PROVIDER WEIGHT BIAS: EXPERIENCES OF OVERWEIGHT AND OBESE CANCER SURVIVORS

By

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A dissertation submitted in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

WASHINGTON STATE UNIVERSITY
College of Nursing

MAY 2016

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the dissertation of SANDRA LEE WYRICK find it satisfactory and recommend that it be accepted.

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ACKNOWLEDGEMENT

I would like to acknowledge and give thanks to the members of my committee and research team.

Dr. Mel Haberman,

You are so patient and kind in your mentorship in my scholarly journey, not only with phenomenology but also descriptive qualitative research design and achieving the highest quality written PhD level dissertation. Throughout the 4 years of study, with our collegial and personal relationship, I have developed as a scholar, research scientist, professional nurse executive, and overall person. Your astute listening skills and keen ability to conceptualize were essential to the creative and complex design of this study. It is with your expert knowledge of the interpretive methodologies and guidance that I was able to develop and implement my very first qualitative study which would not have been successful without your expertise and assistance in the areas of phenomenologic study design. I appreciate your perspective and I have learned how language can be used to understand experiences about the lived human experience. This knowledge will forever be a lens, through which I see the world,

You have expert editing and writing skills that are impeccable and pushed me to dig deeper in my research literature and critical thinking to produce written work that is at the highest scholarly level. Thank you for being the chair of my committee, sticking with me through all of our personal, health, and life issues. But more importantly, thank you for being my mentor, friend, and willingness to share your expert knowledge with me. I appreciate and honor you.

Dr. Phyllis Eide,

You are so kind, flexible, and generous. You have an exceptional knowledge of the
interpretive methodologies and you have willingly shared your expertise with me. Thank you for jumping into my committee mid-stream. Your assistance in guiding me through my first qualitative study with ease and grace and the sound findings of this study are a credit to your expert understandings and interpretations. Thank you for being a member of my analytic team and a member of my committee. I appreciate and honor you.

**Dr. Sterling McPherson,**

Your generosity in the sharing of your time and expertise as a committee member is felt deeply by me. Your critical appraisal was very important to the quality of this study. Thank you for being a member of my committee and analytic team and for allowing me to learn from you about viewing the world in a new way. I am most delighted our paths merged during my Ph.D. journey. Perhaps we can do research together in the future. I appreciate and honor you.

**Cohort 2012 WSU CON and Adopted Cohort Members,**

I am blessed to part of this very special group of nursing women scholars. Though from diverse backgrounds, our common bond as Ph.D. nursing students reached a level of connectedness that surpassed our imaginations. I cherish you and the collegial and personal memories we have had and reveal in knowing that life-long friendships were born in the summer of 2012 at the WSU Ph.D. nursing program. Thank you for being part of my Ph.D. journey and my life. I appreciate and honor each of you.
PROVIDER WEIGHT BIAS: EXPERIENCES OF OVERWEIGHT AND OBESE CANCER SURVIVORS

Abstract

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May 2016

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Declared a disease by the AMA in 2013, obesity claims the lives of over 2.8 million people annually in the U.S. Mounting evidence indicates weight bias is encountered in the interactions with health care professionals; resulting in a decreased health-related quality of life and shorter survival rates. Knowingly or unknowingly, healthcare providers communicate forms of weight bias when they associate negative traits and assumptions with obesity to their patients. Using a descriptive phenomenology methodology, the purpose of this research study is to explore and describe the phenomenon of weight bias as experienced by overweight and obese cancer survivors in their interactions with oncology nurses and physicians.

The study findings report heavy underlying implications related to the psychosocial and cultural aspects related to the overweight and obese cancer survivor population that oncology nurses and doctors are not addressing in their clinical practice. There are strong implications related to the coexisting factors including large body size and increased risks of many types of cancer, yet often nurses and doctors fail to contemplate what constitutes health outcomes for overweight and obese cancer survivors. Findings from this study explicate and illuminate disparities within the oncological healthcare settings. Evidence from this study found oncologists simply do not “want to get involved” in the weight-related implications of cancer.
One participant called it a disservice and others simply described it as ignoring the *elephant in the room*. Additionally, the study findings discovered emerging themes denoting the *participants’ positive experiences* with their cancer care.

The current study advanced the understanding of how overweight and obese cancer survivors experience oncology health care. Given the prevalence of obesity in the U. S. and permeation of weight bias throughout the healthcare industry, meaningful remedies are needed to protect patients against weight bias. Findings may be used to further the state-of-the-knowledge by informing oncology healthcare nurses and physicians of tactics to change current practice to include culturally sensitive, holistic, and respectful delivery of care for the overweight and obese cancer survivor.
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Dedication

To God, who through his grace and love provided the strength and wisdom making this all possible.

This dissertation is first dedicated to Rick, my best friend and husband of 35 years. You are my rock and my soul mate. Thank you for always believing in me, granting the time for this journey, and taking care of me; even while you fought your cancer battles. I will never forget our many long talks and your wise words of encouragement “I am not a quitter and you are not a quitter”. Very effective! Rick, this degree is part yours. I could not have achieved this goal without your daily help in our home and with our kids. You gave of yourself so I could reach for a dream. Thank you! On the next path of your life’s journey, may the blessings you have bestowed come full circle. To Jacob and Jordan, my beloved children: You are my essence, who graciously granted me time to develop my mind and spirit. Thank you for understanding and support. I could not have achieved this without your love and laughter which has sustained me the past 4 years. Now let’s live our life and have some fun! You all deserve it.

To the participants in this study, I dedicate this work to you. I honor you and thank you for sharing openly your experiences as cancer survivors and moreover the emotionally charged topic of weight bias discrimination. May you all be blessed in your recovery and healing process in your survivorship.
In Loving Memory of my mother and father, passing away before their time, both masters prepared scholars whose educational role modelling became an essential component in my life long development and through my education journey. I love and miss you both every day.
CHAPTER ONE
INTRODUCTION

Chapter one presents the statement of the problem that is composed of the following sections: Provider weight bias, obesity, overweight obesity and cancer, and provider weight bias and the healthcare experience. The problem statement is followed by a definition of terms, purpose statement and a description of the population of interest. The primary research question and three specific aims are designated. The chapter concludes with a statement of the significance and rationale for the study.

Statement of the Problem

Affordable, accessible health care is the expectation in the United States (U.S.). When a U.S. citizen goes to the hospital or their healthcare provider, they expect to receive high quality care that adheres to national guidelines and standards of practice. For example, care of the patient with hypertension or a deep vein thrombosis or congestive heart failure follows certain evidence-based practice standards and guidelines. Care may be individually tailored to a particular patient based on important variables such as age, gender, and other health risk factors or comorbidities (e.g., kidney function). For some individuals, such as those who are overweight and obese, unique health care needs are in play. Weight bias, whether conscious to practitioners or not, can impact care. For specific conditions, such as cancer care, weight bias can be a serious impediment to care. Healthcare oncology providers are uniquely positioned to help transform cancer survivorship care and improve the quality of care for their patients who are overweight and obese (Commission on Cancer, 2012). However, if weight bias is active during care, this has been demonstrated to have deleterious consequences for providing effective care (Puhl, 2014; Puhl & Brownell, 2003). Thus, for oncology patients, a looming question remains; are oncology
providers jeopardizing the health of overweight and obese cancer patients due to weight bias? The phenomenon of interest for this dissertation research study is healthcare provider weight bias as it relates to the experiences of overweight and obese cancer survivors in their interactions with oncology providers; nurses and physicians.

**Provider Weight Bias**

Oncologists diagnose and provide a plan of care and treatment for their cancer patients and nurses play a significant role in improving the delivery of oncology care by identifying individual needs and concerns, assessing every aspect of the patient, and triaging appropriately (Commission on Cancer, 2012). Barriers to patient care increase and overall quality of care is jeopardized when a patient is subjected to biases including; mental health, individuals with additions, religious affiliations, socioeconomic, and weight bias from their healthcare providers (Crawley, Ahn, & Winkleby, 2008; Puhl, 2014; Puhl & Brownell, 2003). Weight bias is defined as the discrimination, prejudice, and stigmatization imposed on overweight and obese individuals (Puhl & Heuer 2011; Rudd Center for Food Policy and Obesity, 2008; Rudolph, 2008; Teachman & Brownell, 2001).

Weight bias is well documented within sectors of society, such as employment, education, housing, and popular media (Friedman & Puhl, 2012; Puhl & Heuer, 2011; Schwartz, Chambliss, Brownell, Blair, & Billington, 2003). For example, career success is negatively influenced when a person is overweight or obese for example, getting passed over for promotions and obtaining entrance to college. Furthermore, the obese individual is viewed as lacking self-discipline and control, being less motivated, and having a lower supervisory potential than thinner employees (Giel, Thiel, Teufel, Maye & Zipfel, 2010; Rudd Center for Food Policy and Obesity, 2008). Stereotypes such as “obese people are lazy, sloppy, and stupid”
are commonly associated with the individual who is overweight or obese (Puhl & Heuer, 2011). Believing and accepting these common weight-based stereotypes promotes an environment of intolerance and prejudice, which ultimately leads to the unfair treatment of the overweight and obese individual (Puhl, 2014) and in the case of oncology care, could lead to inadequate or even improper care.

Weight bias permeates healthcare with subtle forms of provider weight bias including; prejudice, stigmatization, and discrimination (Dovidio, Major, & Crocker, 2003; Puhl & Heuer 2011; Rudd Center for Food Policy and Obesity, 2008; Rudolph, 2008; Teachman & Brownell, 2001). The challenge in caring for the large, heavier patient exists in all healthcare settings (Camden, 2009). To illustrate this point, when obese patients need nursing care, issues related to their physical size can complicate even the most basic interventions. For example, equipment must be sturdy and appropriately sized to accommodate patients’ weight safely whether that it is an exam table, hospital bed, or wheelchair. Equipment such as weight scales and blood pressure cuffs must be accurately sized to provide accurate measurements, and will give inaccurate measurements when not appropriate size for medically overweight or obese patients. Additionally, commodes and toilets must be correctly mounted to bear the body size and weight of the obese patient. Simple interventions such as repositioning the overweight or obese patient suddenly become a potential hazard for the healthcare provider (HCP) and patient.

Puhl and Brownell (2003) characterize weight bias within the healthcare industry and with medical providers as robust, powerful, pervasive, and very difficult to change. For example, in a study of 400 physicians, one of every three listed obesity as a condition to which they respond negatively (Rudd Center for Food Policy and Obesity, 2008). While weight bias crosses all disciplines of medical providers, it has been found to be higher in HCPs caring for
general populations, which would include the oncology patient population (Gallagher, Brannan, & Davis, 2008; Schwartz et al., 2003; Teachman & Brownell, 2001). According to the National Association of Bariatric Nursing (NABN) (2014), provider weight bias has been reported and observed in every aspect of patient care, including front desk hospital or clinic receptionists and transporters, medical assistants, patient care technicians, radiology technicians, nurses, nurse practitioners, and physicians, to name a few.

Healthcare providers communicate forms of weight bias when they associate negative traits and assumptions with medical obesity (Rudd Center for Food Policy and Obesity, 2008). Research indicates that health discrimination against overweight and overweight and obese persons is as common as racial discrimination (Rudolph, 2008). To better illustrate this point, in a survey of 2,449 overweight and overweight and obese women, 70% stated they had experienced bias by doctors and 52% stated the bias had occurred on more than one occasion (Rudd Center for Food Policy and Obesity, 2008). The biases reported indicated obese persons of both genders have poor hygiene, are non-compliant, lazy, stupid, dishonest, weak-willed, and hostile (Rudd Center for Food Policy and Obesity, 2008). Furthermore, physicians seeing overweight and overweight and obese patients of both genders are reportedly spending less time with them, engaging in less discussion, do fewer treatment interventions, and are reluctant to perform preventative health screenings including pelvic exams, cancer screenings and mammograms (Rudd Center for Food Policy and Obesity, 2008). Size-sensitive issues including skin care, pulmonary function, hygiene, resuscitation, drug absorption, intravenous access, mobility, and many more obesity-related issues must be anticipated; however, the literature asserts this is not always happening (Bejciy-Spring, 2008; Camden, 2009). As part of their roles, nurses and physicians must adjust the care for these patients by anticipating and developing skills
to manage weight-based issues (Andreyeva, Puhl, & Brownell, 2008; Bejciy-Spring, 2008; Camden, 2009).

Current evidence indicates several gaps in knowledge exist. These include medical and nursing education on the topic of weight bias, a negligible understanding of both subtle and blatant expressions of weight bias by healthcare professionals, the risk to patient safety when size-sensitive issues are ignored by providers, and sparsely documented facets of weight stigmatization experienced by patients. The current study contributes to nursing science and clinical practice by explicating the experiences of weight bias reported by overweight and obese women and men during cancer diagnosis, treatment and survivorship.

**Obesity**

Every year 2.8 million people in the U.S. die as a result of being overweight or obese (Ng et al., 2014; World Health Organization, 2013). Obesity is a common, serious and costly condition that has reached pandemic proportion in the United States. Obesity is defined as having a body mass index (BMI) of 30 or higher; it is a costly condition that can reduce quality of life and increase the risk for many serious chronic diseases as well as premature death (CDC, 2014; CDC, 2010). The prevalence of obesity has increased among all groups regardless of age, gender, ethnicity, socioeconomic status, or race (CDC, 2012; Ogden, Carroll, & Curtin, 2006). Today, almost 30% of the world’s population, a staggering 2.1 billion people, is either overweight or obese, a number that equals the number of individuals suffering from starvation (Buchwald, 2007; CDC, 2012; IOM, 2012). In 2009, not a single state in the U.S. met the healthy people 2010 obesity target of reducing obesity among adults to 15% of the population and, moreover, the overall prevalence of obesity increased by 1.1% since 2007 (CDC, 2010).
Over the last two decades, the percentage of overweight and obese adults and children has been steadily increasing, leading to growing populations of overweight and obese patients’ actively seeking care within our healthcare systems across the United States. The patients may be faced with provider weight bias, stigmatization, and discrimination related to their weight issues; therefore, understanding the complex interactions associated with overweight and obese patients is warranted and subject for ongoing research (Puhl & Brownell, 2001; Sinicrope & Dannenberg 2010). Adherence to treatment regimens, cancer screening activities, and lifestyle modification programs among overweight and obese cancer survivors, could be in jeopardy due to experiences of weight bias and prejudice by oncology physicians and nurses. Current evidence indicates a gap in knowledge related to obesity and caring for the cancer patient. This research study provides a first glance in gaining a better understanding and knowledge of the lived experiences of cancer survivors who are overweight and obese.

**Overweight, Obesity and Cancer**

According to the American Cancer Society (ACS) (ACS, 2014) being overweight or obese is associated with an increased risk for many cancers, including breast, colon, rectum, endometrium, kidney, pancreas, and adenocarcinoma of the esophagus. With that, obesity has been noted as an independent prognostic factor for the development of distant metastases and death after the diagnosis of breast cancer (Sinicrope & Dannenber, 2010). Being overweight and obese may also be associated with an increased risk of aggressive prostate cancer, non-Hodgkin lymphoma, multiple myeloma, and cancers of the liver, cervix, ovary, and gallbladder (ACS, 2014). Furthermore, obesity is associated with a higher cancer incidence, recurrence, progression, and death (ACS, 2014). Recognizing the magnitude of the obesity problem and the
gravity of the associated health risks, the American Medical Association (AMA) declared obesity a disease in June 2013 (Medical News Today, 2013).

Nurses have long been an integral part of the pre-treatment and on-going care planning for newly diagnosed cancer patients. Size-sensitive issues including medical equipment that is size appropriate and mobility issues are some of the additional considerations in preventing barriers to care, and need to be included in planning care for overweight and obese cancer survivors (Andreyeva et al., 2008; Bejciy-Spring, 2008; Camden, 2009).

To reduce the presence of these types of assumptions and better prepare physicians and nurses to care for the overweight and obese oncology patient population, weight sensitivity programs should become a more important aspect of education for healthcare providers in all areas of healthcare including the oncological setting (Bejciy-Spring, 2008; Falker & Sledge, 2011; Puhl, Luedicke & Grilo, 2013). To date, there are no federal laws protecting overweight and obese people from forms of weight bias (Rudd Center for Food Policy and Obesity, 2008).

This research study has advanced our understanding of provider weight bias related to overweight and obese cancer survivorship. The interviews conducted with survivors identified patient-centered tactics to lessen health burdens and barriers to care due to the impact of weight bias. The study findings offer a deeper understanding of the complex medical and psychological factors related to the co-occurrence of being overweight and obese and being diagnosed with cancer.

**Provider Weight Bias and the Health Care Experience**

The experiences of overweight and obese persons within the healthcare community can be filled with mistrust, fear, humiliation, and embarrassment, all of which negatively impact their care and future utilization of health care services (Dovidio, et al., 2003; Malterud &
Ulriksen, 2011; Puhl & Brownell, 2006). Consequently, the overweight and obese individual is reluctant to seek medical care, delays or cancels appointments, and postpones preventative screenings such as cancer screenings and mammograms (Bejciy-Spring, 2008; Puhl & Brownell, 2006; Rudd Center for Food Policy and Obesity, 2008).

Unfortunately, many healthcare providers have strong negative attitudes and reactions toward the obese person that can alter their ability to accurately interpret the attitudes of others during interpersonal interactions (Bejciy-Spring, 2008; Gudzune, Huizinga, Beach, & Cooper, 2011). The end result for the person with obesity is higher medical usage, which at first glance might seem contradictory. However, since patients put off getting preventative care and screenings, they are usually very sick when they eventually seek help and the care they require becomes resource intensive and significantly more costly (Andreyeva et al., 2008; Puhl & Brownell, 2006; Schwartz et al., 2003). Today, nurses and physicians will encounter obese patients in almost every type of healthcare practice and specialty (Gallagher, Brannan, & Davis, 2008). To facilitate the optimum care of this patient population, it is imperative to more closely uncover and explore the overweight and obese patients’ experience of provider weight bias.

Psychologists ascribe more negative and severe symptoms and worse prognosis for overweight and obese patients compared to non-obese patients (Rudd Center for Food Policy and Obesity, 2008). Consequences of weight bias include becoming more vulnerable for depression, anxiety, having low self-esteem, poor body image, and even suicidal acts and thoughts (Rudd Center for Food Policy and Obesity, 2008). Furthermore, persons with cancer and weight issues have higher occurrences of diagnosed depression which is elevated even further when a person has cancer and is overweight or obese (Rudd Center for Food Policy and Obesity, 2008; Somerset, Stout, Miller, & Musselman, 2004; Stunkard, Faith, & Allison, 2002). Depression can
diminish a person’s quality of life adversely affecting medical treatments and therapeutic compliance, ultimately reducing the rate of survival (Somerset et al., 2004). Stunkard, Faith, and Allison, (2002) examined depression and obesity and found obesity to be related to major depression, especially among women. There is also a prevalence of depression in patients with cancer with demonstrated high association of depression among the following cancers including oropharyngeal (22%-57%), pancreatic (22%-50%), breast (1.5%-46%), and lung cancer (11%-44%) (Massie, 2004).

Healthcare nurses and physicians are exposed to the same social messages about obesity and obese individuals as the general population. They are also aware of the negative health consequences linked with obesity. Unfortunately, strong negative associations are often expressed by healthcare professionals toward obesity as a health condition and against patients with obesity (Malterud & Ulriksen, 2011; Puhl, Moss-Racusin, Schwartz, & Brownell, 2008; Teachman & Brownell, 2001). For cancer survivors who face weight issues, quality of life and ultimately their rate of survival could be in jeopardy when exposed to oncology provider weight bias. For a better understanding of the phenomenon of weight bias, this research study is designed to explicate, describe, and illuminate rich data from the stories of overweight and obese cancer survivors.

Current evidence indicates several gaps in knowledge exist: medical and psychological consequences for overweight or obese cancer survivors; perceived barriers to healthcare; and the impact of weight bias on quality of life, healthcare delivery, and health outcomes. The current study has advanced our understanding of these gaps by exploring the healthcare experiences of overweight and obese cancer survivors within the oncology setting. Furthermore, this study has served to further the state-of-the-science by informing oncology healthcare nurses and physicians
of tactics to change their current practice to include culturally sensitive, holistic, and respectful delivery of care for the overweight and obese cancer survivor.

**Statement of the Purpose**

The purpose of this dissertation study is to describe the phenomenon of weight bias experienced by overweight and obese cancer survivors using a descriptive phenomenologic methodology.

**Population of Interest**

Purposive sampling was used to obtain a sample of 10-15 overweight and obese cancer survivors.

**Research Question and Specific Aims**

The research question that guides this study is “What are the weight bias experiences of overweight and obese cancer survivors regarding interactions with their medical oncology nurses and physicians?”

The specific aims are as follows:

Aim 1: Describe the demographic and disease characteristics of the sample.

Aim 2: Explicate and describe the experiences of overweight and obese cancer survivors of both genders in their interactions with oncology nurses and physicians within the medical oncology setting.

Aim 3: Illuminate specific experiences that illustrate the presence and impact of weight bias in the provision of oncology health care.

**Significance and Rationale**

Provider weight bias interferes and impacts the health and care of overweight and obese patients (Puhl et al., 2008). Ironically, these individuals have significantly higher needs for
medical services due to their higher risk of comorbidities including the risk of cancer. The evidence is mounting that demonstrates weight bias, including associated stigmatization and discrimination, is encountered in the daily lives of overweight and obese individuals across a broad spectrum of healthcare settings (Puhl et al, 2008). Cancer is increasingly being regarded as a chronic disease with improved odds for survival. The growing number of cancer survivors with serious weight issues and prominence of cancer in the U.S. raises cause for examination.

In 2014, a staggering 1,665,540 new cancer cases are expected to be diagnosed and 585,720 (1,600 people per day) Americans are expected to die of cancer; 40,430 of those are breast cancer deaths alone (ACS, 2014). In the U.S., there are over 12 million American cancer survivors and a staggering two-thirds of Americans (2 out of 3 adults and 1 out of 2 children) are considered overweight or obese (ACS, 2014; IOM, 2012; Rudd Center for Food Policy and Obesity, 2008). According to the National Cancer Institute (2014), roughly 50,500 new cases of cancer in women and 34,000 new cases of cancer in men in the U.S. were due in part to having a BMI of 25 or greater. Furthermore, being overweight and obese was found to contribute to 20% of all cancer-related mortality in the past decade; a number that is reasonably projected to be much higher today due to the increased prevalence of obesity (ACS, 2014). Increasing evidence suggests cancer recurrence and a decrease in the likelihood of survival are convincingly associated with having medical obesity (IOM, 2012).

Despite the lack of evidenced-based research specifically related to overweight and obese cancer survivors and provider weight bias, marginalized populations of overweight and obese patients face multiple forms of weight bias resulting in their reluctance to seek medical care and a pattern of ignoring potentially life threatening symptoms (Gallagher, Brannan, & Davis, 2008;
Huizinga, Cooper, Bleich, Clark, & Beach, 2009; Merrill & Grassley, 2008; Schwartz et al., 2003; Teachman & Brownell, 2001).

Negative bias towards persons who are overweight or obese in the healthcare industry has been documented for over 40 years; yet, weight bias continues to affect millions at a steadily increasing rate (Huizinga et al., 2008; Rudd Center for Food Policy and Obesity, 2008). Given the prevalence of obesity in the U. S. and presence of weight bias throughout the healthcare industry, meaningful remedies are needed to protect patients against weight bias. Health Care Providers have a moral and professional responsibility to address weight bias-related behaviors, attitudes, communication skills, and the capacity for empathy since these greatly affect their ability to adequately meet the needs of obese persons. Similarly, healthcare organizations and administrators need to include language on weight bias in their patients’ rights policies, provide accommodations in equipment, logistics and manpower which are essential when caring for this patient population (Malterud & Ulriksen, 2011).

The current study has contributed evidence in support of changing current practice and advancing the state-of-the-knowledge regarding provider weight biases expressed by oncology providers. The findings are significant in that they inform professional education and raise awareness regarding the manifestations of provider weight bias and the medical and psychological consequences impacting cancer patient outcomes. By understanding the impact provider weight bias has on overweight and obese cancer survivors, oncology providers can begin to evoke changes in their practice to include culturally congruent, sensitive, respectful care. These changes will be more cost-effective, and decrease perceived barriers when seeking preventative cancer screenings and treatments, ultimately increasing the quality of life and rate of survival. Science has documented consistent evidence supporting how overweight and
overweight and obese people face discrimination in employment, education, and healthcare (Rudd Center for Food Policy and Obesity, 2008). The significance of the current study findings benefits society by contributing evidence supporting change in making weight bias an unacceptable form of prejudice within healthcare.
CHAPTER TWO

REVIEW OF LITERATURE

Chapter two presents a review of the literature for the concept of provider weight bias that is composed of the following five major knowledge domains and four secondary topics framing this study: Cancer and being overweight or obese, characteristics of the population and phenomenon, weight bias and obesity, provider weight bias, weight bias power differentials, and four topics including: obesity, cancer survivorship, trends in cancer, being overweight and obese, and assessing body mass. A conceptual model based from Madeline Leininger’s theory of Culture Care: Diversity and Universality, also known as the Transcultural Care Theory, will be examined followed by a summary statement.

