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THE LIVED EXPERIENCE OF BODY IMAGE IN WOMEN UNDERGOING
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HERMENEUTICAL PHENOMENOLOGICAL INQUIRY

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THE LIVED EXPERIENCE OF BODY IMAGE IN WOMEN UNDERGOING ACTIVE TREATMENT OF HEAD AND NECK CANCER: A HERMENEUTICAL PHENOMENOLOGICAL INQUIRY

A Dissertation

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in

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Department of Nursing

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ABSTRACT

The Lived Experience of Body Image in Women Undergoing Active Treatment of Head and Neck Cancer: A Hermeneutical Phenomenological Inquiry

Background: Women with head and neck cancer (HNC) are at risk for changes in body image due to tumor presence and the side effects of the treatments. Physical, psychological, and social constructs of body image (BI) can influence the patient's perception of body image.

Problem: Little is known about women's experiences during HNC treatment and how body image is perceived in the process. As healthcare professionals it is important to hear their stories and understand the struggles they experience in their own words during their treatment.

Study Method: A hermeneutical phenomenological inquiry into the lived experiences of women diagnosed with HNC (excluding thyroid cancer and skin cancers), undergoing treatment (currently or within three months) was conducted with a sample of 20 participants with both data and theoretical saturation obtained. Participants were recruited from three different sites where women with HNC are undergoing active treatment of HNC cancer with radiation therapy, chemotherapy/immunotherapy, surgical treatment, or any multimodal treatment of cancer and from an online support group where several participants had membership. Individual interviews were recorded face to face or using a virtual platform, transcribed, and analyzed using van Manen's method.

Findings: Data analysis revealed three themes, (1) Being and becoming: Seeing myself as a changed person, with subthemes (a) physical changes and body image, and (b) role, social, psychological changes and body image; (2) Inward feelings and meanings, and (3) Navigating the journey, with subthemes (a) internal motivation and (b) external support.

Conclusion: Women treated for HNC experience life-changing alterations in BI demonstrated through the physical, psychological, and social constructs of BI. The physical components of dysfunction, disfigurement, and debility, contributed to women perceiving themselves as less than ideal. Psychological components included negative emotional well-being and altered perceptions of self and sexuality. Social components included changes in social functioning around food, changing roles and relationships with others, and feelings of stigma. The BI changes women experienced as a result of HNC are intertwined with a feminine viewpoint and resulted in women reaching out to personal female friends and support groups with women in similar situations to help them cope. Women relied on support from partners, family and friends to help them find an inner strength to work through the struggles of the disease and treatment and eventually look to the future as a changed person. It is essential for healthcare providers to recognize how treatment side effects holistically impact BI and quality of life. Continued research is needed to determine the best supportive interventions that best promote coping and long-term recovery related to changes in BI.

Keywords*: women, head and neck cancer (HNC), body image, active cancer treatment, hermeneutical phenomenology*

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

HNC- head and neck cancer

SPOHNC-Support for People with Oral and Head and Neck Cancer

ADL-activities of daily living

BID-body image dysfunction

PROM-patient related outcome measures

QOL-quality of life

BIS-Body Image Scale

DAS-59- Derriford Appearance Scale-59 DAS-59

MBIS-HNC-McGill Body Image Concerns Scale

ODS-Observer-rated Disfigurement Scale

HADS-Hospital Anxiety and Depression Scale

SECEL-Self-Evaluation of Communication Experiences Laryngeal Cancer

MDASI-HN-MD Anderson Symptom Inventory Questionnaire-Head and Neck

NDI-Neck Disability Index

FACT-H&N-Functional Assessment of Cancer Therapy-Head & Neck Scale

CES-D Center for Epidemiological Studies Depression Scale

BIQLI-Body Image Quality of Life Inventory

IMAGE-HN- Measure and Assess ImaGe disturbance-Head & Neck

TORS transoral Robotic Surgery

NG nasogastric

CHAPTER 1

INTRODUCTION

This chapter contains the background of the study, the problem statement, research questions, definitions of terms, assumptions, limitations, and significance of this study. A hermeneutic phenomenological approach was used to develop the operational definition of body image in a population of women at risk for body image changes.

Background of the Study

All human beings routinely face obstacles that challenge their perception of their body image. The phrase body image first used by Schilder in 1950 was meant to "mean the picture of our own body that we form in our mind, or the way in which the body appears to oneself" (Schilder, 1950 as cited in Rhoten, 2017, p. 534). We manage and adapt to these obstacles differently as a result of our self-perception of these changes. The concept of body image is a "multidimensional, subjective and dynamic concept that encompasses a person's perceptions, thoughts, and feelings about his or her body" (Neagu & Rainer, 2015, p. 30). Components of body image are physical, psychological, and social in nature. Self-perception as well as the perception a person has of the reactions of those in social circles impacts the reaction to these physical, psychological, and social factors surrounding a person's belief in their own body image.

Head and neck cancers (HNCs) are the sixth most commonly occurring cancer and account for about 5-10% of all cancer cases (Davidson & Shank, 2017). Even though HNC only accounts for a small percentage of diagnosed cancers, "the disease and its treatment have a disproportionate impact on all aspects of patient quality of life" (Ojo et al., 2012, p. 924). Treatments for HNC include surgery, radiation, and/or chemotherapy/immunotherapy. These treatments, as well as the cancer itself have the potential to profoundly impact women as they cause changes in personal appearance (Rhoten et al., 2013; Ellis et al., 2019a). Treatment of HNC can result in temporary or permanent body disfigurement and affect the ability to do activities often taken for granted, such as eating or speaking (Chen et al., 2015). Such changes in physical appearance and ability could impact the overall quality of survival and potentially cause stressors in personal and social interactions (Ojo et al., 2012). With no known qualitative research studies in the literature that focus exclusively on examining the self-perceived body image of women with HNC, it is difficult to identify what is needed to support them psychosocially.

Scarpa (2016) noted that there are several predictors of body image dysfunction (BID) which can be identified. "Gender is widely recognized to be a strong predictor of body image dissatisfaction in the general population, with women experiencing higher levels of difficulties and concerns in this area" (Scarpa, 2016, p. 129). Hence, side effects from chemotherapy, immunotherapy, radiation therapy, or surgery that cause disfigurement to facial features can potentially impact even the most confident and resilient of women. Head and neck cancer (HNC) treatments have the potential to cause temporary and/or permanent physical changes as these changes are seen on the "most visually prominent area of the body" (Scarpa, 2016, P. 129). Although no studies have specifically asked women who are treated for HNC about their self-perception of body image constructs, studies of women undergoing treatment for breast cancer note that body image is a concern (Paterson et al., 2016; Zangeneh et al., 2019; Zhou et al., 2020). Fingeret et. al (2013) hypothesized that a patient's self-perceived body image adds to the belief in the overall success of care they received. This linkage of body image to success of care received has relevance for patients with HNC, as they are impacted by acute and chronic side effects of treatment, including disfigurement, debility, and dysfunction, which can affect overall individual survival and wellbeing (Ojo et al., 2012; Rhoten et al. 2013).

In addition to the physical changes that can take place with a cancer diagnosis or as a side effect of the multiple treatment modalities used in cancer treatment, there can be a perceived stigma with regard to physical changes and guilt related to personal habits can be attributed to certain cancer diagnoses (Formigosa et al., 2018; Ellis et al., 2019a). This stigma can influence how a woman sees herself or perceives how others see her, leading to an even higher risk of alteration of her body image. Persons with a history of smoking, alcohol use, poor oral hygiene, or a diagnosis of human papilloma virus have an increased risk of development of HNC (Scarpa, 2016). Each of these modifiable risk factors carries a societal challenge in the mind of the patient. Although patients may not be able to discern how or if these factors are contributory to their HNC diagnosis, they may feel socially ostracized, leading to even more concern over body image. This additional stigma impacts a woman's perception of her body image if she carries some guilt or distress over having put herself at risk for this disease (Formigosa, 2018). Internal beliefs and feelings, as well as a person's perception of how others view them can affect the overall quality of life if body image concerns are not recognized and managed by patients, caregivers, and healthcare providers.

Problem Statement

Few qualitative studies have explored perceived changes in body image as a result of treatment for HNC. No qualitative studies have examined women's perceptions of body image changes experienced while being treated for HNC, and the meanings in the phenomenon. Only a single quantitative study looked at disfigurement and self-perceived body image in women with HNC. The lack of understanding of possible support systems needed by women to help them cope with changes in body image during the diagnosis and treatment of HNC is essential to providing holistic care with interventions to assist this population.

Purpose

This hermeneutic phenomenological research aims to discover and describe women's lived experience of perceived body image changes resulting from HNC and its treatment, and to understand the meanings in the phenomenon.

Research Questions

The following questions guided this research:

1. What are women's embodied experiences of self-perceived body image changes when undergoing active treatment for head and neck cancer?
2. What are the meanings that women ascribe to their self-perceived body image consequential to the reactions of family, friends, coworkers, and healthcare providers to their body changes?
3. How do women with HNC undergoing active treatment describe the strategies they use to navigate the physical, psychological, and social challenges affecting body image, ensuing from active treatment of HNC?

Definition of Terms

The terms below are defined theoretically and operationally and provide a common understanding of the major constructs and intended meanings of the key research question components. The definitions below explain how terms will be used consistently throughout the dissertation and clarify the purpose and methods of the study.

Women

Theoretical Definition

A woman is an adult female human being.

Operational Definition

Those aged 18 or older, who self-identify as females are considered women for this study.

Active Treatment

Theoretical Definition

Active treatment is defined as women currently engaged with the healthcare system for medical care, therapy, or remedy of their head and neck cancer. These treatments include surgery, radiation, chemotherapy/immunotherapy, or multimodal therapy.

Operational Definition

Measurement of active treatment will be by virtue of the study participants affirming they are receiving surgery, radiation, or chemotherapy/ immunotherapy or multimodal therapy or have recently completed this therapy in the past three months.

Body Image

Theoretical Definition

Body image by medical definition is the “personal conception of one’s own body as distinct from one’s actual anatomic body or the conception other people have of it” (“body image”, 2012). Although physical appearance is a critical part of the definition of body image, psychological and social constructs are additionally contributory to the definition. According to Vilhauer (2008), body image is multifactorial and complicated by the personal experiences of each woman defining the concept. These factors of body image are physical, psychological, and social in their context. Physical components of body image can be impacted on changes that make a person feel less than ideal include dysfunction, disfigurement, and debility. Psychological components of body image include participating in activities of daily living

(ADLs), emotional wellbeing, sense of self, and sexuality. Social components of body image are social functioning and stigma.

Operational Definition

Body image will be operationally defined by women in the study through their responses to semi-structured questions during individual interviews.

Embodied Experience or Embodiment

Theoretical Definition

Embodied experience or embodiment "advances three critical claims: (1) bodies tell stories about—and cannot be studied divorced from—the conditions of our existence; (2) bodies tell stories that often—but not always—match people's stated accounts; and (3) bodies tell stories that people cannot or will not tell, either because they are unable, forbidden, or choose not to tell" (Krieger, 2005, p. 350).

Operational Definition

The operational definition of embodied experience will be defined through semi-structured interviews with participants.

Head and Neck Cancer

Theoretical Definition

Head and neck cancers are a group of cancers originating in the upper airway or oral cavity including the larynx, pharyngeal cavity, oral cavity, nasal cavity, tonsillar, parasinuses, and salivary gland not including thyroid or skin cancers originating in this anatomical site (head and neck, 2008).

Operational Definition

Head and neck cancer will be operationally defined by virtue of the participants verifying a medical diagnosis of HNC as theoretically defined.

Meaning

Theoretical Definition

People attach meaning as a process of making sense and understanding life experiences, events, relationships, and themselves. In qualitative research, the researcher seeks to understand the participant's experiences through the participant's words and narrative to create meaning (Hunter Revell, 2013).

Operational Definition

The operational definition of meaning results from the voiced responses of women with HNC describing their body image experiences while undergoing active HNC treatment.

Assumptions

The following assumptions were identified for this research.

1. Women diagnosed with HNC and undergoing active treatment experience challenges in body image.
2. Women diagnosed with HNC and undergoing active treatment ascribe meanings to the experience that can be discovered.
3. Women diagnosed with HNC undergoing active treatment can recall the experience of body image challenges and convey their insights about the consequences of their experiences.
4. Women diagnosed with HNC undergoing active treatment will respond honestly.
5. A phenomenological baseline of meanings regarding living through body image challenges can be developed based on the feelings, knowledge, perceptions, memories, and verbal/nonverbal responses revealed in interviews with women diagnosed with HNC who have lived through body image challenges.

Limitations

The following limitations are recognized for this research.

1. The quality of the interview data is limited to the individual woman's ability to communicate their embodied experiences of body image challenges and its impact.

2. The findings might be applicable to only the small number of women participating in the study.

3. There are possible limitations when conducting interviews virtually, particularly if a woman does not want to use the video feature; thus, nonverbal cues cannot be discerned.

4. Because the number of women diagnosed with HNC is small, a possible limitation is the accrual of a sufficient number of participants to achieve data and theoretical saturation.

Significance of Study

In adults treated for any cancer, Rhoten (2016) identified three attributes of body image disturbance in a concept analysis. Both men and women in Rhoten's analysis indicated self-perception and displeasure with their appearance, a decline in functional ability, and psychological distress. Participants recognized this displeasure in appearance or change in functional ability as defining characteristics for body image disturbance. Although the study was based on literature including individuals with a multitude of diagnoses including both men and women, the analysis is relevant for healthcare providers working to support cancer patients not only survive a cancer diagnosis, but also to thrive in survivorship of the diagnosis. In recognizing the potential for body image disturbance in the general cancer population, healthcare providers can develop holistic, comprehensive treatment plans as well as interventions to assist them in developing coping skills to manage the changes experienced physically, psychologically, and socially. Yet, there is still a gap in understanding if these same attributes are seen in women being treated for HNC.

Understanding the experiences of body image as lived by the women undergoing active treatment for HNC will assist nurses in understanding special care needs that women with HNC may have and help healthcare providers identify women who are at risk for physical, psychological, or social distress secondary to body image changes resulting from HNC treatment. Understanding the needs of this population of women can assist nurses and other healthcare providers in general by receiving feedback from participants on how positive body image can be promoted. Awareness of women's perceptions can guide researchers and healthcare providers to work on interventions to facilitate a positive transition to survivorship in this population.

Interventions directed at helping women adapt to physical and psychological changes have been studied extensively in women diagnosed and treated for breast cancer where 128.8 women per 100,000 or about 269,000 women are diagnosed each year (U.S. Cancer Statistics Working Group, 2019). Yet, there is a lack of knowledge about needed interventions for the smaller population of women who are diagnosed with HNC where there are about 6.3 new cases per 100,000 women per year or about 16,000 women each year diagnosed (Siegel et al., 2019). In fact, there is little data published on women's unique perception of the impact of the diagnosis and decision to treat HNC and the support that these women need to achieve positive outcomes. The difference in size of the populations of women diagnosed with breast cancer and those diagnosed with HNC does not discount the importance for them to have support. There are numerous support programs for women undergoing treatment for breast cancer based on gender, stage, age, and ethnicity compared to only 125 support groups nationwide for those with head and neck cancer (Support for People with Oral and Head and Neck Cancer, [SPOHNC], 2019). Additionally, the SPOHNC support groups are not solely for women.

There is a lack of research specific to women with HNC and how findings in this subset might differ from the studies with both male and female patients with HNC. Interventions and support systems can be developed to help women cope the permanent or temporary changes that occur because of HNC treatment if needed and assist in maintaining or obtaining a more positive body image in this population. Without eliciting the body image perception experiences of women with HNC, there is a gap in our understanding of the aspirations and needs of this population. Supporting women with HNC through this life-altering diagnosis is essential for successful transition to survivorship and life beyond the diagnosis and treatment of head and neck cancer. This hermeneutic, phenomenological study seeks to construct robust meaning and understanding of the phenomenon of being a woman who undergoing treatment for HNC. Gaining insight into the physical, psychological, and social lived experience of women experiencing body image changes will enable healthcare providers to glimpse the daily challenges faced beyond management of physical symptoms.

CHAPTER 2

REVIEW OF LITERATURE

A review of the literature was undertaken to explore published articles that addressed body image, women with HNC receiving active treatment for the disease, and attributes surrounding the concept of body image. This review of the literature was organized according to how body image has been measured, what was measured, and evidence examining the three constructs of body image (physical, psychological, and social). Appendix A topically organizes the articles by construct and author(s). Organization of the information in this manner allowed for the succinct discussion of research found surrounding not just the constructs of body image but also the difficulties previous researchers have encountered with the measurement of body image in multiple different populations. This organizational method provided evidence of a gap in research exploring the lived experience of body image in women with HNC undergoing active cancer treatment.

Search Strategy

A review of the research and scientific literature using CINAHL and PubMed databases with the search terms “body image”, “women”, “active cancer treatment”, “hermeneutical phenomenology”, and “head and neck cancer (HNC)” on three different occasions during 2/20/2020 thru 7/7/2021. When completing the database search, there were publication limitations based on year of publication or type of research methods. Qualitative, quantitative, mixed methods, and systematic reviews were considered for content and included if relevant. Only publications in English were considered. Approximately 50 articles were initially obtained through the database search. The articles were reviewed for relevance to this study first by reading abstracts and excluding those not related to the description of body image in women undergoing cancer treatment or attempts to measure this concept. Remaining articles were read, organized, and compiled using the three constructs of body image (Appendix A) or methods by which researchers sought to identify and measure body image changes in specific populations.

Measuring Body Image in Women with HNC

Most researchers in HNC recognized body image as more than just physical attributes, however, they differed in how the concept of body image was measured. Few researchers asked an all-female population with HNC how the three attributes of body image (physical, psychological, and social) affected them. It is essential to consider the physical, psychological, and social attributes identified in the body image literature that supports the need to understand the lived experience of this population to understand the body image of women undergoing active treatment for HNC.

Addressing the multiple aspects of body image is essential to provide women with HNC the best opportunity for holistic care focused not only on cure or control of the disease, but on optimum quality of life. “Body image is an important quality-of-life issue for patients that must be acknowledged” (Rhoten, 2017, p. 1). Even in a population of people without a current cancer diagnosis, body image was impactful. For both men and women, there were situations that could result in an increased feeling of body dissatisfaction. According to Brennan et al. (2010), there were more situations such as “sociocultural and situational factors, and body image perceptions in sexual contexts” (p. 130) that made women feel negative about their body image when compared to men. Women also had lower body self-esteem scores and higher reports of internalized sociocultural appearance standards. These findings support the negative correlations of appearance and attribution with negative body image perceptions and differences in body image dissatisfaction between men and women (Brennan et al., 2010). Polivy and Herman (2007) provided additional insights into the multifactorial aspects of body image and the strain it can cause for women reporting it is “not surprising that in our society, the body has become a focus for evaluation by others and by oneself, particularly for women". (p. 66) If these findings were similar in the population of women with HNC, it is reasonable to believe that understanding their lived experience while battling cancer is essential to understanding and determining how to support them in their journey.

Body image in a multidimensional and individualized aspect of part of one's being. It "is a critical psychosocial issue for the patient with head and neck cancer, as the disease and its treatment can significantly alter physical appearance and result in loss or impairment of function" (Scarpa & Hickey, 2016, p. 129). In a state of the science review of the literature surrounding body image in patients with HNC, Rhoten et al. (2013) noted that there was a lack of longitudinal research surrounding body image in this population, little consensus on the mediating and moderating factors associated with a patient's body image, and no specific tool to measure body image in this population. These findings were supported by Ellis et al. (2019) who stated that understanding body image disturbance for HNC is "in its 'infancy'….and the results of this systematic review confirm that statement" (Ellis et al., 2019, p. 952). The scant research found specific to women with HNC would exemplify that stage of "infancy."

With an initial lack of a tool with established validity and reliability in the HNC population, attempts to measure body image in this population was a struggle. Two systematic reviews examined research studies using quality of life (QOL) tools to measure QOL in this population (Ojo et al., 2012; Djan & Penington, 2013). Although QOL is not a direct question to be addressed in this dissertation research, components of body image were incorporated into both systematic reviews.

Djan and Penington's (2013) systematic review aimed to identify questionnaires that captured patient-reported outcome measures (PROM). From a review of over 530 articles, 18 QOL questionnaires were identified with data reported as a PROM. Further review resulted in five questionnaires being identified and "evaluated based on their development and validation criteria, appearance domain content and use in assessing QOL outcomes in HNC patients" (p. 648). In their review, Djan and Penington recommended using the University of Washington QOL questionnaire due to proven psychometric properties in the HNC population included in the questionnaire, and the additional ability of the participant having the opportunity to enter free-text comments. Researchers did not include a place in this tool for the participants to address concerns about disfigurement, which is a major side effect of HNC and its treatment and can impinge upon QOL.

Ojo et al.'s 2012 systematic review failed to identify a "gold standard questionnaire" (p.923) to assess QOL in the population of patients with HNC. After reviewing over 57 different tools used in more 710 research articles, researchers could not identify a single instrument to measure the complex heterogeneity of physical, psychological, and social factors impacting QOL. Findings of Ojo et al. noted that part of the inability to adequately measure concerns in the population who were diagnosed with HNC was the large number of different tools used. Such a large number (57) of heterogenetic tools resulted in an inability to build on knowledge from one study to another. Thus, there remained a gap in knowledge on the struggles with essential components of QOL and a subset of QOL, body image, for those with HNC.

Sundraram et al. (2019) conducted a systematic review of body image measures for people diagnosed with HNC and reviewed 18 articles. The objectives of the systematic review included: "(1) identify HNC-specific patient-reported outcome measures (PROMs) used to assess body image, (2) evaluate their conceptual coverage, (3) appraise their development process and psychometric properties, and (4) determine appropriate body image PROM(s) for use in the HNC setting" (Sundraram et al., 2019, p. 3657). From these 18 articles, eight different measures of PROM and body image disfunction (BID) were identified. Sundraram et al. (2019) reported a missing part of the framework of essential information required to address body image in this population and the researchers concluded there was a lack of conceptual coverage of BID in the HNC population. Based on psychometric properties and tool mapping, Sundraram et al. (2019) recommended the use of the Body Image Scale (BIS) or Derriford Appearance Scale-59 (DAS-59) to assess PROM and BID in patients with HNC. Use of the BIS or DAS-59 addressed over 55% of the PROM and BID issues identified in the HNC population (Sundaram et al., 2019, p. 3657). This provided researchers with evidence-based validation for the use of body image measurement tools in the HNC population.

Pertinent to this current research, Sundaram et al. (2019) explicated the psychometric properties that were identified as important for assessment in patients with HNC. Articles included in his review identified 18 measures important in the assessment of body image in patients with HNC. Satisfaction with appearance, self-consciousness, self-esteem, general psychosocial functioning, role functioning, noticeable change in appearance, ability to look at self, family and friends' response to appearance, and avoidant behavior were just a few of the attributes of body image measured by the tools reviewed by Sundraram et al. Attributes of body image identified in this study are similar to those of other researchers including Djan and Penington (2013) and Ojo et al.(2012), however a lack of consistency in tools used to measure body image in the HNC population was reported resulting in the inability to statistically synthesize findings. Development of a validated tool would have provided researchers with homogeneity in the review.

