when responding to Question 41 "Have you had a dry mouth?" and three individuals similarly indicated a "4" when responding to Question 48 "Has your appearance bothered you?".

Further to the individual questions from the H&N35, the domains scores generated from the H&N35 reveal a variety of symptom related concerns. Of these domain scores "dry mouth" (xerostomia) was the only area of questioning where the majority of participant responses suggested concern. In contrast, the remaining 17 domains were not reported as being a concern for the majority of participants. The extent of individual participant differences illustrates variability among the population and once again suggests that mediating or moderating variables, such as gender, age, specific site of cancer diagnosis or time since that diagnosis, may influence the perceptions of symptoms and the impact that symptoms may have on perceptions of QOL. However, because of the exploratory nature of the present study, clear indices of such factors cannot be ascertained currently. Further study that seeks to generate larger populations who share a common set of characteristics (e.g., site of lesion, treatment type, among others) would likely provide valuable additional data specific to the influence of these, as well as other variables on functional capacity that impacts QOL.

In summary, the data obtained from the EORTC QLQ-C30 and H&N35 have illustrated that significant variability exists among the perceptions of the individuals who

participated in this study, both in specific symptoms and broader categories of functioning and QOL. The essential finding is that this variability in perceptions suggests that additional influences exist among individuals who are diagnosed and treated for HNC. These may include other perceptual influences such as body image, gender, age, specific site of cancer diagnosis or the time elapsed since that diagnosis, as these characteristics varied among the participants and may not have been fully addressed with these two instruments.

Gender Comparisons

It is well recognized that women are known to experience greater concern relative to perceptions of body image (Boquiren, Esplen, Wong, Toner, & Warner, 2013; Cash & Grasso, 2005; Murnen, 2011; Tiggemann, 2004). Given this recognition, a comparison for scores on the BIS, BIDQ and Global QOL between men and women was judged to be of importance to the present project. While no a priori prediction was made given the relative paucity of information on body image in those diagnosed with HNC, gender was certainly of interest given past literature on body image in other populations. Gender was considered an essential element to determine the potential influences on the perceptions of body image by both women and men and its influence on QOL following diagnosis and treatment for HNC.

A comparison of the mean scores for men and women on each the BIS, BIDQ and Global QOL from the EORTC QLQ-C30, revealed that a statistically significant difference was identified between the two sexes on the BIS score only. This finding suggests that the female participants in this study experience increased concern or preoccupation with body image in comparison to the male participants in this study.

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However, this suggestion is clearly limited by the relatively small and uneven sample of men and women herein. For this reason, a comparison of the median was also done using the Mann-Whitney U-test in an effort to further understand potential differences between men and women studied because nonparametric tests are not contingent on the assumption of a normal distribution or homogeneity of variances across groups. This analysis also revealed a statistically significant difference between men and women on both the BIS and BIDQ scores, illustrating greater body image concern among the women. This finding further suggests that women report increased concern with body image in comparison to their male counterparts, similar to what has been found using the BIDQ in non-clinical populations (Cash & Grasso, 2005). However, despite this finding, it is important to recognize that the different number of scores between the female and male participant groups may influence these statistical findings and, thus, require careful interpretation. This recognition of a potential trend for women to suffer more significant changes in BI secondary to HNC is of importance and certainly deserves additional exploration with an increased number of participants. At a minimum, this variability likely points to the presence of multiple factors that influence an individual's dynamic perception of body image with associated influences on perceived QOL. While the external validity of this finding is certainly limited, the findings generated raise many additional questions which may provide a fruitful area of further study.

Comparison of BIS and BIDQ

The decision to use two instruments to measure the experience of individuals' perception of body image was made strategically. The choice of instruments involved determining how to identify individuals who appeared to experience a potentially

clinically significant concern or suspected preoccupation with body image. Preoccupation with body image may be considered excessive or constant thought about one's body image that disrupts the ability to function in life roles (Cash et al., 2004). For this reason, both an instrument designed specifically for an oncology population and an instrument designed to identify individuals with body image disturbance were selected. Unexpectedly, a statistically significant difference between these two measures emerged. Thus, BI as a conceptual entity may not be equally, or possibly incompletely covered across such measurement instruments. In seeking to further understand these observations, a careful post-study analysis of the questions on both measures was conducted. The difference identified between the two instruments suggests that while both measures address "body image" concerns, the two measures would appear to assess several different concepts. Specifically, it appears that the BIS seeks to gather more general information regarding an individual's perception of body image and how that perception influences social interaction, while the BIDQ focuses on a specific perceived "defect" that the individual identifies and how that "defect" has disrupted the individual's ability to function in life roles. Ultimately, it may be that while these two instruments have a similar nature, they are fundamentally different.

Correlation Analysis

The domains selected for analysis were those that were considered to have a greater social impact rather than those that are more symptom-specific. This means that the score for Global QOL, each of the five "functioning" domains, and 10 of the 27 "symptom-specific" domains from both the EORTC QLQ-C30 and H&N35 were selected in addition to the scores from the BIS and BIDQ. The items were identified from

a current understanding of aspects of psychosocial functioning that are known to contribute to body image including aspects of social relations, sexuality, and eating behaviors (Cash et al., 2004). The correlation analysis revealed a number of positive and negative relationships that are notable.

First, and not unexpectedly, a strong positive relationship was found between the BIS and the BIDQ. This strong positive relationship suggests that the general concepts that are comprised within each questionnaire are related to some extent and that resultant scores from participants varied together. However, as previously noted, when a comparison between the scores obtained from these two measures was performed, a significant difference was found. Consequently, this finding suggests that despite the similar nature of the two questionnaires, each has a focus that is likely inherently different. This difference can be appreciated by considering the nature of the questions contained within each instrument. More specifically, it may be that the BIS is considered a measure of the severity of symptoms, while the BIDQ is more a measure of functional impact (Kostanjsek et al., 2011). Each instrument, therefore, may offer unique clinical value that can help identify and quantify the broader impact that the diagnosis and treatment of HNC has on an individual's life. Collectively, this finding might then be viewed to support the notion of using both measures as part of a clinical screening procedure to detect changes in perceive BI. Given that both tools are relatively short, are time-efficient and of low burden to the individual who completes them, such a suggestion may carry even greater potential for widespread clinical applications for those with HNC.