Literature Review Search Strategies and Language

The concept of provider weight bias used as a key term for database inquiry found few responses to clarify the definition among healthcare professionals caring for obese cancer survivors specifically. The term was narrowed to weight bias. Combining this term with prejudice and discrimination by healthcare professionals yielded the best results in defining and conceptualizing weight bias. It became evident with each subsequent database search that a large cavernous gap in nursing literature prevailed and other disciplines must be explored.

The CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane, PubMed, Web of Science, and Google Scholar databases were utilized and searched to help define the concept of weight bias. The key words used with the search in CINAHL included weight bias, healthcare, obesity, and cancer where no articles were found relevant to the organization of the literature review out of the reported 3,342 results. The next search was in the Cochrane database using the same key words which resulted in 50 articles with only 5 titles.
deemed relevant to the organization of the literature review. The search was refined to include the key word nursing with weight bias AND obesity OR cancer. This search yielded 222 articles and only 23 titles were relevant to the topic. PubMed search using the same key words yielded 8,002 with only 6 titles found relevant to the organization of the literature review. Searching for the use of theoretical models regarding caring for obese patient population using key words theoretical model AND obesity, came up empty in Google Scholar and Web of Science search indexes.

The Web of Science database was the database with the most refined results for my concept and phenomenon of interest. The disciplines of medicine and nursing contributed to a richer understanding of the concept. Key words for the search included weight bias AND nursing AND obesity which resulted in 20 articles of which 13 titles were reviewed for relevancy to the organization of the literature review. Refining the search within the same database and including the search key word AND cancer resulting in 37 articles of which 12 titles were found relevant to the organization of the literature review. This database was further explored using the search terms weight bias AND weight stigma AND obesity which yielded only 2 articles of which 1 title was reviewed and found relevant to the organization of the literature review.

Due to the void in literature that specifically described weight bias and obese cancer survivors, a fifth database, Google Scholar, was searched using key words including weight bias and obesity on the initial search. The results netted over 19,000 titles so the search was refined with the addition of the key words cancer survivors. This search resulted in over 10,000 articles and narrowed to 67 articles relevant to the topic. That being said, there was only 1 article out of 10,000 related to weight bias from healthcare professionals. The search was refined once more
to include the key words *weight bias, prejudice, healthcare professions* which yielded over 15,000 results and 15 articles found relevant to the organization of the literature review.

**State of the Science**

There are serious and catastrophic implications for public health practice regarding the obesity pandemic that warrants addressing obesity through a comprehensive approach across multiple settings and arenas. Furthermore, over the past decade, obesity has become recognized as a national health threat and major health challenge (Centers for Disease Control, 2014). To better illustrate this point, in a study of women’s stories of their experiences as overweight patients, the study found women struggled to fit in, felt they were being dismissed, and felt not quite human (Merrill & Grassley, 2008). Being cognizant to the obese patient experience and their own weight biases, healthcare professionals must begin to help in changing the risk factors, environments and policies affecting overweight and obese patients, and moreover the weight-based biases that are putting this patient population at risk. Believing and accepting weight related social stigmatizations promotes an environment of intolerance and prejudice, which ultimately leading to the unfair treatment of the overweight and obese individuals (Puhl, 2014).

**Cancer and Obesity**

Obesity can be related to emotional, environmental and genetic factors. Obesity comes with an array of significant and serious comorbidities (Camden, 2009). Between 1980 and 2013, the prevalence of the overweight and obese population rose by 27.5% for adults and 47% for children (Ng et al., 2013). In the U.S., the prevalence of obese and overweight people has more than tripled since 1980 (IOM, 2012). Today, it is estimated that over 60% of American adults, approximately 700 million, are considered obese in the U.S. Furthermore, approximately 12.5 million children and adolescents aged 2-19 are reported to be obese (Ogden, Carroll, & Flegal,
2014). Of the top 10 leading causes of mortality in the U.S., five are related to obesity including; cancer, heart disease, stroke, diabetes, and kidney disease (Ng et al., 2014; Schmitz et al., 2013). Disparities in cancer survival and treatment outcomes across levels of medical obesity have been noted (Schmitz et al., 2013).

According to the American Cancer Society (ACS), breast cancer is the second most common cancer in American women, after skin cancer, and the second leading cause of cancer death after lung cancer (ACS, n.d; Ekwueme et al., 2013; ). Obesity and cancer are common conditions that often coexist; yet, we seldom consider what constitutes survival for individuals with breast cancer who are obese. Take breast cancer for example, the ACS estimated that 290,170 new cases of breast cancer (in situ and invasive cancers) were diagnosed in American women in 2012 and over a woman’s lifetime, there is a 1 in 8 chance she will get breast cancer. The increased prevalence of breast cancer diagnosis may be reflective of increased prevalence of obesity (DeSantis, Siegel, Bandi, & Jemal, 2011). Researchers note that while the incidence of breast cancer has demonstrated a small decline, the decline would have started earlier and been steeper had it not been for the increasing prevalence of obesity (ACS, 2014).

Being overweight or obese and lack of sufficient physical activity are avoidable causes of cancer (CDC, 2008). In an extensive review of the literature of more than 7,000 studies on excess weight, nutrition, physical activity and cancer risk, there was convincing evidence of an association between excess weight and female breast cancer, among six other cancer types (CDC, 2008). Evidence is clear regarding the prevalence of obesity increasing the risk of breast cancer for women particularly those up to age 50 (Ekwueme, et al., 2013). The incidence specifically related to obesity in cancer statistics remains unclear; however, what is known is that 11,000 to 18,000 deaths per year associated with female breast cancer in the U.S. might be
avoided if the woman maintained a BMI under 25 throughout their adult lives (Sinicrope & Dannenberg, 2010).

A positive association between obesity and the risk of cancer has been consistently observed in epidemiologic studies and has repeatedly shown to be a risk factor for cancer recurrence and poor survival (Ligibel & Strickler, 2013). Looking again at breast cancer as an example; research indicates that obese postmenopausal women have double the risk of developing breast cancer as compared to normal-weight women (Hudis, 2014). Additionally, women who are obese at the time they are diagnosed with breast cancer have a 30% higher risk of dying from breast cancer or other causes due to weight based comorbidities (Hudis, 2014).

Mortality as it relates to disparities in cancer death rates is currently evidenced by the individuals’ state of residence, socioeconomic status, and race/ethnicity, with no indication of obesity as a marker (American Cancer Society, 2014). The evidence that having a BMI of 25 and greater is associated with cancer incidence and mortality is compelling and by contrast the role of obesity in cancer survival far less understood (Schmitz et al., 2013). The variability of these findings is in part due to cancer treatment efficacy which becomes altered due to the comorbidities associated with BMI’s of 25 and greater itself (Schmitz et al., 2013).

Characteristics of the Population and Phenomena of Weight Bias

**Overweight and obesity.** The terms *overweight* and *obesity* are both labels for ranges of weight that are greater than what is generally considered healthy for a given height. For adults, overweight and obesity ranges are determined by using weight and height to calculate a number called the "body mass index" (BMI) which correlates with their amount of body fat. An adult who has a BMI between 25 and 29.9 is considered overweight and adult who has a BMI of 30 or
higher is considered obese (CDC, 2014). For the purpose of this study, participants having a BMI of 25 or greater will be referred to as overweight and obese.

**Cancer survivor.** The National Coalition for Cancer Survivorship (NCCS) defines Cancer survivorship as “from the time of diagnosis and for the balance of life,” one is considered a cancer survivor (NCCS, 2014). A cancer survivor is a person who has been diagnosed and achieved statistical cure (typically 5 years) and the term “survivor” will follow the person for the remainder of life. The NCCS recognized cancer survivors as a unique population in and of itself (Grant, Economou, & Ferrell, 2010). Overweight and obese cancer survivors have numerous comorbidities, acute and chronic, which will require more attention in assisting them with barriers to care for cancer screenings and treatments, with consideration to their size and physical limitations due to obesity (Commission on Cancer, 2012).

**Trends in cancer related to obesity.** Medical obesity contributes to 15-20% or as many as 1 in 5 cancer-related deaths in the U.S. (Hudis, 2014). Mechanisms linking obesity and cancer include having (a) increased levels of insulin and insulin-like growth factor-1 (IGF-1) in the blood; (b) increased fat tissue that produces higher amounts of estrogen, which may drive development of certain obesity-related cancers including estrogen-sensitive breast cancers and endometrial cancer; (c) chronic low-level or “sub-acute” inflammation; and (c) extra fat cells (adipocytes) that may also have effects on certain tumor growth regulators (Hudis, 2014).

In the U.S., breast cancer is the second most common cancer in women (after skin cancer) and the second leading cause of cancer death in women after lung cancer. It is estimated that over a woman’s lifetime, there is a 1 in 8 chance she will be diagnosed with breast cancer (CDC, 2013; ACS, 2014). Research indicates the risk of breast cancer is higher among the obese population (DeSantis, Siegel, Bandi, & Jemal, 2011). Increased prevalence of breast cancer
diagnosis may be reflective of increased prevalence of obesity as well as increased mammography screening and menopausal hormone use (DeSantis et al., 2011). Prostate cancer is the number one cancer in men of all races, next to lung, bronchus, colon and rectum cancer (CDC, 2013). For overweight and obese cancer survivors, early detections and screenings may come at a high price in the forms of weight bias; delaying treatments and further screenings, leading to an increased rate of mortality (DeSantis et al., 2011).

The literature indicates that in a study of breast and cervical cancer survivors, obese patients had a higher mortality rate, in part due to lower rates of preventive care (Wee, McCarthy, Davis, & Phillips, 2000). At the same time that evidence connecting excess weight to increased cancer risk has been accumulating, trends in overweight and obesity prevalence have been increasing dramatically (ACS, 2014). There is speculation from researchers that the longstanding and historic increases in life expectancy in the U.S. may begin to decline during the early onset of this century as a result of the obesity pandemic (ACS, 2014).

The prevalence of obesity in the U.S. more than doubled between 1976-1980 and 2003-2006 and, although obesity levels have stabilized in recent years, more than one-third of adults – 36% of both men and women – were obese in 2009-2010 (ACS, 2014). While the mechanisms underlying the obesity-carcinogenesis relationship are not fully understood, mounting evidence exists to support recommendations that adults maintain reasonable weight for their height and ages for multiple health benefits, including decreasing their risk of cancer (Center for Disease Control and Prevention, 2009; Center for Disease Control, 2014). To illustrate this point, research evidence indicates that in 2007 roughly 50,500 new cases of cancer in women and 34,000 new cases of cancer in men in the U.S. were associated with obesity (National Cancer Institute, 2014). The projection of the future health and economic burden of obesity is estimated that
continuation of existing trends in obesity continues at the annual rate to over 500,000 persons in
the U.S. by 2030 (National Cancer Institute, 2014). Furthermore, if every adult reduced their
BMI by just 1% (or 2.2 pounds), this could possibly decrease the number of new cancer
diagnosis to 400,000 by 2030.

Researchers noted that while the incidence of breast cancer has demonstrated a small
decline, the decline would have started earlier and would have been steeper had it not been for
the increasing prevalence of obesity (ACS, 2014). Evidence is clear regarding the prevalence of
obesity increasing the risk of breast cancer for women particularly those aged 50 and older;
however, unclear in the literature is the actual percentage of increased risk (Ekwueme, et al.,
2013). Disparities in breast cancer death rates are evident by state, socioeconomic status, and
race/ethnicity, with no mention of obesity as a marker (ACS, 2014). This dissertation research
has served to close this gap and further nursing science related to obesity and cancer
survivorship.

**Overweight and obesity: Assessing body mass.** There are several ways to assess a
person’s body mass. Some methods are based on mathematical calculations of the relationship
between height and weight, while others are based on measurements of body fat to establish
certain risk factors for comorbidities, such as the waist-to-hip ratio (Gallagher, Langlois, Spacht,
Blackett, & Henn, 2004). Health organizations and policy makers use the Body Mass Index
(BMI) to measure and define overweight and obesity and to establish criteria for certain
procedures, and BMI has become the most frequently used and widely accepted gold standard
measurement of choice for obesity (Camden, 2009).

In 1995, the World Health Organization (WHO) recommended using BMI to establish
three grades or levels of overweight. Two organizations within the National Institutes of Health,
the National Heart, Lung, and Blood Institute and the National Institute of Diabetes and Digestive and Kidney Diseases concurred, with the caveat that cutoff points are used only as a guide for obesity-level definitions and for comparative purposes across populations over time (Camden, 2009). This caveat is important because an overweight individual with a BMI of 29 does not instantly acquire all of the health consequences of obesity after crossing the threshold of a BMI of 30. However, health risks do increase gradually as BMI increases. The above organizations have agreed that Classification I severe obesity corresponds to a BMI 30 – 34.9, Classification II morbid obesity corresponds to 35 – 39.9, and Classification III super obese corresponds to a BMI equal to or greater than 40 (Camden, 2009; Centers for Disease Control, 2014).

The BMI is not gender specific and uses a mathematical formula based on height and weight assigning a number to an individual’s relative risk for morbidity and mortality (Camden, 2009). The BMI as an assessment tool does carry certain limitations. One problem with using BMI as a measurement tool is that very muscular people may fall into the category of overweight when, in fact, they are very physically fit. Additionally, people who have lost large amounts of muscle mass may be in a healthy BMI category, when in reality they have diminished nutritional reserves. Therefore, the BMI has been most useful in tracking trends in the general population (Camden, 2009). The value of using standardized measurements and definitions is that all stakeholders are speaking the same language for reimbursement, guidelines, protocols, and assessment tools (Camden, 2009).

**Weight Bias and Obesity**
This section of the literature review consists of two major topics: Provider weight bias and provider weight bias health power differentials beginning with three definitions of terms including; stigmatization, discrimination, and prejudice.

**Stigmatization.** Stigma is a socially constructed powerful phenomenon involving at least two fundamental components including the recognition of difference based on some distinguishable characteristic and consequent devaluation of the person(s); exploitation and domination, designating a lesser value than “normal” people (Dovidio, Major, & Crocker, 2003; Malterud & Ulriksen, 2011). Social stigmatization is characterized by dehumanization, aversion, marginalization, prejudice and stereotypic depersonalization are central components; bringing with it consequences of deep-seated, negative personal, interpersonal and social costs (Dovidio, et al., 2003).

**Discrimination.** Discrimination as it relates to medical care practice is defined as differences in care that result from biases, prejudices, and stereotyping (Crawley, Ahn, & Winkleby, 2008). In its essence, discrimination is when there is a conscious decision made to treat a person or group differently and deny them access to treatment or care to which they are entitled (Farlex, 2012).

**Prejudice.** Prejudice is a word that is strongly related to and commonly used in the same context as stigma. It can be thought of in the sense that the person who is stigmatized is usually the target of prejudice. More specifically, weight prejudice is defined as a “negative attitude” toward a group or individual (Dovidio et al., 2003).

**Provider weight bias.** The concept of weight bias by medical providers is best defined as discrimination and prejudice which conjures up feelings of stigmatization to the obese individual who are then more likely to avoid routine preventive care and/or compliance to
treatment (Puhl & Brownell, 2001). Discrimination has been shown as a major causal factor in health disparities yet there is little known about the relationship between perceived medical discrimination and cancer care (Crawley et al., 2008).

Discrimination as it relates to medical care practice is defined as differences in care that result from biases, prejudices, stereotyping (Crawley et al., 2008). In its essence, discrimination is when there is a conscious decision made to treat a person or group differently and deny them access to treatment or care to which they are entitled (Farlex, 2012). Prejudice is a word that is strongly related to and commonly used in the same context as stigma can be thought of in the sense that the person who is stigmatized is usually the target of prejudice; defined as a “negative attitude” toward a group or individual (Dovidio, Major, & Crocker, 2003).

Weight bias is well documented within areas of society such as employment, education, housing, and portrayals in popular media; however, this concept is not conceptually or empirically examined in the healthcare literature (Schwartz, Chambliss, Brownell, Blair, & Billington, 2003). The current phenomenological research study will explicate experiences regarding disparities and barriers to healthcare due to forms of weight bias expressed by oncology nurses and physicians within the oncology healthcare setting.

In a 1961 research study regarding weight bias, six-year old children reported the perceptions and obese people are lazy, dirty, stupid, ugly, and cheats (Richardson, Goodman, Hastorf, & Dornbusch, 1961). This point is significant in understanding the prominence of societal weight bias over the past five decades for the general populations and children as young as six-years old. More current research reveals acceptance into college and employment advances have been lost as a result of the applicants’ size and/or weight (Puhl, Schawartz, & Brownell, 2005). The evidence demonstrating how weight bias, including associated
stigmatization and discrimination, are encountered in the daily lives of obese individuals and moreover, within healthcare is mounting (Puhl et al., 2008). Due to similar interactions occurring within health care, the overweight and obese patient is at risk for a decreased quality of life and shorter survival rate (Malterud & Ulriksen, 2011; Puhl et al., 2008).

**Weight bias power differentials.** Understanding the therapeutic relationship between practitioner and patient is difficult without comprehending the dynamics of power in a therapeutic relationship (Benjamin, 2004). As healthcare professionals, we must recognize the social construct of power differentials surrounding healthcare providers, weight bias, and the obesity, for the purpose of enhancing quality of life for cancer survivors who are overweight and obese. Growing populations of overweight and obese patients diagnosed with cancer are actively seeking care within healthcare systems across the United States. They face forms of healthcare provider weight bias related to their physical size and health conditions associated with obesity (Puhl & Brownell, 2001; Wee, McCarthy, Davis, & Phillips, 2000). The emerging awareness of weight bias within the healthcare industry has brought about rising concerns in caring for the nation’s obese population. One can ask: Are medical providers immune to the growing societal acceptance of weight bias when caring for the marginalized obese patient population?

A power differential is the role difference between the health care professional’s authority and patient’s vulnerability; this directly affects the well-being of the patient (Baca 2011; Benjamin, 2004). Within healthcare, the power differential is amplified by the physical, verbal, and psychological aspects of practice and at times is related to one’s own beliefs and biases (Benjamin, 2004; Puhl et al., 2008). Power differentials in healthcare can also include stereotyping, prejudice, and discrimination from the healthcare provider(s) to the patient (Fore, 2006). Healthcare provider barriers such as hostile behavior and lower quality of care towards
patients due to stereotyping, labeling, and stigmatizing patients were identified in affecting clinical judgments (Fore, 2006; Friedman & Puhl, 2012).

Recognizing that weight bias exists within a broader context of healthcare can help prevent multiple forms of bias that may be unintentionally communicated between the patient and the healthcare provider (Rudd Center for Food Policy and Obesity, 2008). Weight bias exists in every aspect of patient healthcare and crosses all disciplines of medical providers; however not well documented within the oncological healthcare setting (Gallagher, Brannan, & Davis, 2008). Thus, medical oncology providers must be cognizant of the fact that weight bias is recognized as universal and no longer ethnocentrically limited to those seeking bariatric surgery and weight loss treatments (Teachman & Brownell, 2011). Research evidence supports how obesity can alter healthcare providers’ ability to accurately perceive the attitudes of others during interpersonal interactions; (Gudzune, Huizinga, Beach & Cooper, 2008). Therefore, the importance of implementing sensitive and respectful holistic care for the overweight and obese crosses the boundaries of mainstream clinics and hospital units throughout America (Teachman & Brownell, 2001).

**Theoretical Framework**

Phenomenological research seldom uses a theoretical framework other than a foundational philosophical stance to guide the process of inquiry. Findings of the study interface with Leininger’s theory and validates tenets of the theory or offer a new conceptualization based on caring for the obese patient.

The theoretical framework considered during this research study is Madeline Leininger’s theory of Culture Care: Diversity and Universality, also known as the Transcultural Care Theory (Sitzman & Eichelberger, 2011) and the Sunrise Model (see Figure 1). This theory reminds
nurses and other healthcare providers of the value in assessing ones beliefs and biases while incorporating the patients’ beliefs, values, and culture in providing sensitive and culturally congruent care. Obese persons, not unlike other culturally diverse populations, have beliefs, values, and rituals which are congruent with the assumptions of Leininger’s theory. To better illustrate this point, in a course offered by the American Society of Clinical Oncology University (2014), regarding cultural competence for oncology practice, the faculty described the importance of the concept of cultural competence as it enhances the patient experience throughout the cancer care continuum. They concluded the appropriate strategies to minimize cultural issues that may impact barriers to healthcare must address race, gender, religion, age, language, and cultural issues unique to the population (Gelhert, Haozous, & Henry-Tillman, 2014). Interestingly, a gap in incorporating cultural competency education exists for persons misusing alcohol and/or drugs, the homeless, and bariatric or obesity cultures. This lack of inclusion of the obese population is a gap in knowledge that impacts the science and practice of cultural competency. Oncology nurses and physicians can no longer disregard the unique and fast growing obese patient population.

The key in providing quality, patient-centered care to obese patients is to include sensitive care and respect (Bejciy-Spring, 2008). The theory has been integral in providing a framework for holistic nursing practice and continues to drive nursing practice inquiry in defining culturally congruent and sensitive care today (Sitzman & Eichelberger, 2011). Leininger’s theory, first derived through qualitative methodology and the interpretive view, can be adapted across various methodological approaches and can cross over to other health disciplines (Sitzman & Eichelberger, 2011).
Leininger’s theory can be operationalized within nursing practice as well as across multidisciplinary provider practices. The theory is conceptualized as four quadrants (see Figure 2). The first quadrant includes the environment/culture of care, the second is the population/people, the third is the health/education, and the fourth is nursing.

These four quadrants inform the conceptualization of the problem and may guide the analytical interpretation of results. Quadrant one (Theory) would guide the description of a culture of obesity including; physical, social, symbolic, and environmental aspects. Quadrant two (Research) includes the population of cancer survivors with medical obese patients’ cultural and biological variations and health/illness behaviors. Quadrant three (Practice) frames nursing research and best practice and would include; the nurse/patient interactions and cultural encounters, nursing sensitive care and holistic practice, and the nurse/physician culture. Quadrant four (Education) includes; health, beliefs and biases regarding weight, weight bias sensitivity training, the art and practice of healing holistically, and barriers to care within the healthcare systems. Within the third and fourth quadrants, provider weight bias and stigmatization with obesity sensitivity training and nursing research for best practice and self-assessment could be explored; this is where nursing decisions and actions for care are delivered (see Figure 2). In this way, considerations of Leininger’s theory scaffold the data collection and analysis activities and enrich the understanding of the phenomenon as a whole, so that participant responses and nuanced recalled events are not lost but brought to the full phenomenological understanding that is the purpose of the study.

Operationally, the transcultural care theory has been integral in providing a framework for holistic nursing practice and continues to drive nursing practice inquiry in defining culturally congruent and sensitive care today (Sitzman & Eichelberger, 2011). The concept of weight bias
can be operationalized by using the R-E-S-P-E-C-T conceptual framework that is based on Leininger’s theory (Bejciy-Spring, 2008). The acronym R-E-S-P-E-C-T stands for rapport, environment/equipment, safety, privacy, encouragement, caring/compassion, and tact (Bejciy-Spring, 2008). This conceptual model can be utilized by nurses and across health provider disciplines in providing quality, patient-centered, sensitive care to patients with BMI’s of 30 or greater and will be used to drive the operationalization of this study’s concept of provider weight bias and the qualitative methodology chosen for this study (Bejciy-Spring, 2008).

My ontological perspective embraces the culture and quality of life issues surrounding the overweight and obese cancer survivor and, moreover, the contributing factors related to weight bias expressed by healthcare providers. This ontological and postmodern world view emphasizes meaning and understanding of individuals in the world and self-interpretation based on relativism and subjectivity, where the truth is viewed within a holistic lens (Newman, 1992). Due to the nature of investigating the holistic effect of provider weight bias on cancer survivors with medical obesity, the appropriate philosophical underpinning of Amadeo Giorgi’s psychological phenomenological qualitative approach will serve as the foundation for this methodology.

**Summary**

The concept of weight bias as it relates in healthcare and among healthcare professionals caring for overweight and obese cancer survivors is poorly defined in nursing literature. The findings of this study have provided further explication of this emerging concept to advance nursing knowledge. There remains a clear gap in literature specifically as it relates to medical providers treatment and care of overweight and obese cancer survivors. Unknown is the magnitude of oncology provider weight bias and the role stigmatization plays in patient
compliance to cancer screenings and prescribed oncology treatments. Considering best practices for oncology provider training and education regarding the overweight and obese oncology patient requires empirical evidence on which to advance nursing science of nursing and practice, ultimately leading to more appropriate and effective communication and care. Additionally, not evident in the literature, are the effects of the social constructs and power differentials surrounding forms of weight bias from medical providers towards the care of cancer survivors with medical obesity.