The development of the McGill Body Image Concerns Scale for HNC (MBIS-HNC) patients specifically addressed body image in patients with HNC (Rodriguez et al., 2019). With the development and validation of the MBIS-HNC, researchers were provided a standardized tool to use with research on body image in the HNC population (Rodriguez et al., 2019). The

MBIS-HNC asks 21 questions divided into two subscales, social discomfort, and negative self-image. The downfall of potentially using the MBIS-HNC in assessing women with HNC is a lack of published studies using the MBIS-HNC after its development and validation, and a lack of studies specific to women with HNC with uncertainty as to how findings in this subset might differ from a mixed gender study of those with HNC.

Soon after the MBIS-HNC was published, Graboyes et al. (2020) published their own validation study of a tool to measure not only self-perceived appearance changes, but also changes in function which can be seen in patients with HNC. This new tool called the Inventory to measure and Assess ImaGe disturbance-Head & Neck (IMAGE-HN) was validated using over 300 patients diagnosed with HNC. While doing confirmatory factor analysis during the development of this tool, four subscales of PROMs were isolated with a global domain also included. These categories include other-oriented appearance, social avoidance and isolation, personal dissatisfaction with appearance, and distress with functional impairments. The 24-item tool has questions which showed reliability in identifying BID in the HNC population.

As evident by the extensive number of tools developed in attempts validly measure body image in specific populations, body image is a recurrent concern for multiple populations. “Body image is an important quality-of-life issue for patients with cancer that must be acknowledged by oncology nurses and other health care professionals” (Rhoten, 2017, p. 534). Rhoten (2017) recounted that understanding body image is not a static trait but can change during a person’s life related to experiential states with “body image in patients with cancer (being) a focused phenomenon to which specific attention must be paid” (Rhoten, 2017, p. 535). The potential impact of changes in body image has garnished the attention of researchers across multiple populations. Yet in the population of those with HNC, researchers have yet to demonstrate the understanding of the lived experience of those at risk for body image change, particularly the unique experience of women with this diagnosis who battle with not just the devastating diagnosis of cancer but strive to understand and accept pervasive changes resultant from the diagnosis and treatment of HNC.

Physical Attributes of Body Image

Personal Appearance

Body image is in part defined by personal appearance and a person's perception of their body image, so it is not surprising that body disfigurement resulting from HNC and its treatments is distressing. Olsson et al. (2018) completed a purposeful sampling of young adult (aged 15-29) cancer survivors obtained from the Swedish National Cancer Registry in 2016. This study used an investigator-developed questionnaire validated through qualitative research. Young adult survivors one-year post-treatment were identified from the national registry and compared to a randomly selected control group of people with similar demographic data. The questionnaire asked participants about how their scars made them feel. Using a Likert-type scale, the questionnaire asked, "Do scars make you feel less attractive?", "Do scars make you feel more attractive?", "Have you had negative thoughts about your body during the past 6 months?" (p.361), in addition to other questions.

Olsson et al. (2018) performed Spearman correlation analysis, Kruskal-Wallis tests, and χ^2 tests to determine potential differences between control (N=255) and survivor (N=285) groups after data was collected. Findings of the study included indications that in participants who survived cancer, having scars significantly impacted their feelings of unattractiveness ($p<0.01$) when compared to the control group. The location of the scars was statistically more concerning ($p<0.001$) when compared to the control group although the researchers did not clearly define what location meant. "Furthermore, the women in the cancer survivor group felt less attractive compared to women in the control group, regardless of scars ($p<0.001$)" and "had more negative thoughts about their bodies compared to women in the control group (*p*=0.02)" (Olsson et al., 2018, p. 362). Women in this study were more likely to feel less attractive than men participating in this study when scars were present (*p*=0.01) and less likely than men to feel attractive because of scars (*p*<0.01) .

The study conducted by Olsson et al. (2018) was primarily focused on the young adult cancer survivors, but the findings are not limited by age as noted by Fingeret et al. (2014). In order to develop a theoretical model of body image for patients with a cancer diagnosis, Fingeret et al. (2014) reviewed 10-years of published data surrounding body image and cancer, that included 92 studies (2003-2013). The data synthesized and findings which included reports of body image difficulties across multiple cancer sites and throughout treatment of the cancer. The diagnosis of cancer puts a patient at risk for body image disturbance. Age, certain types of treatment, and body mass index were all considered to be additional risk factors for body image disturbance. One study in Fingeret et al.'s (2014) report even noted that out of 280 patients surveyed, 209 (75%) of patients with HNC undergoing surgery experienced some degree of body image difficulty following treatment and after surgery in particular. Although younger patients did tend to report higher amounts of body image difficulties, the fact that HNC typically occurs in an older population and 75% of patients with HNC reported body image difficulties provides an inference that is sufficient to investigate the impact of body image in women with HNC. The findings in this and other studies provide evidence for the need to examine women with HNC, specifically, as opposed to the mixed gender studies found throughout the literature on HNC.

An overall dissatisfaction in the personal appearance of the patients with HNC was reported in multiple studies (Branch et al., 2017; Chen et al., 2017; Chen et al., 2015; Davidson & Williams, 2019; Ellis et al., 2019b; Fingeret et al., 2014; Formigosa et al., 2018; Graboyes et al., 2019; Jeans et al, 2018; Qualizza et al., 2018; Rhondali et al., 2015; Rhoten et al., 2013;

Rhoten et al., 2018; Taylor, 2016). Researchers reported dissatisfaction was caused by disfigurement, dysfunction/debility, and symptoms/side effects of the treatments of the HNC cancer, extenuated by several risk factors including being female (Graboyes et al., 2019).

Disfigurement

Disfigurement is defined as "to mar or spoil the appearance or shape of a person'" (Rhoten et al., 2013, p. 753). Disfigurement can result in feelings of stigmatization and social anxiety (Rhoten et al., 2018) and can impact the desire of women to be socially active. A woman's body image is based not solely on her own vision of self, but her interpretation of how others view her (Chen et al., 2018). While completing a review of the literature and state of the science, Rhoten et al. (2013) hypothesized that "personal, social, and environmental factors moderate the effect of dysfunction and disfigurement on body image" (p. 753). Nine publications meeting Rhoten et al.'s inclusion criteria of "examined body image as a psychosocial construct in a research study, included body image as a study variable and were in English" (Rhoten et al., 2013, p. 754). Six of these studies assessed the relationship of other variables to body image. Eight studies were descriptive in design and used quality of life tools as a measurement for body image. After the review of these diversely constructed articles, Rhoten et al. (2013) were able to identify an overwhelming report of the importance of body image concerns in patients with HNC and concurred with Ellis et al. (2019b) in the belief that this is an "understudied and undervalued issue facing patients" (Rhoten et al., 2013, p. 759).

In a study conducted by Fingeret et al. (2010), 75 newly diagnosed patients with oral cavity cancer with scheduled surgical intervention were surveyed to explore pre-operative concerns in this patient population. This descriptive, cross-sectional study involved having participants complete several questionnaires including the BIS which is commonly used throughout the literature for HNC and body image correlation. Researchers found no significant difference in the findings between male and female patients, but 56 (75%) participants identified concerns with post-surgical appearance related to swelling, scarring, and disfigurement. The researchers noted that 27 (36%) participants reported that thoughts about their post-surgical appearance were causing them a moderate amount of distress. Notable univariate findings, such as smoking status, stage/size of the tumor, age, marital status, and ethnicity, were identified as being limitations of the study and required further research. Fingeret et al. believed that identification of possible modifiers would help in long term survivorship planning and support. As identified by Fingeret et al., this exploratory study had several limitations including not controlling for multiple comparisons, but indicated that information gained in the study could provide information that could help in the direction of future research studies.

Ellis et al. (2019b), in a qualitative study, explored body image in patients involved with surgical treatment of their HNC with a sample of 22 participants who were post HNC surgery and treated for HNC within the past 36 months. Ellis et al. described the emergent themes as personal dissatisfaction of their appearance, recounting of attempts at camouflaging their appearance using long sleeves, turtlenecks, hoodie sweatshirts, and sunglasses, as well as personally avoiding mirrors and pictures of themselves. These post-surgical struggles appeared to be influenced by pre-operative expectations, social support available to the patient, and recognition by the patients of “strategies to emphasize acceptance of one’s body image and positive thinking about appearance” (p. 283). When exploring the practical implications and recommendations for future research, Ellis et al. believed that although effective interventions addressing BID in patients with HNC remain unknown, a needs assessment with cognitive behavioral therapy interventions for those noted to be at risk for BID could be developed targeting the interruption of negative effects of BID. According to Ellis et al. validation of

"PROMs of HNC-related BID severity, as well as identifying strategies to manipulate these potential therapeutic targets" (p. 284) would be beneficial.

Formigosa et al. (2018) conducted a descriptive qualitative research study with patients with HNC exploring the alteration of body image by disfigurement. Formigosa et al. used free word association and semi-structured interviews with a convenience sample of 23 participants, 14 male and 9 female. Participants were selected based on having a body alteration due to tumor or surgical intervention and participants were currently receiving radiation treatment and/or hospitalized at the site where the study was taking place. Using content analysis, Formigosa et al., developed five themes from interviews and words relevant to body disfigurement. Study participants reported feelings of sadness and anguish because they are "'different" from others, changes in their life, feeling ashamed of their image, religion to support healing, and concern that personal habits impacted their diagnosis (Formigosa et al., 2018). Sociocultural data including age, gender, tobacco use, place of origin, marital status, religion, and level of education was gathered from participants to lead healthcare providers to better understand the context behind the themes that were developed with the goal of assisting healthcare providers in creating care for this population that is more adequate and meets the holistic needs of patients with HNC. Participants reported feelings of sadness and feeling ashamed, ugly, and different from others as well as the alteration that cancer brings to life in general. Findings of this study are similar to findings of studies by Chen et al. (2018), Ellis et al. (2019b), Fingeret et al. (2010) and Rhoten et al. (2013) regarding issues of body image concerns surrounding disfigurement. Formigosa et al. (2018) stated that an individual's body image perception can be aesthetically altered leading to a lack of what society sees as a "ideal" body creating a diminished self-concept and impacting their social interactions.

With the potential grave impact disfigurement can have on the overall positive outcome of treatment of HNC, it is imperative that a deep understanding of the impact of these changes on women be further explored since they are underrepresented in the literature of body image in female patients with HNC. Davidson and Williams (2019) explored quality of life in a review of the literature of patients who had facial disfigurement resulting from surgical intervention for the treatment of HNC. The researchers completed a search of four databases for qualitative studies in this population. From the 13 identified qualitative, primary research studies that involved research on surgically treated patients with HNC, four themes emerged: changes within self, help from healthcare professionals, information, and social support. A subtheme of social reintegration was identified within the information theme. Davidson and Williams recommended education and support for caregivers and social contacts of the patient to build acceptance and management of the patient's temporary or permanent changes visible in the mirror.

Chen et al. (2018) conducted a cross-sectional study that specifically evaluated women with HNC for "factors associated with self-perceived body image in female patients with head and neck cancer (HNC)" (p. 1). The study was composed of 105 women with HNC at least three months post-treatment with concurrent chemoradiation therapy, radiation therapy, or surgical treatment with radiation or chemoradiation treatment. Women included in this study had stages I-IV cancer. Researchers administered the Chinese version of the BIS to the participants followed by the Observer-rated Disfigurement Scale (ODS) to all participants. Descriptive statistics (numbers, percentages, means and standard deviation) were calculated for demographics, clinical data, level of body image dissatisfaction, and degree of disfigurement with the BIS scale data collected from the participants. This data from the BIS was then correlated to findings of the ODS using Spearman's rank correlation.

Using the ODS, comprised of a nine-point Likert-type scale, 83 (79%) of the patients reported minimal disfigurement, 16 (15%) had moderate disfigurement, and 6 (5.7%) reported that their disfigurement was severe (Chen et al., 2018, p. 4). Inter-observer reliability was 0.98 between the BDS and ODS questionnaires. There was a weak correlation between disfigurement and self-perceived body image (r=.244, p=.012) (p. 4). Cancer location (r=.439, p=.001), stage of disease (r=.339, p=.001), medical treatment received (r=.610, p=.001), radiation dose received (r=-.594, p=.01), and age (r=.220, p=.024) were correlated to disfigurement (p. 4) and body image with positively correlated with medical treatment (r-.360, p=.001) and negatively correlated with radiation dose (r=-.297 p=.002) (Chen et al., 2018, p. 4)

Multilinear regression demonstrated the most significant predictors of disfigurement were cancer location (p=.026), cancer stage (p=.000), dose of radiation received (p=.026) and type of medical treatment (p=.000) (p. 5). The most severe dissatisfaction and body disfigurement were reported in those with oral cancer (52.4%) (p. 5) and the mean reported disfigurement score for those having had surgery was higher (2.53 ± 1.33) than those who had not received surgical intervention (1.15 ± 0.39) Chen et al., 2018).The “most important body image concerns were related to ‘feeling self-conscious about your appearance’, ‘dissatisfied with body’ and ‘less physically attractive’” (Chen et al., 2018, p. 6). The fact that moderate to severe disfigurement was reported in 16 (15.2%) and 6 (5.7%) women, respectively, in the participants underscores the importance for healthcare providers to develop interventions to assist in management of body image for this population.

Chen et al.’s 2018 study emphasized the need to address psychosocial factors in evaluating patients’ motivating factors in managing disfigurement. Prior to this, Chen et al. (2017) addressed such an intervention in a study using camouflage in women with HNC undergoing treatment. Sixty-six women with HNC, a subset of a larger study, having completed radiation therapy at a single site were randomized to participate in a four-session skin camouflage program. There were 34 women in the control group and 32 in the experimental group. This prospective, repeat-measures, randomized controlled study involved patient selection based on confirmation from plastic surgeons of disfigurement based on scars and skin status assessment. Participants had to be three-months to three-years post-treatment of newly diagnosed HNC and >20 years old. The control and intervention groups completed the BIS, Hospital Anxiety and Depression Scale (HAD)-Depression subscale, Liebowitz Anxiety Scale, and Rosenberg Self-Esteem Scale along with demographic and clinical treatment characteristics at the beginning and end of the study. Baseline analysis was completed using statistical tests including independent t-tests, chi tests, and mixed-model related-measure analysis of variance. There were no statistically significant differences between the control and experimental group with regards to disfigurement, self-esteem, social interaction, and body image when analysis of the baseline was completed.

A four-step intervention with the intervention group took place at two-week intervals and included consultation, planning, and preparation with a 25-page educational book being given to participants, information on camouflage, camouflage skill development with cosmetologists certified in cosmetic science, and supportive care (Chen et al., 2017). Telephone follow-up was done every two weeks for four more sessions upon completion of the camouflage intervention. Post-intervention follow-up testing was done at three months. Using ANOVA, there was a statistically significant decrease in reported facial disfigurement and depression (F= 10.887, p=<.001), increased self-esteem (F=2.722, p<0.05), decreased fear of social interaction (F=10.782, p <0.001), decreased avoidance of social interaction (F=4.530, p<0.05) in the intervention group (p. 1381). Although there was no statistically significant difference in body image between the groups (F=0.702, p=.556) post-intervention, researchers believed that failure to address motivating factors and the type of treatment received, presented a limitation that could have influenced the outcomes of the trial.

Dysfunction

Dysfunction is a “disturbance, impairment, or abnormality of functioning of an organ” (dysfunction, n.d., para 1) and can be impacted by HNC or cancer treatment (Chen et al., 2015; Ellis et al., 2019a; Jeans et al., 2019; Qualizza et al., 2018; Rhoten et al., 2013; Rhoten et al., 2018). Qualizza et al., (2018) conducted a systematic review exploring experiences of patients with HNC. Findings from the 13 studies included for review dysfunction was characterized by a general function deficit (weakness and fatigue), function loss specific to the head and/or neck such as speech, swallowing, or smell, and an impairment of the musculoskeletal system in the jaw, shoulders, or neck. Participants could have experienced HNC dysfunction as changes associated with side effects of HNC itself or its treatment, including but not limited to swallowing/eating difficulties, speaking difficulties, or alternative airway placement (tracheostomy). Although some surgical changes are made to manage the side effects of the HNC cancer or cancer treatment, dysfunction can result in changes in performance of basic activities of daily living (ADL) in this population and impact the body image as a part of psychological wellbeing (Chang et al., 2018; Rhoten et al., 2014; Rhoten, 2018; Walter-Brown & Hall, 2012). Rhoten et al. (2103) noted that dysfunction was a causal factor for body image disturbance in patients with HNC; in adjunct with disfigurement, participants reported that dysfunction negatively impacted their overall body image.

Ellis et al. (2019a) conducted a systematic review of outcome measures of body image disturbances in patients with HNC. Articles selected for the review included those that used patent related outcome measures as their variables. The seventeen studies included in the review cited dysfunction in the form of challenges with eating or speaking and issues surrounding lymphedema as indicators for BID. In one such included study, researchers “showed that BID is more severe in the functional difficulties of the patient population relative to the appearance concern-related subset" (Ellis et al., 2019a, p. 945). Ellis et al. concluded that BID in the HNC population had negative associations with function and psychosocial factors.

Other researchers have confirmed that dysfunction was a contributing factor in BID in the HNC population. Qualizza et al. (2018) completed a systematic review and meta-synthesis of 12 qualitative studies exploring the lived experiences of a mixed group of patients with HNC undergoing chemotherapy and/or radiation therapy. From this sample of 12 articles, four themes were developed. These themes included self-body image and perceived quality of life, experiences and treatment of symptoms, cancer journey, and the relationship with healthcare professionals (Qualizza et al., 2018). Part of this perceived quality of life was identified as being eating issues, especially eating with others. "Patients suffered constant embarrassment because of their need to change food textures and types" (Qualizza et al., 2018, p. 6). Dysphagia caused problems with eating favorite foods, taking extra time to eat, embarrassment with needing to clean their mouth and other eating issues caused them anxiety and shame resulting in wanting to eat alone. Thus, eating became "a mandatory action in which they engaged only to gain, or at least not lose weight, and continue with treatments" (Qualizza et al., 2018, p. 6). Researchers depicted how women with HNC experienced daily dysfunction issues and treatment sequelae in their lives.

Chen et al. (2015) explored the relationship between communication disfunction, body image, and the amount of time spent speaking by patients treated for HNC. Patients > 20 years old and who had completed their treatment were included. In this cross-sectional study, 130 patients with HNC (126 male and 4 female) who received surgery or surgery plus other treatments from two medical centers were surveyed. Questionnaires were completed in an interview process with researchers. Researchers administered the Self-Evaluation of Communication Experiences Laryngeal Cancer (SECEL) questionnaire and the BIS-m and

Symptom Severity Scale-modified. Demographic data included age, gender, and disease-related data included tumor site, disease stage, medical treatment, and type of operation completed. Karnofsky performance status was assessed on a scale of 0 (dead) to 100% (normal function). Demographic and clinical data was analyzed using descriptive statistics. Logistic regression was completed with dummy variables included for types of cancer and marital status.

Chen et al. (2015) found that 92 (70.8%) of patients reported speaking less after surgery and had a moderate level of communication dysfunction. The amount of speaking reported was the dependent variable in completing the logistic regression compilation. Patients with a higher level of BID, increased symptom severity, or diagnosed with hypopharyngeal or laryngeal cancer reported speaking less. Negative body image in this population was seen in patients with advanced cancer (OR= 0.63 ± 0.06, CI 95%), tumor in the facial area (OR=0.72 ± 0.07, CI=95%) or having had reconstructive surgery (OR=0.77± 0.07, CI 95%) (p. 2378). Several limitations identified by the authors of this study included possible recall bias, especially since the mean time from diagnosis in this group was 23.7 months. Despite this limitation, dysfunction, in the form of communication, was correlated with a decrease in perceived body image.

Jeans et al. (2019) attempted to understand the patient's perceptions of how head and neck lymphedema impacts their ability to swallow as well as their voice and speech function. The researchers completed a qualitative study comprised of 12 prospectively recruited participants (eight male and four female) with HNC who had completed treatment with either chemoradiation or surgery with radiation at least three months before the study and had resulting, residual lymphedema. This study was part of a larger quantitative study and included interviews with the participants which were recorded. The authors reported limitations including lack of participant diversity, lack of differentiating early and late impacts of HNC treatments on participants, and lack of having different HNC subtypes represented. Researchers identified strengths were the use of more than one investigator to interview, peer review of transcripts, and thematic coding.

Findings reported by Jeans et al. (2019) revealed participants were more concerned with the impact of HNC on their swallowing than on speech. Thematic analysis yielded four themes regarding swallowing, including it feels tight, it changes throughout the day, it requires daily self-monitoring and management, and it affects me in other ways. This fourth theme included the recognition of emotional wellbeing, negative body image, and frustration over the slow rate of improvement. Of particular interest was the report that all the “female participants spoke of issues with body image” (Jeans et al., 2019, p. 6) while men reported having adjusted; hence, supporting the need to further investigate the perception of body image in women with HNC.

The problems with HNC-related dysfunction can persist over time. In a longitudinal study of 83 subjects treated for HNC by Rhoten et al. (2018), patients with > stage II HNC and willing to participate for the duration of the five data points over 18 months at a single study location were approached for participation. A significant association was found between the incidence of depressive symptoms and social anxiety when compared to the participants’ with associated ranking on the Neck Disability Index (NDI) trajectories “(Cramer’s V, CES-D: 0.55, $p < .001$; LSAS Total: 0.35, $p = .002$; LSAS Fear: 0.35, $p = .002$; and LSAS Avoidance: 0.35, $p = .003$)” (Rhoten et al., 2018, p. 1448). Simply stated, 23 of the 30 participants on the severe-moderate trajectory of symptom monitoring had the highest levels of depression.

Rhoten et al. (2018) noted that “self-reported neck-related function is not only associated with depressive symptoms and social anxiety but these issues also cluster into one of three distinct symptom trajectories” (p.1449). Only a small number of patients in the study reported minimal symptom occurrence. Over a third of the participants reported a moderate to severe symptom trajectory. The final trajectory was one that started with minimal symptoms that escalated during and immediately after treatment but then began to decline reaching a mild level over the 18 months following treatment. In this group symptoms never did return to a minimal level of symptom burden. Reports of social anxiety during the length of the 18-month study was higher in participants reporting severe-moderate disability then moderate to mild disability and participants reporting mild-to-moderate disability had higher social anxiety than those with minimal disability. This was demonstrated with statistical significance in both groups with a (*Bonferroni* $p<0.001$) (p.1449). Reports of depressive symptoms had the same occurrence of significance across symptom trajectory (*Bonferroni* $p<0.01$) (p. 1449) with more than 50% of participants in the severe-to-moderate NDI trajectory group reporting ongoing depressive symptoms compared to the other groups who had less than 10% of participants reporting depressive symptoms at the completion of the study.