Next, a moderate negative relationship was found between the Global QOL domain and both the BIS and BIDQ. This inverse relationship suggests that as concern or

preoccupation with body image increases, as illustrated by high numerical scores on the BIS and BIDQ, the perception of positive Global QOL decreases. Essentially this relationship demonstrates that increasing concern regarding appearance, as well as the (in)ability to function due to those concerns, may result in a negative perceived QOL. Ultimately, this suggests that perceived body image does, in some way, influence QOL.

In addition to the above noted relationships, both moderate and strong relationships were present among the BIS, BIDQ, Global QOL and the social functioning and item scores. These relationships suggest that as concerns regarding body image increase, the ability to function socially may decrease. While not unexpected to identify such a relationship, these data confirm that body image is an important area of consideration relative to both shorter- and longer-term outcomes post treatment for HNC. These associations also reveal that perceived QOL is influenced by one's ability to function in social roles or environments. This finding is not surprising as social interaction and functioning are recognized as essential components of the multidimensional construct of QOL (Niezgoda & Pater, 1993).

In evaluating the correlation data, a strong relationship was also found between the BIS and the "financial difficulties" domain from the EORTC QLQ-C30. This finding is not one that might be easily identified as a consequence of changes in perceived body image. This relationship can be interpreted such that increased concern regarding body image may impact the level of concern one experiences specific to financial and economic stability. The reason for this is not clear, however, this finding may be related to an increased concern with body image that may result in financial difficulties secondary to one's inability to return to work. Whether this is a result of concerns related

to direct physical changes that may be observable (visual or auditory) to others, or because of preoccupation with body image and an inability to function socially is unknown. In addition to the above finding, a moderate relationship was also found between the "financial difficulties" score and each of the BIDQ and Global QOL scores. This relationship may further support the notion of the impact of body image concerns on financial difficulties and ultimately the impact that such concerns may have on perceptions of QOL. Overall, these findings are not surprising, as it has been previously recognized that HNC can result in financial burden even though the cause of this burden has not been extensively studied (Taylor et al., 2004). This finding likely results from multiple interactive factors that potentially include body image as well as levels of physical fatigue, and social stigma and their collective effects on general functioning for those treated for HNC.

The "fatigue" domain score from the EORTC QLQ-C30 was found to have a moderate association with both the BIS and BIDQ scores. This suggests that as one experiences increased fatigue or exhibits concerns related to fatigue, this might subsequently influence perceptions regarding body image. Further, the "fatigue" domain was found to be strongly correlated with the Global QOL domain and each of the five "functioning" domains. These collective findings suggest that perceptions of heightened fatigue may be associated with perceived decreases in body image and QOL and decreased ability to function on all levels - including physical, roles, emotionally, cognitively and socially. Yet, at present, it is difficult to determine which is the precipitating factor; that is, is the individual fatigued from attempting to function or is it that the fatigue prevents the individual from being able to function? Regardless of which

factor precipitates the relationship, it is highly evident that the presence of interactive factors exists for individuals who have experienced the diagnosis and treatment of HNC. At the very least, however, this finding is not unexpected, as cancer patients are known to frequently experience fatigue along with weight loss (cachexia) (Evans et al., 2008; Fearon, Voss, & Hustead, 2006; Tisdale, 2002). While this may be a result of the disease itself, fatigue is often reported in association with treatment variables including radiation and chemotherapy (Campos, Hassan, Riechelmann, & Del Giglio, 2011). Additionally, weight concerns are considered an essential element of body image, which has been demonstrated with research on eating disorders and body dysmorphic disorder (Crowther & Williams, 2011; Phillips, 2011; Selwyn Delinsky, 2011). Furthermore, weight loss has been demonstrated as a common concern among cancer patients in general and may be considered critically important to outcomes (Evans et al., 2008; Fearon et al., 2006; Tisdale, 2002). Thus, it was not surprising that strong and moderate relationships were found between the weight loss domain from the EORTC H&N35 and each of the BIS, BIDQ, Global QOL and social functioning and item domains. This suggests that individuals' perception of weight loss impacted or interacted with their perceptions of body image, QOL and the ability to function in a variety of social roles.

Supplemental Observational Analysis

The presence of the multiple relationships observed in the present study may offer some useful information related to deficits in the perception of body image and the post-treatment experiences of individuals following diagnosis and treatment for HNC. Yet even considering several associations identified herein, there continues to be extensive variability among the participants' perceptions, across functional domains and symptom

experiences. Given this variability, supplemental analyses of the data were performed to further consider potential influences on perceptions of body image and QOL. This included visual examination of potential trends related to the age of participants, the influence of time since diagnosis, grouping of participant scores by specific cancer site, and finally, by treatment modality for each the BIS, BIDQ and Global QOL scores. This supplemental evaluation of the data was completed for both the male and female participants. Each of the above noted factors will be addressed briefly below and preliminary observations will be identified.

When data from the group of participants who ranged in age from 31 to 65 years were evaluated via trend lines, the Global QOL scores suggest that individuals who are younger tend to report decreased QOL when compared to those who are older. Further, when the BIS and BIDQ scores are considered similarly, younger participants seemingly report a greater concern with body image. These two findings suggest that the younger individuals may be at a higher risk of experiencing greater concerns specific to body image and quality of life following diagnosis and treatment of HNC. This is not unexpected because previous findings have shown younger individuals exhibit continual distress and poorer QOL following treatment for HNC (Katre et al., 2008; Pandey et al., 2009) and the general finding that younger individuals will experience greater concern for body image (Tiggemann, 2004). This finding may be related to the increased amount of time that a younger individual will have to function with the treatment related physical changes in comparison to older individuals. Similarly, this finding may be related to the stage of life that younger individuals are in (i.e., building relationships, demands of a

younger family, etc.) in comparison to those who are relatively older when diagnosis and treatment occur.