What is clear in the literature is that weight bias exists and is well documented within areas of society such as employment, education, housing, and portrayals in popular media; however, weight bias within the healthcare industry and expressed by health professionals remains a major concern (Schwartz, Chambliss, Brownell, Blair, & Billington, 2003). Today, nurses and physicians will encounter obese patients in almost every sector of healthcare practice and specialty; however, although weight bias is well documented in healthcare, it is not at all documented in oncology nursing or medicine (Gallagher, Brannan, & Davis, 2008). The review of literature revealed a gap in evidence describing or defining oncology nurses or physicians attitudes toward weight bias, specifically in overweight and obese cancer survivors. Furthermore, the experiences of overweight and obese cancer survivors are not described and/or addressed in the literature. This descriptive phenomenological study has addressed these gaps in literature and evidenced-based practice. Little has been known about overweight and obese cancer survivors related to their lived experiences and interactions with oncologists and oncology nurses, this dissertation study has offered a first glance.
CHAPTER THREE
RESEARCH DESIGN AND METHOD

Chapter three describes the research design and paradigm selected for this dissertation research study including; psychological descriptive phenomenology and social constructivism. Additional topics include: Methodology, sampling, data collection, and evaluation criteria. An overview of this research design and methodology is now provided.

Qualitative Descriptive Phenomenology Methodology

This qualitative study uses a psychological descriptive phenomenology design. Case intensive face-to-face or telephone interviews were conducted on a single occasion. The empirical and positivist scientific methodologies may not always be the most appropriate in answering every research question (Holliday, 2012). In qualitative research, the process is largely inductive with the inquirer generating meaning from the data collected (Creswell, 2009). Phenomenology is a qualitative methodology based on the philosophy of Edmund Husserl. It is descriptive, epistemological, and emphasizes individuals’ construction of their everyday lives; in essence, it is used to gain better understanding of the meaning of a phenomenon (Ironside, 2005). The uniqueness of the qualitative descriptive phenomenology is that it aims for a rich description of the participants’ lived experience, remaining close to their own words (Kahlke, 2014; Neergaard, Oleson, Andersen, & Sondergaard, 2009). A postpositive and social constructivist stance through a qualitative methodological worldview is based on relativism and exploratory breadth and depth of the individual’s subjective meaning of human experiences (Creswell, 2009).

The philosophical assumptions are congruent with social constructivism in that meanings are constructed by individuals as they engage and interpret the world based on their historical, cultural, and social perspectives (Creswell, 2009, Crotty, 1998, Newman, 1992). In social constructivism, the goal of the research is to rely as much as possible on the study participants’
views of their experiences (Creswell, 2009). The constructivist researcher often addresses the processes of interactions among individual which is accomplished by using more open-ended questioning to elicit subjective meanings (Creswell, 2009). Meanings are usually formed through interactions with others through historical and cultural operating norms within the participants’ lives (Creswell, 2009). Basic assumptions associated with psychological descriptive phenomenology include: (a) some lived experiences are common to all individuals who have experienced it; (b) sharing a rich description of a human experience does not necessarily require interpretation, but interpretation is not discouraged; (c) organizing data will be processed through content analysis and the researcher will want to explore the who, what, where and how of the experience or phenomena (Dicicco-Bloom & Crabtree, 2006; Lopez & Willis, 2004; Sandelowski, 2000; Thorne et al., 1997).

The concept of weight bias is well documented in the literature; however, little empirical evidence exists pertaining to the meanings breast cancer survivors with medical obesity ascribe to their world as they move through the oncology healthcare settings. Understanding the types of meanings constructed by breast cancer survivors with medical obesity in their interactions with oncology nurses and physicians is congruent with the philosophical underpinning of Amadeo Giorgi’s psychological phenomenological qualitative approach, a branch of descriptive phenomenology (de Witt & Ploeg, 2005).

**Historical and Philosophical Foundation**

**Psychological descriptive phenomenology.** Psychological phenomenology is a methodological strategy within qualitative research that has been emerging during the last twenty years and is research based upon an individuals’ description of experiences as they occur in everyday life (Willis, 2007). Amadeo Giorgi, an American psychologist, was an early pioneer in
the 1970s of the humanistic psychology movement and the use of phenomenology in psychology and qualitative research. Giorgi developed the descriptive phenomenological method in psychology in which the raw data consists of concrete descriptions from the perspective of a specific experience within everyday life; the analyses takes place within a disciplinary attitude and scientific phenomenological reduction, and a special sensitivity or attention is given to the phenomenon being investigated (Giorgi, 2009).

Giorgi concentrated on the work of Edmund Husserl, the founder of phenomenological philosophy focused on the work of Merleau-Ponty (1962) who articulated steps of a philosophical phenomenological method based upon Husserl (Giorgi & Giorgi, 2008). Husserl articulated the legitimacy of a philosophical phenomenological method as a scientific practice, based on his professional experience in psychophysics and Giorgi modified the steps of the philosophical method so that when applied to descriptive data, scientific psychological results could be forthcoming (Giorgi & Giorgi, 2008).

Donald Snygg, initiator of the grass-roots phenomenology movement, believed phenomenology is best characterized as “the world of naïve, immediate experience in which each individual lives, the everyday situation of self and surroundings which the unsophisticated person takes to be real” (Giorgi & Giorgi, 2008, p. 165–178). The term “grass-roots” refers to the phenomenological movement that emerged in the United States independent of the Continental philosophical context of phenomenology (Cerbone, 2006). The history of phenomenology dates back to the 1800s and Franz von Brentano, considered the father of phenomenology, whose ontology and epistemology surrounded the belief that internal perceptions are true and exist and external perceptions cannot be proven (Cerbone, 2006). Edmund Husserl was a student of Franz von Brentano and there are many students of Husserl.
who have written on methods in pre-transcendental phenomenology (Cerbone, 2006). Both Giorgi and Moustaka described their methods for psychological analyses based on Husserlian perspectives; however, each method differs significantly from each other’s methods (Giorgi & Giorgi, 2008).

Psychological phenomenology focuses on consciousness and perceptions with no effort to equate perceptions with external reality (Willis, 2007). The term *phenomenon* refers to the actual grasp that one has of the lived experience that exists in the real world or world transcendent; real things signified by *noumena* and *phenomena* as our perceptions of those things (Willis, 2007). To specify *phenomena* one must articulate memories, images, cognitions and objects as precepts (Giorgi, 1995, p.30; Willis, 2007). The concepts of acts used in phenomenology distinguish acts of consciousness and the objects that are correlated by those acts (Willis, 2007).

**Transcendental phenomenology.** Psychological phenomenology is also referred to as transcendental phenomenology. Participants’ experiences are reduced to a description of the "universal essence" or composite description of what they experienced and how they experienced it, not explanations or analyses (Creswell, Hanson, Clark, & Morales, 2007). Transcendental means "perceived freshly as if for the first time;" therefore, the researcher must bracket out their own experiences (Creswell et al., 2007, p. 236-264; Giorgi, 2009, p. 88). This signifies that researchers must discipline themselves in keeping their original assumptions and judgments separate in order to remain open to the emerging data and to reduce bias (Creswell, et al., 2007). Husserl spoke about his philosophical method as a transcendental reduction which implies viewing what is given from a non-human perspective (Giorgi, 2009). Transcendental consciousness is a global form of essential consciousness which Husserl claims is capable of
being intuited, actually experienced with the proper attitude (Giorgi, 2009). Pre-transcendental consciousness is appropriate when examining the psychology of human beings (Giorgi & Giorgi, 2008). The descriptive phenomenological method does not use deduction or induction to derive meaning. Instead, it asks the researcher to use phenomenological intuition as a guide to understand what is essential to the phenomenon being studied (Giorgi, 2009). Simply stated, intuition is used by the researcher to get a sense of the lived meaning.

**Phenomenological psychological attitude.** The main focus of this type of inquiry is to describe particular phenomena in terms of subjective lived experience (Wall, Professor, Mitchinson, & Poole, 2004). Thus, assuming an analytical phenomenological psychological attitude, also referred to as the transcendental phenomenological perspective, ensures research results reflect everything from the perspective of consciousness, looking at all objects/experiences from the perspective of how they are experienced regardless of whether or not they actually are the way they are being experienced (Giorgi, 2009). For example, most children who see Santa Claus in a store around the Holiday Season believe him to be a real person who will bring toys on Christmas. Phenomenologically, we know there is no real Santa Claus, but the perception of the child’s lived experience must be examined as an experiential given (Giorgi, 2009). Researchers are human beings, and it is natural that they will bring their own personal experiences, preconceptions, beliefs and attitudes to the research situation (Wall et al., 2004). Assuming this psychological attitude requires the researcher to move through the method of phenomenological reduction to reach a level of transcendental consciousness, pure, flowing, and essential (Giorgi, 2009).

**Bracketing.** In every research study there is a possibility that an investigator’s bias may skew the data leading to an invalid study with faulty conclusions (Lukiv, 2007). Bracketing is a
scientific concept requiring clear, methodologically sound decisions by the researcher to suspend empirical subjectivity curbing potential problems regarding internal validity (Fleming, 2011; Gearing, 2004). Husserl used the term *epoche*, Greek, for “a cessation,” to refer to this suspension of judgment regarding the true nature of reality and a sort of neutralization of belief regarding the study phenomenon (Giorgi, 2009; Lopez & Willis, 2004). Bracketing requires the researcher to hold a neutral stance regarding his/her belief(s) and put aside all questions concerning the objective existence or non-existence of the phenomenon to consider only the experiences being expressed (Creswell et al., 2007; Gearing, 2004; Giorgi, 2009; Lopez & Willis, 2004; Luvik, 2007). There are several phases and elements of bracketing that include the start point, duration, and end point or reintegration (Creswell et al., 2007). Additionally, there are six types of bracketing and each type is used based on the methodological approach by the researcher. The six types include: Ideal bracketing (philosophic), descriptive bracketing, existential bracketing, analytical bracketing, reflexive bracketing (cultural) and pragmatic bracketing (Gearing, 2004). For further expressions of validity and concreteness, this researcher will explicitly list descriptions of bracketing (biases) in this phenomenological study.

Psychological descriptive phenomenology methodology is primarily used in situations with a strong emotional element, due to its emphasis on experience over thought, to describe the essential elements of the lived experience being studied (Berman, 2003). Giorgis’ method of condensing qualitative data into a meaningful form results in a descriptive statement rather a list of categories or themes, differs significantly from empirical and positivists generalizability (Berman, 2003). The primary means of obtaining data using psychological descriptive phenomenology is through interviews and questioning, regardless of the external reality investigated (Willis, 2007). The processes for data collection are systematic, critical, general and
methodical, and they are open to intersubjective verification by the committee of scientific scholars (Willis, 2007). In psychological descriptive phenomenology there is less focus on the researchers’ interpretation, associated with a hermeneutic phenomenology approach, but both methods explore and analyze a phenomenon of interest through participants shared experiences or stories (Vandermause & Fleming, 2011).

Methodology

The research question that guides this study was: “What are the weight bias experiences of breast cancer survivors with medical obesity regarding interactions with their medical oncology nurses and physicians?”

To answer this question, three specific aims were formulated.

Aim 1: Describe the demographic and disease characteristics of the sample.

Aim 2: Explicate and describe the experiences of overweight and obese cancer survivors of both genders in their interactions with oncology nurses and physicians within the medical oncology setting.

Aim 3: Illuminate specific experiences that illustrate the presence and impact of weight bias in the provision of oncology health care.

The research design and paradigm selected for the dissertation was psychological descriptive phenomenology. The philosophical underpinning of Amadeo Giorgi’s psychological phenomenological qualitative approach, as a branch of descriptive phenomenology, was the methodology chosen for sample selection, data collection, analysis, and write-up.

Sample and Inclusion/Exclusion Criteria

Charmaz (2006) states the study aims are the ultimate driver of the study design and sample size; thus, a purposive sample of 10 overweight and obese cancer survivors was selected.
Qualitative research is very labor intensive thus larger sample sizes can simply be impractical (Mason, 2010). Sampling for the entire study was guided by inclusion and exclusion criteria. Inclusion criteria are (a) cancer survivors of both genders with an initial or current Stage I-IV disease, (b) overweight or obese (BMI > 25); (c) 18 years of age and older; (d) any length of survival post-initial treatment; (e) all types of prior/current treatment modalities (e.g., surgery, chemotherapy, radiation, hormonal); (f) English speaking, and (g) all races/ethnicities. The exclusion criteria are (a) both genders under 18 years of age, non-English speaking, and (b) physically or emotionally unable to participate in the interview. Additional sampling criteria are described next.

**Purposive Sampling**

In qualitative methodology, sample selection has a profound effect on the ultimate outcome and quality of the research study (Coyne, 1997). Purposive sampling started with participant #1 and up to the final participant #10. Purposive sampling is a type of non-probability sampling technique which focuses on sampling based on the judgment of the researcher; a form of theoretical sampling (Coyne, 1997). The purposive sampling method employed to recruit participants who have experiences with similar phenomena is recommended to gain a deeper understanding of the phenomenon being investigated (Coyne, 1997; Creswell, 2007).

Theoretical sampling originated with the discovery of grounded theory and is utilized in qualitative data analyses to produce a theory through collecting, coding and constant comparative analysis of data (Coyne, 1997). The benefit of using theoretical sampling for qualitative studies is that it is controlled by the emerging theory or themes as in this descriptive phenomenologic study (Coyne, 1997; Sandelowski, 2007). The notion that the sampling will change is critical to purposive sampling by selecting a wide range of cases by maximum
variation sampling and negative-case sampling. Maximum variation sampling seeks representatives by including a wide range of extremes and is used when the sample size is very small, less than 30, or when no population information is available (List, 2004). This method works well in places where a random sample cannot be drawn and is utilized as an extension of the statistical principle of regression towards the mean (List, 2004). Negative case sampling avoids slanting participant selection to those that would merely confirm the investigator’s personal expectations (Given, 2008). For example, sampling is based on the need to collect more data to examine categories and their relationships and to assure that representation in the category exists by way of simultaneous data collection and analysis until saturated and integrated into an emerging theme (Coyne, 1997; Saldana, 2013). Sampling and data analysis proceeded simultaneously. Codes or themes were elicited from the raw data from the start of data collection through constant comparative analysis as the data was collected (Sandelowski, 2007). Constant comparative analysis involves taking one piece of data, for example, one interview, statement or theme, and comparing it with all others that may be similar or different, to develop conceptualizations of the possible relations between the various data (Thorne, 2000).

**Recruitment**

Recruitment occurred through the researcher’s circle of influence of known contacts, outreach to cancer survivorship support groups, weight loss centers, and cancer clinics in both Washington and Arizona, and through social media including; Craig’s List, Facebook and LinkedIn. Participants for the study were recruited from cancer organizations including; Cancer Center Northwest in Spokane Washington and Susan G. Komen Cancer Support Group in Phoenix Arizona. The researcher met with Jenny Craig weight loss centers in Arizona and Cancer Center Northwest directors, in person and over the phone and email, to explain the study
and ask permission to post the flyer. A flyer regarding this research study was posted in the centers and cancer clinics advertising the recruitment process and criteria (see Appendix A, recruitment flyer). The flyer included the researcher’s phone number tear-away feature at the bottom for potential participants to take with them. Additionally, flyers were mailed and emailed to prospective participants fitting the inclusion criteria for age, BMI, and cancer diagnosis. Once the participant contacts the researcher, they will be asked additional screening question related to weight bias experience(s) by nurses and physicians while in the oncology setting (see Appendix C, phone scripting). Sampling of patients included those in active treatment such as; in the chemotherapy infusion clinic, radiation clinic, at follow-up appointments, bariatric clinic, medical-surgical oncology units, and during admission to the hospital for complications. Consent for participants was obtained verbally at the beginning of the phone call interview (see Appendix, G, verbal consent).

Participants contacted the researcher via phone or email which was provided on the recruitment flyer (see Appendix A, recruitment flyer). To confirm the inclusion and exclusion criteria of the potential study participant the researcher will ask 4 questions:

1.  *Are you 18 or older?*

2.  *Please provide me with your height and weight (to calculate BMI)*

3.  *Have you been diagnosed with Cancer?*

4.  *Have you had any experience(s) regarding weight bias during your interactions with oncology provider that you perceived as prejudice (prejudged), stigmatization (strong disapproval), having a non-caring and/or negative attitude due to your size?*

If the applicant did not qualify the researcher stated “*Unfortunately you do not qualify for this study, thank you for your time*” and explain the reason for disqualification for example; their
BMI is less than 25 or not having interactions with oncology providers to include, physicians and/or nurses, related to weight bias. If the applicant qualifies the researcher stated “congratulations, you qualify to participate in this study” and will proceed with the phone script related to the interview process, benefits, risks, informed consent, and honorarium. The phone script included an introduction of the research, an overview of the research study subject and process, qualification to participate, the honorarium for participating and potential risks and benefits and obtaining a verbal informed consent (see Appendix C, phone script). The study is WSU IRB approved. IRB will be described in more detail later in the IRB section of this dissertation.

**Data Collection**

The major topic examined in this section is the data collection for this research study and three topics including: Interview questions, structure of the interview, setting the tone of the interview and framing the questions. An overview of the data collection is now provided.

The method for data collection was an intensive single-case phone interview conducted by the investigator/PhD candidate that was digitally audio-recorded. The study started with an opening statement that explains the interview and types of questions that were asked (see Appendix F, interview scripting).

All interviews were transcribed verbatim into written transcripts. A medical transcriptionist, utilized within WSU College of Nursing, transcribed the recorded transcripts into Microsoft Word files. The interviews ranged between 45 and 90 minutes in length. Fourteen open-ended and structured questions were utilized to allow the participant to guide the storytelling from their lived experiences (Cohen et al., 2000; Creswell, 2007; Munhall & Chenail, 2008). Examples of these questions are provided in the following section (see Appendix
B, interview questionnaire). The researcher asked for clarifications for anything that seemed unclear. Probes were used to obtain further information. Some examples of probes included getting the participant to describe in more detail their experiences with prejudice(s), discrimination, and/or stigmatization. For example, “You mentioned you felt your oncology nurse was prejudging you because of your weight. Tell me more about that?” To establish rapport between the researcher and study participant and for demographic data needed to enrich the findings of this research, a structured demographic questionnaire was obtained over the phone as the first phase of the interview process (see Appendix D, demographic questionnaire).

**Interview questions.** Careful thought went into designing the interview questions including; being mindful to begin the interview by asking less threatening warm up questions, followed by asking the most threatening questions, and ending with some cool down and closing questions (Haberman , Personal Communication, 2014). These were the core items to assure coverage of all aspects of the phenomenon of interest. Some examples of early, hot, and cool down questions include the following; for entire interview questionnaire see Appendix B, Interview Questionnaire.

Examples of some early open ended warm up interview questions include:

- How would you describe your overall health at this time?
- Describe your satisfaction with your cancer care?

Examples of the more threatening and hot interview questions include: fixed

- Describe the experience(s) you have had in interactions with your cancer physician(s) and/or nurse(s) related to weight bias.
- Describe what the physician and/or nurse did or said to make you feel uncomfortable due to your size?
Examples of some cool down and closing interview questions include: fixed

- If you could tell an oncology nurse and physician caring for medically obese cancer survivors one thing, what would you say? (Probe for both).

- If you could tell another cancer survivor who is medically obese one thing, what would you say?

The researcher asked each question in sequential order even if the participant answered the question in a previous question due to the possibility of obtaining new emerging themes (see Appendix B, interview questionnaire). Additional probing questions to further elicit the dialogue when new emerging themes arise was asked by the researcher, for example; *that sounds like it was difficult for you to go through, is there anything more you would like to share about that experience? Tell me more about that feeling.*”

**Structure of the interview.** Following verbal informed consent, the interview process began. The interview setting was selected to reflect an environment that is free from constraints, where the participant feels free to share their story, where trust and rapport could be established between the researcher and participant to allow the phenomena to emerge (Benner, 1994; Crist & Tanner, 2003). All interviews were conducted over the phone. The researcher used two digital audio recorders in the event one failed. Participants were consented and offered information about strictness of confidentiality regarding the recorded session for purposes of accuracy in the final written transcript. No participants refused being recorded and all participants acted alone on the phone interview. Field notes and demographic data provided an elemental source of data for analysis which denoted events such as vocal intonations that might not be heard in the digital media (Crist & Tanner, 2003). Field notes were taken by the researcher during and after the interview. The field note taking cut down on interrupting the participant by keep track of things
that the participant mentioned in order to come back to these subjects at the appropriate time (Seidman, 2009).

**Setting the tone of the interview and framing the questions.** As stated by a philosopher in the Socratic and phenomenological traditions, the thoughts and feelings related to the phenomenon has a direct impact on the quality of the data obtained (Fleming, 2011; Ironside, 2005). The researcher sets the tone of the interview by presenting the participant with a well-defined opening statement (Benner, 1994). An example of the initial opening dialogue and question was; *I am interviewing overweight and obese cancer survivors. I am interested in the experiences you have had with oncology providers related to weight bias.* The researcher asked the interview questions in sequential order to be mindful of the warm to cool question sequencing. It is important for the researcher to ask questions that elicit a response but avoids leading the participant to a set answer, for example: *Describe your overall health?* (Vandermause, 2008). Paraphrasing statements shared by the participants can clarify any uncertainties and avoid putting words in the participant’s mouth so to speak (Benner, 1994). The researchers’ role acts as both facilitator and translator of the shared meaning that emerges and all subsequent questions should be posed in an open and reflexive manner (Vandermause, 2008).

The research questions evolve and change during the research study in a manner consistent with the assumptions of the emerging phenomena, however, the most important skill in the interview process is listening (Creswell, 2009; Seidman, 2013). Additional questions were added to the interview while keeping the core questions intact. The researcher listened at all three levels including: (1) Listening to what the participant is saying, concentrating on the substance and making sure they understand it including assessing if what they are hearing is as detailed and complete as they would like it to be, (2) listening for the *inner voice* versus the outer
more public voice; the participants’ challenges and adventures in grappling with a difficult experience, and (3) remaining conscious of the interview process and substance while being sensitive to the participant’s energy level and nonverbal cues he or she may be offering (Seidman, 2013). The concentration and focus it takes for this type of active listening goes beyond what we usually do in our everyday life and requires the researcher to diminish their normal instinct to talk; but be ready to speak whenever a navigational nudge is warranted (Seidman, 2013).

A specific question was asked, but the question was altered based on emerging themes that needed saturation. Questions were changed to explore emerging themes, for example, when asking the question: “What is living with obesity and having cancer like for you personally,” the question would change and be re-stated if the study participant answered the question with a general statement such as “It is really hard.” Using a probe such as “Can you be more specific?” “What do you mean by hard?” “Tell me more about that.” These changes and probes further elicited dialogue to gain richer descriptions of the experience. The researcher added questions if a theme emerged that the researcher wanted to capture further data on.

In summary, psychological phenomenology identifies, explicates and illuminates experiences that could be overlooked within clinical practice. This scholarly approach was applied to explore the experiences of overweight and obese cancer survivors interactions with oncology providers. The interviews and demographic questionnaire were the primary research tools used by the researcher in which the emerging phenomena were identified through accurate interpretation (Vandermause, 2008).

**Evaluation Criteria**
The evaluation criterion and analysis for this research study is the main topics of this section. Additional topics include: Establishing trustworthiness of findings, strengths, limitations, final product for qualitative findings, and human subjects review.

Analysis

Data collection and analysis proceeded until saturation of data occurred (Coyne, 1997; Mason, 2010; Saldana, 2013). Saturation is defined as a tool used for ensuring that adequate and quality data are collected to support the study and the point in data collection when no new or relevant information emerges with respect to the newly constructed theory (Given, 2008; Walker, 2012). Hence, the investigator looks at this as the point at which no more data needed to be collected. When there appears to be no gaps or unexplained phenomena saturation has been achieved (Given, 2008). However, it is recognized that some themes will emerge late in analysis and these have been accounted for in the findings as requiring further research. Saturation is frequently reported in qualitative research and is considered to be the gold standard (Walker, 2012). Within qualitative research, there is a point of diminishing return to data; additional data serves only to confirm an emerging understanding (Mason, 2010). Some of the factors determining saturation include; the sample size, aims of the study, the scope and nature of the study topic, and the quality of the data (Mason, 2010).

Connections among the stories told by participants led to the derivation of common themes, such as structural and social forces, that formed patterns related to their experience (Seidman, 2013). This sampling process is ongoing and cannot be strictly predetermined as it is determined by the themes that emerge (Coyne, 1997). A theme is an outcome of coding, categorization, or analytic reflection that describes a pattern, trend, or concept (Saldana, 2013). Themes were brought to the analysis team’s attention for inspection and exploration. Interpreting
the data is not a process researchers’ do only at the end of the study, thus, analysis occurred simultaneously while sampling and interviewing the participants as tentative interpretations may begin to influence the line of questioning (Seidman, 2013). Pseudonyms were chosen to protect the participant’s identity.

The logistics of the analysis included interviews that were transcribed verbatim into written transcripts and de-identified using pseudonyms. The investigator verified corrections to each transcript by listening to the audio tapes to ensure 100% accuracy of transcription. The Microsoft ® software program Word was utilized to organize and manage the researcher’s data. The encryption and electronic sharing of files included the use of the secure SharePoint site through WSU that was firewall password protected. The files stored in SharePoint include; the transcripts, audio files and exchange files. Only the analysis team had access to these files. The analysis team consists of the researchers PhD Dissertation Committee.