Participation in Activities of Daily Living (ADLs)

Activities of daily living (ADLs) are identified as bathing, hygiene, grooming, working, homemaking, exercise, and other actions that are routine and necessary to be functional in routine daily activities. The participation or lack of participation in ADLs can be linked to overall wellbeing and personal feelings of self-worth, self-esteem, and confidence in appearance and mental wellness (“ADL”, 2020). Participation in ADLs is essential in daily functioning. Failure to perform ADLs were indicative of difficulties in coping physically and psychologically with changes experienced in those with HNC (Ellis et al., 2019b; Fingeret et al., 2010, Ichikura, et al., 2016; Nayak et al., 2016).

Treatment-related Side Effects Experienced

Qualizza et al. (2018) in their systematic review cited side effects of radiation or chemoradiation including “dysgeusia, dry mouth, fatigue, and loss of weight, appetite, and energy” (p.6-7) as symptoms which further add to the distress and that compromise quality of life and in turn impact body image of the HNC patient. Xerostomia, coughing, loss of smell, pain, halitosis, erythema, dry/wet desquamation, and mouth ulcers were among other radiation-related symptoms that required medical intervention (Branch et al., 2018; Qualizza et al., 2018). Although not an all-inclusive list, these radiation-related treatment side effects contributed to patients’ perceptions of their body image. The strategies that patients implemented to manage these and other threats to body image integrity and quality of life required support from healthcare providers, family, and friends.

In Branch et al. (2017) cross-sectional descriptive study 30 participants were recruited from a single site as one of two groups to investigate body image concerns in the HNC population receiving radiation alone or in combination as chemoradiation. The first cohort of participants were in their last week of radiation with/without chemotherapy (n=15) and the second cohort was at either their 8- or 24-week post-treatment follow-up appointment (n=15). Cohorts completed the BIS and MD Anderson Symptom Inventory Questionnaire-Head and Neck (MDASI-HN) along with demographic data collection. These questionnaires explored the impact body image has on quality of life, sense of self, and self-confidence to determine its prevalence in this population. The BIS results were either mild, moderate, or severe, reflecting the measure of the MDASI-HN scale. In those recruited during their last week of radiation, ≥75% rated BI concerns from the BIS as mild to moderate regarding self-consciousness, less sexually attractive, less physically attractive, and felt their body was “less than whole” (Branch et al., 2017, p. 163). In the first cohort only 8 subjects completed the MDASI-HN Scale with 4 (50%), reporting overall score of low distress, and 2 (25%) reporting scores of severe distress including dry mouth, thick mucus, and difficulty swallowing/chewing.

In the second cohort of 15 subjects (8-24 weeks post-treatment), 13 subjects(>85%) rated BI concerns as mild or moderate with regards to self-consciousness, less sexually attractive, less physically attractive, dissatisfaction with body, and 14 (93%) reported low distress (p. 162). Two participants in this study reported using supportive services to manage distress. Researchers suggested an implication for practice should include education of radiation therapist, who see these patients daily for 7 weeks, to assess and refer for counseling patients at high risk for BID.

Psychological Attributes of Body Image

The linkage between physical and psychological attributes of body image is interrelated and can be difficult to discern whether they are individual problems or result from the interaction between the physical and psychological attributes. Although physical appearance is a critical part of the definition of body image, psychological and social constructs substantially contribute to defining body image.

Emotional Wellbeing and Sense of Self

Emotional wellbeing involves living fully and completely despite hardships (Peterson, 2018). Emotional wellbeing means the person is not ruled by the emotions they experience. In the context of HNC body image, emotional wellness encompasses acceptance of the diagnosis, scars, and side effects experienced while actively treating HNC. Simultaneously, while accepting the changes, persons with HNC are not denying the impact these experiences have on thoughts, feelings, and the vacillating emotional and physical stresses associated with a cancer diagnosis and treatment (Peterson, 2018). The mental health issues surrounding negative changes in body image can impact the emotional wellbeing of women (Walters-Brown & Hall, 2012).

As defined by Pam (2013), sense of self is the image of how the person identifies themselves spiritually, emotionally, mentally, and physically on a daily basis. Identifying with your sense of self is integral in developing a sense of identity and self-worth. Strongly linked to self-esteem, self-concept, and identity, a strong, positive sense of self is integral to maintaining purpose in life and overcoming hardships (Pam, 2013). Part of the psychosocial constructs of body image are reflected as a part of the sense of self women possess (Formigosa et al., 2018). Davidson and Williams (2018) reported participants had negative emotions associated with facial disfigurement and felt like they had lost “part of who they were” (p. 181) and lost control with diminished self-esteem.

Ichikura et al. (2016) conducted a longitudinal study of 160 patients diagnosed with HNC admitted to a single healthcare center over a two-year period. They administered the Hospital Anxiety and Depression Scale (HADS) and the Functional Assessment of Cancer Therapy-Head & Neck Scale (FACT-H&N) to assess the constructs of psychological distress, anxiety, and depression. Researchers wanted to determine if “reducing pretreatment distress may contribute to prevention of persistent distress” (Ichikura et al., 2016, p. 43). The HADS questionnaire measured psychological distress based on 14-items on anxiety and depression. Results from this scale were used to separate participants into four groups: no-distress, reduced-distressed, increased-distress, and continued-distress. Using ANOVA statistical analysis these four groups were correlated to findings of the functional level of participants as determined by the FACT-H&N questionnaire. Logistical regression of this data demonstrated that participants who were age <65 years old, scheduled surgery, and poor physical, emotional, and functional well-being had a higher risk of psychological distress at the time they were admitted to the hospital with odds ratios of 0.33 (95% CI= 0.12-0.92), 4.18 (95% CI=1.15-15.24), 0.79 (95% CI=0.67-0.90), and 0.85 (95% CI= 0.76-0.94) respectively (p. 45). Psychological distress was reported in over 52% of participants over the course of the hospitalizations. A limitation of the study was that pre-treatment distress was not evaluated to determine if there were possible pre-existing factors to be considered. Seventy percent of patients reported psychological distress for the duration of their hospitalization. Researchers acknowledged that a potential for selection bias existed in this study; however, researchers emphasized that understanding how to identify patients with HNC at high risk for distress and beginning to build interventions and education for this population was essential.

Chang et al. (2019) explored the factors influencing body image in HNC cancer patients that specifically had oral cavity cancer. A group of 168 patients, 76 (45.2%) of which were female, treated for oral cavity HNC were surveyed to examine factors associated with three specific measures, overall body image, perceived attractiveness, and body image dissatisfaction. Chang et al. used the BIS, HADS, Liebowitz Social Anxiety Scale, and the University of Washington Quality of Life Scale to assess for these three factors.

Chang et al. (2019) aimed to identify variables impacting the aforementioned measures. Multiple regression analysis was done to identify these variables. Chang et al. were able to explain 49% of the variance in body image scores from the tools with six variants from the tools used: “greater depression (β=0.0022), greater fear of social interaction (β=0.224), poorer reported social-emotional function (β=-0.249), having received surgery as part of treatment (β=0.210), being female (β=-0.125), and had a greater avoidance of social interaction (β=0.170)” (p. 1130).

The second specific measure, having a poor perceived attractiveness, was explained by three variables with a 25.4% total variance. These variables were having a fear of social interaction (β=0.284), reporting depression (β=0.335), and having received surgery (β=0.230). The final specific measure, dissatisfaction with body appearance had 52.2% of the total variance for this measure explained by five variables. Reports of poor social-emotional function (β=-0.414), increased fear of social interaction (β=0.417), and demographically linked to having had reconstructive surgery (β=0.280), advanced-stage of cancer (β=-0.153), and being female (β=-

0.136). Chang et al.'s(2019) findings support Rhoten et al.'s (2014) findings in which 43 patients diagnosed with HNC were followed from the end of treatment to 12-weeks post-treatment for measures of body image and depression using the Body Image Quality of Life Inventory and Center for Epidemiological Studies Depression Scale (CES-D).

Rhoten et al. reported statistically significant increased concerns surrounding body image and increased reports of depression in this group of participants at the end of treatment ($p<0.001$) that returned to baseline scores at 12 weeks after completion of treatment ($p<0.115$). The association of body image and depressive symptoms was also statistically significant in the study not only at the end of treatment, but also at both the 6 and 12 week points at which measurements were taken. ($p<0.05$). Researchers listed this as a clinical implication for supporting early assessments of body image in patients with poorer baseline body image concerns. Although this study was small and not specific to women, findings continue to support further research regarding long-term potential emotional wellbeing complications resulting from treatment of HNC and the HNC disease process itself.

Health Above All

Cancer survivors reported that regardless of changes in body image or side effects of the treatments, what is most important was their health and wellbeing. "Health above all" represented several related constructs. This theme, health above all, emerged as a measure of psychosocial adjustment to the symptoms experienced by the patient with a focus on the result of successful treatment of the cancer and eradication of the disease (Davidson & Williamson, 2019; Ellis et al., 2019a; Formigosa et al., 2018; Nayak et al., 2016; Qualizza et al., 2018; Taylor, 2016). Ellis et al. (2019b) identified modifiers associated with 'health above all' involving social support, pre-operative experience, and positive rational acceptance of the situation experienced by the patient. Participants' belief that overall survival was the ultimate goal did not discount the findings of attributes associated with body image changes but appeared to modify the outlook of the participants in the Ellis et al. 2019b study. This belief in health being the most important goal was similarly supported by other researchers (Davidson & Williamson, 2019; Formigosa et al., 2018; Nayak et al., 2016; Qualizza et al., 2018; Taylor, 2016).

In a mixed methods research study conducted by Nayak et al. (2016), phenomenological interviews were conducted with women in treatment for HNC (radiation or chemoradiation). Seven female participants were purposively sampled and subsequently interviewed from a larger participant pool. Two themes emerged from the interviews: appearance was inconsequential, and good health was the ultimate goal. Participants "remained immaterial about external beauty and felt they are possessing good qualities" (Nayal et al., 2016, p. 333) and reported that their external appearance was not as important as "being in a state of good health was the supreme need" (p. 332). These findings support the idea that some patients are adamant about receiving treatment regardless of possible impacts or side effects, including on body image.

Sexuality

Sexuality is defined in broad terms of sexual orientation or sexual activity in most literature but is more than just the physical identity one holds (Rhoten et al., 2013). Sexuality can be defined in the context of the feelings held. Feelings related to one as a sexual being are frequently linked to physical appearance in society and, as a result, changes in appearance can impact the feelings of sexuality a person may experience. For example, a woman having a mastectomy or losing her long hair that her husband frequently told her he loved may affect her feelings of sexuality. A component of her sexuality has been altered and can result in either a positive or negative impact on her feelings of sexuality, as researchers have found that sexuality and body image are positively correlated (Rhoten et al., 2016).

Rhoten et al.'s (2016) literature review included nine studies with quality of life as a construct. Studies in the review “demonstrate, to varying degrees, that HNC and its treatment have a negative impact on sexuality” (p. 315) and “individuals with impaired sexuality also have poorer quality of life” (p. 319). Investigators found inconsistencies regarding moderating factors that influenced negative reports of sexuality among the studies, leading to the identification of multiple gaps in knowledge regarding the impact of HNC on sexuality regarding demographic and tumor related items. Rhoten et al. (2013) found a lack of education and support provided by healthcare providers to patients with HNC regarding sexuality. If nurses and healthcare providers aim to provide holistic care to patients, sexuality is a vital concern for patients and should be expressed before treatment and in survivorship after treatment. The need to support patients with HNC holistically included recognizing their sexual being and was noted by Branch et al. (2017). Participants in Branch et al. study not only reported body image concerns, but also “perceived themselves as less sexually attractive” (p. 162) in addition to decreased physical attractiveness.

In 2017, Rhoten and Dietrich explored concerns about sexuality and body image in the recurrent HNC population. In their landmark study addressing sexuality in the HNC population, they recruited 39 participants with a previously treated HNC to complete the BIS, Body Image Quality of Life Inventory (BIQLI), and the Derogatis Sexual Functioning Inventory-Sexual Satisfaction Scale (DSFI-SSS). Rhoten and Dietrich reported 26 participants (66.7%) were at least a little self-conscious about their body image and 23 participants (60.5%) were dissatisfied with their body. Only 22-27 (56%-69%) of the participants answered the DSFI-SSS. Over half of the participants (15 participants) that completed the DSFI-SSS reported that they did not feel that they had sex frequently enough. Rhoten and Dietrich’s HNC and sexuality study reiterated the significance for nursing and healthcare providers to deliver holistic care for patients with HNC that included recognition of the associations between body image and sexuality.

Social Attributes of Body Image

Avoidance/ Lack of Social Functioning

Social functioning is the participation in typical activities and interaction with others in everyday settings, celebrations, and in work situations (“social functioning”, 2019, paragraph 1). The ability to continue to work, attend social functions, and be as involved as they were pre-HCN diagnosis, is part of the body image attribute. Social isolation was seen in women reporting a poor body image (Walters-Brown & Hall, 2012). Changing social isolating behaviors through addressing positivity in body image and sense of self are integral to overall positive outcome of any cancer treatment, especially HNC which can cause disfigurement and dysfunction and lead to social isolation (Ellis et al., 2019b).

Ellis et al.(2019b) developed five different themes in their study of body image in patients with HNC and social avoidance was one of these themes. Distress with functional impairments and appearance led to avoidance of public places by study participants. Systemic changes, such as skin toxicities related to radiation therapy, were noted as reasons to avoid social settings (Cashell & McQuestion, 2019), as were disfigurement (Davidson & Williams, 2018; Graboyes et al., 2019; Taylor, 2016) and changes in functional abilities such as speaking (Ellis et al., 2019a). Chang et al. (2017) reported an association between poor overall body image and greater avoidance of social interaction.

Support

In previous studies, patients reported primary support from their family and friends (Qualizza et al., 2018), and healthcare providers as most beneficial(Cashell & McQuestion, 2019; Davidson & Williams, 2019; Qualizza et al., 2018). Social support systems were important (Davidson & Williams, 2019). Additionally, some patients found support from their strength in faith (Formigosa et al., 2018).

Graboyes et al. (2019) conducted a prospective cohort study exploring risk factors for BID in patients with HNC receiving surgical treatment. Fifty-six people were purposefully recruited to participate in this study from a multidisciplinary clinic which manages patients with HNC. Patients were asked to complete several questionnaires (BIS, PROMIS, Shame and Stigma Scale) at the time of enrollment, one month after surgery, and again three months after the completion of therapy.

Graboyes et al. (2019) found several influences which contributed to an increased risk for BID being reported on the BIS. Being a female [OR=4.8 (1.3-19.9), 95% CI], having a large (T3-T4) tumor [OR=19.6 (2.8-352.3), 95% CI], report of depression on the PROMIS Emotional Distress-Depression scale [OR=1.25 (1.06-1.51), 95% CI], report of social isolation [OR=1.21 (1.01-1.49), 95% CI], and a severe baseline score on the Shame and Stigma Scale [OR=1.06 1.01-1.13) CI 95%] all contributed to an increased risk for BID being reported on the BIS (p. 108). Graboyes et al. (2019) concluded there was sufficient evidence to support healthcare providers' need to screen patients for risk of BID pre-operatively, and then educate, and support patients post-operatively, if the patient has one or more attributes of being at high risk for BID.

In patients with HNC, their feelings about perceived body image were affected by the way others reacted to them (Cashell & McQuestion, 2019; Ellis et al., 2019a). After completing HNC treatment, many patients with HNC felt uneasy returning to their workplace. "Negative or discomforting responses to facial disfigurement in the workplace have been documented" (Rhoten et al., 2017, p. 757). Ellis et al. (2019b) found that perceived social support and positive acceptance are reported to be "experiential modifiers of perceived BID severity" (p, 284).

Stigma

Stigma is defined as "a depreciative attribute, a disadvantage, an uncommon characteristic that is not well accepted by society, which makes the individual be ostracized by the community" (Formigosa et al., 2018, p.185). Formigosa et al. (2018) in their qualitative study during thematic development found that patients with HNC often feel isolated due to changes in their appearance and body image, which presented a barrier to social interactions, and subsequently led to social isolation. Social interaction has been reported to help reduce stigma and improve social integration (Davidson & Williams, 2019).

Feelings of stigma were noted in a qualitative study of 75 post-operative patients with HNC interviewed by Jagannathan and Juvva (2019). This study was part of a larger study investigating the psychosocial impact of cancer. Following in-depth interviews by the researchers, content analysis was completed, and themes were developed. One of these themes was "object of blame" (p. 144). This theme was reported in all 75 interviews as participants attempted to come to an emotional acceptance of their illness. In this study, participants with an addiction to nicotine, alcohol, or other substances that put them at high risk for HNC, also reported blaming themselves for their HNC. As part of Jagannathan and Juvva's conceptual framework developed to understand the emotions and coping of patients with HNC, this internal stigmatization is central to understanding emotions of the patients with HNC. "Understanding the phenomenon of the patient's 'knowing' is essential for any health care professional working with cancer patients to understand and provide for their psychosocial needs" (Jagannathan & Juvva, 2019, p. 147).

Threader and McCormack (2019) conducted an interpretive phenomenological study with nine patients with HNC and identified themes regarding the development of feeling stigmatized and distress. "Behavioural risk factors associated with head and neck cancer, such as alcohol consumption and smoking cigarettes, can elicit blameworthy attributions" (p. 158). Grief, blame, and identity struggle due to changes in physical appearance led to feelings of stigmatization, and many participants reported a deep sense of regret for participating in high-risk behaviors or contracting a sexually transmitted disease. Some reported being shunned by others for developing a ‘blameworthy’ cancer felt to be preventable in many cases.

Research Synthesis

Although multiple publications addressed body image in persons with HNC, researchers have not identified specific issues confronting women with HNC. Additionally, only one research study attempting to address body image issues was found (Chen et al., 2017). There were multiple tools addressing how to assess for body image disturbance (Djan & Penington, 2013; Ojo et al., 2012; Rodriguez et al., 2019; Sundraram et al., 2019) yet few researchers examined the relationships between women with HNC and resultant impacts on women’s perceived body image. The findings of the systematic reviews using multiple tools to explore the constructs of BID in patients with HNC demonstrated need for a consistent conceptual framework to define body image constructs for this population and a validated tool to assess body image based on qualitative study theme development and expert review (Rhoten et al., 2013).

The minimal amount of long-term research data for this patient population is a concern. To address the needs of women with HNC and determine the impact of changes in body image over not only the course of treatment, but into survivorship, longitudinal data is needed. Whether support systems or counseling needs are addressed during acute treatment or require long term follow up is yet to be seen. Such data could impact healthcare delivery via the need for interprofessional clinics for women with HNC, or the need to encourage the formation of more support groups to help women with HNC manage chronic changes to their personal appearance and body image.

Little research has been conducted on the association or the effects of various forms of treatment on women with HNC and BID. Is there more or less BID related to the modality of treatment completed by the patient? Research surrounding the treatment and cancer-related complications seen in women with HNC is unable to be fully synthesized until a conceptual framework can be developed with more research that explores the causes of body image changes and identifies mediating factors that predispose patients to BID. Further complicating factors include the large number of primary sites included in the classification of HNC. The variability of cancer sites, treatment modalities, intensity of treatment, support systems, and psychological factors yield many variables impacting women's with HNC perception of body image. Listening to the women's stories and understanding their lived experiences of perceived body image changes will add to the limited research in this population of patients with HNC.

CHAPTER 3

METHOD

This chapter overviews the design of the study, beginning with the philosophical and methodological framework that guided the study. The procedures used for sample inclusion criteria, sample size, recruitment, setting, data collection procedures, data analysis, human subject protection, and study rigor are presented.

Design

When exploring the lived experiences of women with HNC undergoing active treatment, it is important to provide participants the opportunity to tell their stories, in their words, and for them to reflect on the meanings that their lived experience holds for them. Use of a qualitative approach with semi-structured, open-ended interview questions facilitated this exploration.

Phenomenology has been used in research to explore topics with little reported data or little known about the subject (Marshall & Rossman, 2016). As a method of qualitative research, phenomenology was described by Edmund Husserl in the late 1800's. Husserl's descriptive phenomenology was used as a means of understanding the lived experience of a person from their own point of view. As a student of Husserl, Heidegger believed that phenomenology was more than just describing the phenomena experienced by subjects, but a deeper, hidden dimension of ontology (Smythe & Spence, 2020).

The use of hermeneutical phenomenology as described by Heidegger seeks to look beyond the phenomenon being explored and find understanding in that which cannot be seen or understood without seeking to gain understanding of the lived experience. "This could be because we are so close, we cannot see and/or because the taken for granted ways of doing things have covered over the phenomenon. We no longer notice how it plays out in lived experience" (Smythe & Spence, 2020, p.1). Yet for those living the experience itself, the significance of the changes that take place relative to the phenomenon are palpable, significantly changing their life prior to being part of the phenomenon itself.

Heidegger sought not only to describe the phenomenon of interest but to interpret the meaning behind the human reality that is the phenomenon. To accomplish this task, Heidegger focuses on the existential concept of Dasein, defined as being-there (Smythe & Spence, 2020). Dasein is used to describe the perspective of the world from the experience of the person living the phenomenon and is explored in phenomenology. According to Heidegger, hermeneutical phenomenology asks the question, what does it mean to be? (Hollowell & Gavin, 2017).

Hermeneutical phenomenology delves into experiencing and making sense of lived experiences and questions the essence of existing or owning (mine). Existing is merely a part of being. Owning and embracing that which is the reality of the phenomenon is living as a fully encompassed person and not simply the shell of a being. In the same respect, Heidegger encouraged us to look beyond what is said and seek to find meaning in what is not said. "The insights one seeks lie '*Hidden*' in the telling of an experience and the interpretation of another's meaning. It is to take on the question of uncovering, revealing, and bringing to light" (Heidegger, 1962 as cited in Smythe & Spence, 2020, p.8).

As a scholar of hermeneutical phenomenology and pedagogy, van Manen explained that phenomenology was more than just an existential philosophy, but a way of practice in that the use of hermeneutic phenomenology became known as phenomenology of practice. Van Manen explained that "the goal (of phenomenology) is to reach a level of depth that reveals the essential structures that make up the experience being studied and that are universal to all human beings regardless of their context" (van Manen, 2015, as cited in Errasti-Ibarrondo, 2018, p.1725). Van Manen's beliefs on hermeneutic phenomenology are best understood by examining the three forms of knowledge that can be used in our daily practice.

The forms of knowledge defined by van Manen are “knowledge as text (product), knowledge as participation (understanding), and personal knowledge (being) phenomenological text, it has recalled situations that they face with their patients and helped them to reflect on them.” (van Manen, 2015, as cited by Errasti-Ibarrondo, 2018, p.1727). Simply explained, van Manen urged researchers to reduce and analyze from the phenomenon being explored an understanding of the lived experience being explored, not just a recanting of the descriptions of the participants. Thus, understanding the lived experience being explored yields resulting knowledge. This ultimate phenomenological knowledge of the phenomenon provides a pathic kind of knowledge of the subject. This creates a developed understanding of the experience, not necessarily through cognitive recognition, but through a deepened sensitivity to the experience itself (van Manen 2015, as cited by Errasti-Ibarrondo, 2018, p.1728). This pathic knowledge creates a means for professionals to see into the lived experience of the person experiencing the phenomenon of interest. Hence, those not experiencing the phenomenon personally can become better at understanding the lived experience of the participant and embrace their individuality in holistic practice.