In addition to considering age as a potential influence on perception of body image and QOL, time since diagnosis was also explored. Trend lines for these data show an increase in perceived Global QOL as time since diagnosis increases. This may suggest that individuals' perception of QOL improves over time, perhaps as part of a general pattern of acceptance and adjustment in regard to cancer treatment. Further, a trend showing a potential decrease in scores on the BIS and the BIDQ as time increases was also noted. This finding also may suggest that individuals experience less concern with body image or a have a more positive body image as time passes post-treatment. The above observations are in fact speculative at this point and valid generalizations of the data cannot be made. However, based on these supplementary findings, it seems reasonable to suggest that the factors of participant age and time since diagnosis and treatment requires further research to help distinguish this pattern and potential factors that influence these observations (e.g, personality and or adjustment factors).

As a general observation, those in the classification of HNC as a disease entity are heterogeneous by nature. This heterogeneity is primarily due to the number of sites of cancer origin that comprise the disease class. Given this heterogeneity, a preliminary evaluation based on cancer site also was considered in the supplementary assessment of the data. In pursuing this assessment, individuals' scores were placed into one of three cancer site groups - oral, larynx or other (a group comprised of all the individuals that did not fit into the first two broad categories). Although this exploration is limited for cause, the only slight trend noted was found for the BIS score where the larynx group had a

slightly decreased trend in scores relative to the other two groups. This observation may suggest that this site group experiences less concern with body image. However, this finding may be influenced by the treatment (conservation treatment vs. total laryngectomy) that these individuals received. This consideration may impact self-perception because the two treatment options clearly result in different post-treatment physical outcomes.

The heterogeneity among diagnostic sites leads to a variety of treatment options. The location and stage of the tumor along with other variables will often decide the treatment or treatments that are appropriate for a given individual. The modalities of treatment afford various potential outcomes not only in physical appearance, but also in one's post-treatment functional capacity and associated disability. Therefore, additional analysis that considered three treatment groupings including surgery alone, combination treatment, and non-surgical treatment was completed. However, simple observational analysis did not reveal clear patterns among the groups and statistical analysis is not possible due to sample size. This seeming lack of difference may suggest that treatment modality may not influence the perception of body image or QOL for individuals who have been diagnosed and treated for HNC. While no clear-cut data exist in the literature on body image in HNC that are available to verify this suggestion, it is not unreasonable to assume that greater levels of physical alteration due to treatment (e.g., total laryngectomy and reconstruction) may hold potential for more substantial changes to one's perception. In addition to this assumption, a variety of literature would suggest that more aggressive treatments increase the likelihood of more significant functional impairments that may be both visual and/or auditory. Further consideration of body

image among individuals diagnosed and treated for HNC with larger and more clearly defined treatment groups may identify whether type of treatment may in fact influence body image.

Summary

The results from this preliminary study suggest that perception of body image is influenced by HNC and its treatment for both men and women, but the perceived changes are highly individualized. The present data also suggest that alterations in perceived body image may have a significant impact on perceived QOL. Further, perception of body image may be associated with perception of one's ability to function socially, the perception of financial difficulty, fatigue, and weight loss. Finally, the findings suggest that body image may be influenced by a number of demographic variables including age of participants, time since diagnosis, cancer site, and by treatment modality. However, the variability among the participants in this study has demonstrated the difficulty in determining the effect each of these factors may have on perception of body image following HNC. Nevertheless, these initial findings provide considerable guidance for future research on the perception of body image and QOL following diagnosis and treatment for HNC.

Limitations

It is important to recognize that certain limitations exist relative to the present preliminary research project and several specific limitations must be noted. The first limitation is clearly the sample size of participants studied. Given the limited number of participants, we are unable to draw causal conclusions specific to changes in body image following diagnosis and treatment for HNC. This study is also limited in part by the use

of a single recruitment site, as we cannot generalize the results to participants who were diagnosed and treated at different locations or in different countries. Also, as with all studies involving self-assessment by participants, we are limited by potential participant bias and cannot make assumptions about the well-being of those individuals who chose not to participate. Lastly, the data used in this study were collected at a single time point that spanned a range of time post-diagnosis and, therefore, may not capture the full experience and/or variability in perception for each individual.

The demographic variability of the participants studied further limits the ability to make generalized claims at this time because we are unable to fully identify the potential influence of specific mediating or moderating factors. For example, variation in cancer site or treatment type, age, gender, and the time elapsed since diagnosis are critical variables. The identification of these potential influences may help to guide future explorations on the impact of body image in individuals with HNC.

In order to address the above noted limitations, it would be most beneficial to expand the number of participants in future studies to help identify sub-groups with the specific characteristics previously noted. Increased homogeneity among participants may help to determine the features that may influence perceptions of body image and ultimately the impact on perceptions of QOL. Thus, while the present project is certainly limited to some extent by sample size and the heterogeneity of participants studied, the data collected may guide the design and conduct of future studies that seek to enhance our understanding of body image and its potential impact on those treated for HNC.

Future Directions

This study provides a starting point for research that seeks to increase understanding relative to the perception of body image and its impact on QOL following diagnosis and treatment of HNC. To date, limited information on the topic of body image in those with HNC exists. However, continued research in this clinical area holds great value as it may provide guidance to help mitigate the consequence of HNC treatment, offer a framework for counseling, decrease the potential for associated distress, and ideally, optimize rehabilitation efforts and outcomes. Future research into body image will include a substantial expansion relative to participant recruitment that will allow for more elaborate analysis of the potential influence of gender, age, time since diagnosis and specific site of cancer diagnosis or specific treatment(s). The findings may help to identify individuals who are experiencing body image associated distress and further may aid the identification of specific characteristics among the HNC subgroups which may assist clinicians to pre-identify individuals with similar characteristics before treatment-associated body image distress can develop. While changes in body image cannot be eliminated in this context, the ability to understand the relationship of such changes to other areas of functioning may at the very least facilitate improved patient education. The identification of specific characteristics among HNC patients also may help to guide the development of targeted screening using time efficient, low cost, and low burden instruments to identify individuals for whom perceived body image might be of concern. A primary goal of our continued research into perceived body image and QOL in those with HNC seeks to determine a potential "threshold score" for identifying body image disturbance. The potential application of such a score may then help to identify and

provide guidelines for referral and intervention. Increased understanding of change in perceived body image following treatment for HNC may help to prevent clinically significant distress that emerges from perceived decrements in one's body image. Continued efforts that permit a more broad understanding of the experience of individuals who have been diagnosed and treated for HNC may help to guide survivorship planning from the point of diagnosis to end of life care (Hausman, Ganz, Sellers, & Rosenquist, 2011).