Content analysis was the primary method of organizing data into themes. With psychological phenomenology analysis starts with four basic steps. Step one is to obtain a concrete description of a phenomenon as lived through by a person and before analyzing the description (Giorgi & Giorgi, 2008). This is accomplished by either a direct description or by interview; for this study it will be by interview. The researcher must assume the phenomenological attitude, a psychological perspective towards the data where one is mindfully sensitive to the type of phenomenon being researched (Giorgi & Giorgi, 2008). Then within that complex attitude, the researcher reads the entire description to establish a sense of familiarity with it. The second step begins once a sense of the whole has been established, the researcher goes back to the beginning of the description and begins to read it again and more slowly with a goal of establishing meaning units; parts of the description that seems to convey a delineation by
partial meaning of the whole also referred to as themes (Giorgi, 2009; Giorgi & Giorgi, 2008).

At this time, the researcher will not conduct any further analysis.

Step three begins when the second step is completed. The researcher returns to the beginning of the description again and starts transforming each theme into expressions that more directly convey the psychological sense of what the research participant said. Some examples of this might include; pain, prejudice, discrimination, being invisible, barriers, humiliation, and fear. Up to this point the data have remained as the participant expressed them, but to have psychological significance the psychological sense contained within the data have to be rendered explicit (Giorgi, 2009; Giorgi & Giorgi, 2008). The fourth step is based on the transformed themes that have been derived; a general structure of the experience of the phenomenon is now articulated (Giorgi, 2009; Giorgi & Giorgi, 2008; Giorgi & Giorgi, 2003).

Coding. Coding began by unitizing the narrative data in the written transcripts. A meaning unit of analysis is defined as a complete idea and may consist of a sentence, noun and verb phrase, single word expression or entire paragraph (Lewis, Haberman, & Wallhagen, 1986). The researcher coded the first five interviews and began forming a code book. The codebook consisted of all themes and subthemes, a definition of each theme based on the narrative data, and all exemplars for the theme. The derivation of themes followed a multi-phased process based on the manifest and not inferred meaning (Lewis et al., 1986). Themes represent broad conceptual domains and subthemes are considered dimensions or factors of the themes (Lewis et al., 1986). Whenever possible, emic or verbatim phrases or metaphors expressed by the participants were selected to prevent premature closure of the analysis (Lewis et al., 1986).

The researcher coded the first five interviews using constant comparative analysis to insure the induction of themes is mutually exclusive and exhaustive. To check the accuracy of
the first codebook, a member of the analytic team examined the narrative data and fit among the
data, themes, emerging definition of themes, and exemplars. The researcher and team member
shared reviews of the products of analysis and made changes to the code book until consensus
was reached. The researcher then coded the next five interviews to fit the data to the codebook
and to refine the themes, definitions and exemplars. The process employed by the first member
of the analytic team was followed by a second member of the analytic team on the second data
set. Once consensus was reached, the researcher refined the codebook as needed, and derives a
more parsimonious set of themes to encompass all of the codebook into an explanatory scheme
(Lewis et al., 1986). The researcher employed the third member of the analytic team, who
represents the posture of critical appraisal, for one final review the final codebook, and reached
an 85% acceptable consensus on all components.

**Establishing Trustworthiness of Findings fixed**

Techniques were used as a method to assure the primary criteria was met and
trustworthiness was established. Establishing validity criteria in qualitative research is complex
due to the subjective nature of the research in which subjectivity and contextual life experiences
are studied rather than the generalizable objective concerns in quantitative research (Holliday,
2012). Quantitative validity and reliability are concepts which do not translate well to a
qualitative paradigm due to the diversity of opinions presented within the phenomenological
study (Berman, 2003). In a qualitative study the truthfulness of the findings is what constitutes
validity and reliability looks at the stability of the findings; both noteworthy (Altheide &
Johnson, 1994). Sandelowski (1993) reminds us that validity rests on reliability and to not
ignore the indiscriminate transfer to interpretive research which assumes that valid work must be
reliable and qualitative research is as much an art as science. The proposed framework for
validation is described as the expressions of evaluative rigor specific to qualitative phenomenology and chosen for this study, is outlined by de Witt & Ploeg (2005). They developed an evaluative rigor of five primary criteria including: balanced integration, openness, concreteness, resonance, and actualization (de Witt & Ploeg, 2005).

**Balanced integration.** Balanced integration is the congruency between the philosophy, the researcher, and the phenomenon of study (de Witt & Ploeg, 2005). The researchers’ ontological perspective and postpositive world view balances well with the use of the descriptive paradigm used in guiding this research.

**Openness.** The expression of openness, also referred to as accountability, was achieved by the systematic and explicit process of accounting for the descriptive phenomenological study process as defined by Giorgi’s and Giorgi’s (2008) phenomenological method; requiring an in-depth interview to be collected from individuals who have experienced the phenomenon.

**Concreteness.** Concreteness, as described by de Witt and Ploeg (2005) is the expression of rigor when the study is written in such a way that examples situate the reader concretely in the context of this phenomenon and link with their experiences in their life-world. The researcher avoided asking the participant to rely on their memories, instead, asked the study participants’ to reconstruct the event or tell a story about their lived experience (Seidman, 2009).

**Resonance.** The expression of resonance was justified by the experiential effect the study findings had upon the reader in very generalizable manner (de Witt & Ploeg, 2005). The researcher used language to convey the meaning of expressions of rigor that mirrors the researchers’ openness to the experience under inquiry with excellent integration of Giorgi’s philosophical method, and data analysis (Morse, 2003). For this study, to iteratively validate proposed findings and themes, the researcher utilized triangulation within the analytical team.
With that, the original transcripts were reviewed several times to verify validity of the surmised themes from the analytical team (Neergaard, Oleson, Andersen, & Sondergaard, 2009).

**Actualization.** Justifying the expression of actualization, is the suggestions for additional research to further realization of the resonance of the study findings in this area of phenomenology (de Witt & Ploeg, 2005). Included in this study is a narrative description regarding the need for future studies of this phenomenon.

The phenomenon of overweight and obese cancer survivors is an emerging topic within the nursing literature. The theoretical gap in the literature related to the concept of weight bias and overweight and obese cancer survivors requires additional attention related to changing the current practice standards. The hope for the future and the science of nursing is that this research contributes to a better understanding of the experiences of overweight or obese cancer survivors’ desires for better outcomes, increased quality of life, and ultimately higher survival rates.

**Strengths**

Findings evidenced by this qualitative descriptive phenomenologic study provided stories that may resonate with oncology nurses and physicians to change their current clinical practices for the overweight and obese cancer survivors. The greatest strength of this study is the realistic experiences of these men and women. The aim of the purposive sampling strengthens this study by examining participants who have similar experiences of the phenomenon being study. Confirmability was achieved through adequacy of information reported by the research questions, protocol for data collection, and various stages in the analysis of data leading to the interpretation of findings (Sharts-Hopko, 2002). Additionally, personal experiences with working as an oncology nurse who with overweight and obese cancer patients bring insight direct from the patient bedside.
**Limitations**

Limitations of any qualitative study include the researcher’s personal biases and idiosyncrasies that may affect the study outcome as well as the researcher’s presence during the data gathering having a possible effect on the participant’s responses. Other potential limitations would be participants who choose not to complete the full interview or answers that are untruthful. This study did not incur any of the aforementioned limitations but was limited due to 2 participants who passed away before completing their interview.

**Final Product for Qualitative Findings**

Findings, first in the forms of patterns and themes will emerge, resulting in a final product of a descriptive statement (Berman, 2003). Development of thematic summaries will be discovered, changed and confirmed by consensus of the analytic team; this action enhances the study outcomes validity (Morse, Mayan, Olson, Spiers, & Hon, 2002). The study’s final descriptive statement will be a representation derived from the rich text of the participants’ own words. To allow the reader to evaluate the rigor of the research study, the findings will also include a description of the data collection and analytical process.

**Human Participant Review**

The Washington State University (WSU) Institutional Review Board for human subjects’ approval was obtained before any enrollment of participants. There were no external IRB reviews needed for this study.

The WSU IRB application information includes; (a) general information about the researcher and study, (b) study description, (c) data collection method, (d) confidentiality and protection of data, (e) human subject population, (f) human subject recruitment, (g) informed consent process, (h) potential risks and benefits assessment, (i) potential reportable activity, (j)
research involving deception, (k) research involving Health Insurance Portability and Accountability Act (HIPAA), (l) research involving investigational drugs, devices, alcohol, blood, tissue, (m) bodily fluids or other biological specimens, (n) and the investigator’s responsibilities and assurances. Informed consent to participate included; verbal consent obtained by telephone to convey the potential participant’s willingness to take part in the study followed by the phone interview (see Appendix, F, verbal consent and interview script).

Potential risks and benefits were anticipated. Potential risks to the study participants included: (a) risk for anxiety, stress, and/or depression by conjuring up emotionally charged and/or current memories of experiences with oncology providers’ related to weight bias, (b) risk for fatigue depending on where the participant is in the cancer survivor continuum, and (c) risk of contact with oncologist and/or oncology nurses from the lived experiences related to provider weight bias.

The interviews took place in a private comfortable and safe environment to eliminate the risk of contact with the participants’ oncology providers. Risks were minimized as the researcher remains sensitive to the participants’ emotional and physical well-being and energy level during the interview process, by being alert to any cues he or she may be offering, and will be conscious of time during the interview. The researcher will periodically ask the participant how they are doing and offer time for breaks if needed. The study participants’ will receive a reference list for cancer survivorship support groups within geographic area of Arizona and Washington (see Appendix E, cancer survivor support groups). A small honorarium in the form of a $20 gift card was provided to the study participants’ following the conclusion of the interview. Potential risks and benefits were explained up front upon the initial phone and email communication with the participants (sees Appendix C, phone scripting).
CHAPTER FOUR

Chapter four describes the research study formative findings and provides an overview of the sample demographic data including: Age, Gender, Body Mass Index (BMI), Ethnicity, Cancer Type and Stage, Overall Health Status, Emotional Health Status, and Quality of Life Status. An overview is now provided of the demographic data, collective comorbidities and formative findings that include major themes, sub-themes, definitions, and exemplars of phenomena. The chapter closes with a discussion of how the analytic products were reduced to a parsimonious framework that accounts for all of the major themes and subthemes.

Sample Demographic Description

All demographic and disease-related data were obtained by self-report. The study sample consisted of 10 overweight or obese cancer survivors (See Tables 1-4). The median age of the participants was 55.9 years with a range of 39-79 years. Participants were from Arizona and the state of Washington living communities. The sample population consisted of primarily women (N=8) and persons of Caucasian descent (N=9), with one participant of African American/Caucasian descent (N=1). Types of cancer diagnosis included: endometrial, thyroid, lung, breast, melanoma, colon, Hodgkin’s lymphoma, multiple myeloma and breast cancer.

The study participants’ cancer staging varied from the unknown stage to stage IV, with more participants being diagnosed with Stage II cancers (N=6). The cancer staging I-IV is a process utilized by oncologists upon diagnosis that provides information about tumor size and degree of cancer cell invasiveness; in addition it assists in the treatment planning (Mayo Clinic, 2015). Staging is completed using an ordinal scale using Roman numerals I – IV with I being the smallest size tumor and least invasive and IV being the largest size tumor and most invasive.
Invasiveness of the cancer can include whether the cancer cells have spread to lymph nodes and/or spread to other parts of your body (Mayo Clinic, 2015). Study participants’ reported several comorbidities: hypertension (N=3), hypothyroidism (N=2), sleep-apnea (N=1), pre-diabetes (N=2), diabetes (N=1), hypertriglyceridemia (N=2), idiopathic peripheral polyneuropathy (N=3), migraines (N=2), lymphedema (N=1) and some had a secondary cancer diagnosis (N=3). Body Mass Index (BMI) ranged from 28-42 and a median of 35.1. Based on their BMI’s, 90% of the participants (N=9) were considered obese or morbidly obese.

A BMI score of 30 or greater represents being obese. Using an ordinal scale of 1-10 with 1 being the least satisfied and 10 the most satisfied, the study participants’ median overall health status, emotional health status, and quality of life status was 6.8, 6.7 and 7.9 respectively.

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>AGE</th>
<th>GENDER</th>
<th>BMI</th>
<th>ETHNICITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>57</td>
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<td>39</td>
<td>Caucasian</td>
</tr>
<tr>
<td>65</td>
<td>M</td>
<td>37</td>
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</tr>
<tr>
<td>51</td>
<td>F</td>
<td>39</td>
<td>Caucasian</td>
</tr>
<tr>
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<td>F</td>
<td>29</td>
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<td>79</td>
<td>M</td>
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<td>40</td>
<td>Caucasian</td>
</tr>
<tr>
<td>39</td>
<td>F</td>
<td>39</td>
<td>African American/ Caucasian</td>
</tr>
<tr>
<td>70</td>
<td>F</td>
<td>30</td>
<td>Caucasian</td>
</tr>
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</table>

*Body Mass Index (BMI) scale based on >25-29 = overweight and >30 = obese*
Table 2: Age Demographics

<table>
<thead>
<tr>
<th></th>
<th>Age 39-49</th>
<th>Age 50-60</th>
<th>Age 61-70</th>
<th>Age 71+</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>3</td>
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<td>1</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Males</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 3: Cancer Type; Stage; Overall Health, Emotional and Quality of Life Status.

<table>
<thead>
<tr>
<th>CANCER TYPE BY PARTICIPANT (N=10)</th>
<th>CANCER STAGE</th>
<th>OVERALL HEALTH STATUS</th>
<th>EMOTIONAL HEALTH STATUS</th>
<th>QUALITY OF LIFE STATUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endometrial</td>
<td>1</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Thyroid</td>
<td>unknown</td>
<td>3</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Lung</td>
<td>1</td>
<td>9</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
<td>7</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Colon</td>
<td>2</td>
<td>9</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Hodgkin’s Lymphoma</td>
<td>2</td>
<td>8</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>4</td>
<td>6</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
<td>7</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

*Based on an ordinal scale from 1-10 with 1 being the least satisfied and 10 the most satisfied*
Table 4: Median Scores for Demographics; Age, BMI, OHS, ES, QOL

<table>
<thead>
<tr>
<th></th>
<th>Median Age</th>
<th>Median BMI</th>
<th>Median Overall Health Status (OHS)</th>
<th>Median Emotional Health Status (ES)</th>
<th>Median Quality of Life Status (QOL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=10</td>
<td>55.9</td>
<td>35.1</td>
<td>6.8</td>
<td>6.7</td>
<td>7.9</td>
</tr>
</tbody>
</table>

*Based on an ordinal scale from 1-10 with 1 being the least satisfied and 10 the most satisfied

*Body Mass Index (BMI) scale based on >25-29 = overweight and >30 = obese

**Formative Findings: Organization of Interpretive Phenomenologic Narrative Data**

The interpretive phenomenologic findings were organized by major themes and sub-themes that emerged from the rich texts of participants’ own words. All digitally recorded interviews (Q1-Q14) were transcribed and the transcriptions were used for the interpretive analytical process. Each interview question was coded and the analytic findings reported separately. The inductive, analytical derivation of major themes, subthemes, definitions and exemplars were organized into a codebook during interpretive and reflexive content analysis. The coding of data began after the first interview and continued with the transcription of each new interview. Codes, or themes, were derived initially and recoding occurred as new data provided additional substantive content to better understand the themes (See Chapter 3 for an in-depth description of the coding process). The major themes, sub-themes, definitions of major themes, and exemplars are provided below for each of the 14 interview questions. Identified were 14 major themes and 83 sub-themes (see Appendix F - Table 5). The major themes identified include:

1. Perceptions of Health
2. Satisfaction with Overall Cancer Care
Categories of Major Themes and Sub-Themes Codes for Q1- Q14 for all Participants

**Question 1: Please describe your overall health at this time?**

**Major Theme - Perceptions of Health**

Perceptions of health ranged from not being healthy to healthy; however, one’s perceptions of health were bounded by multiple factors: time, functional status, a comparison reference group of similarly aged people, medication regimen, being cancer free while managing debilitating treatment side effects, happy to lose weight during treatments, and obesity affecting health. There were 4 subthemes identified.

**Sub-theme: Not Healthy**
Not healthy signified three components: being overweight to the point of obesity, having another surgery related to the cancer diagnosis, and the diagnosis of comorbidities due to weight issues including pre-diabetes, diabetes and high blood pressure.

“I am obese. That’s my biggest health issue. And if I wasn’t, probably some of my other, um, medical problems would be better.” [P001-q1]

“I am overweight to the point of being obese. I have sleep apnea and I had thyroid cancer.” [P002-q1]

“Um, well, I just had another surgery, so my overall health is not the best right at this time.” [P007-q1]

“Um, I – I would think I’m in generally good health, um, although I do have – was just diagnosed as pre-diabetic, and I do have high blood pressure.” [P008-q1]

“And I do have lymphedema.” [P008-q1]

Sub-theme: Healthy

Healthy was defined in terms of being very good and was conditionalized in four ways (a) to a current timeframe, (b) having good overall functional status, (c) situating health in the context of a known reference group of others of similar age, and (d) mentioning the number of medications one takes.

“My health is very good at this time.” [P003-q1]

“Right now, I’m (age reference) years old and – and I think my health is pretty good. I have to take three pills every day, but otherwise my health is – I think it’s outstanding for my age.” [P006-q1]

“Ah, overall pretty good. I still deal with some of the, ah, side effects from chemotherapy and radiation like, um, hypothyroidism and adrenal problems. Um, but overall, I’m
back to work. Um, you know, exercise regularly. So I’m pretty functional overall.” [P010-q1]

Sub-theme: Cancer Free and Feeling Fantastic

Cancer free and feeling fantastic was defined by study participants as managing side effects of treatment, and getting one’s energy and life back to normal. Participants experienced a sense of happiness for the weight loss during chemotherapy treatments even though the treatment side effects included debilitating nausea and neuropathy.

“Okay, so, um, at this time, I’m cancer-free and, um, I’m going through radiation. And I went through eight rounds of chemotherapy. The last treatment was on the first of October. I’m getting my energy back. Um, everything’s kind of back to normal. I don’t have nausea. I’m just kind of dealing with a little bit of neuropathy in my feet. Um, my fingernails are kind of weird. But overall, compared to how I felt in treatment, I feel a lot better. I actually lost weight. I wasn’t supposed to lose more than four – five pounds, but I lost about fifteen pounds during treatment. So I’m actually – I mean, comparatively – comparing myself to how I felt a month-and-a-half ago, I feel fantastic. But I know I still have to build up my strength and, you know, my overall wellbeing.” [P009-q1]

Sub-theme: The Biggest Perceived Health Issue

The biggest perceived health issues were being obese and how obesity affects health and other medical and health issues that limit physical activities due to aches and pains.

“I think my health is pretty good. I am obese. That’s my biggest health issue. And if I wasn’t, probably some of my other, um, medical problems would be better. But, um, I feel healthy. I feel strong. Um, I have some aches and pains that limit me in doing some physical activities, but otherwise I feel good.” [P001-q1]
“I am overweight to the point of being obese. I have sleep apnea.” [P002-q1]

Question 2: Describe your satisfaction with your cancer care?

Major Theme – Satisfaction with Overall Cancer Care

Satisfaction with overall cancer care was defined by the participants as having a satisfying experience, or adequate experience, or being unsatisfied with their overall cancer care. Being satisfied was defined as having amazing nurses and doctors, slipping through the cracks only a couple of times, and being a good fit. There were 3 subthemes identified.

Sub-theme: Being Satisfied

“I have – I’ve had very good results with my cancer care. I think I’ve had really good care” [P003-q2]

“So I was very satisfied with my cancer care. It was several years ago, though. You know, as cancer goes, you have to have checkups the rest of your life. So I’m at the annual stage of checkups and, um – but when I was back to where I was going through all of the stuff associated with it like in the acute level, I was very happy with my care at the time.” [P004-q2]

“At this time, I would say – I’m in the middle of a reconstruction process. Um, my cancer – I’m cancer-free. And my cancer started June of 2014. Um, I feel like I’m doing pretty good, to be honest.’ [P005-q2]

“I thought it was – I had a very good doctor then and I thought it was outstanding. I know to start with, they said it – they probably thought I won’t make it, but it turned out to be good.” [P006-q2]
“Um, wonderful. I ended up with a well-known doctor. I’ve only slipped through the cracks a couple of times. Um, I was taken very good care of at (hospital reference). Um, I – I have – every time I’ve come to an obstacle, I’ve had someone help me.” [P007-q2]

“It’s been excellent. I have absolutely no complaints. Dr. (name reference) is, um, absolutely wonderful.” [P008-q2]

“So initially, um, I love my – I love my surgeon. I’ve had her for a while. Um, dating back to 2009 was the first biopsy. And when I met my oncologist, I felt, um – I didn’t know if we were going to be a good match ‘cause I’m used to a little bit more overt caring. But after I had a friend and my husband sit in on our first appointment after I was diagnosed, they gave her the thumbs-up.” [P009-q2]

“So – but overall, the nurses were amazing. I – I had a really good experience. But with my actual oncologist, it’s always been a little bit not a hundred percent for me.” [P009-q2]

“Ah, they were great. Um, the clinic I went to, um, they just did a great job, um, setting up appointments – you know, getting me in when I needed it. Um, so. I’d recommend ’em to anyone.” [P010-q2]

“So – but overall, the nurses were amazing. I – I had a really good experience.” [P009-q2]

Sub-theme: Not Satisfied

The experience of not being satisfied with cancer care was multidimensional including having to listen to the oncology doctor speak about a family member’s own weight issue as a problem, post chemotherapy and radiation treatment weight gain, lack of communication,
explanations and recommendations from oncology doctors and nurses related to bloodwork and lab results, and chemotherapy and radiation side effects and how to handle them.

“Um, it was thirteen years ago and they, um – they told me that the cyst they removed from my neck – or the lump – was clear, but then a week later called and said, “Oh, by the way, your thyroid has cancer. Not the lump.” So that was kind of weird. Um, and then it took weeks and weeks and weeks, if not a couple year, to get the thyroid levels back to what is considered a normal level. And in the meantime, I ended up gaining a lot of weight. At that point, when I had the cancer and the surgery, I was probably maybe 30 pounds overweight. And in the first year, I gained about 40 pounds. There was surgery and then nuclear therapy, and that was it.” [P002-q1]

“Um, there’s been ups and downs. Actually, I’m having concerns more about oncology. Like there’s different – where I’m going, like they do not do like CA-125. I just had hysterectomy and I was told that that does – what that does for your, um, estrogen level. So it’s like I – I’m getting conflicting information about what blood work should be done. So that’s kind of a concern.” [P005-q2]

“– wasn’t real happy about, ah, nobody ever discussed with me the – the, um, side effect, which is lymphedema. And I do have lymphedema. And – ah, but that wasn’t initially discussed with me as, you know, a possibility, um, you know, when I first had the surgery. It came out later.” [P008-q2]

“Um, the only weight thing that came up initially was we were talking about our daughters and she was talking about how her daughter is overweight, and I think initially there was a little conversation about my weight and estrogen and how it could’ve
contributed to the cancer. But with my actual oncologist, it’s always been a little bit not a hundred percent for me.” [P009-q2]

Sub-themes: Adequate Care

Adequate care is defined as less than professional communication between the oncology doctor and cancer survivor.

“Well, number one, my cancer was cured, so that’s very satisfying. And, um, I felt like the care I received was, ah, professional and adequate.” [P001-q1]

“Well, overall, the – the care was, um, adequate. I think it could’ve been handled differently in different aspects of when they told me that I had cancer and how they told me I had cancer. I had good care. I didn’t have any complaints at that point.” [P002-q2]

Question 3: Please describe what it was like to be diagnosed with cancer?

Major Theme – Reactions to Cancer Diagnosis

Reactions to the cancer diagnosis was a major theme characterized by many subthemes including frightening, strong feelings that death was eminent and not wanting to die, being surprised, not being surprised due to family history and genetics, feeling blessed, surreal, self-blaming for getting diagnosed with cancer, and acting defiant in a way of taking back control of their lives from the cancer diagnosis. There were 10 subthemes identified.

Sub-theme: Frightening

Frightening was defined by participants as going through treatments and the uncertainty as to the cancer coming back. Fear is a constant unnerving feeling that does not go away; a nightmare. It is feeling scary like one just drove off a bridge. Additionally cancer diagnosis was defined in terms of types of cancers and disease staging upon
diagnosis; from being either a “good cancer” to be diagnosed with or a “bad cancer,” or diagnosed with Stage I versus Stage IV disease. The use of good cancer for this participant was endometrial cancer that was diagnosed at Stage I.