Applying van Manen’s explanation of hermeneutic phenomenology to the proposed research, the benefits of understanding the lived experience of body image changes in women undergoing active treatment for HNC can result in healthcare professionals gaining a better understanding of the needs of the women. Holistic management of women in the acute care phase of treatment with interventions as well as during survivorship can guide healthcare providers in assisting women with HNC to manage their new normal as a cancer survivor.

Sample

Purposive sampling of female patients being treated for HNC was employed. The inclusion criteria included female participants over 18 years old, diagnosed with HNC (excluding thyroid cancer and skin cancers), undergoing active treatment of HNC cancer with radiation therapy, chemotherapy/immunotherapy, surgical treatment, or any multimodal treatment of the cancer. Participants were actively receiving treatment at the time of the interview or had recently completed treatment within the past three months. The inclusion of a three-month post-treatment time period was based on intensive HNC treatment that may preclude participation during the active phase of treatment (lack of physical ability to actively participate due to time constraints, side effects, and/or physical recovery from treatment).

Sample Size

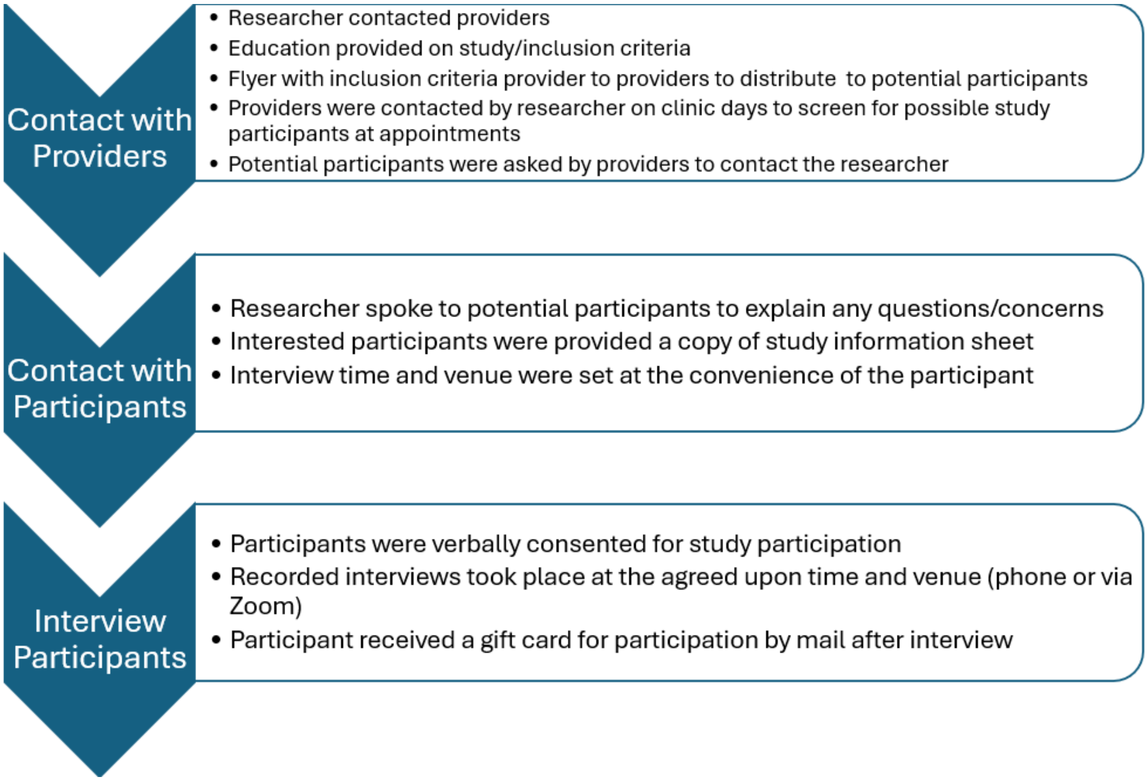
Recruitment of 20 participants that met the inclusion criteria was completed over a 1-month period. Saturation of data was reached at that time with no additional new information or novel experiences emerging from the last five interviews, demonstrating data saturation or information redundancy. Theoretical saturation was demonstrated with sufficient data present to exemplify theory development related to body image (Saunders et al., 2018), meaning "when the complete range of constructs that make up the theory is fully represented by the data" (Starks & Trinidad, 2007, p. 1375).

Recruitment

After the attainment of IRB approval from Louisiana State University-Health and 4 local hospitals had been obtained, the researcher met with service line directors, physicians, medical residents, nurses, nurse navigators, and speech therapists in direct care with the participant population being recruited. Recruitment letters were sent to radiation oncologists, medical oncologists, otolaryngologist surgeons, and nurse navigators that work with this patient population at three local medical centers known to treat patients with HNC. Presentation of the research study was done at two didactic seminars involving medical residents specializing in head and neck cancer as well as at three tumor board meetings. Nurses and physicians in the clinics and meetings were educated on the inclusion criteria of the study and asked to do preliminary screening of patients using a brief, easy to use recruitment letter with study information developed by the researcher and provided to the medical centers' healthcare providers (Appendix B). Nurses and physicians screening patients with HNC were asked to provide a copy of the recruitment letter with the researcher's contact information to potential study participants. The researcher followed up with the healthcare providers at participating sites routinely to determine if potential participants had been identified. Participants who had granted healthcare providers' verbal consent to be contacted by the researcher were then contacted by their preferred method. All potential study participants had the ability to contact researchers. Healthcare providers were only involved in recruitment of study participants. (Figure 1)

Figure 1

Mapping of Process for Participant Recruitment



Contact with Providers

- Researcher contacted providers
- Education provided on study/inclusion criteria
- Flyer with inclusion criteria provider to providers to distribute to potential participants
- Providers were contacted by researcher on clinic days to screen for possible study participants at appointments
- Potential participants were asked by providers to contact the researcher

Contact with Participants

- Researcher spoke to potential participants to explain any questions/concerns
- Interested participants were provided a copy of study information sheet
- Interview time and venue were set at the convenience of the participant

Interview Participants

- Participants were verbally consented for study participation
- Recorded interviews took place at the agreed upon time and venue (phone or via Zoom)
- Participant received a gift card for participation by mail after interview

Note: Process used to recruit participants in physician offices. For online recruitment, participants were approached directly by the researcher.

The initial IRB approval was amended to allow participant recruitment through online support groups due to failure to recruit using participants through physician referral. With the permission of the administrators of the groups, a recruitment flyer (Appendix F) was posted on Facebook groups including Head and Neck Cancer Survivors, Head and Neck/Oral Cancer chat and support, and Head, Neck and Oral Cancer support group. Online recruitment was initiated to reach a larger sampling population due to the small number of women who develop head and neck cancer and the geographic limitations seen by using only regional cancer centers for recruitment. This broadened scope of recruitment resulted in reaching women that may not otherwise be able to share their story and participate in this research study. This online support group recruitment allowed for the inclusion of women world-wide to investigate women's experiences across several countries. Although online recruitment was not the exclusive method of recruitment, it became the method of choice due to the success in the ability to contact women and interview them at their convenience. Two women were recruited through physician offices that had been previously approved through IRB.

Setting

Interviews were completed via telephone or virtual platform. Zoom and Facebook messenger were the virtual platforms used to facilitate participation in the study. A preference for interviews using virtual platforms was recommended to participants initially due to the risk of infection to the patients posed by face to face interviews. Once the decision was made to begin recruitment of participants through online methods, use of virtual platforms for interviewing became essential due to the varied locations of the women who agreed to participate in the study.

Participants were given the option whether to be visible or not be visible on the screen during the interview. Instructions were provided to participants prior to the virtual interview on how to alter their profile so that pictures are not seen by the researcher to assure confidentiality if they chose. (Appendix C). Although this option was presented to the participants, none chose to deidentify themselves. Only six did not make themselves visible on the screen during the interview, including two women who reported needing to interview by phone due to poor internet connections. The four women interviewed on virtual platforms that chose not to be on the screen cited reasons including poor internet service and one having chosen to be interviewed while she was in the hospital.

Zoom, phone, and Facebook messenger interviews were audio recorded by the researcher. Participants were interviewed at a time convenient to them including the weekends and evenings. With the exception of one participant, all women preferred to be interviewed while in their personal home. All recordings were done using a handheld recording device and downloaded onto the researcher's computer.

The recordings were de-identified and sent to a transcription service. The transcription service transcribed the recordings verbatim maintaining the confidentiality of the participants. Fictious names were used to protect the confidentiality of the participants when sending the recordings for transcriptions and was carried forward to the writing of the findings.

Instrumentation

Demographic Questionnaire

Prior to beginning the interview, participants completed a brief demographic questionnaire (Appendix E). The questionnaire asked participants to provide several personal aspects of their cancer and planned care. Information collected included questions about the participants' age, race, ethnicity, and relationship status. Information about their cancer obtained included the date of diagnosis, site, stage, and planned/current treatments for the participant. All information about cancer and treatment plan was obtained from participants' report not through medical record access. The researcher recorded this part of the data collection from the form prior to beginning the interview with the participant.

Individual Interviews

"The phenomenological interview is used as a means of exploring and gathering experimental material, while the hermeneutic interview is used to explore interpretative meanings of material obtained from the phenomenological interview or other data sources" (Heinonon, 2015, p. 37). Individual semi-structured interviewing is a recognized method of data collection for qualitative research to elicit the participant to reveal experiences and meanings, (Holloway & Galvin, 2017). Therefore, an interview guide was developed and used to conduct individual interviews with each participant (Appendix D). Probing questions were interjected as needed to clarify or seek further insight to responses from the participants regarding their experiences with body image and living through head and neck cancer. Field notes and observations were recorded by the researcher during and after the interview sessions. Analytic memos and journaling were done by the researcher during and after the interview to assist in the recollection of specific non-verbal data collected and for purposes of understanding the context of the information obtained from participants. The interview session for each participant took approximately 45-90 minutes. Breaks were offered to participants, but none required extensive breaks, only pauses to be able to take sips of water to keep their mouths moist during the interview. Following the interview, several participants reached out on Facebook messenger to thank the researcher for the time to talk and described personal insight they gained during the interview. Notes of these findings were included in the field notes collected by the researcher.

Interview Guide

The interview questions were derived from results of literature review and developed research questions. Areas of interest for the interview guide emerged from findings in the literature review focusing on the potential relationship of cancer to body image, as expected in this population. These areas of interest included physical changes reported, social functioning, and psychological attributes of body image as defined by conceptual analysis (Formigosa et al., 2018; Jeans et al., 2019: Ellis et al., 2019a; Cashell & McQuestion, 2019; Davidson & Williams, 2019; Qualizza et al., 2018; Ichikura, 2016; Rhoten, 2016).

The questions used in the interviews served as a template to facilitate data collection during the interview process. The interviews were used “to explore interpretive meanings of material obtained from the phenomenological interview" (Heinonen, 2015, p. 37) during which the researcher explored the phenomenon while retaining the meaning of the phenomenon itself and its impact on the participant.

The interview guide (Appendix D) was developed to answer the three research questions proposed by the study. Opening questions were introductory in nature and allowed the participant to tell her story. Understanding how she was diagnosed and the plan that was developed for her with her physician allowed insight into her perceptions and feelings about her diagnosis and understanding about the treatment plan. Each question started with simple broad questions allowing the participant to elaborate on specific areas of interest to the researcher including how changes due to treatment have made her feel, what a typical day was like before diagnosis and treatment compared to how it is now, and what kind of influence her support systems have had on her perception of these changes. Specifically, how interactions with family, friends, coworkers, and healthcare team members impacted her perceptions about her body image.

More complex and specific questions were asked about each of these subjects based on her responses, with encouragement for her to provide examples of how or why something made her feel a certain way. Probing questions were used to get more examples and add to the richness of the information received from the participant. After fully exploring these questions and allowing the participant ample time to verbalize any questions or concerns, the researcher asked her if there were other things regarding body image she would like to discuss. Asking if there are things that could be done differently to support her through her cancer treatment journey, in particular, things she wished she had known about and would want to share with women getting a similar diagnosis allowed the participant to reflect back on her own lived experience in order to gain personal insight into the expected and unexpected consequences of having HNC and being treated for this disease.

Researcher as an Instrument

Congruent with van Manen's method of phenomenology, the researcher recognized potential biases as an oncology nurse and someone who has seen close friends and family battle not only physical side effects of cancer treatment, but the psychological and social stressors that result from the cancer and treatments. Therefore, the researcher had to be observant of the potential to influence the interview and remain neutral yet supportive during the interaction. The researcher kept field notes and journaled about the mannerisms and specific signs of discomfort or ease, and observations were recorded to coincide with the verbal data obtained from the participant. Journaling and analytic memos written after the conclusion of each interview provided a source of remembrance for the researcher pertaining to the interaction and holistic presentation of the interview which allowed for a fuller understanding of the experiences of the women as data analysis began.

Data Collection Procedures

Data collection proceeded along the following steps:

1. Researcher contacted potential participants to explain the study.
2. Informed consent was obtained from all women.
3. Information on the date, time, and venue (face-to-face versus virtual platform) was mutually decided. The researcher provided participants with instructions on accessing the virtual platform as well as Zoom links for the platform.
4. Demographic information was obtained from participants prior to the start of the interview.
5. Individual interviews began after demographic data collection was completed.

6. Debriefing occurred at the completion of the interview, with referral for any counseling services offered.

Ethical Issues

Head and neck cancer patients undergo intense chemical and surgical procedures causing fatigue, disabling side effects, and discomfort. The use of a virtual platform as an option for interviews afforded added ease and convenience as well as offering “invisibility” or “cloaking” for participants if they desired. Because the study addressed body image concerns, this may have helped participants feel more comfortable and willing to participate in the study. Considering this possible concern, participants did not have to be visible on the screen during the interview if they so desire.

Protection of Human Subjects

Institutional Review Board (IRB) approval from Louisiana State University Health Sciences Center (LSUHSC)-New Orleans and healthcare institutions from which patients were recruited was obtained prior to any research activities as part of the ongoing assurance of human subject protection. Informed consent was obtained from the participants by the researcher after an explanation of the research study was completed and participants had the opportunity to discuss any questions or concerns. The participants’ capacity to provide informed consent was determined by asking them to repeat what the study is about and her role in participating in the study. Verbal consent to participate was obtained at the time of the interview prior to beginning any data collection. Participants were able to complete the demographic data questionnaire (Appendix E) at the time of the interview.

Study records were kept in the researcher’s locked file cabinet, in a locked office, and only accessible to the research team (major professor). Demographic data and de-identified transcribed interviews were kept in an encrypted, password protected computer that is housed in a locked office within the LSUHNO School of Nursing; demographic data was not linked with transcript information. Similarly, all observations, field notes, analytical memos, and journaling were secured in the same encrypted, password protected computer. Data collected will be held for three years before being destroyed.

As part of the ethical practice of qualitative research data collection, the researcher ‘checked in’ with the participant during each interview, ascertaining that they were okay to continue the interview, to assure continuation of informed consent. At the end of each interview, the researcher provided participants information on counseling services should they have felt overwhelmed, emotionally upset, or should any participant request counseling.

Study participants were compensated for their time with a $25 gift card offered at the time of the interview. Not all participants wanted the gift card and some requested that it be used as a donation to patients needing gas money for transportation to and from treatments. Gift cards were mailed to addresses provided by the participant.

Data Analysis

van Manen’s method of interpretive phenomenology (Figure 2) guided data analysis. Following these steps prepared the researcher to focus the inquiry and data analysis on the essence of women’s lived experiences with head and neck cancer.

Figure 2

van Manen's Method of Phenomenology

- 1. Turning to the nature of the lived experience
    - Orienting to the phenomenon
    - Formulationg the phenomenological questions
    - Explicating assumptions and pre-understandings
- 2. The existential investigation
    - Exploring the phenomenon by generating data using personal experience as a starting point
    - Tracing etymological sources
    - Searching idiomatic phrases
    - Obtaining experiential description from subjects and locating decriptions in the literature
- 3. Phenomenological reflection
    - Consulting phenomenological literature
    - Conducting thematic analysis by uncovering thematic aspects of the lifeworld descriptions, isolating thematic statements, composing linguistic transformations and gleaning thematic description from artistic sources
- 4. Phenomenological writing
    - Detemining essential themes
    - Attending to the speaking of language
    - Varying the examples
    - Writing and rewriting

Note: Steps involving the use of van Manen's method of phenomenology relative to this study Adapted from van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology + Pedagogy*, *2*(1), 42. https://doi.org/10.29173/pandp14931

In alignment with step one of van Manen's proposed method of phenomenology (Figure 2), turning to the nature of the lived experience, the researcher has worked in oncology as a clinic nurse, infusion nurse, navigator, and survivorship nurse, providing care to numerous patients undergoing active treatment for cancer for almost two decades. During this time, it was noted repeatedly that patients frequently struggled with the side effects of treatment modalities for cancer on multiple levels, demonstrating a complexity in psyche and emotion.

Following this process and in alignment with the second step of van Manen's methodology (Figure 2), the existential investigation, the researcher reflected on the personal feelings of helplessness and concern as a healthcare worker over how to best help patients who were noted to be struggling with the consequences of cancer treatment and the challenge to understand their battle with not only cancer, but with trying to maintain an intact self-image psychologically and socially during their cancer journey. This feeling was augmented on a personal level when trying to support and encourage a friend challenged on multiple levels while being treated for HNC. Tracing etymological sources was completed with the development of a concept map identifying attributes of body image. Literature review focused on search words “women”, “head and neck cancer”, and “body image” was completed to further assist with this existential investigation.

Phenomenological reflection in step 3 necessary for data analysis began with review of the literature (Figure 2). During the review of the literature, the complexity and interrelatedness of the constructs of body image were revealed in the works of multiple researchers. The understanding of the interplay of these constructs as it is related to demographic data and specifically to being female and diagnosed with HNC is undocumented from the prospective of their lived experience, yet essential to understanding how to screen, counsel, and prepare them for their cancer journey. Reflection of the immenseness of body image and the impact on a person is vast and somewhat intimidating and requires the putting aside of bias and expectations when trying to understand. This review of literature also supported the development of the interview guide to elicit experiences and rich descriptions from affected women recruited into the study and use this information in thematic development.

Phenomenological reflection continued as reading of interview data and initial data analysis occurred simultaneously during and following each interview. Probing questions were used to gain more insight into the meaning of the data collected from the participant at the time of the interview. Recordings were transcribed verbatim and resulting transcripts were reviewed for accuracy. Transcripts were read multiple times by the researcher to determine meaningful units. Description of phenomena with similar meanings were linked and initially coded into a phrase. This linking occurred in conjunction with a review of observations, analytical memos, journal entries, and field notes written during the interviews as well as a review of the transcripts to reflect upon insights, thought processes, and potential researcher biases which may occur while working with both participants and data.

The initial coded phrases were further clustered into contextual organizing categories for final thematic development. The use of rich descriptions and quotes from the participants supported and substantiated the developed themes. Two additional researchers read transcripts and participated in phenomenological reflection and discussion with the primary investigator and reached consensus on the initially developed themes. The identified themes were examined through the methods of reduction while avoiding “abstraction, theorizing and generalization, and researchers should remember that phenomenological enquiry is continually oriented to experience” (Heinonen, 2015, p. 37).

The fourth, final step of van Manen’s methodology, Phenomenological Writing, started as initial themes were developed, and the researcher attempted to understand and interpret the themes and reflect on the meanings. Essential themes that clearly exposed the unique nature of the body image changes being experienced by women being actively treated for head and neck cancer and the common meanings were derived from the experience. Writing thick and rich descriptions to correspond to the meaning of the respective themes included looking not only at the different contextual situations different women presented, but also what was common among them. The process of describing the final themes and rewriting the varied stories provided further clarity to fully describe the phenomenon and meanings of women’s experiences.

Study Rigor

Trustworthiness in data collection was demonstrated through credibility, dependability, confirmability, transferability, and authenticity during data collection and analysis (Guba & Lincoln, 1994). Credibility was secured throughout data collection using participant validation though probing questions during the interview process. Through the interview process of each participant, frequent restating of information they provided and asking for verification of that information from them using probing questions to better understand their prospective allowed for increased clarity in the information they provided. Theoretical triangulation was done using demographic questionnaires and interviews entwining information gained from the demographic data into the interview itself to better understand how the specific information such as age, employment, and marital status could impact their lived experience and create differences in their perspectives. Dependability was assured using rigorous data collection. Interviews continued until data saturation was reached and it was noted that participants were reporting very similar lived experiences and no new data was being gained through interviews. Demonstration of confirmability of the data was completed by checking and rechecking of data gathered and using node and theme development as well as three researchers to reading the text.

Although generalizability is not seen in qualitative studies, transferability of findings in this population of women may be similarly transferable to women with other cancer diagnoses causing body changes or even men with HNC. Rich descriptions of women's experiences included in the study results will assist other researchers in evaluating transferability of study findings. This was explored after data collection was completed and will be discussed in future chapters. Authenticity and confirmability were further demonstrated using van Manen's phenomenological approach in not only identifying themes developed through interviews, but through developing an understanding of the impact on women with HNC.

Summary of Methods

The primary purpose of this study was to describe the lived experience of women undergoing active treatment for HNC and meanings derived from any perceived body image changes. Semi-structured interviews were completed with 20 participants meeting the inclusion criteria to explore the meaning of their experiences. This chapter addressed the sample, recruitment, setting, data collection procedure, and the methods in which data were collected. The three research questions identified in chapter one were used in steering the development of the interview guide used in these interviews with probing questions further clarifying and adding to the richness of the data, van Manen's hermeneutical phenomenological approach was used to explore the essence and meanings of their experiences and guide coding of interview data and thematic development to be presented in the next chapter.

CHAPTER 4

RESULTS

This chapter describes the phenomenology of women's experiences with body image while undergoing or having recently completed treatment for HNC and summarizes phenomenological meanings. Guided by van Manen's process of phenomenological inquiry, essential themes and subthemes were uncovered as the researcher and participants sought meaning of the lived-experience descriptions gathered during semi-structured interviews. The researcher sought to answer three questions: (1) What are women's embodied experiences of self-perceived body image changes when undergoing active treatment for head and neck cancer?; (2) What are the meanings that women ascribe to their self-perceived body image consequential to the reactions of family, friends, coworkers, and healthcare providers to their body changes?; and (3) How do women with HNC undergoing active treatment describe the strategies they use to navigate the physical, psychological, and social challenges affecting body image, ensuing from active treatment of HNC?