Conclusions

New and more effective medical advancements have resulted in increases in post-cancer treatment survivorship; however, these survivors are often faced with real, long-term physical and psychosocial health consequences as a result of treatment(s). Outcomes from these treatments can create myriad psychosocial challenges that may be further impacted by distress with subsequent decreases in one's functional ability and ultimately a decreased QOL (Bornbaum et al., 2012). Treatment for HNC holds substantial potential for changes in physical appearance and secondary changes in overall functioning, which may include alterations in perceived body image. The present preliminary findings suggest that changes in perceived body image may not be a concern only for individuals with an obvious physical disfigurement secondary to treatment. The findings from this study further suggest that perceptions of body image may be experienced by both women and men, and may be further influenced by factors including age, treatment modality, specific site of cancer diagnosis, as well as the time passed since that diagnosis. Given the negative implications associated with altered perceptions of body image and its potential influence on rehabilitation outcomes including long-term QOL, the use of

targeted screening measures, such as the ones employed in this study, may offer a low burden, cost effective way to initiate intervention and potentially optimize QOL. Future study that seeks to address the gaps in knowledge surrounding the potential influence(s) of perception of body image and QOL following the diagnosis and treatment of HNC would appear to hold promise with the findings being of direct benefit to those treated for HNC. Consequently, continued efforts toward exploring this important concept may foster better patient care with improved short- and long-term rehabilitation outcomes.

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APPENDIX A

DATA SHARING AGREEMENT

This Agreement is entered into this 17th day of January, 2014

- between -

The University of Western Ontario (Institution's Name)
and
Dr. Philip Doyle (Researcher's Name)
(collectively "Requestor")

- and -

Lawson Health Research Institute, a joint venture of London Health Sciences Centre
Research Inc. and Lawson Research Institute (Institution's Name)
and
Dr. Kevin Fung
(collectively "Disclosing Custodian")

WHEREAS REQUESTOR and DISCLOSING CUSTODIAN wish to enter into an agreement with each other to disclose to REQUESTOR certain Personal Health Information ("PHI") currently in the custody and control of DISCLOSING CUSTODIAN for the purposes of collaboration on the study entitled "An Exploration of Body Image and Quality-of-Life in Individuals with Head and Neck Cancer" (REB 104498), and

WHEREAS DISCLOSING CUSTODIAN is willing to disclose the information under the terms and conditions set out in this Agreement for handling PHI, and

NOW THEREFORE, in the consideration of the promises and the mutual covenants hereinafter contained, and in alignment with the Personal Health Information Protection Act, Ontario ("PHIPA") the parties hereto agree as follows:

1.0 PURPOSE OF THE AGREEMENT

1.1 The purpose of this agreement is to set out the terms and conditions governing the disclosure of data, including personal health information.

2.0 INFORMATION TO BE PROVIDED

2.1 REQUESTOR has asked for, and DISCLOSING CUSTODIAN has agreed to provide certain personal health information of participants between the ages of 18 and 65 years of age who have been diagnosed and treated for Head and Neck Cancer The data elements that will be shared include: participants' full name, address, postal code, telephone number, email, and month/year of birth (Hereinafter the "Data")

2.2 Disclosing Custodian shall not provide Data until both Disclosing Custodian and Requestor have obtained approval from their respective Research Ethics Boards and provided each other with evidence of such approvals.

3.0 USE OF THE INFORMATION

3.1 REQUESTOR shall use the Data collected under this agreement only as necessary for mailing study packages to participants. Date of birth will be collected to determine the age of the participants (hereinafter the "Study").

3.2 Secondary uses of the Data by the Requestor are prohibited.

3.3 Requestor shall not provide Data to any third party.

3.4 Requestor shall contact individuals whose identities are contained within the Data only for the purposes of the study.

4.0 SECURITY OF PERSONAL HEALTH INFORMATION

4.1 Data will be securely stored in the following way: When study packages are returned to Dr. Doyle, participant identifiers (name, month/year of birth, address) will be removed. De-identified, coded information collected will be stored on a password-protected computer within the locked office of Rm 2200 Elborn College. As a back-up, an encrypted and password protected memory stick will also contain the de-identified, coded information collected, which will also be kept in a locked filing cabinet within the same room. A master list containing participants' codes, names and contact information will be held separate from all data in a locked filing cabinet in Dr. Doyle's locked laboratory at Elborn College. All identifiable electronic information, demographic data, and questionnaire data will be kept on an encrypted thumb drive that has been password protected as well as on a laptop computer accessible only to the research team and stored in a locked cabinet within Dr. Doyle's laboratory. The Disclosing Custodian and Requestor are responsible for the security and integrity of the Data entrusted to them under this Agreement and will safeguard the Data against accidental, unauthorized access, disclosure, use, modification and deletion.

4.2 Data will be securely transferred in the following way: data will be transferred between UWO and LHSC locations on an encrypted and password protected thumb drive by one of the researchers.

4.3 Data will have the following administrative, technical and physical safeguards: All data from Dr. Kevin Fung's Clinic will be transferred only via the transfer protocol outlined above in Section 4.2.

4.4 It is agreed that the Disclosing Custodian, at its discretion, has the right to inspect the security and confidentiality procedures of the Requestor. In the event of an accidental or unauthorized access, disclosure, use, modification or deletion of Data while in the custody of the Requestor, the Requestor will promptly take all reasonable steps to resolve the event and prevent a recurrence and will promptly notify the Disclosing Custodian of the occurrence and steps taken.