“Well, um, of course, it’s scary. Um, even though I’m a (occupational reference), when it’s yourself having that issue and knowing that what I was diagnosed with tends to be a relatively easily treated and, um, “good” cancer to get, it’s still unnerving. And, um, having to go through the treatment and having the unknown – the period of time where you don’t know if it’s going to come back or not, that – that sense of uncertainty is stressful.” [P001-q3]

“Oh, it’s frightening.” [P002-q3]

“It’s like – it’s like, ah, going along driving on a nice sunny day, and all of a sudden you drive off a bridge.” [P003-q3]

“Well, I had a one-year-old and a two-year-old, and it was horrific.” [P004-q3]

“Um, you know, kind of frightening……There’s not a lot I can do about it except deal with it.” [P008-q3]

“So I heard from my doctor, and she said, “Okay, I’ve got the results. You have carcinoma.” And I’m like, “What?” You know, I said, “Oh, is it more DCIS?” And she said, “No, it’s cancer.” And I just – I – it was horrible. It was absolutely terrifying ‘cause we didn’t have enough information. And the kind of person I am, I want all the answers, and we didn’t have enough to go on for staging. All she could say is that it was high-grade. And I was on – ready to go visit my son in (geographical reference) in college, and it was just kind of a nightmare. It was really scary.” [P009-q3]

**Sub-theme: I Don’t Want to Die**
I don’t want to die was defined by study participants as thinking that one’s days were numbered and contemplating how many days remained. Participants found themselves wondering “what if” they would see their children grow up.

“Well, the first thing you think of is, okay, how many days will I have before I’m long gone.” [P006-q3]

“You start thinking about, you know, will I be around to see my child grow up? Will I, um, be at the next family dinner? You what if a lot.” [P002-q3]

“Well, the first thing that came – because she couldn’t – because of the type of, um, physician she is – she’s very factual, doesn’t speak out of -- you know, “Oh, it’s going to be fine” – -- she has to have the facts in front of her, um, she said, “I don’t have all the answers.” And the first thing that came out of my mouth was, “I don’t want to die.” She goes, “You know, it’s okay. We have an eighty percent success rate.” So she was trying to reel me back.”[P010-q3]

Sub-theme: Not Surprised

Not surprised was defined as always being afraid that one would eventually be diagnosed. Consequently, getting cancer was just a question of when and what type due to family history and positive genetic testing results.

“Um, I wasn’t surprised at all, to be honest. I was always afraid that I was going to get it. I found it myself, and the minute I felt it, it just felt like hard – like a rock. And I called my husband and said, “I have cancer.” And he said, “Oh, no, no.” And I said, “Oh, yeah. I do.” (Laughter.) So I wasn’t too surprised, but it was kind of a shock.”

[P005-q3]

Sub-theme: Surprised
Surprised was defined by study participants as going in for surgery and coming out with confidence that everything was fine, only to hear later the diagnosis of cancer was confirmed by post-operative lab results.

“And, um – and, you know, I came home from the hysterectomy and everything was fine. And four days later, I was actually – I felt the best I had ever felt since I’d started my period when I was eleven years old. And I was actually camping the motorhome to go camping for the weekend. That’s how good I felt. And he called and he said, “I need you to sit down. I have something to tell you.” And it turned out that the mole was melanoma, according to the lab, and he had – he had not excised clean margins because he – he didn’t think it was melanoma, or he wouldn’t have taken it off, he said. And I didn’t think it was melanoma. I’d had it checked twice. And so he was just being extra cautious, saying, “I hate it when doctors leave stuff on that you might as well just take off.” And I’m like, “I want you to take it off.” And it turned out to be melanoma. It was a Friday. It was horrible because I knew that it had been cut into and clean margins hadn’t been excised. The lab report said not. And I had to wait all weekend before I could talk to anybody to even think about getting in because the rest of them had taken off. It was terrible.” [P004-q3]

**Sub-theme: Blessed**

A sense of feeling blessed was defined as going into neck surgery with the potential risk of ending up paralyzed for life and instead finding out everything was “all fixed” but the diagnosis was cancer, equating the cancer diagnosis to a blessing and thankfulness to God to be alive.
“Well, I was very blessed. I went in with an injury to my neck. Um, x-rays showed that there was a bone missing in my neck, and I went into surgery thinking that my outcome would be—I’d be paralyzed or in a brace for the rest of my life. And when I came out of surgery (laughter), I said—they said, “You’re all fixed, but you have cancer.” (Laughter.) And so I said, “Oh, cancer’s not so bad.” And so that’s how I found out. I—I didn’t know I had cancer. Everybody else knew, but I didn’t. Nothing. I had no idea. Um, I was training for (running event reference), a run — in (geographical reference), and I was lifting weights. And the weights would rest on the back of my neck, so I thought it was just a sports injury.” [P007-q3.

“So when they told me I had cancer, I said thank God I was alive. So I was happy. I was fine.” [P007-q3]

**Sub-theme: Surreal**

Surreal is defined as being strangely busy; moving rapidly from the diagnosis of cancer to having multiple tests performed and then realizing the pace of care slowed with the initiation of chemotherapy.

“Ah, kind of surreal. I had had a cough and I just hadn’t been feeling well. And, you know, I’d gone in to walk-in clinics and they just kinda, you know, blew it off. Um, and then finally I got in to see my regular doctor, and, you know, within a week I had a biopsy done and had a diagnosis of cancer. So it was kind of surreal. Um, gosh. It was just, um, let’s see. You know, at first it was a lot of tests, so it was just kind of—it was keeping busy, but then things kind of slowed down before I started chemo, and I—I had to go to a chemotherapy class to kind of learn about it. And it just—it kind of struck me like what—
you know, nobody else my age is dying (laughter), so what the heck is going on? So it was just strange.”[P010-q3]

**Sub-theme: Self-Blame**

Self-blame is defined as regret due to not being compliant with follow up appointments for cancer monitoring.

“And my brain just kind of – you know, it just went away. ‘Cause I waited two years – I skipped my mammogram for two years thinking that I had a false sense of security that the Oncotype testing said it would never – it wouldn’t go invasive. It wasn’t the type. So a lot of self-blame. Just – it was like a worst nightmare. I wanted – I had had so much intensive care from 2009 through 2012 that I was burned out. I had had, you know, two surgeries. I had the reduction. I had been flying down every six months for mammograms and MRIs. And I was like, okay, with the Oncotype testing, it’s good. I’m gonna skip it. And, you know, looking back, I should’ve never skipped it.

**Sub-theme: Defiant**

Defiant is defined as being overconfident that everything was good after surgery and that after several years of annual follow-up exams that were normal, further exams would be a waste of time and/or nonessential because recurrence wasn’t going to happen.

“But I was – I was really defiant and I was overconfident that everything was good. It was – well, yeah. I was a 42DD, so it was nice anyway, but it was considered a partial mastectomy to get all of the DCIS out of my left breast. Um-hum. So – and I had, you know, triplets and a son, so I had four kids. “[P009-q3]

“Ah, it was endometrial cancer, ah, Stage 1A. And I believe there was a number 0 after that because there was no cancer found in the surgical pathologic, ah, specimen after the
definitive surgery was done. Only in the biopsy sample. Ah, well, hmm. There was a period of time when I was to have regular follow-up visits. There was no other kind of treatment after the surgery. Um, I – in terms of whether or not I was successful, ah, I will say that I, um, pretty much adhered to the recommended follow-ups for four-and-a-half years. And then, um, I decided not to continue following up after that, even though, ah, annual follow-up for the rest of my life is what was recommended. Well, because it would involve a pelvic exam every time, which I felt was somewhat of a – and – and a visit – an appointment. So it takes time out of my day. Time out of my life. I know it’s only, you know, part of a day out of an entire year, but, um, I felt like there really wasn’t much reason to do it. There was no cancer found at the time of the hysterectomy, and, um, the first, um, GYN oncologist I had said if it was going to recur, it would typically recur within the first two years, and it didn’t. So even though the last gynecologist that I saw in follow-up, ah, said that I should have annual follow-ups forever, which I – I did after, I thought, oh, good, at five years she’ll say I don’t need to do this anymore. But she didn’t. So I just decided, you know, there wasn’t any point in going back and having a pelvic exam every year to look for recurrence when that wasn’t going to happen. So that’s why.” [P001-3]

Sub-theme: Not Feeling Vulnerable to Cancer

Not feeling vulnerable to breast cancer was having a false sense of security, not believing one would get breast cancer even though one was overweight or obese.

“So because I had had so much treatment with my DCIS and I was so diligent, I actually was being treated down in (geographical reference) because I didn’t want to go through a mastectomy at the time and I wanted to watch and wait. You know, just kind of doing
the breast reduction and getting the Oncotype testing, I really had a – a sense of – a false sense of security that I wasn’t going to get breast cancer. I had nursed my children for two plus years. I was nursed. I have this, you know – and even though I’m overweight, I’m really tall and muscular. So I wasn’t really – I didn’t – and it wasn’t in our family. So the DCIS was kind of a bump in the road for me, but it wasn’t like cancer. So when I had the biopsy in January and – what – I’m sorry, it was in April. I had the mammogram in January and then we got the records. And then in April, I had the biopsy. And so when I received the phone call, I was waiting to hear from the actual – the radiologist.”[P009-q4]

**Question 4: When you hear the term “weight bias,” what thoughts come to mind?**

**Major Theme: Self-Reflections on the Meaning of “Weight Bias”**

The meanings survivors gave to the concept of weight bias were complex and individualized. Meanings included weight bias discrimination; assumptions, pre-judging, and stereotyping by others; being prepared, feeling vulnerable, and feeling like there is nothing one can do but except it and deal with it. People with weight issues are biased against others of larger size; they lack personal control, and found their physicians treated obesity symptoms but not underlying cause. Some participants never heard of the term “provider weight bias.” There were 10 subthemes identified.

**Sub-theme: Assumptions/Pre-Judging and Discrimination**

Assumptions and pre-judging was defined as conveying negatively discriminant behaviors towards somebody of a larger size including not treating them the same as those who are not overweight or obese and not having the same interactions with them versus those
individuals of normal weight. Discrimination was defined as exhibiting prejudicial behaviors and making assumptions based on the size of a person.

“Ah, people being – you know, making assumptions or, um, exhibiting some sort of prejudicial behavior toward someone simply because of their large size.” [P001-q4]

“Um, discrimination mainly.” [P002-q4]

“Ah, people that are overweight – grossly overweight are treated different than people who are not grossly overweight.” [P003-q4]

“Well, when I hear weight bias, I – I really think of somebody discriminating against somebody else because of their weight. So they’re not treating them the same, or they’re altering the way in which they interact with someone based on their weight.” [P004-q4]

“Um, things like, ah, being, ah – someone else being promoted in jobs, um, being sat at a table that is not as desirable as another one in a restaurant. Um, things like that.” [P007-q4]

“Um, kind of negative. I mean, people do like to say – like I’ve heard quite a bit like, “It’s pretty smart estrogen. You’re overweight. You need to lose weight. And, you know, that will cut down your risk of cancer.” I’m not – I don’t know. I’m not a hundred percent convinced of that. My grandmother wasn’t overweight, and she got it. My cousin wasn’t really overweight, and she got it. So I think it’s just in your – I truly believe it’s in your genes.” [P005-q4]

Sub-theme: Being Flawed and Stereotyping

Being flawed was defined by the study participants as a term that described how they felt about weight bias discrimination and stereotyping. Stereotyping was defined as discrimination
against those who do not conform to that “perfect size.” Stereotyped attitudes included being stupid, lazy, and that losing weight was in their control.

“Um, I think about the old stereotypes. You know, if you’re not a perfect stereotypical size, whatever it is in fashion, you know – you know, under 25 BMI, then, you know, there’s a little bit of discrimination that you’re not healthy, that you’re not as intelligent, that basically you’re flawed.” [P009-q4]

“I, you know, hear from a lot of women that, you know, instead of trying to treat the underlying cause, a lot of physicians just tell them they need to lose weight and they’ll feel better. I mean, I kind of think about things like that. Yeah, I think there’s an assumption that if someone’s overweight, they’re lazy. And, I mean, I don’t think that’s usually the case, but I think that’s the assumption a lot of people make. Probably more the obese. I mean, I think that overweight can include a lot. I mean, I think I’m in the overweight category and I work out a lot. So, I mean, a lot of that’s – you know, I don’t think I – I carry it a little better even though I’m, you know, technically overweight. But I would say more the obese that is probably more the discrimination. Okay. And so you – your – you know, BMI-wise, you know, you’re going to be categorized as being overweight.” [P010-q4]

Sub-theme: Be Prepared

“Being prepared” meant not having the appropriate sized equipment and supplies ready for larger sized patients. Being prepared signified the patient would not need to draw uncomfortable attention to oneself by asking for larger sizes.

“And the other thing that I think of is – ‘cause really this came out of having filled out the questionnaire beforehand, but also, um, coming from having been a (occupational
reference) a long time – I mean, I think part of weight bias is just not having the right equipment available for someone just to accommodate a variety of sizes. So – but I – I – when I think of weight bias, I think of overweight. I really honestly don’t think of it other ways. So I’ll just like close it with that.”[P004-q4]

Sub-theme: Feeling Vulnerable

Feeling vulnerable was defined as a fear of the increased risk of cancer due to family genetics; because many family members had been diagnosed with cancer including their grandmother, father, and cousins.

“My grandmother had breast cancer on my dad’s side, and I have a cousin on my dad’s side that did. I don’t know. My whole life, I’ve always had a fear of getting breast cancer. It was July of 2012. No, no one was ever concerned. But I always had it in the back of my mind. And especially with my dad had died six months previously from cancer. And I had like other relatives that have died of cancer, but not necessarily breast cancer.”[P005-q4]

Sub-theme: Accept and Deal With It

Accepting and dealing with the cancer diagnosis was described as knowing that one cannot change the cancer diagnosis so one just might as well deal with it.

“Um, you know, kind of frightening. I mean, I worked the entire time, ah, at my job. I lost no time, you know, from work. It was kind of frightening, but over the years now, you know, I’ve grown to – well, I’ve had the skin cancer now and breast cancer. No other cancers, so, you know, it’s just something you deal with. And – and I know that every day, um, you know, they’re getting more treatments out there and medications. They know so much more about it, so I – I don’t really worry about it. I just know what’s
going to be is going to be. There’s not a lot I can do about it except deal with it.”[P008-q3]

Sub-theme: Obese People are Biased Too

The study participants described their experience while in the military, as observing biases against other large individuals who required a special weight loss programs while in the military.

“Well, I was kind of, um, a little sad to hear that I was obese. That didn’t sound real good to me. But other than that, I haven’t had any real bias. Like I say, I was in the military for twenty-five years – so I really had to watch my weight. And I was never put on the weight program. They have a weight program with the (military branch reference) – - and I was never put on the program there --- for that. But when I was in the Reserves, you know, I kept my weight, ah, in tow pretty – pretty good. I mean I had to. About people that have weight biases against other people who are larger size.”[P008-q4]

Sub-theme: Lack of Control

Lack of control was described as a sense of helplessness and as being a terrible thing because they could not do anything about it.

“Well, yeah. I think it’s a terrible thing that, ah – there’s some of these folks that are overweight, um – I mean, it’s a medical kind of thing that, ah, no matter what they do -- you know, unless they take real drastic kinds of measures, there’s not a whole lot they can do. So I think, you know, to – to be mean to these folks is a terrible thing.”[P008-q4]

Sub-theme: Not Treating the Underlying Cause of Obesity
The participants described having their oncologist inform them they needed to lose weight to feel better but ignoring possible underlying causes of the medical weight issue.

“Um, gosh. I would think probably – I would think in terms of healthcare, you know, um, I guess I talk about hypothyroid now. I, you know, hear from a lot of women that, you know, instead of trying to treat the underlying cause, a lot of physicians just tell them they need to lose weight and they’ll feel better. I mean, I kind of think about things like that” [P010-q4]

Sub-theme: Never Heard of That

Never heard of that was defined by participants as never hearing the term weight bias or thinking oncologists are pre-judgmental.

“Yeah. I don’t know. I – I don’t think people are, but they are. I don’t think I’ve ever heard of that.” [P006-q4]

Question 5: Describe what the physician and/or nurse did or said that made you feel uncomfortable due to your size.

Major Theme: Actions by Physicians/Nurses in Response to Personal Size

This major theme was defined in terms of how providers regarded the survivors’ large body size. Patients were regarded as being unhealthy, fat or the wrong size; not fitting the society norm for beauty and weight; and being treated as a business entity. All of these attributes implied providers were unaware that the clinical environment conveyed a non-welcoming message that obesity does not fit societal norms for weight. Participants described having their spirit crushed, and providers’ insinuating it was the fault of the survivor for getting cancer. Nurses conveyed an attitude that the survivor was “trying to pull the wool over their eyes” by not telling
the truth, and perceived that the nurse treated them like a handicapped individual. There were 7 subthemes identified.

Sub-theme: Unhealthy

Study participants described being unhealthy as defined as being the “wrong size;” in one word, fat.

“I’ve gone in and they needed a blood pressure cuff and not had one available or said, “Oh, wait. You need – you know, you need a bigger cuff.” And how did that make you feel? Fat.” [P002 – q5]

“My doctor now told me – last time I saw him, which was last month – that he has cured me of cancer, but he doesn’t want me to die of a stroke because my blood pressure is so high, in part due to my size. So that’s what he said.” [P003- q5]

Sub-theme: Fitting the Society Norm for Beauty and Weight

Being athletic and having a “good body shape” was defined as fitting the society norm for beauty and weight.

“So I have a lot of sort of – I struggle with my own image. And part of that was because I – before I had kids when I was young, I was – I was what society would term today as athletic and had what society would say was a good body. And then after having kids and the hysterectomy and all the hormone issues that went along with it and then the cancer and all the carving up, I just didn’t feel good about myself.” [P004-q5]

Sub-theme: Just Business as Usual

The study participants’ described feeling like the provider was simply providing a business service during clinical visits. The clinic environment was filled with images of beautiful
women that fit the societal norm of beauty negating the population of women of larger body sizes and cancer related surgical scars and poor-self-images.

“I – I really – no, I can’t think of any time like that. I don’t think that anybody that I had working with me at the time made me necessarily feel, ah, uncomfortable like by saying or doing something. Unless you count that office with all beautiful women (laughter), which I can say, you know, societal form of beauty, meaning correct height and weight and, you know, facelifts and the whole nine yards. Boob jobs and everything. And I think that you could consider like that as potentially, um, not overtly doing something, but --- definitely doing something to portray a certain image. But I don’t fault the – I don’t fault the dermatology office for that necessarily because I’m only – in fact, I’m probably the smallest part of their percentage of patient kind of clientele that they see. So it’s a business. I get that.” [P004-q5]

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Sub-theme: Crushing My Spirit
Being labeled as overweight or obese at a time when one is feeling the most vulnerable while in cancer treatment was a crushing blow to the spirit.

“So I think that – I said – I said those kinds of things more to myself than any provider said to me. But let me tell you, if I had had the bad luck of having a provider that would have said anything like that to me, I would’ve been crushed. And I don’t know that that would have been a unrecoverable crushing of my spirit really honestly. I was lucky that I had physicians that, um, for the most part actually knew me from the (department reference) and were – were just really, really good to me.” [P004-q5]

**Sub-theme: Oncology Physicians Insinuations**

The study participants defined feeling insinuations from their doctors that getting cancer was their own fault due to their weight issue.

“Well, what she said was, “As long as you’re overweight, you’re going to produce more estrogen.” ‘Cause I was asking about if I have estrogen, you know, type of cancer, that’s where it came from. I said, “So I’ve had my ovaries taken out. I’m taking” – at the time, I was taking tamoxifen, but they changed that to Extazine (spelled phonetically) I think is how you say it. Um, ‘cause I’m postmenopausal now. So I said, “So is this going to cut – you know, my estrogen level?” She was like, “Well, no, not as long as you’re overweight.” And I was like, “Okay.” And it was just like she was like – I don’t want to say harsh, but it’s like, yeah, I do need to lose about forty to fifty pounds. So I understand. I know I need to lose weight, but I don’t – I’m not going to blame it – I don’t feel my weight today – you know what I mean? It’s like I – I need to do what I need to do to get my estrogen levels down, too, but I don’t think that that’s the only factor.” [P005-q5]
Sub-theme: Pulling the Wool over their Eyes

Study participants described nurses who conveyed the attitude that the survivor was not telling the truth and were trying to “pull the wool over the nurses’ eyes.”

“Yeah. Once the nurses get to know you and know that you’re not trying to pull any wool over their eyes, they start to believe what you say. Or maybe it’s me just learning to trust my nurses. I – it’s usually, um – for me, it’s, ah, new people I meet.” [P008 –q5]

“And then when I did, um, lose weight, I had to mention – I mentioned it to my chemo nurse. I said, “I’ve lost over five pounds.” And she’s like, “Okay.” Like she didn’t check my chart, but she weighed me in. So she had to go back to the pharmacist and re-dose it or something. Like maybe she assumed I didn’t lose weight.” [P009- q6]

Sub-theme: I’m Not Handicapped

Being treated like a handicapped person was experienced when the participant needed to transfer and re-position their body and staff assumed they needed extra assistance. This was perceived as stereotyping.

“And I – you know, when I’m getting radiation and when they go to help me up, I just lift myself up. It’s like, yes, I can do a sit-up. My stomach isn’t overflowing. You know, just kind of little things like that. Like I’ve got good mobility. I’m not – you know, I’m not handicapped. I don’t want people to feel sorry for me.” [009-q5]

Question 6: Describe if the physician and/or nurse made any negative comments, displayed negative body language, or non-caring behavior related to your size.

Major theme: Non-Caring Behavior, Negative Verbal and Non-Verbal Language

Non-caring behaviors, negative verbal and non-verbal language displayed by physicians and nurses was defined as fearing treatment and being perceived as a liar; having expectations of
the nurse that were unmet, having anticipatory nausea prior to treatment visits, and feeling unsafe. There were 3 subthemes identified.

**Sub-them: Fearing Treatments**

Fearing treatments was defined as not feeling safe and feelings of being treated like a liar by their nurses. This led to anticipatory reactions such as nausea and vomiting to the chemotherapy and radiation treatments.

“My blood pressure would spike when I, um, got there ‘cause, you know, I was having the – I forget what’s it called. Basically, it’s remembering your treatment, and you get sick. You get nausea. Anticipatory nausea. And my blood pressure would get really super high. And so my doc was like, “Well, we’re going to have – you’re going to have to make some lifestyle changes” – which I think she meant stress, but I didn’t know how to take that. And she said, “You know, I want to know how you’re reacting or if you’re mad at your husband.” So she upped my blood pressure medicine twice. So I don’t know if she was just kind of saying that, but she was really meaning my weight or – because when I wasn’t in her office and when I would get – ‘cause I’m getting acupuncture as well – I would have a perfect blood pressure reading.” [P009-q6]

**Sub-theme: I Felt Unsafe**

Participants experienced feeling unsafe during hospitalizations and treatments when there was not enough staff present to help physically transfer them. Unsafe was defined as being afraid of falling.

“Ah, sometimes I would be fearful because I didn’t think they had enough people like to move me, but not as responsible as they should be. Not as – sometimes I felt unsafe because of my size.” [P007 – q6]
Sub-theme: There Were No Overt Weight Bias Gestures or Language

Some of the study subjects did not experience any overt forms of weight bias by their oncologist and nurses.

“No. Not that I can recall” [P001 q5 q6]

“No. No, they weren’t. No.” [P003 q5 q6]

Question 7: Describe what the physician and/or nurse might have done to make you feel discriminated against due to your size.

Major Theme: Lack of Support

Emotional support and resources were lacking from their doctors and nurses related to the body size of the survivor. Participant experiences included insinuations, fear of dying, stereotyping, not feeling discrimination, and getting conflicting messages about their cancer.

There were 6 sub-themes identified.

“Actually, I looked – I was looking (laughter) for myself. I went to the (facility reference) – So then I’m like, okay, so this is where I need to go. I need – I need help with this and this. You know, I was looking for emotional support, too. So it’s been a huge overall stress” [P005-7]

“So then I’m like, okay, so this is where I need to go. I need – I need help with this and this. You know, I was looking for emotional support, too. I don’t know how much of this I’m supposed to talk about my personal life, but it’s like I’ve also been struggling like in my marriage. I mean, this was like before that, so that was kind of like an icing on the cake. And I live by myself now. So it’s been a huge overall stress --- within the last year-and-a-half. You know, I live by myself now.” [P006-q6]
“So at the end of my treatment when I go back to, you know, my family doc and things have calmed down, I’ll reassess that dosage. But they never specified to you exactly what kind of lifestyle changes they were talking about? Like weight – like a weight program? Or was it more of a counseling, you know, program for your, um, you know, stress and anxiety over – They didn’t offer anything. And there’s lots of resources, so I kind of was surprised I never was referred to the – um, is it social worker – until I did the – another intake form for radiation. And I was really –And so the – the social worker reached out to me. She goes, “I don’t know why we haven’t seen you before now.” So I – a couple things my oncologist said. She goes, “Well, you’re just doing fantastic. You’re just like a poster child for chemo.” And she just kept applauding me, but I felt like it was – you know, it was horrible. I think it was because I wasn’t hospitalized or didn’t have infection. But, you know, I threw up almost every day. It was horrible. So maybe she thought, oh, you’re fine. Um, because you haven’t gotten to this degree, I’m not going to worry about you kind of thing.” [P009-q7]

Sub-theme: Conflicting Message

One oncologist said the cancer wouldn’t return and another said the survivors’ body already knows how to make the cancer could return. This left the participant with a conflicting message.