Demographic Characteristics of Participants

Participants in this study consisted of 20 women who had been diagnosed with HNC and were actively being treated for the cancer or had recently completed treatment for the cancer. As described in Table 1, the ages of the participants ranged from 25 to a maximum age of 68 reported by a participant. The largest number of participants, nine women, was in the 56-65 age bracket (45%). Seventeen of the participants (85%) reported being in a committed relationship and 3 (15%) reported being single. The types of cancer reported by participants included five tonsillar cancers (25%), six glottic/tongue cancers (30%), two sinus/parasinuses cavity primary cancers(10%), three vocal cord cancers (15%), one unknown primary site (5%), and three participants (15%) reported their primary cancer site to be in places other than those specified on the demographic sheet. These sites included the hypopharynx, mastoid muscle, and a salivary sarcoma. Although not included in the primary data collection, all but one of the women (95%) reported having worked outside of the home prior to treatment or retiring from their job. These jobs varied but included employment as laborers, farmers, educators, office managers, and healthcare workers. They all reported that multiple modes of treatment for their cancer that were planned or completed at the time of the interviews. One woman reported having been previously treated for a different type of cancer.

Table 1
Demographic Characteristics

Characteristics	Frequency	Percentages
Age in Years		
25-35	1	5
36-45	2	10
46-55	6	30
56-65	9	45
Over 65	2	10
Relationship Status		
Single	3	15
Married/In a committed relationship	17	85
Site of Cancer Diagnosis		
Tongue	6	30
Tonsillar	5	25
Sinus	2	10
Vocal Cords	3	15
Other	3	15
Unknown	1	5

Women reported receiving or having received treatments including surgery (18 women), chemotherapy (15 women), and radiation (20 women). For all women reporting surgery, this was the primary treatment, followed by adjuvant radiation or chemo/radiation being done after healing from surgery. Stages of cancer for participants included 5 (25%) with stage 2 cancer, 10 (40%) with stage 3 cancer, and 5 (35%) with stage 4 cancer.

Phenomenological Reflection

Using van Manen's (1990) method of hermeneutic phenomenological reflection, interview transcripts were reviewed by the study author, the chairperson, and another member of the dissertation committee to search for the essence and meaning of women's experiences with changing body image living through head and neck cancer. Each transcript was examined line-by-line, coding phrases and sentences that described the essence of changing body image embedded in the woman's cancer experience. Using a more selective approach, phrases thought to be most representative of the essence of body image were compared and validated across transcripts. This was followed with a more holistic approach to discern the overall meaning of body image noted within the narrative. This reflection enabled the formation of essential themes and identification of key thematic statements to describe the multi-dimensional aspects of the essence and meaning of self-perceived body image while experiencing HNC.

Essential themes, and thematic statements

The essential themes, subthemes and thematic statements reflect the phenomenology of women living through changes in body image as they experience head and neck cancer and medical treatment. Through reading and reflecting on the participants' recounting of their experiences, three essential themes, and four subthemes were uncovered, (1) *Being and becoming: Seeing myself as a changed person* with subthemes, (a) *physical changes and body image,* and (b) *role, social, psychological changes and body image;* (2) *Inward feelings and meanings*; and (3) *Navigating the journey* which included two subthemes, *(a) internal motivation* and *(b) external support* (Table 2). The themes revealed the women's struggles making meaning of changing self-perceptions of body image as they go through an altered physical body and drastic changes in their usual roles, family responsibilities, and social relationships. The themes make explicit the complexity and interwoven challenges faced by the participants as they struggled to understand “who I am” as a woman with differing roles and responsibilities and relationships while dealing with the life altering challenges of HNC and its treatment.

Table 2

Essential Themes and Subthemes

Theme 1:	Being and Becoming: Seeing myself as a changed person	
	Sub-themes:	a. Physical changes and body image
		b. Role, social, psychological changes and body image
Theme 2:	Inward feelings and meanings: Guilt, stigma, isolation, depression	
Theme 3:	Navigating the journey	
	Sub-themes:	a. Internal motivation
		b. External support

Theme 1: Being and Becoming: Seeing myself as a changed person

Being and Becoming: Seeing myself as a changed person describes the participants’ experiences with not only physical changes, but also with role, social, and psychological changes that occurred in their lives as a result of HNC and the side effects of its treatment. The identified subthemes of physical changes and body image, and role, social, psychological changes and body image give context to the dimensions under which women began transitioning their perceived body image due to the changes in their physical body and in social roles (of wife, mother, grandmother, employee, friend, etc.) due to the cancer treatment impacting their everyday lives. The change in the way they saw themselves in their everyday lives impacted their body image and overall sense of being.

All participants described how physical changes and limitations impacted their usual roles, family responsibilities, and social relationships. The women’s self-perceptions and desire for positive outcomes from their cancer diagnosis led them to adapt to physical and social changes and is essential to understanding their journey. For these women, the devastation of the diagnosis was only the beginning of the changes they experienced while being treated for the disease. The changes were frequently entwined within the complex psyche of the women's perceived body image. Although the cancer journey for the participants was similar in respect to surgical, chemotherapy/immunotherapy, and radiation treatments and physical changes, the context of experiences and the impact on their lives and body image perceptions were different depending on multiple personal factors, as shared in their recollection of experiences.

Subtheme: Physical changes and body image. All women experienced physical changes in this journey. For some women, the physical changes in their body image began before diagnosis and treatment and were often the initial reason the participant went to the physician. Women described losing their voice or voice changes that brought them in or some physical alternation in the face or jaw. One woman explained, "I looked like Sid from Ice Age" (Betty). Once diagnosed, the physical altering effects of treatment began and, in many instances, continued months beyond the completion of treatment. The statement by one woman that "the treatment is worse than the problem" (Annie), was restated by many participants. Scars from surgery and burns from radiation resulting from treatment of HNC caused physical discomfort and psychological distress for the women interviewed and began the process of changes in body image.

Several of the women in the study reported having had transoral robotic surgery (TORS), while others reported more invasive surgeries resulting in extensive external scars, tracheostomies, or partial glossectomies. The TORS surgery is a robotic, minimally invasive surgery to remove tumors in the mouth and throat. One woman, Hannah, reported having Horner's syndrome as a result of the TORS surgery. Hannah stated,

> *I got this really big scar, about nine inches long. I had trouble getting my mouth open afterwards (from the TORS surgery) and "one pupil in my eye doesn't dilate like it*

> *should and a real drooping of my eye (and) this side of my face doesn't sweat*. *(Plus), my voice has changed quite a bit. I think, I wonder if that's gonna be a permanent change or if that's gonna be temporary, that's gonna be interesting.*

Not only were the physical changes seen by Hannah concerning for her, but the uncertainty over the possible length of time that these changes would be seen and bothersome became an added stressor itself.

In public settings, the tubes and scars made them self-conscious and reminded them of their changing image. For example, Hannah stated, "I went to the store and this guy was really loud and he said, what's wrong with you? Why do you have all those tubes? I was really embarrassed."

Betty, a 48-year-old participant who reported feelings of distress over the physical changes of her face, particularly her eye, as a result of her paranasal sinus cancer, reported similar encounters when out in the community stating,

> *By the time I went to surgery I already knew I already had people looking at me like and adults are the worst for staring and just…I don't know, they're just not very kind and I'm totally opposite. I'm very compassionate. I'm very kind and understanding to anybody no matter what they look like and there's so many people out there that aren't that way. And I just, … I didn't wanna have to deal with that really.*

Skin changes from the radiation also proved to be problematic when skin became reddened, dry and peeled. Women in the study reported they just followed the directions of the radiation therapy nurses and "used the Aquaphor and it never peeled, it just flared up a bit" (Bridget). Although bothersome, most felt it to be more an inconvenience at the time of treatment.

One specific physical change often described as significant resulted from changes in the saliva in the oral cavity. Thick, ropy saliva, and dry mouth were frequently experienced during and after the treatment was completed. These changes caused great distress on multiple levels. Changes in oral cavity and repeated episodes of thrush impacted their perceptions of being a woman and a sexual being. Franny, a single, 58 year old woman who went through chemoradiation described how changes to the oral cavity affected her perception of being someone to be kissed, in stating,

> *Nobody's really interested in like kissing somebody because your mouth is so dry. You have no saliva. You don't know what your breath is gonna taste like, you have this horrible taste in your mouth all the time.*

Franny's story was reverberated by Leah. Leah is a 52-year-old married grandmother who became tearful and apologetic during the interview because she had to stop frequently to take sips of water to be able to speak more than a sentence or two at a time. She added to the reports of the distressful side effects in the oral cavity stating,

> *I cannot eat or drink anymore after the third week. It hurts even drinking. Water's like swallowing razor blades…. That's the hardest part. When it was just a tumor, it didn't hurt. I didn't have any pain. I didn't have any discomfort. The treatment is worse than the problem. Saliva's thick and I have a machine because in the middle of the night, if I lay too flat, I get junk in my throat too.*

In addition to the general discomforts in the oral cavity, the loss or change in their voice was also distressful for them. "We don't realize how much we depend on our voice to communicate," said Rose a 61-year-old mother who could speak only in a whisper after her diagnosis of cancer in her vocal cords which required tracheostomy placement, but still wanted to tell her story**.** The loss of voice for the women was impactful in so many different ways.

Physically, the loss of the ability to speak or only being able to whisper was devastating for women. Even having hoarseness caused them distress wondering if the changes would be temporary or permanent. Just talking during the interviews for several of the women was taxing for them and they reported pain early in the interview at times although none wanted to stop the interview due to the discomfort. Most reported learning to compensate by keeping a water bottle with them at all times as that seemed to help to an extent, especially if they started coughing. "The speech pathologist said that sometimes even the tiniest speck of something can make you get that coughing reflex" (Carla), so keeping water nearby tends to help with the voice and throat concerns. Betty, who had throat cancer and has residual vocal cord damage, recounted a powerful story about her voice.

> *I had lost my voice for over four months…. my voice never came back until the end radiation. And one day I just yelled at the dog and my voice came out. The dog was going after a meter man and I reacted. (when I realized what happened), I just grabbed him (the meterman) right by the shoulders and I go, "oh my God. you're on your own. I gotta go."* Carla stated that she ran to the house followed by the dog and called her 83 year old mother who lived two and a half hours away. *"She hadn't heard my voice in (almost) six months and doesn't do text very well at 83 years old. I rang her up and I go, you wanna hear something weird? She (her mom) goes, oh my God."*

Losing their voices and ability to communicate with others was a greater concern than just a physical change. Women affected by voice changes were concerned that it caused them to "close off" (Betty) from others because of the challenges with communication. Victories over the challenges were vocalized by women like Maggie when able to talk all day to train someone at work.

> *I rang my oncologist, and he did a phone consult with me, and he said, what's happened to your voice because it was really bad when I first started training her and I'd done a full week of talking nonstop all day, every day and he told me, you cannot do that. He said, you need to tell them that you can only do it two maximum, two and a half days a week. So, we started getting her to go to another office to get trained by someone else in the meantime.*

Another frequently reported physical change experienced was that of changes in senses, specifically hearing and taste. Participants reported ringing in the ears and some reports of deafness by participants. The tinnitus was reported as intermittent and brief by participants. Those who experienced this problem compensated by doing such things as “having subtitles on the telly (television)” (Carla). Yet, another woman reported that noises seemed to be “amplified…..the kids playing (in the house) was like a hurricane going through my house for me” (Annie). Medications often supplemented the non-pharmacologic management methods developed by the women in the study, but those too were met with side effects. Gabapentin was the treatment drug for this pain among all participants as well as the peripheral neuropathy and tinnitus they experienced, but the side effects of the medication itself was more bothersome to some and made them feel limited in their independence. “I don’t drive cuz I’m afraid to with the Neurontin and I’m kind of nervous about being out on the road. I don’t wanna hurt nobody” (Annie).

Changes in overall body weight due to altered ability to chew and swallow, was a significant physical change for women that directly influenced their body image. Franny described her personal feelings about the results of extreme weight loss that was changing her perception of body image in this narrative,

> *Looking at your body…. where the feeding tube was, there's no way I would want to be with anybody looking like that, you know? And now after losing 20 pounds, I feel like whatever little butt I did have is like flat. I just feel like I was always a young 50. I'm not an old-fashioned person. I have tattoos, I'm whatever, but this just really aged me. It really made me feel like, (showing arms to camera) look the skin on my upper arms. They just look like chicken arms now, it seems like the skin is looser and flabbier, and I just feel more unattractive than I did when I started, I haven't wanted to put makeup on just all the things that you usually do for yourself.*

Attempts to maintain nutritional intake or at least minimize weight loss without the presence of a feeding tube was a resounding concern for the women. Challenges in swallowing, lack of appetite, dry mouth, and extreme fatigue all played a role in the food choices made by these women. Yet their desire to avoid extreme weight loss and potential gastrostomy tube placement was a constant reminder of their personal battle. Physical changes to the mouth and gastrointestinal tract often necessitated a change in diet, since the women were often unable to eat the same foods they did before. Maggie, a 56-year-old office manager who had cancer at the base of her tongue reported,

> *Eating is such a chore….. I don't like sweet things anymore. I used to, I was a real sweet tooth. I loved cakes and you know that sort of thing, not so much chocolates, but cakes and biscuits and I don't like them anymore cuz they don't taste right. So that's, that's probably a plus. Eating, my stepmother used to say to me in her bland way, eating is just a way to survive and that's kind of how I look at it now, like it is true. You don't have to have all those things to be able to still be a whole person.*

The pain of swallowing and eating was described by others who stated, “The worst part is it is burning in the back of my throat and down lower in my throat” (Annie) and “It hurt too much to swallow and all the food tastes disgusting, like dried pieces of sponge”. (Franny) The feeling of being hungry, but not being able to push through the physical pain became a recurring theme in their stories. The conflict between forcing themselves to eat was paralleled by their desire to avoid a gastrostomy tube at all costs for most of them. Betty described this, “They didn’t really want to encourage a feeding tube because they wanted me to be able to swallow.”

In several cases, the weight loss they were experiencing had them teetering on the need to get a tube for nourishment and hydration. One such situation was with Maggie,

> *I'm doing speech therapy to hopefully get improvement…. I forced myself to eat I didn't want a feeding tube, so the dietician and I had an agreement that if I could just keep eating, she wouldn't make me get a feeding tube or recommend I get a feeding tube. I was not having, there was no way I was having a feeding tube. I went from 94 kilos to I'm now 72 kilos.*

Jenny’s story was slightly different as she could not eat after surgery but continued to drink even with a feeding tube. Yet Elizabeth, a 51-year-old grandmother, reported,

> *I use it [feeding tube] for almost all my nutrition. I go to speech therapy twice a week to work on my swallowing. I’m not really supposed to have thin liquids but I’m still doing a little bit of thin liquids because my mouth gets so dry and thickened liquids are just unpleasant.*

For others, the presence of a feeding tube evoked psychological stressors. “(My daughter) was afraid of me” (Jenny), was reported by one woman who had a nasogastric (NG) tube placed. She perceived that her toddler was apprehensive of her with the NG tube placed. Another grandmother reported “when they put in the feeding tube, I’ll have to be very careful with her (granddaughter) because she might rip it out when she is climbing on me," (Annie) evoking concerns over being able to interact with her granddaughter in their usual manner.

Not only were there concerns about gastrostomy tubes affecting social and family roles, but it was part of their "...mental state of mind. When you got this 18-inch tube coming out of your body….it was just like a constant reminder of being sick" (Franny). Others like Leah had traumatic stories surrounding the NG tube placement. After two unsuccessful and uncomfortable attempts by her physician, she ultimately needed to have a gastrostomy tube placed for nourishment.

Although weight loss is regarded as detrimental to positive outcomes in cancer management by health care workers, a few women in the study reported happiness and a sense of humor in the fact that they lost weight with comments such as, "well I've been trying to lose weight for years and you know, but that's one heck of a diet. I don't recommend it" (Maggie), "I think why I couldn't have done this before the cancer" (Betty), and another stated that after looking in the mirror noting that "it was a heck of a way to lose the 10 pounds of baby weight" (Jenny). Positive feedback from significant others and girlfriends added to the comfort they reported from the weight loss and all of them expressed hope to keep the weight off, for medical reasons like "maybe it will help with the diabetes in the long run" (Leah). Although none recommended their "chemo diet," these comments indicated a search for positivity and humor about the physical changes they experienced and provided a sense of comfort and happiness during a time of physical, social, and psychological changes. Their comparisons of pre and post disease body weight exposed the importance of female body weight to their body image, based on societal and personal expectations.

The meaning of physical changes and body image brought on by their diagnosis and treatment varied based on factors such as past life experiences that had preceded their diagnosis, their ages and how it changed their lives. These issues will be further presented in the following subtheme.

Subtheme: Role, social, psychological changes and body image. A holistic view of body image involves the social and psychological aspects. Due to the intense nature of the treatments of HNC, body image in this population was profoundly influenced by their ability to continue in their role as wife, mother, grandmother, the need to be cared for by others, the change in their ability to continue employment, the fatigue experienced, and the mealtime isolation and food aversions resulting in social isolation. Much of the feelings of wholeness and self-esteem associated with body image for the participants seemed dependent on how they saw themselves through the eyes of others. Hence, role changes inherently impacted body image, as described in this subtheme.

Changes in roles were seen in multiple different ways. “Sometimes it just pisses me off. It makes me angry” said Jenny. Sometimes I want to be able to go to the grocery but I’m just tired physically and emotionally, she recounts. “Like through this whole process, I am just not healing fast enough for myself.” Distress that they cannot drive themselves or have no energy to clean the house, cook for the family, socialize with friends becomes distressful. One woman reported having a role change from her caring for her 70-year-old mother to her mother now having to care for her. Another reported having to depend on her adult child to assist her, and others noted a change in their roles in the house when their husband or significant other became the one to do the laundry and cook meals, a role they usually filled. Family relationships sometimes changed due to having this disease during COVID, which limited socialization. Maggie recounted,

> *My son did get it (COVID) right at the end of my treatment. Just when I'd finished. After he'd been taking me down there, he got COVID, but my daughter she's vaccinated I didn't see her off and on……she was really paranoid about giving it to me.*

Jane, a 68 year-old grandmother, also said her family limited their contact with her during treatment and detailed her experience stating, "My kids have been cautious for a period of time. They wore masks in our house." She reported that she and her family were all concerned about her catching COVID with her white count already low due to chemotherapy.

Changes in maternal and childcare roles, were especially difficult for younger women. Jenny, a 25 year-old mother of a toddler, recounted her concerns about how the treatments and physical changes would affect her ability to mother her daughter and impact her ability to have another baby in the future.

> *I was really worried about the surgery. I didn't want a big indention here (pointing to her neck), and I was really concerned about having the feeding tube and about having a baby. My daughter was still breastfeeding so I had to push it (treatment) out until she turned a year old. I was only like two weeks away. She had a little shock to her system, but now she's old enough, she's one year old now, so she can go on regular milk.*

Even after managing her treatment to allow her to continue to breastfeed her infant, she continued to struggle with her ability to parent her daughter.

> *I feel like I can't be on my own (with her). She wants to be up and going on walks and being outside and I'm still having a hard time staying hydrated. ……. I used to walk all over and visit the neighbors and my daughter would play with the kids a couple of times a week.. I have to build up my endurance now though……. I think my daughter was afraid of me (speaking about her nasogastric tube). The better I got, the more that I could*

> *interact with her, she would try and pull on it so I had to kind of keep my distance or hold her for a split second…..I feel like I can't comfort her.*

Although Jenny struggled with how the physical changes of the disease treatment subsequently changed her role as a mother and a young wife, she was planning to attempt to have another child after waiting the recommended 6 months to a year after finishing treatment.

Not only were the traditional roles of family caregiver altered, but the roles they filled outside the house as well. Employment during treatment for HNC was very challenging due to the intense nature of the treatment. Some women, however, voiced a need to resume working for income to pay bills and maintain health insurance or for some, a sense of fulfillment and socialization with others. When a person is depending on their income to pay bills and suddenly becomes unable to do so, the added stress of trying to navigate the disability system, or depend on the kindness of their employer to work with them, or their coworkers to have fundraising activities to assist them in maintaining their home becomes a humbling experience described by some of the women in this study. None reported loss of their home or utilities during this time, though stress from finances was reported especially when it came to being able to maintain their insurance. One participant, 51-year-old schoolteacher, Elizabeth, reported, "I went back for one month in June to work, because I needed to, my insurance, it was ending."

Maggie described the attempt she made to resume working, hoping to maintain normal activities during treatment. She tried to do her usual duties until feeling she had failed because she needed others to step up and do jobs traditionally done by her.

> *I have a lovely, very generous boss and he set me up at home with a home office as soon as I got diagnosed, he said, right, get your computer. You can work from home if you don't feel like getting dressed all good….I did it until, I think I got into about week four or*

> *week three, it was about my third chemo. I think I pulled the pin. I said, I can't, I just need to concentrate on just vegging.*

Misty, a 53-year-old physician working in an urgent care center, was more successful at returning to work, but quickly found that work modifications, including a reduction in hours was necessary.

> *So, the good news is I work in urgent care, but my main role for the last five or six years was with the electronic health record. I make the electronic health record work for us. So, I've been able to work remotely. I don't know how long it would be working though. We kind of play it by ear. Luckily, I have good disability insurance and FMLA was great and I've been there 10 years so they've been super supportive. I cut down prettier early on, right after surgery, I cut down to about 12 hours a week remote. The surgery itself was, pretty bad, you know, the pain, it was about two weeks recovery and then I went right from surgery to treatment and really part of it was just the time, I mean, Mondays, I'm there (the hospital) like eight hours. The chemo is 5-6 hours plus the start time and driving time and then the radiation every day you have to be there for radiation. The drive and the getting there and then there's usually another appointment or, now and then, I started doing fluids on Thursdays…. so, I'm probably in and out of the hospital driving about 20 hours a week. So, um, so I cut down to 12 hours a week (of work) and then just this week and next week I'm gonna do, I'm doing eight and then I'm taken off for a while.*

The physical changes that affected their ability to eat and swallow also had social, role, and body image implications as well. The feeling of loss of pleasure in mealtime proved to be challenging physically and mentally for the women on this journey. Mealtime isolation was reported by women in multiple interviews. Not only did they not want to eat, but even if they did feel they could try to eat, they did not want to do it in the presence of others due to the difficulties they experienced while eating. Coughing and differences in food textures that they required in order to be able to continue oral intake made them self-conscious. Maggie recounted a story where she felt like an outsider at her daughter's house when they were having a family dinner. Everybody was eating their pizza, and she was having some sort of chicken wrap.