5.0 CONFIDENTIALITY

5.1 The personal health information disclosed under this agreement is confidential and mechanisms for maintaining the confidentiality of this information are described in Section 5.4 of this Agreement.

5.2 Before disclosing any personal health information under this agreement, the DISCLOSING CUSTODIAN shall exercise due caution in providing access to only that personal health information that is determined to be necessary for the purposes set out in Section 3.1 of this Agreement.

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5.3 REQUESTOR, in requesting personal health information under this agreement, warrants and represents that the personal health information is necessary for the purposes set out in Section 3.1 of this Agreement.

5.4 REQUESTOR agrees to the following precautions and safeguards in the handling of the confidential personal health information:

a) REQUESTOR will allow access to personal health information in the custody of the DISCLOSING CUSTODIAN only by the following individuals: Dr. Philip Doyle, Melissa Nash (Master's Student).

b) Agents of the REQUESTOR requiring access to personal health information in the custody of the DISCLOSING CUSTODIAN will be approved for access in writing by the DISCLOSING CUSTODIAN prior to their being granted access.

c) Requestor warrants that all agents of the REQUESTOR are subject to the information handling policies and practices of the REQUESTOR. Requestor also warrants that all agents are in good standing with their professional colleges as regards clinical practice competency and privacy practices.

d) Where either party determines that a person specified in Section 5.4.a should no longer have access to personal health information in the custody of the DISCLOSING CUSTODIAN, that party shall notify the other party by email (tagged with a read receipt) within 24 hours.

e) REQUESTOR will keep any disclosed information confidential in accordance with the information handling policies and practices of the REQUESTOR regardless of whether the information is collected or used by REQUESTOR.

f) REQUESTOR will store any collected information disclosed by the DISCLOSING CUSTODIAN in a secure and confidential manner in accordance with the information handling policies and practices of the REQUESTOR.

6.0 FINANCIAL ARRANGEMENTS

6.1 Each party shall bear its own cost of implementing this agreement.

7.0 ACCURACY OF INFORMATION

7.1 The DISCLOSING CUSTODIAN shall provide on a one time basis following each period of data collection to the data elements that are the subject of this agreement, pursuant to Sections 2.1 and 4.1. The DISCLOSING CUSTODIAN will use reasonable efforts to ensure the information provided under this Agreement is an accurate representation of the information contained in its datasets.

8.0 PUBLICATION OF STUDY RESULTS

8.1 Subject to the terms of this Agreement and the provisions of this Section 8.0, Requestor may present or publish the Study results. Only de-identified information may be presented or published. The contributions of the Disclosing Custodian are to be recognized in accordance with academic standards for authorship and acknowledgement.

8.2 Requestor will submit to Disclosing Custodian any proposed presentation or publication for review and comment thirty (30) days in advance of such disclosure.

9.0 AMENDMENTS

9.1 This agreement may be amended if the parties agree to such amendments in writing. Any amendments so made shall be consistent with the requirements of the Personal Health Information Protection Act.

10.0 TERMS, COMMENCEMENT AND TERMINATION OF AGREEMENT

10.1 This agreement shall take effect on the date set out on page 1.

10.2 This agreement shall continue in effect for as long as the DISCLOSING CUSTODIAN provides Data, unless there is an amendment or termination, subject to Section 9.1.

10.3 The DISCLOSING CUSTODIAN may cease disclosing any one or more data elements, without cause by giving REQUESTOR notice in accordance with Section 12 of this agreement.

10.4 If the DISCLOSING CUSTODIAN ceases disclosing personal health information under 10.3 the entire agreement is not terminated but continues with respect to the remaining data elements which the DISCLOSING CUSTODIAN is willing to continue to disclose.

10.5 Nothing in this Agreement permits the DISCLOSING CUSTODIAN to disclose data to the REQUESTOR that may be subject to an express instruction that has been received by the DISCLOSING CUSTODIAN from the person to whom the personal health information relates, in accordance with the Personal health Information Protection Act.

10.6 This Agreement may be terminated by either party without cause on at least two months notice and on breach by the other party immediately on notice.

10.7 This Agreement may be amended or terminated on mutual written agreement by the parties.

10.8 This Agreement may be terminated immediately by Disclosing Custodian in the event of a privacy or security breach.

10.9 On termination the DISCLOSING CUSTODIAN shall cease disclosing Data and REQUESTOR shall cease accessing Data and at the request of the Disclosing Custodian, return or destroy all Data in accordance with accepted standards and provide evidence of the same to the Disclosing Custodian.

11.0 SURVIVAL OF OBLIGATIONS

11.1 Terms and conditions relating to

a) use and destruction of the information
b) confidentiality; and
c) indemnification

shall survive the termination of this agreement.

12.0 NOTICE

12.1 Notice of intention to terminate as per section 10.6 shall be given in writing to the other party.

12.2 Notice shall be deemed to have been sufficiently given 72 hours after it has been mailed, postage prepaid, or on the date of receipt where the notice has been delivered by hand or by read-receipt email or facsimile transmission.

12.3 Any notice or other communication required or permitted to be given by either party to the other shall be sent to the following addresses:

If for DISCLOSING CUSTODIAN:

Lawson Health Research Institute
750 Base Line Road, Suite 300
London, ON N6C 2R5
Attention: Contracts Office

and

London Health Sciences Centre
800 Commissioners Road East, B3-427A
London, ON, N6A 5W9
Attention: Dr. Kevin Fung

If for REQUESTOR:

The University of Western Ontario
London, Ontario, Canada, N6G 1G9
Attention: Mr. Dan Sinai

The University of Western Ontario
School of Communication Sciences and Disorders
Rm 2518 - Elborn College
1201 Western Road, London Ontario
Attention: Dr. Philip Doyle

13.0 NO WARRANTIES BY DISCLOSING CUSTODIAN

13.1 Data are provided on an "as-is" basis and PROVIDER makes no representations or warranties, express or implied, with respect thereto. RECIPIENT accepts that there are no representations, warranties, conditions or liabilities expressed or implied herewith in relation to the Data by PROVIDER or its trustees, directors, officers, affiliates, investigators, students, employees, servants, authorized representatives or agents.