And, um – and so then when all of these other moles started coming back as really high levels of dysplasia -- and what they were – the doctors were saying to me is that they wouldn’t necessarily turn to melanoma even if we left them on, but they could because my body already knows how to make melanoma, so that’s what made them want to take them
off until they had all of ‘em off. So they were taking moles off that were benign basically.” [P004-q7].

Sub-theme: Cancer is Your Fault Because you Lack Personal Control to Lose Weight

Oncology doctors insinuated that it’s the survivors lack of control and own fault for having cancer due to not losing weight and remaining overweight or obese. Remaining overweight increases the production of estrogen levels that increases chances of reoccuring breast cancer. Survivors perceived the oncologist as forgetting to acknowledge current weight loss efforts including weight loss surgery.

“Um, I think just going back more and telling me, you know, as long as you’re overweight, you’re going to keep producing estrogen. So it’s your fault and you can control it. Yeah, pretty much that’s what they said. I mean, that – that – I guess that’s a good way to say it. Like you – you didn’t feel like it’s – it was like, “If you just lose weight.”” [P005-q7]

“Well, obviously, I’ve always had a weight problem or I wouldn’t have had the gastric sleeve to begin with.” [P005-q7]

Sub-themes: Being Afraid of Dying: That Weird Phase

Being afraid of dying was defined by the study participants as “that weird phase” where one is freaking out, thinking there is no hope in sight and one’s life is over.

“I was more freaked out about radiation than I was with chemo. And I put, you know, fear of dying, all that stuff because, you know, you’re still in that weird phase. And I put, you know, fear of dying, all that stuff because, you know, you’re still in that weird phase.” [P009-q7]

Sub-theme: It’s Second Nature to Me
The study participants described weight discrimination by other people as expected and defined it as being “second nature” to them due to being overweight or obese for such a long time in their life.

“Well, I – you do feel uncomfortable, but it’s been going on so long that it’s like second nature. And we shouldn’t – you know, nobody should really have to put up with something that’s kind of, um, making fun of you. You shouldn’t have to put up with that.” [P007-q5 q6]

Sub-theme: Stereotyping Related to Large Size

The study participants experienced feelings of being stereotyped because of their fix space body size when nurses assumed that all large patients need the largest size blood pressure cuff.

“I think there were like three sizes. You know, the small – and then I actually would’ve fit the medium/large, but then she went to the bigger one and it was almost too big. And I think that happens a lot. Like I have a large arm, but if it’s too big, they’re not going to get the right reading. Like it’s wrapping around twice. So that was a subtle kind of thing that I remember.” [P009-q7]

Sub-theme: I Was Not Discriminated Against

Some study participants did not experience weight discrimination during their cancer journey.

“No, I – I’ve never felt any discrimination whatsoever.”[P008-q7]

“Um, not that I can think of. I think so. I haven’t – I haven’t noticed anything or I don’t – yeah, I don’t – not that I can think of.”[P010-q7]
Question 8: Describe what the physician and/or nurse might have done to be more accepting of your size.

Major Theme: The Clinical Appointments

The clinical appointments theme is comprised of what the physician or nurse could do to be more accepting of the size of the patient including; the hatred of the weight scale, providing appropriate size exam gowns, acknowledging the elephant in the room, providing sensitive care, and addressing education and resources. Other accepting actions included providers clarifying their statements, not rushing the appointment, being mindful of body language, avoid labelling as obese, and to be mindful there is a high degree of being self-conscious due to larger body size and image. There were 10 sub-themes identified.

Sub-theme: Hatred of the Weight Scale

Having to get weighed in at every clinic appointment even if it is not medically necessary was described as hatred of the weight scale because the weigh-in reminds them of their weight issues.

“Option of not being weighed. Um, I really hate getting my weight taken, but, um, one of the things is that, you know, they rarely give you the, they just sort of, you know, walk you over to the scale and say, “Get on.” (Laughter.) So I think – I mean, maybe – and it wouldn’t be appropriate to only target, you know, people that look overweight to go, “Hey, maybe you wouldn’t want to get weighed today.” But I think just to somehow indicate people have the option of not getting a weight taken. And some patients are willing to just say, “I don’t want to be weighed today.” But not everybody is. I’m one of those people. It never occurred to me to say no until like when some of my patients started refusing to be weighed. I was like, oh, you can refuse to be weighed. I’ll do that
next time.  But, um, I think just somehow just sort of making it okay.  I think for some treatments you have to know somebody’s weight, like I they’re going to get chemo or something, but otherwise you don’t really need to weigh ‘em every time.  And then I think just acknowledging without being judgmental at all that, you know, this problem that you are here about today, you know, has something to do with your weight.  Or your weight has something to do with this problem.  And so it does need to be addressed.”  [P001 – q8]

“Um, I guess the only thing that I don’t like is having to be weighed every time, but I understand there’s a medical purpose for it.  I mean, they could hide the scale or something.  (Laughter.)  But I do understand there’s a medical purpose for that, but it’s that, you know, lovely reminder.”  [010 –q8]

“Um, they just – it’s always the same story.  (Referring to high BP and weight issue)”[P003 – q8]

**Sub-theme: Providing the Appropriate Size Exam Gowns**

Study participants described experiences of being given the inappropriate size gowns at the start of the exam which made them feel over exposed or embarrassed by having to ask for a bigger gown.

“Well, I think, um, you know, the things for me that were helpful was being given a correct-size hospital gown to wear, whether it was in the office for an exam or in the hospital itself -- ah, without having to ask, you know, um, or say, “Well, that one’s not going to fit me.  Get me a bigger one.”  [P001 – q8]

**Sub-theme:  Acknowledge the Elephant in the Room**
The study participants described their oncologist and nurses as omitting the subject of weight by not acknowledging the elephant in the room. They further defined this omission as a disservice and felt weight issues should be openly talked about in a sensitive manner.

“I think it’s also a disservice to not bring that up. And just say, “Oh, you’re here about diabetes, but we’re not even going to talk about the fact that you’re overweight.” That just – that would be incorrect to do as well. But there are sensitive ways to bring it up to talk about, um, behavior change toward that.” [P001 – q8]

“It’s OK to tell me I’m overweight but do so in a way that couches the issue in non-threatening ways. My obesity is multifactorial and not due to a single cause. Think of me as a holistic being that is more than my estrogen levels.” [P005-q8]

Sub-theme: Provide Sensitive Care

Providing sensitive care at every clinical appointment was described as treating the overweight and obese cancer survivor holistically, talking about weight loss behavior changes, and in terms of non-superficial beauty.

“But there’s one thing that I still remember to this day, and that was the oncology surgeon. And when I was still in recovery after the wide local excision and I was – I was definitely already awake – I was getting ready to go home actually – and I overhead the surgeon say to one of the nurses at the station – at the nurses’ station – something about taking care of, um, my beautiful lady. And I knew that he was referring to me because he had just – I knew enough about medicine and the medical field to know that he had been just giving her orders that were my, you know, going-home orders – my discharge orders – and then he had said that. And so it – it still stuck with me that even though I had, you know, been carved up and I wasn’t like this young, athletic body build like I used to be,
he was still seeing me as a beautiful person. And – and I was – I still remember that. It like gave me a boost." [P004-q8]

But there are sensitive ways to bring it up to talk about, um, behavior change toward that (referring to weight).” [P001 –q8]

Sub-theme: Addressing Education and Resources

Providing education and resources at the clinic appointment and allowing survivors to be involved in their own cancer edification was an important aspect in the cancer journey. Oncologists were admonished to be clear and to clarify any communication.

"But if you’re going to address it (weight and weight loss) and tell me like, “Okay, the more estrogen you produce” – give me more, you know, like education on – show – show me stuff where – like I could go back and read about how being overweight produces that estrogen. I understand the effect it has on your body, but I also – I’m the kind that likes to research and read things myself. So point me in the direction that I need to go to get the extra education.

"Um, maybe clarifying the lifestyle changes instead of just saying lifestyle changes. For overweight and obese patients, I think that means, you know, lose weight and exercise. Ah, and obviously I’m not in a position when I’m getting chemo to do that, so she could’ve said something like, you know, “A lifestyle change in the area of stress management, and so I want to refer you to X, Y, Z. Maybe meditation or just taking some deep breaths.” You know, something like that instead of just that broad-brush of lifestyle changes. ” [P009 –q8]

Sub-theme: Don’t Rush the Appointment Time
Being focused on the single narrow subject of cancer and not taking time to examine the patient in a holistic manner was defined as a rushed clinic appointment.

“And I feel like a lot of times when you get in there, you’re – they’re focused on one thing and kind of rushed. And I’m the kind of person who goes in with a list of questions because I don’t want to forget anything. And then I don’t always get my answers, or I’ll get, “Well, I’ll call you back on that.” This just happened at my last appointment. And I never did get a phone call. And I’m like, okay. So I keep calling, and I said, “I want this answer. I want to know what you’re going to do.” It was regarding, um, my risk of colon cancer. I was told I was supposed to have colonoscopies every two to three years is what the genetic testing told me.”[P005-q8]

Sub-theme: Body Language Speaks Volumes

Study participants experienced nurses rolling their eyes and displaying other subtle non-verbal nuances such as acting like they didn’t hear survivors the first time. Nurses were perceived as non-verbally communicating their lack of care for cancer survivors who are overweight or obese.

“Um, I guess, um, nurses – I think they should, um, be a little more trained when it comes to body language. And, ah – and that’s really hard because you can say something to somebody and then you can put a real, ah, spin on the end of the sentence and make it sound like you don’t believe me. So I – I guess it would be a little more training, ah, for nurses.-- some subtle nuances that they – that are being expressed, but aren’t – you know, and maybe subconsciously being expressed. Rolling of the eyes. Um, yeah, questioning me – -- like I didn’t hear them the first time, or I didn’t answer the question
the way they thought I should. You know? But I took it – I took it negatively. Probably because I was sensitive about the issue.” [P007-q8]

Sub-theme: Labeled as Obese by the Provider

No one wants to be labeled as obese or made to feel bad by their provider. One survivor did not really understand the meaning of the label of obesity.

“Well, I feel bad. I mean, I don’t want to be obese. I – I did feel bad about it --- but I certainly didn’t, um, get under the weather or, you know, get depressed about it. You know, ‘cause I – I wasn’t really that much over – you know, overweight. You know, if I was grossly overweight, then, yeah, it’d be a real issue. But I’ve never been grossly overweight or – -- you know, I am obese, though.” [P010-q8]

Sub-theme: Negative Self-Talk

Being self-conscious about their large size and weight issue was described as negative self-talk that at times kept survivors from wanting to return for treatment and maintenance medical appointments. Negative self-talk became even more heightened when the appointment involved undressing.

“I don’t – I don’t think there was anything in the environment, um, or anything that anyone said per se that influenced my cancer care. I think it more just came from myself. That because of my self-consciousness and whatnot and, you know, sort of negative self-talk about, oh, well, you know, you have this cancer because you’re overweight, um, that that sort of kept me from wanting to go back. I mean, I was always – I don’t like going to the doctor. I hate going (laughter) when I’m going to have to be undressed. You know, it was more from that perspective. And, you know, whether or not the providers of care had weight bias, I didn’t detect that from them. But, you know, I wasn’t also necessarily

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looking for that. I think I would’ve recognized it if it was there. I certainly have experienced that in other places in my – in my life. Um, so I know what that’s like.”

[P001- q8]

“Um, could they have done anything to make me feel more comfortable or did they say anything? I don’t think they like were going out of their way to strive to make me feel more comfortable. I definitely felt like I was just one of those patients herded through the oncology-type field. You know, appointments, surgeries, and follow-ups, this, that, and you name it. I didn’t feel like they went out of their way to make me feel special. But like they weren’t mean to me either. I just felt like regular, um, except that I – my dermatologist, I actually – I knew him from the (department reference), so, um, you know, it was a little different relationship, ah, just because we had interacted professionally before. Um, ‘cause he was – he – when we had a tough – a tough case at the (department reference), he was always interested in our day, so he was always happy to come in and take a look at the patient. So we had had this – you know, we had – I had been the (occupational reference) for some patient that he had consulted on at the (department reference).

Sub-theme: I Didn’t Experience Overt Forms of Weight Bias

Some study participants did not feel like they experience overt forms of weight bias and quantified this in terms of being able to carry their weight well.

“Um, I’m not – I’m not – my body isn’t that big. Somehow I can carry around a big load of weight and my butt can sit in a regular-sized chair. (Laughter.) So I did not experience that. I did not feel like, you know, gee, I should’ve been in a bigger – a wider gurney or wider bed or something. I – I didn’t encounter that.” [P001- q8]
“No, it was never an issue. Ever.” [P008-q8]

**Second Major theme: Internally Motivated**

Internally motivated is described as altered self and body image and desire for life, young mother and needing to take control back over my life. There were 3 sub-themes identified.

**Sub-theme: Altered Self- and Body Image**

Self-image was defined as internal conflicts related to survivors’ weight and size. Survivors struggled with a flawed sense of one’s own body image due to body size and physical scaring of surgical procedures due to cancer.

“Well, for me, it was more internal. And related to my size, I – I honestly can’t say that I experienced that. But related to general image, um, I have to tell you that, um, I – I don’t know that I was necessarily normal in my response to my cancer and my image. I mean, I was feeling a lot of conflict internally, and so when I – you’re talking about image. Maybe this is, you know, part of the conversation that I should share. So I don’t know. I just throw that out there because we are talking about image. We are talking about what society thinks of us. And, um, there was a point in that where I just decided that I didn’t care. I was going to do what I needed to do. And I think it shocked my dermatologist and some of his staff ‘cause I did feel a little reaction from them on that that was just initial. Like, wow, that was kind of weird. But then you know what? It’s almost like he didn’t miss a beat. He just referred me – he was like, “Hey, this would be a really cool time to do the” – um, what was it called? It’s where they do the high-powered camera. They call it, um, mole mapping. He was like, “This’d be a great time to do mole mapping.” And he sent me down to (clinic reference) to get mole mapping. And, um –
and I guess I just appreciated that response.” [P004 –q7] The need to prevent future melanoma trumped her own image of herself, the dermatologist’s image of her, and society’s image of a person with hair.

“No. Like that conversation or thoughts about that have never came up when I was diagnosed and going through sort of the acute part of the process. I think that, um – I can’t remember how much I weighed when I was there, but I don’t – you know, I think I was just – I definitely wasn’t fit because I’d had a kid a year earlier and had just come off breastfeeding and everything. But I – I was not of a weight that I felt like people focused on that necessarily. I know that I was self-conscious about it, but I never got the feeling that anybody else focused on it. I definitely suffered, um, from feelings of like – well, like in (occupational reference), we call it alteration of body image because I was cut on a lot. So there’s a little more to my story about cancer in that I had the wide local excision of the tissue over my liver, um, of which the scar is probably about, oh, three to four inches long actually. And I think they took out like a good amount of – of tissue maybe in part.” [P004-q7]

“So I have a lot of sort of – I struggle with my own image. And part of that was because I – before I had kids when I was young, I was – I was what society would term today as athletic and had what society would say was a good body. And then after having kids and the hysterectomy and all the hormone issues that went along with it and then the cancer and all the carving up, I just didn’t feel good about myself. So I think that – I said – I said those kinds of things more to myself than any provider said to me. But let me tell you, if I had had the bad luck of having a provider that would have said anything like that to me, I would’ve been crushed. And I don’t know that that would have been a
recoverable crushing of my spirit really honestly. I was lucky that I had physicians that, um, for the most part actually knew me from the (department reference) and were – were just really, really good to me.” [P004-q7]

Subthemes: Desire for Life and Young Motherhood

The stressors of being a young new mother and dealing with a total hysterectomy was described as having a deep desire to be alive for her kids.

“--but even more than that, I was feeling the stress of being a young mother and having the cancer diagnosis, having the surgery related to it, and having just come off of a hysterectomy and going through all the – all of the other stuff that you go through – I had a total hysterectomy – uterus as well as ovaries.” [P004 –q7].

“And three of my girlfriends that were – um, two of them were (occupational reference) and one of them went to my church – they all shaved their heads with me. So we were like four girls with our heads shaved at church. (Laughter.) And so that has to do with image. The fact that I did that and I didn’t have to do that, um, made me think something about how – how I did feel, um, strong. Like I wanted to be strong about my image, but I also wanted to – I had this deep, deep desire to not have anything missed and to be alive for my kid.” [P004 –q7].

Sub-theme: Needing to Take Back Control of My Life

Study participants experienced the strong desire to take back the control of their life by defining it in terms of life over image.

“Um, I actually took my hair off. Like I shaved my head. But it wasn’t because I was going to lose my hair because of chemotherapy, because I didn’t have any of that. Um, what I did have was a hairdresser who – well, a dermatologist – um, when I switched
from the oncology surgeon to the dermatologist, um, the dermatologist found – I can’t remember how many – like three moles on the top of my head. And the oncology surgeon had found relatively the same number. Then I went to my hairdresser, and my hairdresser found seven on the top of my head. And I was like, alright, I can’t take a chance here. I have a one-year-old and I have a two-year-old. I – I need you guys to be looking at every fricking mole on top of my head and not missing anything. And so I actually took my hair off.” [P004 –q7]

Question 9: Describe if there was adequate equipment such as chairs, beds, wheelchairs, gowns, BP cuffs and scales that accommodated your size comfortably.

Major Theme: Inappropriate Sizes

The major theme of inappropriate sizes relates to not having the correct size for supplies and equipment to fit the larger body. This experience mostly occurred at routine clinic appointments, hospital stays, and treatment appointments. There were 2 sub-themes identified.

Sub-theme: Wrong Sized Supplies and Equipment

Having inappropriate sized chairs, blood pressure cuffs, gowns, wheelchairs, and gurneys to properly fit the larger size of survivors was defined as feeling ignored and like one’s needs did not personally matter; only “normal size” people had the correct sized equipment.

“I would say that sometimes the chairs they have in the, ah, offices aren’t very – ah, they’re pretty small. Maybe have a bench rather than a chair that has arms on it.-- I’ve gone in and they needed a blood pressure cuff and not had one available or said, “Oh, wait. You need – you know, you need a bigger cuff.”” [P002 – q9]

“Um, I think – and then I think, um – can you say that question again? Um, I can’t remember inside the exam room. in there, so it’s better to have a chair with no arm rests
so your butt can hang over the sides. And in the exam One of the things I know bigger people have trouble with is chairs with arm – with arm rails on the sides. Like you can’t get your butt – or in the waiting areas, all the chairs had armrests, but they had these like window bench seat things that looked like a window seat – that were kind of a long, skinny bench. So anybody could sit over there no matter how wide they were.” [P001 – q9]

“Ah, yeah. The wheelchairs they push me out in are not that – are not big enough I don’t think. Ah, they’re kind of tight. And the gurney was very short and not very wide. And just the gowns are always too small ‘cause they can’t find an extra, extra large.” [P003 – q9]

“The only thing I’ve had trouble with are the toilet risers and the, um, gowns. So I don’t know how that would work. I mean – I had to ask for a larger gown.” [P007- q9]

“Yeah. I – I can fit pretty much into like standard chairs and everything. The only problem I ever really had is more the blood pressure cuffs. Sometimes they just get too but wheelchairs and all that other stuff, like I didn’t – my size allows me to fit in like the average-size person. No, I’ve never had a problem with that.”[P005-q9]

**Sub-theme: I Did Not Require Special Equipment**

Some study participants indicated that they were not large enough to require special equipment.

“Um, so I don’t think that – I’m thinking about that. So, I mean, regarding equipment, I wasn’t – I wasn’t in a place to require specialized equipment at the time, even though I was overweight. Don’t get me wrong, I was definitely overweight. My – my percent body fat – body fat was probably 30+, but worse than that now. Um, but I don’t think I
required any special equipment at the time, so I don’t think I thought about that at the time.” [p004-q9]

“Everything you felt fit pretty well. Yeah. Even right now, see, I’m sitting here in a rocking chair outside.” [P006-q9]

“Yes. I think my obesity – I mean, my doctor – my primary doctor tells me I’m obese just because of my height and weight. But, um, it’s never to the point that, you know, I can’t fit in the gowns or, you know, they don’t go around me completely or anything like that.”[P010-q9]

“Yes, they were always fine.” [P010-q9]

Question 10: Overall, describe how the weight bias you have experienced might have influenced your cancer care, if at all.

Major Theme: Labeled as Overweight or Obese

This multidimensional theme was composed of several subthemes: Stereotyping, being prejudging based on sex, experiencing barriers to care, being told to lose weight, discrimination as a fact of life, societal weight bias, being disappointed by fellow human beings, and finding a new provider of care. There were 7 sub-themes identified.

Sub-theme: Stereotyped as Being a Women More Than Being Overweight

One participant noted that during her life, she has been stereotyped for being a women more than being overweight and this makes her “hot under the collar.”

“I think I’ve had more bias in my life toward being a female than toward being an overweight person, but they’re kind of in the same category. And I’m much more hot under the collar about, um, you know, behaviors directed at – behaviors and comments,
um, directed at the fact that I’m a woman than – than a fat woman. I don’t know.”

[P001 – q10]

Sub-theme: Barriers to Care

Reluctance due to poor self-image and internal conflicts was a barrier to follow up and annual checkup appointments.

“Like maybe – maybe I didn’t follow up for my annual checkup, you know, quite on time because (laughter) I felt the need to like – I don’t know – exercise for a week before I went in. There probably is that. (Laughter.) But actually, I – um, I believe that that’s there. Um, I think that if I were to be honest with myself, I think that, um, it may subtly inform my – my wanting to go in for my follow-ups. ‘Cause I’m heavier now than I ever have been since I was pregnant with my kids. And – and guess where I go. I go to a dermatologist’s office for my follow-up ‘cause, you know, you’re – I’ve been done with the oncology for – for a long time. So I have to say that at least on a subtle level, that’s in my mind when I’m thinking about scheduling an appointment. So whether that’s weight bias directly related to the way that I’m treated when I’m in the office or – or whether that’s just a personal thing or whether it’s my interpretation of what society thinks I should have, I don’t know the answer to that. Ah, I can tell you I haven’t been overtly, um, talked down to or discriminated to because of my weight” [P004 – q10]

“Um, probably the fact I really object to go in and get naked – ‘cause that’s what you have to do with melanoma. They have to check you head to toe. And to do that is harder. Ah, if I had a beautiful body, I could drop my gown and go, “Here I am.” [P004 – q10]

Sub-theme: Lose the Weight
One participant described feeling like they did not fit the standard mold regarding body size. She felt an obligation to try to lose a few pounds prior to their doctor appointments.

“I don’t care how (laughter) – whether I go in tomorrow or after I, you know, lose ten pounds or fifteen pounds. Or – or twenty or thirty pounds. Let’s be honest here.” [P004-q10]

Sub-theme: Discrimination is a Fact of Life

One participant described discrimination as being a fact of life; good to be aware of but nothing to get depressed about.

“Nobody’s ever really, like I said, been discriminatory or – or anything. It’s just a fact of life, and it’s good to be aware of. And I certainly didn’t get depressed about it or anything like that. So – But now that I’ve – now – now that I’ve been told that I’m pre-diabetic, ah, that was very scary to me, so I’m really trying to watch my weight and – and do something about it at this point.” [P008-q10]

Subtheme: Societal Weight Bias

The study participants described societal weight bias as the stereotyping and discriminatory experiences of large size people during a shopping outing.

“Oh, um, in, you know, retail shopping settings. Like, you know, just standing there and being ignored or – especially like in like clothing stores, you know, that are not – that don’t cater to overweight people – like normal-size clothing stores. I just, you know, feel like sometimes I’m treated like a non-entity there. Like, oh, we can’t – we shouldn’t bother puttin’ any time and effort into you ‘cause you’re not going to be able to buy any of our clothes, or you really shouldn’t buy them ‘cause we don’t want you wearing our clothes. Um, I just – I think sometimes social settings there’s some people who, you
know, just have an automatic opinion about what an overweight person must be like, or is like, and they just don’t want to even spend a minute to find out whether you’re a nice person or not. And that hasn’t been something that, you know, has bugged me a whole lot because generally I’m able to find people that, you know, I can interact with without that being in the way.” [P001 – q10]

“I have some little anecdotes I’ll share once in a while about a long time back I – I went to order some flooring material – like, oh, you know, I guess like linoleum flooring. And I – and it was for – it was for like a kitchen/dining area in my house. And I had measured the space and I had calculated how many feet I needed to order of it ‘cause it was twelve feet wide, and, of course, the room was not exactly those proportions. So I figured out how many feet of flooring I needed to ask for. So I went to the flooring store and I, you know, told the guy what I needed, and he was like, “Who figured this out for you?” (Laughter.)And it was right. So, um, things like that, you know, where people just assume, you know, of course, you wouldn’t – and I knew he assumed that because I was a woman. I mean, I didn’t look particularly stupid, so I think what I looked like was a woman. So he figured I couldn’t have done that myself.” [P001 – q10]

“But, yeah, definitely in my profession – especially in my training – ah, I was told by somebody that I should choose a – a less rigorous residency training program because after all I was a woman and mother, and I really wouldn’t have time to like really, you know, do the really hard program. As it turned out, I got into the really hard program and did just fine, but that was like a straight-faced, you know, piece of advice that was given. Like no sarcasm at all. Yeah.” [P001 – q10]
“I feel disappointed in my fellow human beings that they have to be that way, and I generally just move on to a different situation. If it’s – you know, if it’s a situation where I have control over where I spend my time. Like I don’t have to go to certain stores and whatnot, and I just don’t go there. I mean, why go back and, you know, ask for more unpleasant behavior toward yourself? So I just don’t go back. Get away from there as fast as possible. Um, you know? “[P001 – q10]

Sub-theme: Seeking the Right Healthcare

One participant that was not satisfied with their oncology doctors looked elsewhere until they found a satisfactory oncologist.