> *I just couldn't swallow my food properly. I had to drink water with every bite, I couldn't do anything without swallowing water….. I think it was my lowest food point after treatment when I realized everybody else can just eat like normal and I just couldn't. I just felt like crying and walking out of the room. It was a bit of an eye opener to me that my journey wasn't quite over.*

Leah even stated that she "doesn't like eating in front of people or trying to eat with people because, I struggle to get it down. I don't want to make them worry. So, I go into the kitchen and eat by myself. Franny added to that feeling of insecurity with mealtime stating that:

> *you don't want to go anywhere because of the whole social aspect of having a drink out with friends. I can't drink because it hurts my throat and I can't eat because it hurts my throat……you become somewhat of a recluse.*

Women in this study described their struggles trying to find ways of connecting socially with family and friends when eating is problematic. A grandmother in the study who identified her role as hosting Thanksgiving dinner for the family at her home, expressed hope that she can overcome the fatigue she is experiencing to enable her to make the dinner this year. She expressed feelings of seclusion due to the inability to eat and cook for her family in the past year.

The fatigue, mental, and emotional changes that accompanied the physical changes with treatment also affected their ability to socialize with others and continue their usual roles. Self-care and grooming rituals, previously perceived as important in body image, sometimes changed because they no longer had the energy for grooming. Forty-eight-year-old Jackie tearfully reported feeling like her brain power is not quite there, saying “The chemo brain is real”. She also reported wanting to just stay in bed all day since there is “no reason to get out of bed”. No longer being employed led many to feel they could easily slip into isolation. Although one reported, “The good news is I was allowed to sleep anytime I wanted, I didn’t have to drag myself up except to go to treatment,” (Karen). Others struggled with their desire to get out of bed although they recognized the need to rest. In fact, one woman reported, “Knowing I am not gonna feel like this forever, I just kept telling myself, allowing myself to have a bad day, to just lay there in bed…..knowing that maybe tomorrow I’ll feel a little better.” (Franny)

The fatigue participants experienced changed their usual roles and self-expectations about cooking, cleaning, and grooming. They did not want to shower because they were tired and the noise of the water hitting their head became excruciating. Several stated they would never have left their house without make-up before this, but now did not even care about or prioritize that anymore.

Theme 2: Inward feelings and meanings: Guilt, Stigma, Isolation, Depression

In the theme, *Inward feelings and meanings: Guilt, Stigma, Isolation, Depression,* the women expressed feelings that arose as they negotiated physical, social and body imagine changes and the meanings associated with those feelings. As noted in previous descriptions, struggles with eating, talking, fatigue and role changes presented obstacles for the women to maintain their daily life activities in a manner in which they were accustomed. In this theme, the women provided rich descriptions of their psychological struggles with guilt, stigma, isolation and depression associated with their HNC experiences. Their narratives explain the struggle with these inward feelings and demonstrate the potential detrimental impact on their physical and psychosocial wellbeing, if not addressed. Numerous participants described their emotional struggles similar to Leah who stated, “Sometimes that's the hardest part - is that they can't always see what's going on when it's not outwardly.... They're like, oh, you look fine. Well, I don't feel fine.” The physical appearance of the women was not the only battle they fought.

Feelings of guilt over having participated in habits that could have contributed to the development of HNC was a concern. Karen described, “I feel so guilty over what I’ve put my sons through more than anything. That’s the guilt. Sometimes the overwhelming part is guilt because I drank my whole life….and the cigarettes….the cigarettes are the worst thing.”

Franny reported,

> *It’s not only cancer, but it’s HPV positive. So, you know, especially as a woman, you think about how you got that on the back of your tongue……It’s not a real fun thing to want to talk about, a sexually transmitted disease.”*
>
> She continued that she *“talked to a couple of other people with HPV (positive) status, you kind of feel like it’s almost stigmatized.”*

The internal guilt and stigma affected outward behaviors. One woman described feeling protective about what they want to share when starting a relationship, worrying about their partner or future partners potentially contracting HPV and going through a similar path as them. Franny, who reported that she is not in a current relationship voiced her concerns that she does not “have any desire to be in that kind of situation (sexual) with anybody ever again. I would be too afraid of infecting him.”

Jenny described a circumstance when it was the health care workers who made her feel bad about her HPV history and current cancer. Jenny reported,

> *I came out that surgery, the nurse, the nurses were talking bad about me. It made me feel really dirty. (What were they saying?) that if I would've got my HPV vaccine that I*

> *wouldn't be here and I wouldn't have this cancer and my mom should have made me get it. I was awake and I told them that I had got the vaccines and I still got cancer. So, shove that up your…….And she went and told the other nurse what I said. She wasn't apologetic, just taken aback more than anything I guess….. I think she was shocked.*

The depth of this violation of trust compounded the already fragile body image and self-esteem of this woman, potentially damaging her relationship with other health care providers. Of special concern was that she was in the beginning of her cancer treatment journey and was battling other multidimensional circumstances impacting her coping with the diagnosis and making her more vulnerable.

Aside from stigma and guilt, isolation also contributed negatively to the reaction of women to HNC diagnosis and treatment. Leah recalled,

> *I just wanna get back to work. I'm missing out on all my camping this summer and stuff that we normally do like traveling. We can't do it because of the treatments. It's kind of like a countdown….. We usually take the grandkids, camping and stuff in the summer and that we're not doing that this year.*

For many women, COVID compounded these feelings of isolation. As noted by Maggie, a 56-year-old working grandmother who described how her illness and health status limited her ability to socialize with her family. She stated that before her cancer diagnosis,

> *I would go and see them (my daughter and grandchild), but when I was going through treatment, I avoided them a little bit because of COVID. My daughter worked in childcare, so there was always a risk that she was gonna bring COVID home, and so I sort of avoided her.*

Franny reported using Instacart to have groceries delivered to her house rather than go to the store herself. Often days would go by when the only human contact had by the women was the health care workers at the hospital caring for them and anyone that lived in the house with them. Thus, the isolation manifested itself though the lack of outside contact with other people that were known to bring happiness to their world.

The isolation only contributed to the depression experienced by the women, and several sought out mental health care during their treatment time. Several reported having pre-existing issues with depression which they felt were exacerbated by the negative feelings and experiences associated with the diagnosis and treatment of HNC. Others described how the medicine they took to control the pain associated with the cancer and treatment impacted their abilities. Maggie summed it up when she stated,

> *I was on a drug called Oxynorm, which is an oxycodone medicine. And I had gabapentin, I'm still on two gabapentin a day. And there was a time there where I didn't wanna shower. I didn't wanna see anybody. I just felt so… it's almost like an out of body experience. I wasn't myself. I'm normally a sociable person and I just felt like I didn't wanna talk to anyone. I had this aversion to the shower, the noise and the feeling on my head. I don't know what it was about washing my hair. I could shower if it didn't go on my head. But as soon as it went on my head, I dunno if it was the noise, but it just, for a couple of weeks there, I really avoided wanting to shower (chuckling)…And then when it was more toward like the end of the treatment, was when I was when I was feeling the most pain….I think being on the fentanyl, I didn't like the feeling of the fentanyl either. I found it made you wanna sleep, but it was not a restful sleep. It was very fitful, it was almost like you would be awake dreaming. I don't know if you've ever had fentanyl, but it's just a, a really bizarre feeling. You know, you're doing things and you know, you're asleep, but you know, you are moving. Like I kept thinking I was at work and I'd say to myself, go to sleep (Maggie). you're not at work. And it's like you're kind of sleepwalking,*

> *but you're awake. So that made me feel that made me feel just really antisocial…… I just felt really not even getting up for my sister and I mean, my sister can see me at my worst. And even that, I just, it was a struggle.*

Although the means and manners in which they were motivated internally varied, finding that motivational factor was essential to pushing themselves to overcome the strife. Franny may have stated it best when she recounted her strategy for getting through.

> *Knowing that I'm not gonna feel like that forever. I just keep telling myself, allowing myself to have a bad day, allowing myself to just lay there in bed. If that's what I feel like doing and not feeling guilty about it. And knowing that maybe tomorrow I'll feel a little bit better.*

The changes in body image were seen to extend beyond the physical changes reported by women. The psychological, social, and role changes that were impacted due to the disease and its treatment were often as debilitating as the physical changes experienced. Participants reported changes that extended beyond the side effects they were told to expect. The guilt, stigma, isolation, and depression seen in the participants became a daily battle for them and a reminder of their inability to continue to function in their personal roles as prior to their diagnosis. The manner in which they worked through these additional struggles of HNC treatment became their story of survival.

Theme III: *Navigating the journey*

The theme, *Navigating the journey,* describes the strategies women used progressing through changes in self-perception and body image caused by the profound physical, social, role, and psychological changes inflicted by HNC treatment. Despite the isolation, guilt, stigma, fatigue, and other negative side effects and feelings that women associated with the diagnosis and treatment of HNC, women found reasons to fight and continue on their journey. This third theme provides insight into how women were enabled to live through the negative impact of HNC on their lives, continue in treatment, and begin to look to the future incorporating a changed self and body image. Women repeatedly expressed the importance of family, friends, and support groups in their ability to endure the treatment and find internal strength to continue to fight.

Subtheme: Internal motivation. When asked what words of advice the women might have for others going through a similar journey, the mood and responses were similar. Each expressed they had to find a reason to get up and get out of bed every day and start to focus on their future after treatment. Although the reasons to move on were different for each, they all expressed this need to look to the future. Leah was quick to state,

> *I think it's nice to just get back to… a bit of normalcy in your life. So yeah, I do. Someone said to me, I'm in denial that I ever had cancer. Well, I don't know if there's a bit of truth in that perhaps because to me, once I got the diagnosis, I didn't look back. I was just like, okay, this is what we're gonna do. Let's get through this. And I have never really sat and contemplated my life ever since the diagnosis, I haven't gone there. So, whether it's denial, I don't know, I think it's survival. It's just how I've done it. Right or wrong. It's how it's got me through to this far.*

Finding inner motivation and survival skills to enable them to get past the sadness and stress of the intense treatment was dealt with in different ways. Leah recalled a touching moment she shared with her close friend who was also a cancer survivor,

> *We had a really special day when I wanted to get rid of my radiation mask. I kept it for some reason. I dunno why I'm, I'm a bit of a hoarder for lack of a better word, but I just, when they said you wanna keep it? I went, yeah…. I put it in my back bathroom cuz nobody uses the bathroom. And one day I went in there and I thought it just sort of*

> *confronted me when I opened the door and I was like, I don't really want this. I don't need it. I don't know why I'm keeping it…..it was a really weird morning. I'd sung along to the radio, which I hadn't done in ages, cuz I couldn't sing…not that I was ever a great singer. So, this morning I woke up, the sun was shining. I put my songs on which (was odd because) I'd wanted silence for so long. I didn't want my music anymore. I wanted it quiet. So, this one day when I got up, I just went, I gotta put the music back on. So, I did and I tried to sing and I sounded like crap, but I sang anyway and I had a shower which was, again, something I hadn't been able to do. It was like just this one day where it was like a perfect everything…..I looked at all the creams and stuff I'd used through treatment. I decided to pack 'em all up and put 'em in a box so I didn't have to look at them. I didn't want to see that every day. I wanna get past that. Anyway, my friend turned up and I said, I need to get rid of some stuff that is just holding me back I think so she and I went out and we got the radiation mask. I thanked it for saving my life and I threw it in the bin (laughing) and I didn't look back and I just went I'm done with it now. And then we sat outside and we just had a really good chat about what we'd both been through. And you know, it was just really special.*

Indications of moving on for Leah also included attending to her physical appearance, including new color for her nails and a new wig, as she described,

> *So, once you're finished, that doesn't mean it's over. That's kind of just like the beginning. (Looking at her nails) I just got them yesterday. I just wanted something bright cause of my mood, (I needed) to brighten the mood up a little bit. My daughter went with me. To kind of just trying to brighten the whole situation." She continued, "I started losing my*

> *hair, so that's the other thing I've got the, the new chemo is going to make it fall out even faster than it was with cisplatin. So, tomorrow I'm shaving my head and getting a wig.*

Jenny was pushing to move forward because she wanted to have another child in the future, and another participant wanted to get to know the grandchild that was expected in a couple of months. One participant reported finding strength by just going to sit outside and getting some sunlight and listening to music, whereas another reported relaxing in her recliner with her big fuzzy slippers under the warm crocheted blanket someone made her. Another woman reported that one of the best things that happened to her was her insurance running out forcing her to go back to work to get it reinstated. Franny stated,

> *I went back in May for a little while because they canceled my health insurance and I had to go back to get the health insurance reinstated. I wasn't working full days…. my principal was really cool and told me, just come in……If you need to leave you can work from home, but just seeing the kids and have the kids all say, you're back. Is your cancer gone? Like it's just, it's nice to be at work and have you get up in the morning and you have a purpose, you know?*

According to one participant, the goal was to find something outside of the “blandness of your day. Something you have control over” (Maggie) and find joy in it. Women demonstrated resilience in navigating the journey by finding purpose and inner strength, and wanting to gain back some of the life events that were stolen from them with the disease and its treatment. Although the means and manners in which they were motivated internally varied, it was finding personal motivational factors that was essential to pushing themselves to overcome the strife.

Subtheme: External support. External support systems were recognized by participants as being essential to pushing them to complete treatment and stay strong. Healthcare professionals, family, friends, and support groups served to lift them, support them, encourage them, and sometimes be their motivation when they had difficulty finding motivation on their own.

Health care workers were thought to be helpful with regards to education and answering calls while the participants were on treatment. One woman reported that her insurance company set her up with a nurse that called to check on her periodically and still continues to call. She found that to be very helpful. The participants found the nurses to be easily accessible and able to get answers for them when they were unsure of things and that this was very reassuring. There was concern by several women that there was not one provider that they could call to be centrally responsible when they were having trouble though. For example, Karen and Jenny had concerns over thyroid function post-radiation and were instructed to have the primary care doctor handle it. Leah struggled to control blood sugars due to poor appetite or use of steroids and she was instructed to call the endocrinologist. Franny reported feelings of being punted from physician to physician, which led Franny and other women to report advocating for themselves at times and as stated by Karen, they relied on the "Stubbornness in us…..we got our fight."

Family support was essential to the day-to-day survival of the participants. Noting how their partners or children and parents stepped up to help with shopping, housework, cooking, and driving back and forth to appointments was considered vital to the participants continuing treatment and finding internal motivation. Maggie recounted tearfully how empowering and enjoyable the drives to and from treatment that she shared with her dad and son had been,

> *I had more chats with my son and my dad than I have in a long time. So, another silver lining, I got to hang out with my son who at 25 doesn't wanna hang out with his mum all that often.……and you know, incidental conversations don't happen all that often. So that was actually something nice that came out of it. We got to have a laugh and it's sort of something that ,(becoming emotional),…..it was horrible, but we got to do it together. So,*

> *and as I said, my dad who I still see… but I don't usually sit and have a chat to my dad. And you know, that was nice to see him.*

Maggie also reported a similar feeling on the drives to treatment with her adult son. Although not all the family members were initially able to be supportive having struggled with fears of loss, the women reported that they eventually come around and supported her in having faith that things would be better.

Husbands and significant others had varied responses to the diagnosis of HNC by their partner, but, overall, responses were positive with the men in their lives becoming more protective and supportive to the women. The women often did not notice until asked about it, but then recounted examples, such as Leah, who described how now her partner tended to grab her hand more when they were walking, making her feel somewhat protected, or kissed her head or hugged her out of the blue.

Another participant Maggie recounted,

> *I mean the kissing thing …that the husband won't be revolted by you. I think that that was something that, you know, was a big thing to me that he did. He probably doesn't even know this, but the day that he kissed me and I knew that he wasn't repulsed. That was nice to know that I wasn't disgusting cuz you go through this and you think, you know,…..it's your mouth. It's just….. I don't know. Makes it harder. I think.*

Maggie sent me a message a few hours after our interview describing how she told him how afraid she was that he would be repulsed by her breath and his affection without any signs of being disturbed meant so much to her. She recounted*, "I just went and told my husband about the kiss too. I don't think I'd told anyone else about that until tonight…. Thank you."* Her personal revelation had become a close, intimate moment for the two of them and brought them closer. Although some reported that their spouse did not seem to be interested in sexual contact initially during the diagnosis phase of the disease, all reported feeling closer and having a deeper intimacy as they were able to re-establish a routine to their lives even if they roles had changed.

Even with the close, supportive relationship that Maggie had with her husband, she jokingly stated, *"I always said I wish I had a wife"* while going through treatment. The women in this study reported overwhelmingly the importance of having girlfriends to support them through treatment. One example was provided by Karen who recalled,

> *If it wasn't for them [girlfriends], I would've never went through with it. I've been a mess……They picked me up every single morning at 7:00 AM and drove me an hour in snowstorms. They waited and drove me back every single day. The days I was sick, I was not gonna go, they'd have a smoothie in their hand, a puke bag in the backseat and they would say, get in and shut up. And they pushed food on me…… I never had a girlfriend in my life until just a couple years ago. And now I got these four and they take good care of me.*

Ashley told a touching story of her neighbor who used to come check on her while she was caring for her ill mother and couldn't leave her in the house.

> *She was very supportive when I was taking care of my mom and I always checked in and brought food and, she's (really) a food person (but) she can't really bring me food. So, she's trying to find things that she could do…… She's driving me (to treatments) on Mondays and she texts me several times a day, just words of encouragement and lots of friends are checking in and praying……I'm not usually one that gets help or asks for help but, yeah, it's nice to have.*

Another participant reported having a girlfriend who went shopping and shared clothes with her while losing weight, when nothing seemed to fit her anymore. The women's relationships with female friends were repeatedly reported to be what helped them through their worst days.

The fight in these women is evident in all their stories and the external support systems often becomes an internal motivator to fight. This could not be more evident than in Angel's story. Angel insisted on completing her interview while in the hospital for complications from chemotherapy. She was unsure of what could happen next and did not want to wait for tomorrow. She had been battling cancer continuously for a year enduring several chemotherapies and then surgery to remove her mastoid muscle and replace it with a graft of her thigh muscle. Even in the face of progressing disease Angel stated, "I'm not done with fighting for us*"* referring to her husband and children.

Each woman in this study reported reaching out to online support groups, looking for support from other women who had similar experiences with HNC. Because HNC is not a common diagnosis, finding women who had similar lived experiences is not easy and can leave the women feeling isolated. Online support groups provided women across the globe the opportunity to reach out to other women with similar disease diagnoses and treatment trajectories to build comradery they could not find in their local community. Considering the extreme fatigue associated with the treatment of HNC, online support groups provided a platform for reaching out when they were able to do so, without leaving home.

The women used these platforms to find tricks to minimize side effects, found friends in countries across the globe, shared supplies they no longer needed, and found women who related to them because they were experiencing the same disease path. As stated by Misty,

> *I think when it comes to it….I think you gotta have somewhat of a village. I mean, I don't know what I'd do if I didn't have that, you know. I think the Facebook groups are really*

> *helpful, and a couple of us, you know, went on messenger, and chatted to each other separately too and you know, got to know each other. So, I think just having someone… (to talk to) like I'm having a hard day today…..or checking in on somebody else, like, hey, have you heard from Linda today? You know, she's what's going on with her. It was reassuring to have that connection with someone with a similar journey, a similar life experience.*

As Franny stated, "It's hard to find women within your friend group (with HNC). It seems everybody has breast cancer, but this is such an unusual one" Women felt a sense of friendship reaching out and getting to know women with a similar story. After finding someone with a similar circumstance and similar timeline for treatment, Franny said, "I sent her a friend request and I'm like, since we're starting on the same day, why don't we be friends? We can check in with each other and see how we are doing."

Sadly, none of these women reported that it was a health professional who had suggested these groups to them. Each woman found the groups on their own or with the help of their friends. All women found that even though there were people that reported troubling stories on the sites, the benefits they had received through new friendships and support far outweighed the stress of seeing that not everyone had positive journeys.

Summary of Phenomenological Results

This study highlights the multidimensional journey of 20 women coping with changes experienced following the diagnosis of HNC and the decision to receive treatment.

The physical, psychological, and social changes they endured became exceedingly evident through their rich descriptions of lived experience and the emergence of common themes and subthemes. Women's perceptions and meanings of body image were made explicit as they described what it meant to experience changes in body weight and bodily functions, such as swallowing, eating, hearing, and talking, and to integrate medical equipment into ADL. They explained what it meant to live through changes in previous social roles, such as mother, wife, housekeeper, family cook, and employee, and how relationships were affected. Moving through the changes in the body and body image varied. Most women recognized the changes in themselves as part of the "changed person" they were, due to the disease and treatment. Support and strength from others, including family, girlfriends, and online support groups, were primary to continuing to fight and were essential resources for survival. For some, recognizing body image changes served as an internal motivator to get stronger and resume previous roles and activities in the family and workplace. Although varied, the motivating factors frequently circled back to the core of what they felt was important for self-preservation. This included motivation from strong relationships with family and friends, and their desire to resume their previous role(s), whether it be a mother, grandmother, doctor, nurse, beekeeper, drywaller, or teacher, just to name a few.

In essence, the study results provide a deeper understanding of the complexity of women's struggles with the physical, social, emotional, and psychological challenges of HNC. As the women provided personal stories of how they viewed themselves, the complexities of the female essence and the multiple constructs of body image were revealed. The concept of body image is itself a "multidimensional, subjective and dynamic concept that encompasses a person's perceptions, thoughts, and feelings about his or her body" (Neagu & Rainer, 2015, p. 30) yet even though her world has been upturned she continues to worry about the impact of the disease on those around her. Betty may have stated it best in her comment,

> *Cancer doesn't just affect the person being treated. It affects everybody around you and even if you don't think they're being affected, they are being affected….. cancer is a*

> *family disease……especially for the kids… I told them the truth about what's going on because they're going to see it.*

These women fight the battle of head and neck cancer not just because of the physical symptoms that develop with the disease, but for the hope of a new normal after treatment where they can resume their careers, their roles, and their life with a newly defined body image including a new construct to manage, namely cancer survivor.

They "try to be a hero" (Maggie) and fight for the life they knew, the roles they embraced, and their voice which was often shattered or taken from them completely during their treatment. Although previously stated, it is worth restating that the feeling they have as expressed by Rose, that "the hardest part is that they can't always see what is going on when it's not outwardly there." This could hold true for the cancer growth itself, but, also, with regards to the changes that these women are going through with the sometimes daily challenges to the body image that they once embraced. The "new normal" postulated by Roux et al.(2002) is not just a life after cancer for these women, but a life of battles won, battles lost, and some that were just surrendered in the development of a changed body image.

CHAPTER V

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

This chapter presents a discussion of the themes developed. Themes were further analyzed, and interpretation was conducted using van Manen’s methodology of interpretive phenomenology. Recommendations for future nursing research and practice and nursing education are suggested as well as recommendations for policy change. Study limitations were discussed. Additionally, conclusions related to findings of the research study are included and interpreted for presentation to health care providers to address a gap in knowledge related to the needs of women undergoing active treatment for head and neck cancer.

Discussion

This study was guided by three research questions. These questions were: (a) What are women’s embodied experiences of self-perceived body image changes when undergoing active treatment for head and neck cancer?; (b) What are the meanings that women ascribe to their self-perceived body image consequential to the reactions of family, friends, coworkers, and healthcare providers to their body changes?; and (c) How do women with HNC undergoing active treatment describe the strategies they use to navigate the physical, psychological, and social challenges affecting body image, ensuing from active treatment of HNC? Through the examination of these questions and the themes developed through the investigation of the women’s responses to questions, interpretation of the meaning of this phenomenon is done through the use of theory and review of applicable research.