14.0 INDEMNIFICATION

14.1 The REQUESTOR shall indemnify and save harmless the DISCLOSING CUSTODIAN and the DISCLOSING CUSTODIAN's employees, independent contractors, subcontractors, agents, and assigns from all costs, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature based on or attributable to REQUESTOR's acts or omissions pertaining to this Agreement including but not limited to any disclosure by REQUESTOR or its directors, officers, employees, independent contractors, subcontractors, agents or assigns of

personal health information contained in the Data. This provision survives the termination of this Agreement.

15.0 GENERAL PROVISIONS

15.1 Nothing contained herein or done hereunder shall be construed as establishing any agency, partnership or joint venture relationship between the parties for any purpose whatsoever.

15.2 This Agreement contains the entire agreement between the parties and supersedes all prior agreements, negotiations, representations and proposals, written and oral. Any Schedules attached hereto form part of this Agreement. No amendment or variation of this Agreement shall be effective unless set forth in writing signed by a duly authorized representative of each party.

15.3 This Agreement shall be binding upon and enure to the benefit of the parties hereto and their respective successors and permitted assigns, provided that none of the parties shall assign or subcontract this Agreement or any part thereof or any rights or obligations under this Agreement or with respect to the Services without the prior written approval of the other party hereto.

15.4 All headings in this Agreement are inserted solely for convenience, are not part of this Agreement and do not in any way limit or amplify the terms hereof. Any reference to "days" in this Agreement means calendar days, unless otherwise specified.

15.5 Each of the parties shall sign such documentation and deliver such information as may be reasonably required by the other in order to confirm and give effect to the provisions set forth in this Agreement.

15.6 This Agreement shall be interpreted and governed by the laws of the Province of Ontario and the laws of Canada applicable in such Province. Any action taken relating to this Agreement shall be commenced in the courts of the Province of Ontario, and each of the parties hereby attorns to such jurisdiction.

15.7 This Agreement may be executed in one or more counterparts, each of which, when so executed shall be deemed an original, and all of which together shall constitute one and the same agreement. This Agreement may be delivered by facsimile or other electronic means.

15.8 The parties acknowledge that they have read and understood the above terms and conditions and each has had full opportunity to seek independent legal and professional advice as to their effect.

Signature page follows.

IN WITNESS WHEREOF this agreement has been duly executed by the parties.

DISCLOSING CUSTODIAN

Lawson Health Research Institute

Per: _____

Name: Cheryl Litchfield

Title: Manager, Grants & Contracts

Date: _____

Researcher:

Per: _____

| Name: Dr. Kevin Fung

| Title: Co-Investigator

Date: _____ 1.17.2014 _____

REQUESTOR

The University of Western Ontario

Per: _____

Name: Dan Sinai

Title: Associate VP, Research

Date: _____ January 30, 2014 _____

Research:

Per: _____

| Name: Dr. Philip Doyle

| Title: Principal Investigator

Date: _____ Jan 29, 2014 _____

Reviewed by

Reviewed By

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Letter of Information

Title: An Exploration of Body Image and Quality-of-Life in Adults with Head and

Neck Cancer

Study Investigators: Dr. Philip Doyle, Ph.D., Melissa Nash, B.H.Sc, M.Sc. (Candidate),

Kevin Fung, B.Sc., M.D.

1. Introduction
You are being invited to participate in a research project investigating issues related to body image and its impact on quality of life among individuals diagnosed with and treated for head and neck cancer. We are asking you to take part in this research study because you have been diagnosed with and treated for head and neck cancer and we are interested in how this experience may have impacted your body image and your quality of life.

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 a diagnosis of and treatment for head and neck cancer on self-perceived body image and/or self-concept as it relates to quality of life. We are conducting this study in order to determine how the experience of living with the treatment related changes from head and neck cancer affect 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 quality of life.
The specific questions to be addressed are:

a.) What is the relationship between body image and quality of life for individuals diagnosed and treated for head and neck cancer?

b.) Are there identifiable commonalities in the experience of body image among those treated for head and neck cancer?

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

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 four (4) questionnaires to complete regarding your personal feelings related to your body image and quality of life in relation to your cancer and its associated treatments. The questionnaires have been used before in research and include the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (EORTC-QLQ-C30), and the EORTC Head and Neck module (EORTC-QLQ-H&N35), which measure your quality of life. Also, you will be given the Body Image Scale (BIS) and the Body Image Disturbance Questionnaire (BIDQ), which help identify aspects of body image that may have changed following treatment for cancer. 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 - 30 minutes to complete all of these questionnaires.

Once you have completed all questionnaires, 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 Melissa Nash or Dr. Philip Doyle

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 18 or older than 65 years of age, if you have recurrence of your cancer, if you completed treatment less than 3 months or more than 10 years ago, if you have had a diagnosis of 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 body image and the quality of life in individuals who are between 18 and 65 years of age and whose quality of life 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 quality

of life and/or perceived body image). 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 perceived body image and quality of life 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, pre-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. 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 patient care and may assist health care practitioners in identifying those individuals who are most likely to experience reduced quality of life following completion 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. If you choose to withdraw from the study, you may request that any data you have provided be removed from the study results. You do not waive any legal rights by signing the consent form.

8. Confidentiality

All data collected will remain confidential. <u>All personal identifying information will be removed from the data</u> and your data will be identified by a code known only to the investigators. <u>All data will be kept in a secure locked location at the University of Western Ontario.</u> The data will be kept for 10 years and then destroyed according to the standards of the Faculty of Health Sciences. 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:

If you have any questions about your rights as a research participant or the conduct of the study, you may contact:

<u>By completing and returning the questionnaires, you indicate your consent to participate in the study.</u>

This letter is for you to keep.

Demographic Information Survey

Title: An Exploration of Body Image and Quality-of-Life (QOL) in Individuals with Head and Neck Cancer.