“The only – the only thing I really – this is – this is awful for me to say, and I don’t mean it bad. I used to think people with back pain, oh, you have back pain. How can it be that bad? But one day back in 2010 I woke up with (cuts out) and I couldn’t get out of bed for a month. So until you actually go through something yourself – -- and like even with the cancer, it’s like my previous employer was a (occupational reference), he said to me – I lived in a small town, and that’s why I moved away. I moved up here. He said, ‘Well, I would just go in and do a lumpectomy.’ And I’m like, ‘Why would I do that? I’m (age reference) years old. I said I don’t need my breasts. When you look at the risk of recurrence of it coming back, there’s a higher chance for it to come back. I might as well get it all taken out now instead of having to deal with it later down the road.” He was looking at it from – he wanted me back to work. Well, I ended up quitting. (Laughter.) And it wasn’t – I didn’t quit because – I quit because it was the best thing for me at the time. I needed to go where the healthcare was that I could get the best care. I wasn’t
going to go see a general surgeon when I had breast cancer, and where I was living that’s what they had.” [P005-q10]

Sub-theme: Weight Bias did not Affect my Care

One participant described never feeling overt forms of weight bias from her oncologist or nurses during the course of her cancer healthcare.

“I don’t think it’s affected it a lot ‘cause I – I know that I need to take care of my blood pressure. I don’t think that they’ve curtailed care for me or treated me any different with the cancer care because of my size.” [P003 – q10]

“I don’t really think it has, to be honest.” [P005-q10]

“Yes. I don’t know – I don’t know anything else I could add to that question.” [P007-q10]

“Um, I don’t really think it has, I mean, at least for me. But like I said, I think I’m, you know, in the overweight category, but I think I – you know, if you looked at me, I don’t think that’s your first – like I said, I think I carry it reasonably well. So I – I really have felt that that’s really been an issue for me. “[P010-q10]

Question 11: Thinking back on what we’ve talked about, how would you define the term “weight bias”?

Major Theme: Weight Bias

Weight bias is defined as having preconceived notions, labeling, and pre-judging others based on their outward appearance and size. This includes providers not being proactive in the care of survivors, overt weight bias and non-overt weight bias actions and innuendos, barriers to care, feeling more pain than gain, stereotyping all obese and overweight patients into one type of patient, and not being a motivator for weight loss. There were 7 sub-themes identified.
“Well, I think it’s – like all other forms of bias, it’s applying your preconceived notions about what someone is or should be or needs based on their appearance. And whether it’s the color of their skin or their gender or their age, um, or their size – body mass index – ah, it’s all the same kind of bias.” [P001-q11]

Sub-theme: Not Being Proactive in the Care of Large Sized Survivors

Large sized survivors did not feel accepted due to their size, failure to provide proactive care, and having inappropriate equipment to meet the needs of these survivors in the clinic office.

“Maybe, um, in the sense that if somebody is weight biased, they may not even realize it. I don’t – I don’t ever feel like people, you know, purposely put a smaller chair in a room or purposely have not the right equipment. It’s just not being prepared perhaps than being ignorant.” [P002-q11]

“When somebody looks at you and says – or thinks or says or acts like you are overweight – grossly overweight. Some people are accepting of it and some people aren’t” [P003-q11]

Sub-theme: Bias is not Just Overt Actions

Non-overt weight bias from the oncologist and nurses is defined as subconscious acts that were unspoken such as negative body language.

“I would say it is when you have two similar situations – one person is overweight and one person isn’t -- um, that person that’s overweight gets treated poorly.” [P007-q11]

“Maybe the – it doesn’t have – it doesn’t have to be overt.” [P009-q11]

“Like I think when you’re overweight and obese, you’re always kind of looking for little things. But even, um, I guess not acknowledging the weigh is a --- I don’t know if that –
Yeah. It’s like we’re not going to talk about the elephant in the room, excellent metaphor but, yes, you are overweight and here’s the facts. It doesn’t mean that you’re a bad person, it’s just that, when you’re done with treatment, you can work on getting to a healthier weight.” [P009-q11]

“Well, I guess I might, um, expand on it from the overt – when you hear bias and you think – you think discrimination and, um, sort of more things that we all know we shouldn’t be doing in healthcare. Right? We all learned in kindergarten we shouldn’t treat other people like that. I guess I would – you know, I guess after thinking about it and having a conversation, I really think weight bias does – it goes beyond that. It goes into all of the things that are never said, but that – but that someone who is overweight feels.” [P004-q11]

“So it’s – it – I think the weight bias expands into the – the unsaid, the occurrences, and I think that those are, um – those are not just words. Those are not just what equipment is available or not available. It’s actually all of the things in the environment like, um, pictures that are hanging on the walls of beautiful people or the staffing of an office with all beautiful people. And by that, you know, I – I’m saying that – I’m using beautiful in a very, you know, societalistic way. (Laughter.) I mean, ‘cause to me, beautiful is very different. I’m using it in a very generic way, pointing at what society thinks is supposed to be beautiful like the models that you see on the magazines and on TV and, you know, all of that. So I guess that’s what I would expand it to.” [P004-q11]

“I would expand it to not just, um, overt actions, not just even people, but actually the environment that you can find yourself in, which is all inclusive of people and pictures of things that – everything. -- person’s own culture. Yeah. What we – yeah, it’s very
cultural what we value as beautiful. Yeah, I would say you’re safe to call it that.” [P004-q11]

Sub-theme: Barriers to Care moved

Barriers to care were attributed to forms of weight bias including being prejudged as lazy, fat, and blamed for being overweight or obese; and not being treated as a whole person but as a cancer diagnosis only.

“Um, I would say larger than average and prejudged. Like you’re prejudged because of your size. And then – like I weigh 190. So the minute that they see that I’m 190 and I’m 5’ 3”, you’re – you’re labeled. Yeah, I would say that society is like, okay, you’re fat and lazy. It’s that fat, lazy type of attitude. I mean, I have felt that like – I wouldn’t necessarily say through this – but at other places, I have felt like that.

You know, like it’s your fault that you’re overweight. You’re right. It is my fault, but, you know, sometimes – I mean, it could be your fault for being involved. You know what I mean? You shouldn’t prejudge, and society definitely prejudices you for being overweight.

Sub-theme: Causing More Pain and Distress, than Gain

One study participant described going to their oncology appointments as causing more pain & distress than gain. She would rather take the risk of her cancer recurring than putting up with the emotional stress due to her weight and forms of weight bias she felt when at her she went appointments.

“I keep – every day is a day when I’m trying to do better. But, um, you know – so I think going there is more – just kind of puts more – um, heaps more pain on myself without the gain part. If I knew it would motivate me – like if my labs show that my, you know, blood
sugar is up even more now or my lipids are terrible or something, remove space that will surely get me moving. I just – that hasn’t happened, and I don’t see it happening yet. The distress that it causes. Ah, well, that’s what I’m doing by never going to the doctor.” [P001-q11]

Sub-theme: Lumping us Into One Patient Population

One participant experienced forms of stereotyping and depersonalization when the oncologist and nurses assumed that being overweight or obese automatically qualified her to have all the typical comorbidities associated with a BMI of greater than 25.

“Yeah, I definitely – it’s like – ‘cause at my heaviest, I was like at 245 pounds, and I was – you definitely feel that when you go to the doctor, you know? Well, even sometimes maybe people don’t mean things that – Attributions by others linking obesity to other comorbidities “Oh, I can’t believe you’re not diabetic.” “Well, no. Diabetes runs in my family. Thank God I’m not.” It’s like – and I know that like because you’re overweight you know, obviously my risk factors are higher for all that stuff, and I do understand that. But I don’t think that – sometimes the way it’s sent to you, it’s like, well, you’re fat. You should have – or, “You don’t take blood pressure medicine?” I haven’t – I didn’t start taking blood pressure medicine until two months ago. I mean, my blood pressure was always normal, and I was overweight. But since all this, I – I don’t know what happened. (Laughter.) causal attribution Too much stress in my life and now I do have high blood pressure. But I – I do notice if I – if I walk, its better. And when I just found this, it was like, oh, my God, I just started going back to the gym. I was just doing what I was supposed to be doing. Yeah. Whenever he fills my spacers up to the right size, and that will be my last one I’m praying.” [P006-q11]
Sub-theme: Not a Motivator for Weight Loss

One participant described not being successful at losing and maintaining weight loss because she was unmotivated. Non-motivators had multiple medical comorbidities due to weight were discouraged due to weight bias no matter how helpful the doctor was trying to encourage her to lose weight.

“Well, I have to say I don’t go to the doctor very much. (Laughter.) -- I’m – I think I know – you know, I think I know how to take care of myself, which I know is – you know, the doctor who treats herself has a fool for a patient. Um, that’s number one. Number two, I don’t want to – I don’t want to find out, you know, what my labs are. I don’t want to – because I’m not – because I’m not being successful at weight loss, and so I know theoretically they may not be that good. Um, I know what I need to do to correct that problem, and I’m not doing it. Um, and my doctor will very kindly and gently, um, you know, point out to me that that – that losing weight would really be the very best way to correct the kinds of problems I have. Um, and, ah, I just – you know, so I feel like I kinda know what the conversation will be, but that doing that and getting my labs done and stuff will not – you know, it clearly hasn’t been enough of a motivator in the past years. And, you know, I’m just not at that point where I’m going to make myself do it.” [P001-q11]

Sub-theme: I Don’t See a Lot of Very Overweight People

Some study participants felt they did not many very overweight people and described how elderly cancer survivors try to keep weight on.

“I’m not sure. I – I really don’t. Like, you know, ah, I know that they have that BMI. Yeah. I – you know, I feel for people that struggle with this and are grossly overweight ‘cause I know that – that they do get picked on and – and, you know, all of this stuff, and
– and I feel very bad for them. But I’ve never felt that I was in that category that -- ah, that it was never a problem as far as, you know, how I felt about myself or anything like that.” [P008]

“Um, I mean, I’m sure there’s probably a lot of things I haven’t thought about before. Um – um, not really that I can think of. I guess, you know, when you sit in the waiting room and look around, you know, a lot of the population that have cancer are, you know, elderly people that are trying to keep weight on. So I don’t – I don’t know that you see a lot of very overweight people I guess the weeks at the clinic, you know, when I’ve been there. So it’s – I hadn’t really thought about it in terms of – of being a cancer survivor other than, you know, the fact that I now have hypothyroidism because of it.

(Laughter.)” [P010-q11] Perceives no relationship between cancer survivor and overweight except hypothyroidism

“And, um – and so I think that those feelings come from somewhere because, I mean, let’s face it. If we were – if we were living in the Renaissance, this wouldn’t be a conversation, okay? We wouldn’t be having this conversation. That – that’s the bottom line.” [P004-q11]

Question 12: If you could tell an oncology physician or nurse caring for an overweight or obese cancer survivor one thing, what would you say?

Major Theme: Changing the Current State of Oncology Practice

A suggestion was made for oncology doctors and nurses to make statements openly regarding weight bias at the beginning of the clinical appointment. This action would set the tone that they are open to feedback and it is important that they make the visit as comfortable as possible. Providers should convey to overweight or obese survivors that they are accepted just as
they are. This attitude would improve motivation for survivors to keep coming back for follow-up and maintenance appointments. Participants identified several subthemes including being treated as a whole person, picking the right time for the “weight” talk, adding a personal touch, being more sensitive, ignoring stereotypical labelling, and being aware of the mindset of the overweight and obese individual related to self-perceptions and assumptions. There were 6 sub-themes identified.

**Sub-theme: Being Treated as a Whole Person**

One participant described feeling accepted for who they are by their oncologist and building a comfortable trusting relationship related to weight bias was defined as being treated as a whole person.

“And to just sort of say, you know, “If you’ve noticed there’s a – you know, some issues here with, you know, being given gowns that don’t fit or something else related to weight bias to please let us know.” You know, to make that an open statement so that the person – with the goal of saying, you know, we want you to tell us that because we want you to be comfortable, ah, coming here and wanting to come back. We want – it’s important for you to come back regularly.” [P001-q12]

**Sub-theme: Pick the Right Time for this Talk About Weight**

Picking the right time for this talk is defined as providing education related to weight issues and cancer diagnosis in a non-offending manner at a time when the survivor is ready to hear it.

“I think it’s at least important to provide an education piece about that to make sure that people do understand that there is a relationship between those if there is. Um, and also just to communicate that over time, you know, obviously one of the reasons for ongoing
cancer care is not only to survey – you know, do surveillance and detect recurrence, but is to try to promote healthy lifestyle to prevent future cancers, and one of the things is – is weight loss. Now, the timing of that really depends on the person’s – you know, if they’re in the middle of chemo or radiation, you know, it’s probably not a good time that they should also be on a diet and trying to lose weight, but with acknowledging that there is a good time – there should be a good time at some point to try to work towards normalizing weight, if that’s possible.” [P001-q12]

“Well, I think don’t -- don’t ignore – in terms of the conversation you have with the patient, don’t ignore the fact that the person is overweight or obese. Sort of like the elephant in the room thing where you’re talking about everything else but that. Um, particularly if their cancer or whatever their health issue, you know, it’s related to their weight.” [P006-q12]

**Sub-theme: Add a Personal Touch**

One participant described wanting to have their oncologist and nurses provide a more personal touch during their clinical appointments. This was further defined as the one-to-one time spent between the oncologist and survivor so that the survivor would want to come back for their next appointment. This one-to-one time would be characterized as having more of a casual conversation, making sure that the experience in the clinic is comfortable and pleasant (e.g., making sure the proper size gowns are available), and that the physician would bond with the survivor rather than just being competent and capable. One participant referred to it as creating an environment where the survivor would look forward to going back to.

“Well, actually, what I just said, that would probably come better from the nurse sort of, you know – rather than – ‘cause the doctor things done to patients, it can be sort of more
directive. Like, “We want you to tell us this,” blah, blah, blah, blah. But from the nurse it could be kind of a more casual conversational thing. You know, “Gosh, we really want to make sure that your experience here is comfortable and is as pleasant as possible. If that means – you know, if you’re not getting – if someone’s trying to hand you a gown that doesn’t fit you or something, please by all means let us know that. Of if there’s anything else we can do. You know, if you preferred not to be weighed or you want to weigh yourself at home and just tell us your weight,” something like that where they can just give examples, that might put people more at ease. I – throughout my – my “cancer care” – I mean, I hardly think I had cancer – but anyway, I just – there was really no kind of bonding among – either with the nurse or the doctor. Um, and it’s – and I don’t want to say that I thought they didn’t care. That’s not why. I think it just was very clinical. It was very capable and competent. Ah, and – and also I thought, okay, well, they don’t need to really, you know, dig in here with me because it’s not like a cancer battle. You know, just like I got this thing, and it’s almost like I’m like their easiest patient they’ve ever had. (Laughter).” [P001-q12]

“That would be a great, ah – you know, it’s a small step, but it sort of adds to that personal touch, um, and that one-on-one contact that you want to gain with your patient because you want them to come back. You know?”[P001-q12]

“They didn’t need to give me a lot of extra attention and time. But they didn’t create any kind of personal connection where I would even look forward to going back so I could say hi to that person again.”[P001-q12]

**Sub-theme: Be More Sensitive**
Being more sensitive is defined as wanting the oncologist and nurses to be more sensitive by being less judgmental based on physical appearance alone, and being more encouraging to convey acceptance.

“I don’t think I would say anything about my weight or their weight. I would just tell ‘em that they have to be a little more sensitive. You know? That’s all. How big they are.” [P003-q12]

“Well, just to be sensitive, I guess. You know, I – I felt that my doctor was certainly sensitive and didn’t make any kind of big deal about it. But I know as far as cancer and being overweight, you know, that if you’re grossly or extremely overweight, it really can affect the whole thing. I mean, I don’t know that much about it, but – Right. So anyway, I would hope that any doctor would explain that to the–ah, to the patient and – and – and show a lot of sensitivity as far as that, which I felt my doctor certainly – certainly did.” [P008-q12]

“Well, if I were going to talk to a physician caring for an obese cancer survivor, I – I would just encourage him or her to find some way to compliment. Um, and not just because of their – their spirit of survival or toughness of beating this cancer bug, but I would say right away to actually make them feel beautiful physically on the outside. Um, ‘cause a lot of people with cancer get cut on, and there’s a whole issue of – of alteration of body image that we learned about when people get cut on. Right? And not all cancer patients get cut on, but a lot of ‘em do. If you have that on top of the fact that, you know, you may not be feeling like you’re going to get the right kind of care or the best kind of care or the best kind of attention, um, because – because you’re obese. And what if
you’re – what if you feel like people don’t want to be around you, you know, if you’re – if you’re that obese or something? Um, that would be horrible.” [P004-q12]

“So I would say to the doctors find a way to compliment, find a way to boost their – their image of themselves.” [P004-q12]

Sub-theme: Ignore the Stereotypical Weight Related Labelling

Study participants described wanting their oncologist and nurses to look beyond the size of the physical body and ignore the stereotypical weight related labeling.

“Look past the person’s weight and look at the person and the disease that you’re dealing with. It’s like it’s a life – it’s bad enough to be overweight, but it’s a life-altering thing to find out that you have cancer, and you don’t – I want help with that at that time. I understand the other part needs to play into it, too, but I need you to focus on the cancer at that time.” [P006-q12]

“I guess I would just – if I could just – if I could be a thin person and go up to them and say, “You know, when you talk to your fat people (laughter), treat them just how you would like to be treated. Don’t treat them differently.” [P007-q12]

“Make sure to treat me just like any other patient that you have. And regardless of the weight I might be carrying that the main concern is not how I got here, but how I’m going to survive and, you know, take care of what – what I need to have taken care of. So radiation, the surgery, you know, that’s the main focus. It’s not how I got here.” [P009-q12]

“Um, I mean, I think there are a lot of different causes of, um, being overweight and obese. And, you know, having dealt with the hypothyroid and all the endocrine problems,
“Um, I think instead of, you know, any kind of – you know, I guess helping the patent try to find a cause to it would be the most helpful instead of any judgment.” [P010-q12]

Sub-theme: Weight Bias Self-Perceptions and Assumptions

One participant described her assumptions and self-perceptions regarding a comparison to themselves to others who are overweight and obese.

“Um, I guess the perception of them doesn’t have to be – it’s not about their weight. This – or self-perception is about who you are, not about what you look like. Does that make sense? Yeah, right. And I – I do it myself. I look at people and think am I that fat? Or am I as big as she is? Cause she’s big and then I think – I think I have it myself. You know? People assume things about, um, people that they don’t know. Do they sit around and eat donuts all day? Do they even try? You know, what’s their – why are they in the situation they are in? It’s like driving by a homeless person. How did they lose – lose their home? And I guess for an obese person how did you lose your body? How did it overcome – how did the weight overcome? You know what I mean? You know, you feel better if you’re lighter. Your health is in better shape if you’re lighter. You look better. You feel better. Your clothes fit better. That kind of thing. Yeah. Would it be – would it be fair to say judgmental? Don’t be judgmental – -- based on physical appearance” [P002-q12]

Question 13: If you could tell another cancer survivor who is overweight or obese one thing what would you say?

Major Theme: Honor Thy Self

Honor thy self was defined as validating to oneself that tenderness and excellent care is needed and deserved and if the type of care isn’t provided, one should move on. Other subthemes
included love and focus on yourself, focus on body size, due diligence, and societal perspectives on weight and cancer. There were 4 sub-themes identified.

**Sub-theme: Survivorship Validation**

Study participants described their experiences with provider weight bias as something you shouldn’t have to deal with and if you are not feeling the love from your provider than find someone else. Thinking in terms of honoring themselves and not making excuses for yourself or your provider was defined as validating that this is their survivorship, their body, and it is just as important as anyone else’s body that is fit and trim.

“*Um, I guess I would say if you are having problems – you know, sort of a doctor that you do feel has a bias, then find another doctor. (Laughter.) You shouldn’t have to deal with that.*” [P010-q13]

“*You know, if you don’t feel loved by your physician, find somebody else.*” [P004-q13]

“*Um, no, I guess it’s just persevering and, yeah, getting through it and wanting to be the healthiest I can be –-- now that I’ve been through it, but still not blaming myself for it. I mean, there’s things that just happen. Right.*” [P009-q13]

“*To, um, think of yourself. Like I don’t want to say – ‘honor sounds so cheesy – but basically treat yourself as you – you would treat anybody. Like don’t make excuses for yourself. Don’t think that you’re less than. That your survivorship, your body, it’s – it’s just as important as, you know, someone who, you know, is a – a runner and perfect BMI. That everything is valid. Um-hum. I think honor self is a good phrase. You know, what you had said. And – and to validate that, you know, you are just a person going through the same things. Um-hum (affirmative). I need the same care and tenderness and excellent care. I feel like my radiologist oncologist, he never addressed my weight. And I*
just felt like there’s a lot of care there, a lot of handshaking, a lot of listening. Um, yeah. I mean, I guess if they did it in a way that was – I just don’t – hmm. ‘Cause we’re always beating up ourselves anyway, so I don’t – I just want to be treated normally, but I don’t know how that balance would be for me. “[P009-q13]

“No. Just – I mean, the biggest thing is when you do get cancer, I take every single morning -- when you wake up, you’re thinking about it and happy and you’re awake. Yeah. Even the doctors, you know, they don’t ever say you’ve got a year to live or a day to live. They just say you’ve got a time before your time is up –-- if we can’t get it out. You know? So that’s about what you think of, I think, every moment at the time. No. No, I don’t. Every – I’ve been clear so far for quite a while, so I don’t think about it anymore, except now that (name reference) died of lung. You know? No, I don’t hardly think of it at all except when I see somebody that’s overweight. And then I try and tell ‘em, you know, colon, ah, lung – there’s quite a few things cancer-wise, so please just change your diet a little. Yeah. Yeah, I had no idea except my physical was once a year, and that’s when he said, “Wow, you’ve got colon cancer. We have to remove it.” And treating wasn’t going so great, so he said, “Okay, it’s time to remove it.” And I said, “Great.” This made great sense. But I have it checked every year. I have a physical every year to make sure. Yeah. They’re all military doctors, but, yeah, I like ‘em. You know, I retired out of the (military branch reference) twenty years. So everything is military.”[P006-q13]

“Cause when I was planning to get a mastectomy before I changed my mind, I saw a plastic surgeon and she was taking pictures. And I said, “You know, there’s – I’m thinking also about besides a mastectomy of getting a breast reduction.” She was like,
“Oh, there’s no way. Your – your breasts are so long and heavy that there would be no blood supply.” She’s just looking at my breasts like are you – like just dismissing me a hundred percent. And she was clearly weight biased. It was disgusting. And my surgeon that I saw down in (geographical reference), he was amazing. He said, “Oh, of course we can do this.” And – and he was gentle and sweet. And he actually took pictures of the results, and he was like, “I’m not going to publish these on the internet or anything, but this is great work.” (Laughter.) So that was a totally different experience. “[P009-q13]

“And really, looking back, I should’ve had a mastectomy back then and that could’ve – you know, let’s just say it was a really good experience with her and let’s say she had been kind and said, “You know, maybe this can work. I don’t know, but really we’re looking at” – you know? What if my whole trajectory had been different because of that experience? I don’t – I’m not going to blame her, but let’s just say. Cause I was on the schedule. Yeah. And even prior to that. So when the women are getting their mastectomy -- you know, at that level. Or they’re being consulted. Even before you get to the chemo and the radiation – “[P009-q13]

Sub-theme: Love and Focus on Yourself

Being good to yourself and staying positive was defined as ways to focus on loving oneself because one cannot change the cancer diagnosis.

“Be good to yourself. Don’t worry about your weight at all. You have much bigger things to think about. Stay healthy, you know, try to get fit, and don’t worry about your weight. You take care of yourself and be good to yourself.”[P007-q13]
“I would – I would have to say just focus on yourself. Um, I don’t know how to explain it. For me, cancer – it’s like, yes, it’s an ugly disease. It made me change my life to where – for the better. And I know that might sound crazy, but it also – I look at it as my glass is half full, not half empty. I’d much rather have breast cancer than brain cancer. So for me, I just would say take what you have and make the best of it ‘cause you can’t change it and you have to definitely fight.” [P006-q13]

“I would just say keep fighting, but loving yourself. I think I would say the same thing to nurses. Find a way to compliment and help them feel better about their image. Their – you know, image can be inside and outside.” [P004-q13]

Sub-theme: Focused on My Body Size

Study participants described experiences related to constantly thinking about their external body size image and how they internalize body image into everything in life. This was also defined as putting up a defensive stance.