Phenomenological Interpretation of Themes

The first research question, “What are women’s embodied experiences of self-perceived body image changes when undergoing active treatment for head and neck cancer?” was made explicit through the first theme *Being and Becoming: Seeing myself as a changed person* as well as the two subthemes, *Physical changes and body image and Role, social, psychological changes and body image*. The women described how they felt about themselves in terms of what they saw as their prior selves and a changed existence that presented itself after the diagnosis and treatment of head and neck cancer. Struggling with depression and isolation, often unable or unwilling to get out of the bed, shower, brush their hair, or put on make-up, or have the ability to assume their usual social roles, these women noted the discrepancy in their prior image of themselves.

The participants in this study began their journey and lived experience with the diagnosis of their cancer and were still on a path of recovery and redefining themselves at the time of the interviews. Women reported independence in preforming all activities of their life prior to their diagnosis of HNC and held many varied responsibilities in their everyday lives both inside and outside of the house. The disease symptoms and the treatment side effects resulted in each woman having to relinquish some or all of the aspects of her previous self/life that had been used to define herself as a woman and establish the body image she had before HNC.

As noted previously by Neagu and Rainer (2105), components of body image are multidimensional and subjective in nature. Thus, the self-perception of these women's body image was seen to be impacted in every aspect of their life. Their physical being saw changes including, but not limited to scars, hair loss, skin changes, changes in their voice, and the insertion of tracheostomies or gastrostomy tubes. Although no studies were found addressing how these specific physical changes have impacted body image in this patient population, multiple research studies in cancer populations have addressed the distress felt by patients as a result of physical changes in appearance for example, Fingeret et al. 2014; Olsson et al., 2018; Rhoten et al. 2013 and other researchers. The fact that these study participants were all female put them at greater risk of experiencing distress in body image changes (Graboyes et al., 2019). Hence, the findings from this study are consistent with previously reported research that described experiences of cancer patients and how their physical changes impacted their overall body image.

The physical changes alone were not the most distressing part of the lived experience for these women. Their recounted stories frequently brought forward tearful conversations about distress in their ability to perform duties typically done by them in traditional female roles of mother, grandmother, childrearing, wife, and caretaker. The inability and, in some cases, the lack of desire to do basic ADLs and other activities such as grocery shopping, meal preparation, and mealtime interactions created isolation, similar to what has been reported in other research studies of patients in cancer treatment (Chen et al., 2015; Jeans et al., 2019; Qualizza et al. 2018).

Pam (2013) reported that a sense of self is the image of how the person identifies themselves spiritually, emotionally, mentally, and physically on a daily basis and is strongly linked to self-esteem, self-concept, and identity. A strong, positive sense of self is integral to maintaining purpose in life and overcoming hardships. This is congruent with Higgins' Self-Discrepancy Theory (SDT) (Higgins, 1987) and can be applied to better understand women's experiences with changing body image. According to the SDT, there are "specific emotional consequences of perceiving a discrepancy between one's actual self and one's ideal/ought selves" (Higgins, 1987, as cited in Vartanian, 2012).

According to Higgins (1987), the self can be described in three different states: (a) actual self which is your belief in the attributes of self that you actually possess; (b) ideal self which represents the attributes that you would ideally like to possess; and (c) ought self which is your belief in attributes that you ought to possess. According to the SDT, people are motivated to have their self-states in congruency. When this fails to happen, it can result in self-discrepancies and result in personal discomfort. This makes people susceptible to feelings of dissatisfaction and disappointment.

Based on the knowledge that there are culturally accepted norms for body image, there can be a distinct difference in the body image women are accustomed to for themselves as compared to seeing temporary or permanent body image changes that occur with diagnosis and treatment of HNC. "The crux of this discrepancy is that there is a perceived differential between one's current standing and where one would ideally like to be" (Vartanian, 2012, p. 715). All women in this study reported the multidimensional changes from actual physical changes to social, work, and personal role changes that eventually led to a change in their perception of their actual self as opposed to the ought self that they thought they should be. This research and theoretical data support the thematic development of the body image changes experienced by these women through the changes they experienced as a result of the diagnosis.

The second research question, "What are the meanings that women ascribe to their self-perceived body image consequential to the reactions of family, friends, coworkers, and healthcare providers to their body changes?" As described in the second theme, *Inward feelings and meanings,* negative internal feelings often emerged initially during the realization of their discrepancy in their *ideal* or *ought* self-verses changing body image. Women described feelings and perceptions of isolation, being stigmatized by others by looking different, feelings of guilt from lifestyle choices resultant in an increased risk for HNC, and being depressed over losses.

Other researchers found similar negative feelings and meanings to emerge after experiencing physical changes from cancer and treatment. Walters-Brown and Hall (2012) reported isolating behaviors in women reporting a poor body image in the general population and both Chang et al. (2017) and Ellis et al. (2019a) supported similar findings in a population of cancer patients being treated for HNC.

For a while, these isolating behaviors may have provided some protection, in that they did not have to see family, friends, and coworkers' reactions to the changes. However, over time as they interacted with others and saw cues of acceptance, such as a kiss from a spouse or being accepted at mealtime, even though they had to eat different food, they found strength to accept their changed self. Acceptance by others helped them to move to more positive feelings about recovery. Similar to reports of support and encouragement from family and friends (Qualizza et al., 2018) and from health professionals (Branch, 2018), this perceived acceptance was essential for the women to progress to acceptance of their own changed body image.

Consistent with other studies (Jagannathan & Juvva, 2019; Threader & McCormack 2019), women who sometimes struggled with accepting their changed body image and reactions from others were those who expressed feelings of guilt and self-blame due to lifestyle choices and stigma surrounding the diagnosis of a cancer when possibly related to HPV. Women expected health care professionals to understand and offer understanding support. When a few women in this study women reported the lack of provider support and understanding, they were left angry and then disillusioned by health professionals' reactions. Some of the women reported that anger sometimes changed to motivation for getting over the perceived healthcare provider reactions and regaining their lives.

Even with the feelings of stigma and guilt some participants reported, there was a resounding desire by the women to look to the future, hoping symptoms would subside and they would be able to regain once again some or all of the social roles and previous activities and continue to heal. In the third study question, "How do women with HNC undergoing active treatment describe the strategies they use to navigate the physical, psychological, and social challenges affecting body image, ensuing from active treatment of HNC*?"* the third theme, *Navigating the journey*, and subthemes, *Internal motivation* and *External support*, described the strategies used to regain their future.

The prospect of spending time with friends, cooking for their family, playing with their child or grandchild, returning to work, and even having another child were found to be internal motivation factors for these women to tolerate the changes they were experiencing in hopes of resuming a life similar to that prior to their HNC diagnosis. The importance of health served as a key internal motivator was seen in studies by other researchers including Davidson and Williamson (2019); Formigosa et al. (2018); Nayak et al. (2016) and Qualizza et al. (2018), and is also consistent with the research used by Roux (2002) in development of the Theory of Inner Strength. Inner strength is defined as "a human resource that promotes wellbeing, involves healing and is connected to health. Resilience, sense of coherence, hardiness, purpose in life and self-transcendence are inner resources of importance for recovery after adversities" (Lundman et al., 2010, p. 251). Since its inception, this theory has been used extensively in women's health and in women with chronic or life-threatening illnesses evolved to focus "on the gender specific needs of women" (Dingley & Roux, 2013, p. 34), in development of inner strength.

Roux (2002) found that women in life threatening situations, although struggling with the changed perceptions of self, eventually accepted the changes as intertwined with their hope for the future as their health improved, and cancer treatment was ending. According to Roux et al., (2002), women accomplished this by managing the anguish and searching to find connectiveness with supportive relationships. Women used their inner strength to move from a place focused on the illness to becoming self-reliant and exhibiting independence to manage their daily activities. In similar fashion, the moving stories from women in this study described how they fought to regain their independence, resume previous roles, find inner strength, and embrace their new normal. According to Dingley & Roux, 2013, moving to a new normal is also “characterized by a deep personal satisfaction experienced as a result of helping and supporting others, which in turn serves as a source of inner strength (p.34).” This was demonstrated by women in this study who reached out to other women with HNC in support groups and online forums, becoming a source of strength for each other and other women as well.

The inner strength women in this study found was intertwined with the external support that accompanied their journey and was a catalyst for their internal motivation. Initially, women sought the support of healthcare professionals on their treatment team, similar to findings of other cancer studies (Cashell & McQuestion, 2019; Davidson & Williams, 2019; Qualizza et al., 2018). Eventually the women in this study relied heavily on support from their friends and families and social/work support systems. Despite loving, supportive partners at home, women described how support from other female friends was essential. These female friends could be found in their lifelong friendships, work relationships, neighbors, or women who had experienced cancer diagnoses themselves. Ellis et al. (2019b) found that social support from other women with cancer increased the women’s acceptance of their changed body image and promoted positive feelings about appearance.

Although the SPOHNC support group is an available support for all patients with HNC, support groups are limited and not specific to the needs of women. In this study, online support groups were used as a source of external support from other women with HNC and a way to offer support to others going through similar experiences. Most women in this study had access to generalized cancer support groups through their oncology clinic or hospital, but these groups were not attended by any participant in this study due to feeling their situation was very different from other types of cancer treatment. Instead, the women searched online, joining online groups focused exclusively on women with HNC. All the women in this study concurred that becoming friends with and finding support from women with similar situations was most beneficial to them, even at times more than the advice that was offered by healthcare providers.

Many would ascribe that the physical body image changes are not uncommonly seen with treatment of cancer and might be challenging to women in various stages of life. Yet, more than the physical symptoms, the role changes, social changes, and dependency versus independency concerns, stigma and guilt felt, and need finding support from others were demonstrated through the richness of the description given by women during the interviews conducted. This study made explicit the intricacies of the weblike maze of emotional and physical challenges of HNC treatment compounded by the psychological and societal stressors providing healthcare workers a glimpse into the lived experience of these women. The physical components of dysfunction, disfigurement, and debility, contributed to women perceiving themselves as less than ideal and supported the work of Higgins (1987) in his development of the Self-Discrepancy Theory. Psychological components included negative emotional well-being and altered perceptions of self and sexuality. Social components included changes in social functioning around food, changing roles and relationships with others, and feelings of stigma.

The embodied experiences of self-perceived body image changes when undergoing active treatment for HNC were seen through the resilience of these women as the struggled through the physical, social, and psychological stressors that were presented to them in the form of HNC and treatment side effects. Changes in body image, both acute and long lasting, became constant reminders of the severity of the life changes they endured as they strove to manage acute and chronic changes, and for some, feelings of guilt and blame for participating in activities known to be risk factors for HNC. The devastation that was seen as their self-esteem was impacted through depression and stigma was met with an inner strength and both internal and external motivational factors that encouraged them to push forward.

In contrast, the meanings that women ascribe to their self-perceived body image changed as they engaged with family, friends, coworkers, and healthcare providers. With the exceptions of some stress and frustration caused by health care professionals, the women sought to surround themselves by support systems that could cry with them and pull them forward when they did not want to do this on their own. The women looked outside of the conventional support systems to seek out support of women with similar lived experiences to be supported and yet support them at the same time. By doing so, these women described the personal and sometimes innovative strategies they used to navigate the physical, psychological, and social challenges affecting changes in body image. They eventually found the inner strength to move on with their changed body image over time as they recovered and looked to the future.

Recommendations for Nursing Research

This study was completed to give meaning and understanding to the body image changes women with HNC undergoing active treatment experience. In doing so it became more than a journey of understanding the struggles of that group, but also of the resiliency of women during treatment and recovery. These findings merely touch the surface of the needs and support required for this population. Further research is needed concerning the acute needs and long-term consequences of the changing body image on women undergoing treatment for HNC. Longitudinal studies that follow women from the time of their diagnosis to years after completing treatment to determine problems and efforts at resiliency and long-term survivorship are needed. This will enable the development of best practices to provide extended support to women through their survivorship of the disease.

As healthcare providers, giving patients the best chance for cure or control of disease becomes central to the plan of care and assures that the patients have support services available to help with the acute and long-term consequences of the treatment. Research is needed to investigate the type, number, and availability of services. Included in this is examining health care providers' perceptions of their abilities to provide guidance to this population. An exploration of cancer center practices to determine the availability of holistic support for the population of women with HCN to promote positive patient outcomes is essential. Enlightenment into how this care is being delivered or conversely what is lacking in knowledge and care delivery can lead to the development of increased education into side effect management physically, emotionally, and psychologically in support of these women.

Studies are needed to address empathetic, therapeutic interventions to support the women through the dynamic changes. This includes the use of supportive care including HNC focus groups, cognitive therapy, and linkage of women with other female HNC survivors who have completed their treatment. Exploring how the complement of these supportive therapies for HNC impact body image changes and tolerance of side effects of the treatments should be considered. The benefits of female support groups for survivors of HNC should be investigated to determine if there is a preference or benefit to using this type of support system. The relatively small number of women diagnosed with HNC as compared to men could present a challenge so online groups should be considered.

Body image changes can be studied using grounded theory to fully understand the process of survivorship and the multidimensional physical, emotional, and psychological changes in body image noted for women having been treated for HNC. The use of pre-treatment screening to assess women's self-perceived body image and the support systems they will have available during treatment would be useful in the pre-treatment recognition of variables and which could impact the need for additional support for certain women. Further research identifying specific risk factors for increased difficulty in managing the complexity of the changes that will be experienced as a result of this cancer treatment would potentially affect support services recommended for women with HNC. Development of support measures could address the stigmatization and lack of understanding for this population while facilitating positive adjustment to changes in body image.

The complexity of body image as both tangible and intangible constructs framed by a feminist lens requires further research guided by differences between men and women confronted with HNC. The societal objectification of women and outer beauty, gender roles, and stereotypes associated with women become conflicted as women are being treated for HNC. These societal stigma have the potential to impact their overall body image experience. The treatment side effects of HNC requires consideration of the stereotypical roles of women in society as mothers, caretakers, managers of the house, as well as those of contributors to society in the workplace. Research surrounding the delicate balance of these internal driving forces is needed to identify predictive factors of resiliency and optimal recovery for women with HNC.

The treatment for HNC can be debilitating due to side effects and the associated physical challenges such as fatigue and isolation as well as psychological struggles with emotional wellbeing, role changes, and stigma. The manner in how best to provide holistic care to address these issues from a survivors' perspective has not been researched. Research focused on understanding how this could improve the overall quality of life for survivors and those actively being treated may provide insight into the type of engagement best for this population.

Recommendations for Nursing Practice

The recognition of support systems that have been identified by women with HNC as beneficial, such as online support groups, demonstrates the resourcefulness of this population as well as the need for health care providers to recognize the importance of the shared lived experiences these women have revealed. Local HNC support groups have few female HNC members with similar disease and treatment trajectories, and women frequently seek online forums to connect with other women diagnosed with HNC to discuss their lives. Recognition of the need to evaluate information in online support groups is crucial as women with HNC search for answers and support. Health care providers need to be aware of the HCN online forums' content and information sharing to best support and provide answers to the women with HCN in their care and dispel any misinformation or myths regarding HNC.

Raising the consciousness of the needs of this population should be a focus of nursing practice. Nurses can strive to provide holistic care specific to women with HNC before, during, and after treatment. With the specific multidimensional challenges of this population, screening of women diagnosed with HNC should be done to help determine the best mechanisms for providing support to them emotionally, physically, psychologically, and spiritually. Individualizing a treatment plan for patients should include recognizing the limitations that may be present in medical practice and the best way to address these limitations. Nurse navigators or case managers working within cancer centers or cancer-dedicated units need to look for resources beyond the walls of a cancer center or unit.

In attempts to prevent this devastating disease, nurses need training and/or reinforcement on how to put personal biases and feelings about vaccination and high-risk cancer behaviors aside and focus on evidence from best practices when interacting with patients. Putting personal biases aside will allow nurses to build trusting relationships benefitting the receptive behavior of young women in gaining education that will teach protecting themselves against risk factors of developing HNC by getting vaccinated and other strategies. This teaching should be continued in women's health services as the population ages into becoming sexually active adults.

When working with women already diagnosed with HNC, nurses need to answer patients' questions honestly, but use sensitivity when discussing behavioral factors impacting development of HNC when women are still struggling with a diagnosis of HNC. Offering counseling for women who seem to be struggling with the stigma associated with HNC high-risk behaviors can augment their ability to find positivity and internal motivation to continue their treatment journey.

Recommendations for Nursing Education

Nursing education curriculum needs competencies to evaluate the nurse's ability to offer preventative education about the link of high-risk sexual behaviors to risk for development of HNC and address the benefits of HPV vaccinations such. Likewise, nurses need to be trained and practice teaching and interacting with patients in a non-judgmental manner. Education for nurses should focus on recognition of implicit biases which may prevent them from building trusting relationships with their patients. Implicit bias education should include recognizing and managing personal feelings regarding those who participate in high-risk sexual behaviors as well as the recommended use of vaccines in younger people to prevent HPV.

Nurses entering oncology practice need to be educated about the unique health care and social issues related to HNC diagnosis and treatment and how to develop proactive strategies to provide a support system for women with HNC. Educating nurses and nursing students on gender-specific struggles with identity and body image to promote sensitivity to those being treated for HNC is vital to promoting positive outcomes. Nurses need education to understand women with HNC and gender-specific feelings of need and acceptance as well as the fears of role changes. Understanding of how gendered roles and body image are present in the female persona will add to the depth of understanding of how complicated body image becomes for women during HNC treatment.

Additionally, nurses need to be educated on available resources for social services often needed during treatment, such as transportation and housing for patients with low resources. There is a need for nurses to understand the role of the nurse navigator in the cancer center in providing a consistent contact person for guidance and support and how a nurse can seek further education to prepare themselves for this role.

Recommendations for Policy

Inadequate medical insurance impacts patient outcomes and quality of life needs. State and/or federal policies regarding cancer coverage need to be amended and inclusive of the care for women with HNC. While most insurance covers the medically necessary treatments and interventions, there is limited coverage for assistance with home health care and everyday needs such as shopping and meal preparation while in treatment.

The changes in the household income and added costs over and above their usual expenses can be stressful for the patient and family supporting them. Some examples of unexpected costs that can cause added stress include copays, and expensive medications and treatments as out-of-pocket expenses and deductibles that accompany some insurance plans. These added expenses can negatively impact those who are on a very tight budget with limited resources available especially if, as usual for HNC treatment, the patient stops working. These added financial strains and the gap in income further complicates patients' ability to pay for social services needed in their care. Advocacy by nurses and policy-makers is needed to promote full coverage for cancer care, which includes long term home health care, if indicated.

Study Limitations

Several limitations of this study were recognized. The participants engaged in a one-time interview with the researcher. This could have prevented reflection by the women on potential other information they wanted to share after revelations about other meanings came to their consciousness. This was in fact noted with one participant where she reached back out with follow-up information after the interview. No follow-up was done with the participants which potentially prevented further sharing of other stories. Another limitation of the study could be that several of the participants were struggling with voice concerns at the time of the interviews and this could have impacted the richness of the data collected.

Conclusions

The purpose of this dissertation was to describe the lived experience of the body image changes experienced by women undergoing active treatment for HNC and bring a deeper understanding of the struggles by conducting an interpretive phenomenological investigation using van Manen's method. The three research questions were answered through the themes and subthemes that emerged from analysis of their stories. This was the first study exclusively studying the phenomenon of body change in women diagnosed and treated for HNC. The research sought to provide more than just an examination the many operationally defined aspects of body image threatened during the treatment of this disease, but an interpretation of what these changes mean to those living this experience. Recognizing the intricate entwined conceptual attributes of body image demonstrates the complexity of the disease and its treatment. It should further entice us to further explore how to meet the needs of this population not just through medicinal treatment, but through a holistic approach to treatment and recovery while promoting positive body image.

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Appendix A

Development of Concept of Body Image

Physical Construct	The symptom experiences	Cashell, A., & McQuestion, M. (2019)
	Distress with functional impairment	Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019)
	It feels tight It changes throughout the day. It affects me in other ways.	Jeans, C., Ward, E. C., Cartmill, B., Vertigan, A. E., Pigott, A. E., Nixon, J. L., & Wratten, C. (2019)
	Experiences and treatment of symptoms	Qualizza, M., Bressan, V., Rizzuto, A., Stevanin, S., Bulfone, G., Cadorin, L., & Ghirotto, L. (2019).
	Quality of Life Day-to-day changes Shame of current image	Taylor, S. (2016). Formigosa, J. A., Silva da Costa, L., & Vilela Vasconcelos, E. (2019)
	Personal dissatisfaction with appearance Appearance concealment	Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019)
	Disfigurement	Rhoten et al. (2013)
	Symptom burden in recurrence	Rhoten & Dietrich (2017)
	Communication Dysfunction	Chen et al. (2015)
	Time spent speaking	Chen et al. (2015)
	Self-body image and perceived quality of life	Qualizza, M., Bressan, V., Rizzuto, A., Stevanin, S., Bulfone, G., Cadorin, L., & Ghirotto, L. (2019)
	Perceived attractiveness	Chang et al (2019)
	Function and BID	Ellis et al. (2019b)
	Disfigurement	Davidson & Williams (2019)
	Voice quality and decreased speaking	Chen et al. (2015)
	Distress related to location, stage, treatment type	Chen et al. (2015)
	Disfigurement and BID	
	Camouflage to treat disfigurement	Chen et al. (2017)
	BID and surgical intervention	Chen et al. (2018)
	BID with radiation and/or chemotherapy	Graboyes et al. (2019) Branch et al. (2017)
	Overall appearance causes BID	
	Appearance related concerns	Rhondali et al. (2015) Fingeret et al (2015)
Psychological Construct	The experience of support and information from healthcare team	Cashell, A., & McQuestion, M. (2019)
	Strength comes from faith	Formigosa, J. A., Silva da Costa, L., & Vilela Vasconcelos, E. (2019)
	Help from healthcare professionals Information	Davidson, A., & Williams, J. (2019)

	Social support	
	The relationship with health professionals	Qualizza, M., Bressan, V., Rizzuto, A., Stevanin, S., Bulfone, G., Cadorin, L., & Ghirotto, L. (2019)
	It requires daily self-monitoring and management	Jeans, C., Ward, E. C., Cartmill, B., Vertigan, A. E., Pigott, A. E., Nixon, J. L., & Wratten, C. (2019)
	Comparison to others	Cashell, A., & McQuestion, M. (2019)
	Other-orientated appearance concerns	Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019)
	Changes within self	Davidson, A., & Williams, J. (2019)
	Reinforcing care of self after body alterations	Formigosa, J. A., Silva da Costa, L., & Vilela Vasconcelos, E. (2019)
	Psychosocial well-being	Taylor, S. (2016)
	Immaterial of external appearance Desire of good health	Nayak, S. G., Pai, M. S., & George, L. S. (2016)
	Cancer journey	Qualizza, M., Bressan, V., Rizzuto, A., Stevanin, S., Bulfone, G., Cadorin, L., & Ghirotto, L. (2019)
	Sexuality (psychosocial)	Rhoten (2016) Rhoten & Dietrich (2017)
	Depression	Rhoten et al. (2018) Rhoten et al. (2014)
	Psychosocial factors association with BID	Ellis et al. (2019a)
	Psychological distress caused by BID	Ichikura et al.,(2016)
	Positive correlation between BI and self-esteem and BI and integrity	Nayak et al. (2016)
Social Construct	Social avoidance	Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019)
	Social Functioning	Taylor, S. (2016)
	Sexuality (psychosocial)	Rhoten (2016)
	Communication with Healthcare provider	Rhoten &Dietrich (2017)
	Social Anxiety	Rhoten et al. (2018)
Overall Body Image	Overall body Image	Chang et al. (2019)
	Body image Dissatisfaction	Chang et al. (2019)
Stigma	Shame of current image	Formigosa et al. (2018)
	Object of blame	Jagannathan & Juvva (2016)
	Social Isolation	Ellis et al. (2019B)
	Stigma and distress	Threader & McCormack (2019)

Appendix B

Participant Recruitment Request:

The Lived Experience of Body Image in Women Undergoing
Active Treatment of Head and Neck Cancer:
A Hermeneutical Phenomenological Inquiry

Women with head and neck cancer (HNC) are at risk for changes in body image due to tumor presence and the side effects of the treatments. Physical, psychological, and social constructs of body image can influence the patient’s perception of body image. Little research has been done to support understanding the lived experience of women being treated for head and neck cancer. Therefore, the purpose of this research is to discover, describe, and understand the lived experience of body image in women undergoing active treatment of head and neck cancer.