Study Investigators: Philip Doyle, Ph.D., Melissa Nash, B.H.Sc., M.Sc. (Candidate), Kevin Fung, B.Sc., M.D.

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 body image or perceived QOL, please use the back of these pages to include it.

Sex: M   /   F   / Other

Age: _____

Year of Birth: _____   Month of Birth: _____

Number of months since your diagnosis: _____

Are you still receiving treatment?   Yes   /   No
If so, when is it scheduled to be completed? _____

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:

_____

Method of Treatment:
a)   Surgery
b)   Radiation therapy
c)   Chemotherapy
d)   Chemoradiation therapy
e)   Other

If "other", please specify:

_____

Please provide a brief account detailing the treatment you received. (Example: what type(s) of surgery did you have, in what order did you receive treatments.)

_____
_____
_____

Marital Status (circle one):
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:

_____

Highest Level of Education Achieved:
a)   Completed High school
b)   Completed College
c)   Undergraduate University degree
d)   Post-graduate University degree
e)   Other

If "other", please specify:

_____

Please feel free to include any additional information that you feel is important specific to this project in the space provided below or on the opposite side of this document. Thank you.

_____
_____
_____
_____

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 long walk?	1	2	3	4
3. Do you have any trouble taking a short 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

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 family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social 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

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 <u>during the past week</u>. 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

<u>Please go on to the next page</u>

During the past week: Not at all   A little   Quite a bit   Very much

		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

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BODY IMAGE SCALE

In this questionnaire you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

Participant ID: _____   Date: _____

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	....	....	....	....
Have you felt less physically attractive as a result of your disease or treatment?	....	....	....	....
Have you been dissatisfied with your appearance when dressed?	....	....	....	....
Have you been feeling less feminine/ masculine as a result of your disease or treatment?	....	....	....	....
Did you find it difficult to look at yourself naked?	....	....	....	....
Have you been feeling less sexually attractive as a result of your disease or treatment?	....	....	....	....
Did you avoid people because of the way you felt about your appearance?	....	....	....	....
Have you been feeling the treatment has left your body less whole?	....	....	....	....
Have you felt dissatisfied with your body?	....	....	....	....
Have you been dissatisfied with the appearance of your scar?	....	....	....	....

Not Applicable........

BIDQ (© Thomas F. Cash and Kathleen A. Phillips)

This questionnaire assesses concerns about physical appearance. Please read each question carefully and circle the answer that best describes your experience. Also write in answers where indicated.

Are you concerned about the appearance of some part(s) of your body which you consider especially unattractive? (Circle the best answer)

1	2	3	4	5
Not at all concerned	Somewhat concerned	Moderately concerned	Very concerned	Extremely concerned

What are these concerns? What specifically bothers you about the appearance of these body parts? _____

_____

_____

If you are at least somewhat concerned, do these concerns preoccupy you? That is, you think about them a lot and they're hard to stop thinking about? (Circle the best answer)

1	2	3	4	5
Not at all preoccupied	Somewhat preoccupied	Moderately preoccupied	Very preoccupied	Extremely preoccupied

What effect has your preoccupation with your appearance had on your life? (Please describe):

_____

_____

_____

Has your physical "defect" often caused you a lot of distress, torment, or pain? How much? (Circle the best answer)

1	2	3	4	5
No distress	Mild, and not too disturbing	Moderate and disturbing but still manageable	Severe, and very disturbing	Extreme, and disabling

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Has your physical "defect" caused you impairment in social, occupational or other important areas of functioning? How much? (Circle the best answer)

1	2	3	4	5
No limitation	Mild interference but overall performance not impaired	Moderate, definite interference, but still manageable	Severe, causes substantial impairment	Extreme, incapacitating

Has your physical "defect" significantly interfered with your social life? How much? (Circle the best answer)

1	2	3	4	5
Never	Occasionally	Moderately Often	Often	Very Often

If so, how? _____

_____

_____

Has your physical "defect" significantly interfered with your schoolwork, your job, or your ability to function in your role? How much? (Circle the best answer)

1	2	3	4	5
Never	Occasionally	Moderately Often	Often	Very Often

If so, how? _____

_____

_____

Do you ever avoid things because of your physical "defect"? How often? (Circle the best answer)

1	2	3	4	5
Never	Occasionally	Moderately Often	Often	Very Often

If so, what do you avoid? _____

_____

_____

CURRICULUM VITAE (LIFETIME)

a)   **NAME:**   Melissa M. Nash

        STATUS: Doctoral Student – Year 1

        Full-time or part-time status: Full time

b)   **DEGREE**   **University**   **Department**   **Year**

        MSc   Western University   Rehabilitation Sciences   2012 - 2014

        BHSc   Western University   Health Sciences   2001-2005

c)   **EMPLOYMENT HISTORY:**

Date	Rank & Position	Department	Institution
Sept 2012 – Present	Research Associate The Laboratory For Well-being and Quality of Life in Oncology	Faculty of Health Sciences	Western University
Sept 2013 – Dec 2013	Teaching Assistant HS3050A – Health-related Quality of Life	School of Health Studies	Western University
Jan 2013 – May 2013	Teaching Assistant HS 3040B – Health Management	School of Health Studies	Western University

d)   **AWARDS AND ACADEMIC HONOURS: (not research grants)**

2013 – Faculty of Health Sciences, Western University, Graduate Student Conference Travel Award
2014 – Faculty of Health and Rehabilitation Sciences, Western University, Graduate Student Conference Travel Award
2014 – Society of Graduate Students, Western University, Graduate Student Teaching Award

e)   **SCHOLARLY AND PROFESSIONAL ACTIVITIES:**
1) Rehabilitation Sciences Journal Club, Assistant Facilitator: Date: 2013, Fall Term
2) Rehabilitation Sciences Journal Club, Session leader, Topic: Revision of the ICD-10 to include components of the ICF, Date: March 27, 2013
3) Rehabilitation Sciences Journal Club, Session leader, Topic: Revision of the ICD-10 to include components of the ICF, Date: February 27, 2013
4) Health and Rehabilitation Sciences, Research Forum Committee, Student Member, Date: 2012 – 2013

f) **RESEARCH PROJECTS:**

Start Date	End Date	Principal Investigator(s)	Co-Investigator(s)	Affiliation	Working Title	Funded
2013	2015	Nash, M. Sugimoto, A.	Shaddick, H. Doyle, P.C. Nisker, J.	London Health Sciences Centre, Department of Gynecological Oncology	Prognostic Uncertainty in gynecological oncology and the impact on Quality of Life	
2013	2014	Nash, M.	Doyle, P.C. Fung, K.	London Health Sciences Centre, Department of Otolaryngology, Head and Neck Surgery	An Exploration of Body Image and Quality of Life in Individuals with Head and Neck Cancer	

g) **RESEARCH FUNDING:**

Start Date	End Date	Principal Investigator	Co-Investigator	Granting Agency	Grant Title	Total Amount
2013	2014	**Nash, M.**	N/A	Western University – Western Graduate Research Scholarship	Western Graduate Research Scholarship	$10,000
2012	2013	**Nash, M.**	N/A	Western University – Western Graduate Research Scholarship	Western Graduate Research Scholarship	$10,000

h) **PUBLICATIONS:**

    1) **Life-time summary (count) according to the following categories:**

        Books authored: 0
        Books edited: 0
        Chapters in books: 0
        Papers in refereed journals: 0
        Papers in refereed conference proceedings: 0
        Technical reports: 0
        Abstracts and/or papers read: 12
        Presentations at professional meetings/workshops and others: 13

    2) **Publication Details:**

    Presentations at professional meetings/workshops:

13. Scott, G.M., **Nash, M.M.,** Fung, K., Yoo, J., & Doyle, P.D. Perception of Fatigue in Individuals Diagnosed with Head and Neck Cancer. 5th World Congress of International Federation of Head and Neck Oncologic Society (IFNOS) Annual Meeting (AHNS), New York, NY, Jul 26-30, 2014.

12. **Nash, M.M.,** Scott, G.M., Fung, K., Yoo, J., & Doyle, P.D. An Exploration of Perceived Body Image in Adults Treated for Head and Neck Cancer. 5th World Congress of International Federation of Head and Neck Oncologic Society (IFNOS) Annual Meeting (AHNS), New York, NY, Jul 26-30, 2014.

11. Doyle, P. C., Cox, S. R., Scott, G. M., **Nash, M. M**., Theurer, J., Khalili, S., Yoo, J., & Fung, K. The influence of flap reconstruction on auditory-perceptual evaluation of voice acceptability for tracheoesophageal speakers, 5th World Congress of International Federation of Head and Neck Oncologic Society (IFNOS) Annual Meeting (AHNS), New York, NY, Jul 26-30, 2014.

10. Scott, G. M., **Nash, M. M**., Angel, D., Fung, K., MacNeil, D., Yoo, J., & Doyle, P. C., Utilization of the ICF for indexing Fatigue in Individuals diagnosed and treated for head and neck cancer, Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, May 19-20, 2014.

9. Fung, K., Wickens, B., Bornbaum, C., Scott, G. M., **Nash, M. M.,** & Doyle, P. C. Optimizing Otolaryngology Resident Research Training Through Graduate Student Collaboration, Canadian Society of Otolaryngology Annual Meeting, Ottawa, ON, May 10-13, 2014.

8. Scott, G.M**., Nash, M.M.,** Fung, K., Yoo, J., MacNeil, D. & Doyle, P.D. Effect of Course of Treatment on Perceived Fatigue in Individuals with Head and Neck Cancer, Canadian Association of Psychosocial Oncology Annual Meeting, Winnipeg, MB, April 30-May 2, 2014.

7. **Nash, M.M**., Scott, G.M., Fung, K., Yoo, J., MacNeil, D. & Doyle, P.D. Perceived Body Image and Quality of Life: An Exploration Among Individuals with Head and Neck Cancer, Canadian Association of Psychosocial Oncology Annual Meeting, Winnipeg, MB, April 30-May 2, 2014.

6. **Nash, M. M.**, Scott, G.M., Fung, K., Yoo, J., MacNeil, D. & Doyle, P.D. Perceived Body Image and Quality of Life: An Exploration Among Individuals with Head and Neck Cancer, Department of Otolaryngology Grand Rounds: Student Research Day, London, ON, April 23, 2014.

5. Scott, G.M**., Nash, M.M.,** Fung, K., & Doyle, P.D. Cancer-related Fatigue and Quality of Life In Individuals Diagnosed with Head and Neck Cancer, ARGC/FHS Symposium, Western University, London, ON, Feb 7, 2014.

4. **Nash, M.M**., Scott, G.M., Fung, K., & Doyle, P.D. An Exploratory Evaluation of Perceived Body Image in Individuals with Head and Neck Cancer, ARGC/FHS Symposium, Western University, London, ON, Feb 7, 2014.

3. Scott, G.M., **Nash, M.M** Fung, K., & Doyle, P.D. Perception of Cancer-related Fatigue in Individuals with Head and Neck Cancer, Health and Rehabilitation Sciences Graduate Research Forum, Western University, London, ON, Feb 5, 2014.

2. Cox, S.R., **Nash, M.M**., Scott, G.M., & Doyle, P.D. Factors Impacting Speech Acceptability in Tracheoesophageal Speakers, Health and Rehabilitation Sciences Graduate Research Forum, Western University, London, ON, Feb 5, 2014.

1. Doyle, P.C., Cox, S.R., Scott**,** G.M., & **Nash, M.M**. Auditory-Perceptual Evaluation of Speech Acceptability of Tracheoesophageal Speakers, Annual American Speech-Language Hearing Association Convention, Chicago, IL, Nov 14-16, 2013.

i)   COMMUNITY INVOLVEMENT:
         1) Co-Chair, Jewels and Jeans Gala Fundraiser, The Arthritis Society
         2007 – Present
         2) Volunteer and Member, 100 Women Who Care, London Chapter
         2012 – Present
         3) Volunteer and Team captain, Bust a Move for Breast Health,
         2014, St. Joseph's Health care foundation – breast health program