This **research study is being conducted by:**

Giarratano, Gloria, PhD, APRN, CNS, FAAN, Professor and Colette Baudoin, MSN, RN, OCN, CNE (Doctoral Candidate) Louisiana State University Health Sciences Center-New Orleans School of Nursing

Participants are eligible for this study if they are:

☐ **at least 18 or older;**

☐ **speak and understand English;**

☐ **Have a diagnosis of head and neck cancer (excluded sites); and**

☐ **Are either receiving treatment or completed treatment within the past three (3) months.**

Please call 504-508-8329 or 504-568-4205 to participate in a research study asking you to talk about your experiences with changes in your body image since starting treatment.

Appendix C

Zoom Setting Instructions

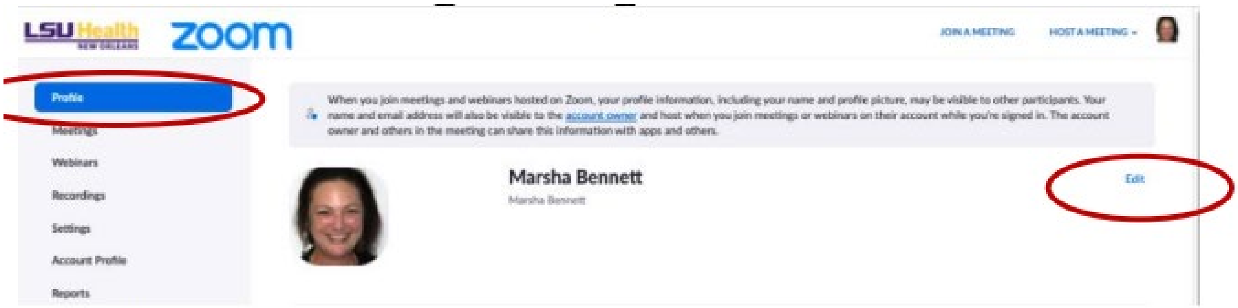
If after accepting the meeting request with the Zoom link you would like to change your picture

1. Select profile in the side bar on the left-hand menu then select "edit" from the right margin
2. Change your display name to an alias of your choosing if you prefer. It can be anything you would like such as a Disney character or other alias.
3. Then proceed to change your picture if you would like. This will be displayed as your screen is turned off to video. Be sure the picture you would like to use is saved to your computer browser.
4. Right click on your picture image on the left side and select the "edit" function which will appear in the middle of the picture. They select "change" from the pop-up box. This will bring you to your browser where you will select the picture you want to display.
5. Save the change in the bottom right hand corner underneath the picture.

Instructions for Changing Zoom Profile Information

1) Log into your Zoom program.

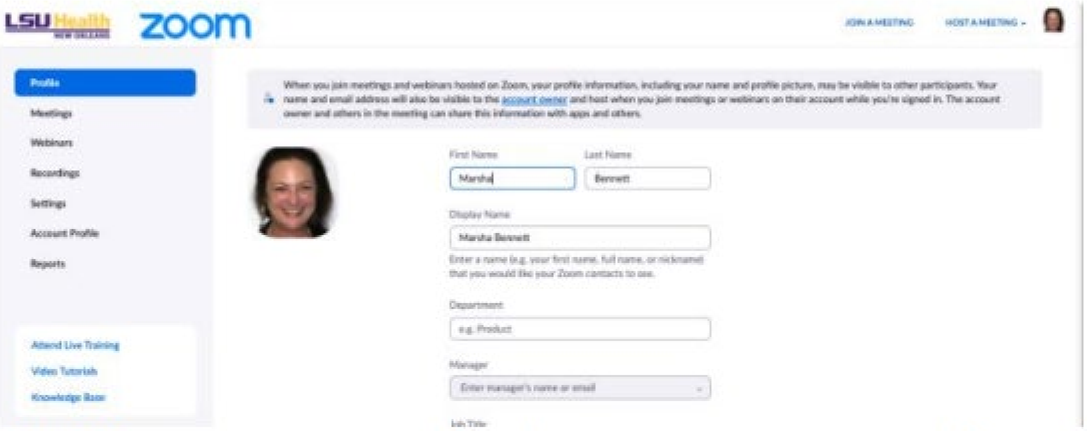
2) Select "Profile" in the side bar on the left-hand menu (highlighted in blue in the image below), then select "Edit" from the right margin:



When you join meetings and webinars hosted on Zoom, your profile information, including your name and profile picture, may be visible to other participants. Your name and email address will also be visible to the account owner and host when you join meetings or webinars on their account while you're signed in. The account owner and others in the meeting can share this information with apps and others.

Marsha Bennett
Marsha Bennett

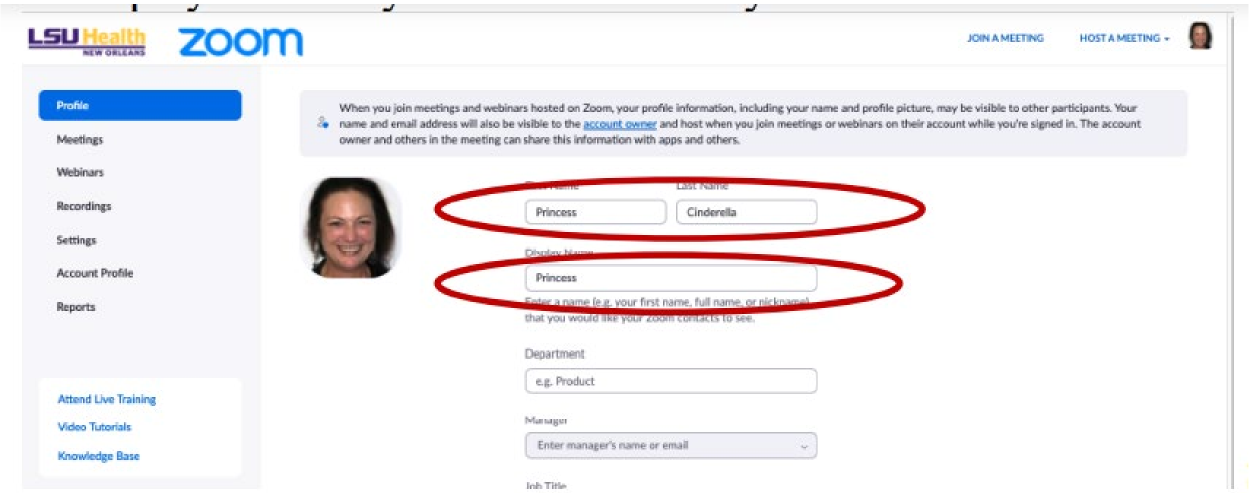
You will see this screen:



When you join meetings and webinars hosted on Zoom, your profile information, including your name and profile picture, may be visible to other participants. Your name and email address will also be visible to the account owner and host when you join meetings or webinars on their account while you're signed in. The account owner and others in the meeting can share this information with apps and others.

First Name: Marsha
Last Name: Bennett
Display Name: Marsha Bennett
Enter a name (e.g. your first name, full name, or nickname) that you would like your Zoom contacts to see.
Department: e.g. Product
Manager: Enter manager's name or email
Job Title

3) Change your display name to an alias of your choosing. For example, you may choose to change your display name to your favorite Disney character.



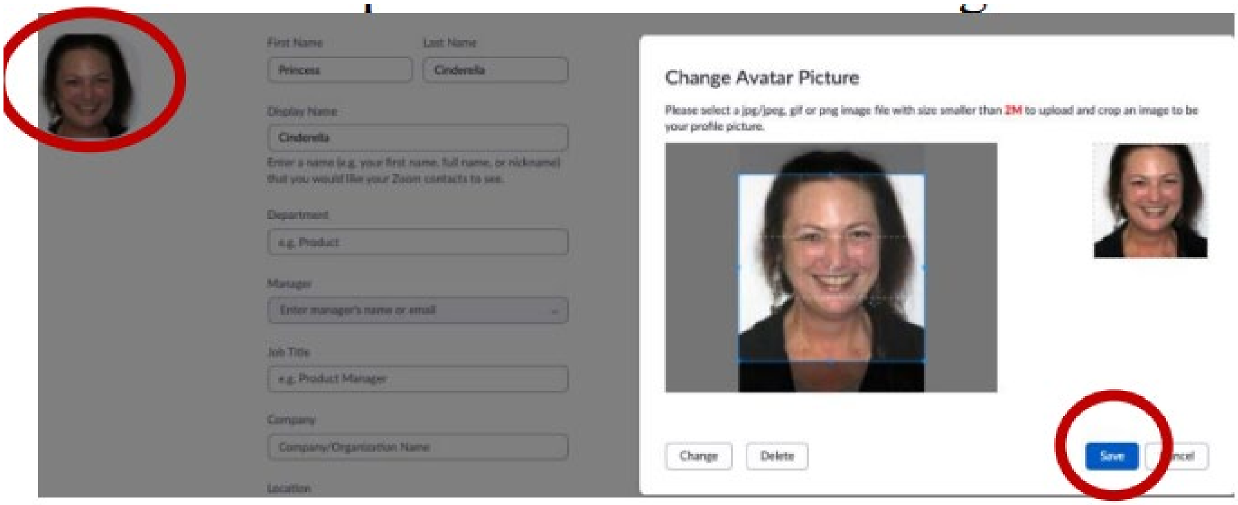
When you join meetings and webinars hosted on Zoom, your profile information, including your name and profile picture, may be visible to other participants. Your name and email address will also be visible to the account owner and host when you join meetings or webinars on their account while you're signed in. The account owner and others in the meeting can share this information with apps and others.

First Name: Princess
Last Name: Cinderella
Display Name: Princess
Enter a name (e.g. your first name, full name, or nickname) that you would like your Zoom contacts to see.
Department: e.g. Product
Manager: Enter manager's name or email
Job Title

Save your changes before the next step!

4) Change your picture:

Right click on your picture image on the left side and select the 'edit' function which will appear in the middle of the picture. Then select 'change' from the pop-up box.

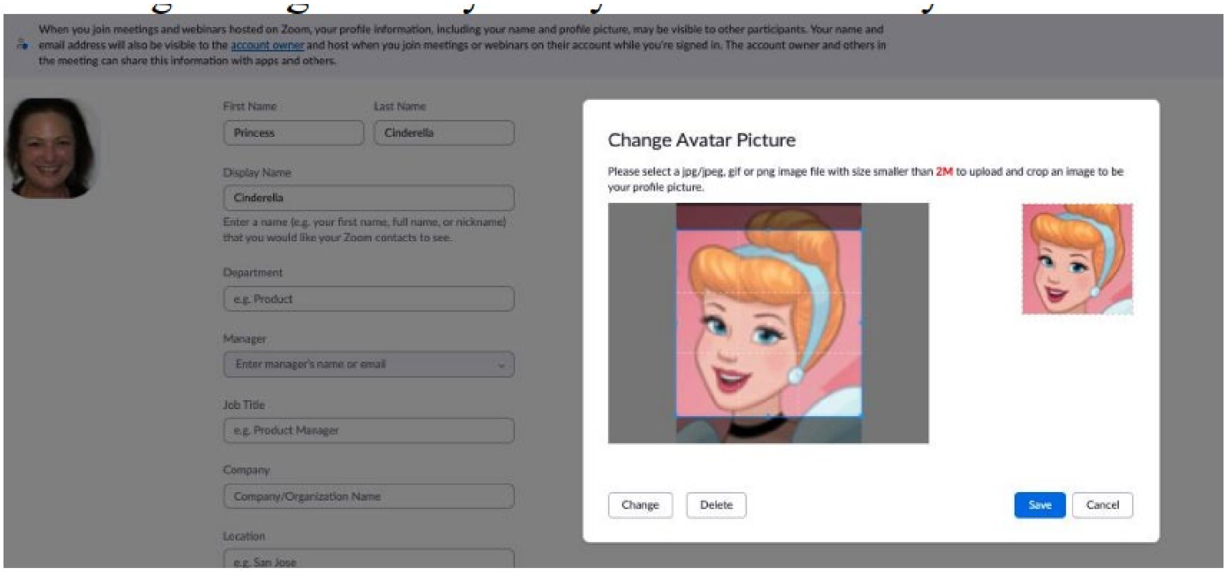


First Name: Princess
Last Name: Cinderella
Display Name: Cinderella
Enter a name (e.g. your first name, full name, or nickname) that you would like your Zoom contacts to see.
Department: e.g. Product
Manager: Enter manager's name or email
Job Title: e.g. Product Manager
Company: Company/Organization Name
Location

Change Avatar Picture

Please select a jpg/jpeg, gif or png image file with size smaller than 2M to upload and crop an image to be your profile picture.

Selecting 'change' takes you to your browser and you then select the picture you want to display:



When you join meetings and webinars hosted on Zoom, your profile information, including your name and profile picture, may be visible to other participants. Your name and email address will also be visible to the account owner and host when you join meetings or webinars on their account while you're signed in. The account owner and others in the meeting can share this information with apps and others.

First Name: Princess

Last Name: Cinderella

Display Name: Cinderella

Enter a name (e.g. your first name, full name, or nickname) that you would like your Zoom contacts to see.

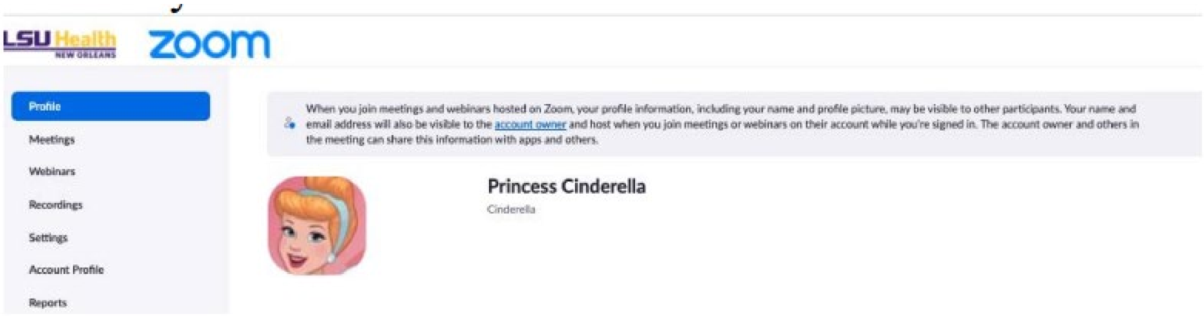
Change Avatar Picture

Please select a jpg/jpeg, gif or png image file with size smaller than 2M to upload and crop an image to be your profile picture.

Be sure to save before you leave this before leaving this page.

Alternately, you can choose to NOT have a picture displayed and simply leave your new name showing.

Sign into your account from a new device or web browser to confirm these changes.



When you join meetings and webinars hosted on Zoom, your profile information, including your name and profile picture, may be visible to other participants. Your name and email address will also be visible to the account owner and host when you join meetings or webinars on their account while you're signed in. The account owner and others in the meeting can share this information with apps and others.

Princess Cinderella

Cinderella

Repeat any steps, as necessary.

After your interview is complete, revert to your original information by following these steps again and filling in your original information

Appendix D

Interview Guide

How did you find out you had HNC?

(Q1)

HNC and treatments for HNC have the potential to change the way you look and feel about yourself.

> Tell me about the side effects of the treatment that your healthcare provider discussed with you and said you may experience.
>
> What were some of your concerns before you began treatment for your HNC?
>
> How has your treatment for HNC affected the way you look and feel about yourself?
>
> Based on your treatment plan, what kind of body changes have you experienced?
>
> > How did these changes affect your own body image (the way you look and feel about yourself)?

(Q2)

Your interactions with other people have the potential to change how you feel about yourself.

> Describe your interactions with friends. How did your friends react to the changes in you resulting from your treatment? How have friends' reactions affected your feelings about changes you have experienced because of your treatment?
>
> Tell me about your interactions with family members. How did your family react to the changes in you resulting from your treatment? How have family members' reactions affected your feelings about changes you have experienced because of your treatment?
>
> How about your interactions with coworkers. How did your coworkers react to the changes in you resulting from your treatment? How have coworkers' reactions affected your feelings about changes you have experienced because of your treatment?
>
> What about your interactions with healthcare providers. How did your healthcare providers react to the changes in you resulting from your treatment? How have healthcare providers' reactions affected your feelings about changes you have experienced because of your treatment?
>
> How have the changes in your body from the cancer and treatment changed the way you participate in social gatherings?
>
> > How has it affected going in public settings?

(Q3)

Tell me what your typical day was like before your diagnosis.

What is a current day like for you now?

How have your daily activities changed since starting treatment?

What are things that have proven to be your biggest challenges?

What helps you to get through the days since you started treatment?

What hinders your ability to get through a day and accomplish daily needs/goals?

How has this affected your management of your daily activities?

How has your management of daily activities affected the way you feel about your body image (the way you look and feel about yourself)?

In following up with interview responses, questions about need for support will follow:

What have you been doing to help yourself manage all the changes (body image, activities, etc.) you have experienced since starting treatment?

Tell me about the people that you feel have been supportive of you during this time.

In what ways were your friends supportive?

In what ways were your family members supportive?

In what ways were your coworkers supportive?

In what ways were your healthcare providers supportive?

What are some things that you think could be done better or differently to help you manage the changes you have experienced?

I might not have covered everything and there might be some things I did not ask, that you would like to tell me….

Based on initial answers to all questions, the interviewer will ask more in-depth, probing questions to allow for full exploration of their experiences such as:

Please give me an example of that.

Elaborate more on that so I can understand.

How did that make you feel?

Appendix E

Demographic Data Questionnaire

Date of interview____

Age____

What is your racial/ethnic background?

Asian___________
Black__________
Latin/Hispanic___________
Native American_____________
White______________________
Other (specify)______________

What is your relationship status?

Single, not dating___________
Married or in a committed relationship______
Widowed_________
Dating______________________
Divorced_________
Separated_________

How long has it been since you were diagnosed: ______________________

What is the site of your diagnosed cancer?

Oral_________________________
Pharyngeal___________________
Nasopharyngeal_______________
Other (specify)_______________
Thyroid___________________
Tonsillar__________________
Glottic (Tongue)____________
Mouth (oral cavity)__________
Uncertain__________________
Skin cancer___________________

What treatments have you received, or did you receive in the past 3 months for your HNC? Please check all that apply.

Treatment Type	**Planned**	**Currently receiving**	**Completed**
Chemoradiation			
Chemotherapy only			
Immunotherapy			
Radiation Therapy only			
Surgery			

What is the stage of your cancer? Please check one.
Stage 1__________
Stage 2__________
Stage 3__________
Stage 4__________
Unknown/not certain__________

Appendix F
Online Recruitment Flyer

Are you a woman undergoing treatment for head & neck cancer?

Volunteers needed for research study on the experience of body image in women undergoing active treatment of head and neck cancer!

Women with head and neck cancer are at risk for changes in body image due to tumor presence and the side effects of the treatments. Physical, psychological, and social aspects of body image can influence a woman's perception of her body image. Little research has been done to support understanding the experience of women being treated for head and neck cancer. Therefore, the purpose of this research is to discover, describe, and understand women's experiences of body image challenges.

This **research study is being conducted by:**

Giarratano, Gloria, PhD, APRN, CNS, FAAN, Professor and Colette Baudoin, MSN, RN, OCN, CNE (Doctoral Candidate), both at Louisiana State University Health Sciences Center
-New Orleans School of Nursing

Participants are eligible for this study if they are:

☐ At least 18 or older;

☐ Speak and understand English;

☐ Have a diagnosis of head and neck cancer and

☐ Are either receiving treatment or completed treatment within the past three (3) months.

Please call

504-508-8329 or 504-568-4205

or e-mail at cbaud4@lsuhsc.edu

to participate in a research study asking you to talk about your experiences with changes in your body image since starting treatment

Appendix G

VITAE

Colette Daigle Baudoin
2010 Giaise St.
Marrero, LA 70072

Education

Undergraduate		
Dates	**Institution**	**Degree**
1985-1986	University of New Orleans	Undergraduate pre-requisites
1985-1986	Southern University of New Orleans	Undergraduate pre-requisites
1986-1989	LSUHSC-New Orleans School of Nursing	BSN
Graduate		
2016-2018	Nicholls State University	MSN
2018-2024	LSUHSC-New Orleans	Ph.D.

Professional Experiences

Date(s)	**Activity**	**Organization**	**Role/Title**
2018-Present	Nursing Instructor	LSUHSC School of Nursing	Clinical Instructor of Nursing
2015-Present	Faculty Practice/Staff Nurse	East Jefferson General Hospital	Nurse Educator/Per diem nurse
2012-2014	Staff Nurse	West Jefferson Medical Center	Infusion Nurse/Nurse Navigator
2006-2012	Staff Nurse	Tulane Medical Center	Bone Marrow Transplant Coordinator/Clinic Nurse
2005-Present	Per Diem Nurse	Gifted Healthcare	Per Diem Nurse
2003-2005	Per Diem Nurse	Egan Home Health, Family Home Health Care, American Nursing	Per Diem Nurse
1997-2003	Staff Nurse	Kimberly Quality Care/Olsten/Gentiva Home Care	Director of Pediatric Home Care/Staff Nurse
1989-1997	Staff Nurse	Children's Hospital	Staff Nurse/Case Manager
1987-1989	Nurse Tech	Children's Hospital	Nurse Technician