“But for sure include the outside in that because they are, um, you know, probably going to innately be associating some of their thoughts with their – with their external image, especially if you’re overweight in today’s society – in this society – in this culture.” [P004-q13]

“Um, don’t let your – if you are an overweight or obese person who has body image issues and, ah, you know – you know, low self-worth or whatever related to that – and I have yet to meet, ah, one who doesn’t – um, don’t let that keep you from seeking and getting the – the care that you need or that you should have.” [P001-q13]

Sub-theme: Due Diligence
Due diligence is thought of in terms of doing what is necessary to achieve good cancer outcomes (e.g., following the instructions of the oncologist, keeping all appointments and maintenance follow-up treatments, asking questions, and doing one’s own research on the disease.

“Ah, just follow your doctor’s instructions and care, you know, as closely as you can. Keep all your appointments and, you know, the whole thing.” [P008-q13]

“And if you’re not comfortable with something or something that a doctor or nurse – research it or ask someone else. There’s no stupid question.” [P006-q13]

“Well, just to, um, make it a point to, um, eat healthier, get some exercise. Those kinds of things. And hopefully they’ll be okay and, you know, the cancer will be gone. Prevention.” [P002-q13]

“I don’t think I’d tell him anything about his care because that’s – each doctor is different and every nurse is different. So I would, you know. I said that I don’t think that I would tell him anything of how to – what to expect from a doctor or a nurse. That would be their – you know, different people expect different things.” [P003-q13]

“And they probably worry about them not eating enough. And to tell you the truth, even though it’s not healthy to be overweight, it’s actually helped me in my triplet pregnancy and with chemo so that I didn’t waste away. You know, I had some weight to fall back on. So that’s where I’m trying to see the silver lining in it. But if I was, you know, a hundred pounds less, I’m sure that wouldn’t have even been a topic.” [P009-q12]

**Sub-theme: Societal Perspective on Weight and Cancer**

One participant described a situation where a thin and weight conscious individual commented that eating is a probable cause for being overweight, obese, and getting cancer.
“I mean, a woman made a comment like – she was really thin and weight conscious – and she said, “Well, maybe you should’ve gotten those organic apples after all.” And I said, “You know, there are vegans and people who run every day and are perfect weight who get breast cancer.” So, you know, there you go. She was horrible. Yeah. No. I was so traumatized. I – the whole – that really – it was horrible. I left crying. I never went back. It was just – I was mortified.” [P009-q13]

Question 14: Is there anything else you’d like me to know about your experience(s) with weight bias?

Major Theme: No Additional Comments

The study participants had nothing more to offer as far as experiences or comments. There were no sub-themes identified.

Conclusion and Final Data Reduction

After completion of the analytic process, the final 14 major themes and 82 sub-themes were reduced to a more parsimonious set of three overarching themes (see Figure 2). The first theme, weight bias and the clinical appointment, was derived by analyzing the responses and sub-themes related to forms of weight bias and the actions by the physicians and nurses. Clinicians responded to survivors’ personal size during clinic encounters with non-caring behavior, negative verbal and non-verbal language, and a lack of emotional and tangible support. The second theme, labeled as overweight or obese and internal self-perceptions, was derived by analyzing participants responses and sub-themes that were related to their perceptions of health, reactions to their cancer diagnosis, being labeled as overweight or obese, and their self-reflections on the meaning of weight-bias. The third theme, barriers to care and changing the current state of oncology practice, was derived by analyzing the participants responses and sub-
themes related to the satisfaction with their overall cancer care which also included how to
decrease the presence of weight bias during the medical encounter, having appropriate sized
equipment and supplies, and remaining true to themselves; all equally important in changing the
current state of oncology practice. Though this research study specifically concentrated on
participants illuminations of provider weight bias, it is noteworthy to recount the study themes
and sub-themes previously mentioned, denoting the participants’ positive experiences with their
overall cancer care.

Finally, one single overarching theme; lack of providing holistic, supportive, and
sensitive care; was identified to depict the entire codebook and the phenomenon of interest; the
experience of being an overweight or obese cancer survivor. The lack of providing holistic and
supportive care included carefully listening to the survivor to fully understand and gather all data
for assessment purposes prior to implementing a plan of care. Holistic and supportive care also
implied the clinician should look at the whole person, including any weight related and
comorbidities issues; and provide resources, education, and guidance to benefit the survivor.
Sensitive care should be purposeful, culturally congruent, and leave a lasting impression of
acceptance. The cancer survivors in this dissertation study wanted to beat the survival odds, but,
believed barriers to care from a weight bias perspective made it difficult to continue their cancer
care and follow through with subsequent maintenance appointments.
Figure 2. Experiences of Being an Overweight or Obese Cancer Survivor

EXPERIENCES OF BEING AN OVERWEIGHT OR OBESE CANCER SURVIVOR

Reduction of 14 Major Themes

1. Inappropriate Sizes
2. Weight Bias
3. Changing the Current State of Oncology Practice
4. Honor Thy Self
5. Satisfaction with Overall Cancer Care

11. Self-Reflections on the Meaning of Weight Bias
12. Labeled as Overweight or Obese
13. Perceptions of Health
14. Reactions to Cancer Diagnosis

Final Overarching Theme
LACK OF RECEIVING HOLISTIC, SUPPORTIVE, & SENSITIVE CARE

Sandra Wyrick PhD Dissertation Chapter 4
Diagram 2: Reduction of Categories of Major Themes and Sub-Themes Codes for Q1-Q14 for all Participants
CHAPTER FIVE
SUMMARY OF FINDINGS, IMPLICATIONS, AND CONCLUSIONS

SUMMARY OF FINDINGS

This dissertation study examined the question, “What are the weight bias experiences of overweight or obese cancer survivors?” The descriptive phenomenologic study collected data to describe the demographic and disease characteristics of the participating sample. Narrative-based themes were explicated pertaining to the nature of oncology providers’ weight bias as experienced by 10 survivors with a Body Mass Index (BMI) of 25 or greater. An adult who has a BMI between 25 and 29.9 is considered overweight and adult who has a BMI of 30 or higher is considered obese (CDC, 2014). This chapter presents the research study summary of the overarching themes and thematic findings, implications for healthcare oncology providers standards of practice, implications for the medical/nursing care of overweight or obese cancer survivors, conclusions with lessons learned, and needs for future research. For the purpose of this research study the definition of healthcare oncology providers describes oncology physicians and nurses.

Overarching Themes

An earlier study of female overweight patients and their experiences with their healthcare oncology providers indicated that patients had feelings of being dismissed by their healthcare oncology providers and being treated as though they were not quite human (Merrill & Grassley, 2008). Similar findings were reported in this study by overweight and obese cancer survivors in their interactions with their oncology providers Analytical coding resulted in the identification of 14 major themes and 82 sub-themes. Data reduction resulted in a parsimonious set of 3 themes: (a) weight bias and the clinical appointment, (b) labeled as overweight or obese
and internal self-perceptions, and (c) barriers to care and changing the current state of oncology practice. One single overarching theme was identified to explain the entire codebook and the phenomenon of being an overweight or obese cancer survivor: lack of receiving holistic, supportive and sensitive care (see Figure 2). Phul (2014) found that believing and accepting weight related social stigmatizations promotes an environment of intolerance and prejudice, ultimately leading to the unfair treatment of the overweight and obese individuals. This reported intolerance is consistent with the outcomes of this study which includes lack of holistic, supportive and sensitive care.

Study Participants’ Health Status and Disease Characteristics

The study participants described themselves as being functional and healthy now as compared to how they felt previously while going through cancer treatments. One participant described feeling healthy as:

*I’m going through radiation. And I went through eight rounds of chemotherapy. I don’t have nausea. I’m just kind of dealing with a little bit of neuropathy in my feet. Um, my fingernails are kind of weird. But overall, compared to how I felt in treatment, I feel a lot better. I mean, comparing myself to how I felt a month-and-a-half ago, I feel fantastic.*

Reference groups, such as others of similar age or the number of medications one takes in a day, provided a context for evaluating one’s health. A 79 year old participant noted:

*Right now, I’m (age reference) years old and – and I think my health is pretty good. I have to take three pills every day, but otherwise my health is – I think it’s outstanding for my age.*

On the other hand, participants defined unhealthy as being the “wrong size,” - in a word, fat. Research indicates the risk of breast and other cancers is higher among the obese population
(DeSantis, Siegel, Bandi, & Jemal, 2011). Obesity contributes to 15-20% or as many as 1 in 5 cancer-related deaths in the U.S. (Hudis, 2014). The participants situated cancer in the broader context of being afflicted by obesity and comorbidities. A key finding to this study is how overall, participants attributed being unhealthy as a consequence of their weight and medical comorbidities, rather than due to cancer. This paradox is illustrated by one participant:

*I think my health is pretty good. I am obese. That’s my biggest health issue. And if I wasn’t, probably some of my other, um, medical problems would be better. But, um, I feel healthy. I feel strong. Um, I have some aches and pains that limit me in doing some physical activities, but otherwise I feel good.*

The participants’ comorbid conditions included diabetes, high blood pressure, neuropathy, sleep apnea and a subsequent secondary cancer diagnosis. Camden (2009), states being overweight and obese comes with an array of significant and serious comorbidities. Of the top 10 leading causes of mortality in the U.S., five are related to obesity including; cancer, heart disease, stroke, diabetes, and kidney disease (Ng et al., 2014; Schmitz et al., 2013). The attribution that participants’ believed their comorbid conditions and obesity was more salient than cancer at this time in survival appears to support the aforementioned literature that links cancer with obesity and comorbidities.

**Satisfaction with Overall Cancer Care**

Participants described satisfaction with overall cancer care as being adequate to high. Adequate was not the same as being completely satisfied. Satisfaction meant having amazing nurses and doctors, good outcomes/results, and getting to the cure no matter what one had to endure. The degree of trust in and satisfaction with the doctor and nurse has been shown to have important implications for cancer treatment outcomes (Holwerd et al., 2012). One participant
described adequate care as; “Well, number one, my cancer was cured, so that’s very satisfying. And, um, I felt like the care I received was, ah, professional and adequate.” A participant described adequate care, but, added some suggestions for oncologists: “Overall, the care was, um, adequate. I think it could’ve been handled differently in different aspects of when they told me that I had cancer and how they told me I had cancer.” Some expressed mixed feelings about their surgical oncologist versus their medical oncologist; however, their reasons for dissatisfaction were vague.

Unsatisfactory care was signified by a lack of communication between the oncologist, nurse and survivor, even if the cancer was cured. The literature suggests that cancer survivors continue to have unmet communication needs, and communication outcomes are enhanced when the emotional needs of survivors is met (Hack, Degner, & Parker, 2005). Effective communication skills between healthcare oncology providers and cancer survivors improve the survivors understanding of their cancer and adherence to treatment regimens (Back, Arnold, Baile, Tulsky, Fryer-Edwards, 2005). Common pitfalls (e.g., blocking, lecturing, collusion, and premature reassurance) can lead to mistrust and dissatisfaction (Back et.al., 2005). Unsatisfied participants described up and down experiences with their oncologist and a lack of communication by both nurses and oncologists about what type of treatment side effects to expect. Cancer survivors often rely on their healthcare oncology providers to provide them with not only decisional support but also social and interpersonal support throughout their cancer journey (Arora, 2003). Back et.al. (2005) noted that that the communication skills learned in medical school focus on the medical, social, and family history or “medical interview.” Back et al. asserted these are not the communication skills required in cancer care such as having attentive listening skills. Furthermore, healthcare oncology providers typically miss the full
range of concerns held by the cancer survivor which increase psychological and existential suffering.

One oncologist described to a participant their dislike of individuals who were overweight, in a non-direct manner, by talking about her own family member: “*she (the healthcare oncology providers) was talking about how her daughter is overweight and all of the issues with that she did not approve of.*” The participant felt it was a non-overt way of saying that she did not like it when individuals are overweight. Healthcare oncology providers typically miss the full range of concerns of the cancer survivor (Back et al., 2005). However, in this study, almost nothing was mentioned about oncology nurses. This finding is at odds with the literature on patient satisfaction with oncology care in which nurses are often identified as meeting difficult patient psychosocial and physical needs. For example, Winters, Miller, Maracich, Compton, and Haberman, (1994) ascertained from an examination of nursing progress notes how a new psychosocial nursing paradigm for the care of marrow transplant recipients offers a useful framework for delineating significant psychosocial needs and improving patient and family satisfaction. Additional evidence from a study of 1,024 cancer survivors of mixed diagnoses found 53% of the study participants indicated their emotional needs were harder to cope with than their physical needs (Gates, Seymour, & Krishnasamy, 2015).

Healthcare oncology providers – patient interaction is of great significance in the delivery of cancer care. The data in this study supports the evidence in the literature that implies a healthcare oncology providers’ bias against overweight people impairs their ability to communicate with their overweight or obese cancer patients. There is a growing body of research demonstrating how the healthcare oncology providers-cancer survivor interaction
positively impacts patient health outcomes such as satisfaction (Arora, 2003). Throughout the cancer journey patients often rely on their healthcare oncology providers to provide them with information, decisional support in selecting treatment options, and social and interpersonal support (Arora, 2003). Yet research findings show that both healthcare oncology providers and nurses feel ill-equipped to treat individuals with obesity and believe that treatment for this patient population to be futile (Phul & Heuer, 2009).

**Being Diagnosed with Cancer**

When told of the cancer diagnosis, participants described being frightened and uncertain if treatment would cure or ultimately result in recurrence and death. One participant described the metaphor of driving along on a sunny day and suddenly the car drives off the bridge. Another participant described the diagnosis as being predictable due to family history and it was never a question of “if” a diagnosis would be made but only a matter of “when and what type” of cancer. Overall, fear was connected to uncertainty about the future.

Participants’ described the diagnosis as a scary nightmare accompanied by a constant unnerving feeling that never went away. Most participants reported a strong desire of not wanting to die, yet felt their days were numbered. They contemplated how many days were left. One participant quantified this in terms of being around to see her child grow up; “You start thinking about, you know, will I be around to see my child grow up? Will I be at the next family dinner? You what if a lot.” Another participant expressed being happy to be alive and thankful to God; “So when they told me I had cancer, I said thank God I was alive. So I was happy. I was fine [referring to the alternative diagnosis of paralysis].”
Being diagnosed with cancer lead to self-blame which was attributed to weight issues and regret for not complying with preventative, follow-up and maintenance appointments. Participants shared their embarrassment and self-consciousness regarding their weight at clinic appointments;

*I decided not to continue following up after that, even though, ah, annual follow-up for the rest of my life is what was recommended. Well, because it would involve a pelvic exam every time, which I felt was somewhat of a – and a visit – an appointment. So it takes time out of my day; time out of my life.*

Additional participants shared:

*I don’t like going to the doctor. I hate going (laughter) when I’m going to have to be undressed.*

*Um, probably the fact I really object to go in and get naked – cause that’s what you have to do with melanoma. They have to check you head to toe. And to do that is harder. Ah, if I had a beautiful body, I could drop my gown and go, here I am.*

Saegrov and Halding, (2004) described getting the diagnosis of cancer as being a very dramatic experience with a constantly looming threat of new cancer cells being detected at any time in survival. The findings of this study are supported by the evidence in the literature indicating patients had lower anxiety levels when they were prepared for the possible diagnosis of cancer. Preparing a patient to receive the diagnosis of cancer demonstrates good patient-centered communication (PCC); which the Institute of Medicine states as essential to improving healthcare delivery (McCormack, Treiman, Rupert, Williams-Piehota, Nadler, Arora, & Street, 2011). Measuring communication in cancer care was recently studied where study findings resulted in six core measurement domains specified in the PCC conceptual framework to include; (1) exchanging information (2) fostering healing relationships, (3) recognizing and
responding to emotions, (4) managing uncertainty, (5) making decisions, and (6) enabling patient self-management (McCormack et al., 2011). Case in point; in a recent study of 138 patients’ attitude toward breaking bad news, results indicate that 90.76% of participants believed they should be informed about their ongoing medical condition and receive the unwelcome news of having cancer (Aminiahidashti, Mousavi, & Darzi, 2016). They also believed that the most experienced healthcare oncology providers should inform them of the cancer diagnosis and do so in a suitable calming place; not in the emergency department or during teaching rounds (Aminiahidashti et al., 2016).

**Weight bias**

The concept of weight bias as expressed by participants is complex. Biases included elements of being pre-judged, stereotyped, and discriminated against for being overweight and obese. Participants identified a lack of control related to their weight. Survivors who perceived they were treated differently than those of normal weight reported oncology providers conveyed negative discrimination behaviors. The concept of weight bias by medical oncology providers is best defined as discrimination and prejudice which conjures up feelings of stigmatization which can act like a barrier to healthcare management; resulting in the avoidance of routine preventive care and/or diminished compliance to treatment (Puhl & Brownell, 2001; Teixeira & Budd, 2010). In a survey of 498 overweight and obese women, 68% reported they delayed healthcare because of their weight and 83% reported their weight was a barrier to getting appropriate care (Amy, Aalborg, Lyons, & Keranen, 2006). Additionally, in a study of 216 women, findings indicate that BMI is associated with an increase in the delay and avoidance of preventive care and participants gave reasons for avoiding medical appointments including; not wanting to be
weighed, having gained weight since their last visit, undressing in the exam room, and knowing they would be told to lose weight (Drury & Louis, 2002).

Discrimination is when there is a conscious decision made to treat a person or group differently and deny them access to treatment or care to which they are entitled (Farlex, 2012). Discrimination has been shown as a major causal factor in health disparities (Crawley et al., 2008). One participant stated:

*Well, when I hear weight bias, I really think of somebody discriminating against somebody else because of their weight. So they’re not treating them the same, or they’re altering the way in which they interact with someone based on their weight.*

Discrimination as it relates to medical care practice is defined as differences in care that result from biases, prejudices, and stereotyping (Crawley et al., 2008). Consequences of weight bias include becoming more vulnerable for depression, anxiety, having low self-esteem, poor body image, and even suicidal acts and thoughts (Rudd Center for Food Policy and Obesity, 2008).

Participants described experiences of feeling uncomfortable due to their size not fitting society’s norm, when seeing their oncologist and nurses. Larger sized individuals felt discriminated against and stereotyped as being not intelligent, lazy, not healthy, and ugly; in a word, flawed. Participants expressed they felt socially unacceptable and flawed due to being heavier. Being flawed is an interesting choice of language since it conveys weight bias discrimination and stereotyping. One participant noted:

*I think about the old stereotypes. You know, if you’re not a perfect stereotypical size, whatever it is in fashion, you know, under 25 BMI, then, you know, there’s a little bit of discrimination that you’re not healthy, that you’re not as intelligent, that basically you’re flawed.*
The finding in this study supports the evidence that weight stigmatization is a socially constructed, powerful phenomenon involving differences based on some distinguishable characteristic and consequent devaluation of the person as being of lesser value than “normal” people (Dovidio, Major, & Crocker, 2003; Malterud & Ulriksen, 2011). The participants in this study also recounted experiences of stereotypic depersonalization, marginalization and forms of prejudice. Yet healthcare oncology providers also report feeling professionally unprepared to treat weight issues including obesity with their patients (Puhl & Heuer, 2009). In a study of 398 nurses only 21.6% agreed they had effective skills in helping obese clients and of 400 dietitians less than half felt prepared to effectively manage obese clients (Puhl & Heuer, 2009).

Prejudice is a word that is strongly related to and commonly used in the same context as stigma. Prejudice can be thought of in the sense that the person who is stigmatized is usually the target of prejudice; defined as a “negative attitude” toward a group or individual (Dovidio, Major, & Crocker, 2003).

**Internal Conflicts**

Participants defined poor self-image as an internal conflict related to one’s weight and size. Being athletic and having a “good body shape” was defined as fitting the society norm for beauty and weight.

*So I have a lot of sort of – I struggle with my own image. And part of that was because before I had kids when I was young, I was what society would term today as athletic and had what society would say was a good body. And then after having kids and the hysterectomy and all the hormone issues that went along with it and then the cancer and all the carving up, I just didn’t feel good about myself.*
Overweight or obese survivors faced a constant battle with their own self-image that was threatened by what cancer was doing to their bodies. One participant described it as an internal conflict, comprised more of psychosocial and emotionally charged components than ones pertaining to their cancer treatments and medical care. Individuals suffering from body image disturbance often experience dissatisfaction with their weight and/or body shape (Harriger & Thompson, 2012). Similar to the previous theme that described participants’ evaluation of their health status, the internal conflict from weight bias discrimination and being stereotyped seemed to be the more prevalent issue surrounding survivorship; rather than the cancer in and of itself. One participant described this struggle as being second nature, “feeling uncomfortable in one’s own skin for so long that it’s like second nature; not something any one should have to put up with.”

The findings of this study are supported by the evidence in the literature that describes how body image is an important component in how cancer survivors evaluate their quality of life. Cancer treatment may result in major disfiguring changes in appearance. Being overweight and obese is associated with an increased risk of negative psychosocial experiences that may contribute to alterations in body image, body dissatisfaction, low self-esteem, and depression (Harriger & Thompson, 2012). In study of 93 obese adults study participants, frequency of weight stigma experiences was positively associated with depression and a higher level of body image distress (Friedman et al., 2005). To increase the quality of life outcomes and promote psychological well-being, changes in clinical practice must be explored. Implementing a Mindful Attention Awareness Scale (MAAS) in oncology practice with cancer survivors is one tool that can be utilized (Brown & Ryan 2003). A more in-depth description about MAAS can be found in the Implications for clinical practice section of this chapter.
**Desire to Live**

Living was a very emotionally charged desire expressed by the study participants. The desire to live included taking back control regardless of the effects one’s personal actions had on one’s body image. One participant who was undergoing multiple surgeries for skin cancer removals stated:

*I had this deep, deep desire to not have anything missed and to be alive for my kid. Like, I shaved my head. But it wasn’t because I was going to lose my hair because of chemotherapy, because I didn’t have any of that. I have a one-year-old and I have a two-year-old. I – I need you guys to be looking at every fricking mole on top of my head and not missing anything. And so I actually took my hair off.*

The desire to live is relative to one’s own developmental stage in life and the desire to be present for family and/or friends. Towsley, Beck, and Watkins (2007) characterize the desire to live as a coping process called “learning to live with it (cancer).” The desire arises from the cancer survivor’s previous life experience, attitudes and personal sense of self, overall coping strategies, and intervening positive or negative factors.

Study findings for these participants are supported by evidence in the literature in that the survivors’ coping strategies was key in their will to live and beating the cancer odds. Lovely et al. (2013) found that living with the cancer diagnosis and its consequences require cancer survivors to take back control of their lives by adapting and coping to the new realities of their lives (Lovely et al., 2013).

**Addressing the Elephant in the Room**

The study participants described their oncologist and nurses as omitting the subject of weight by not acknowledging it is the elephant in the room, further defining this omission as a
disservice and something that should be openly talked about in a sensitive manner. One participant summed it up by saying:

Well, I think don’t ignore – in terms of the conversation you have with the patient, don’t ignore the fact that the person is overweight or obese. Sort of like the elephant in the room thing where you’re talking about everything else but that. Um, particularly if their cancer or whatever their health issue, you know, it’s related to their weight.

The evidence demonstrating how weight bias discrimination and associated stigmatization are encountered in the daily lives of overweight and obese individuals suggests the same discriminant encounters occur in clinical settings (Puhl et al., 2008). Similar to the previous theme of Lack of Support, participants felt oncology providers blamed and faulted them for causing the cancer due to their weight status and lack of food intake control. As one participant stated:

Look past the person’s weight and look at the person and the disease that you’re dealing with. It’s like it’s a life – it’s bad enough to be overweight, but it’s a life-altering thing to find out that you have cancer.

Participants indicated that their oncologist and nurse omitted the option of weight loss or lifestyle modification programs and failed acknowledgment of patients who underwent weight loss surgery. Healthcare oncology providers communicate weight bias discrimination when they associate negative traits and assumptions with obesity and this can include omissions of treatments and services (Rudd Center for Food Policy and Obesity, 2008).

An interesting paradox related to cancer clinical practice and weight bias was discovered in this study. Oncology providers compartmentalized treatment options by placing cancer treatments and care plans on center stage while not addressing the “elephant in the room,”
meaning survivors’ weight problems. A gap in providing holistic care and addressing the comorbidity of overweight or obesity fractured the delivery of cancer care. As one participant observed:

*It’s OK to tell me I’m overweight but do so in a way that couches the issue in non-threatening ways. My obesity is multifactorial and not due to a single cause. Think of me as a holistic being that is more than my estrogen levels.*

Healthcare oncology providers communicate forms of weight bias when they associate negative traits and assumptions with obesity (Rudd Center for Food Policy and Obesity, 2008). Medical oncology providers and nurses must be cognizant of the fact that weight bias is recognized as universal and no longer limited to those seeking bariatric surgery and weight loss treatments (Teachman & Brownell, 2011). Putting the culture of obesity and obese patients within the context of culturally congruent care can minimize barriers; therefore, healthcare oncology providers must address cultural issues unique to their patient population (Gelhert et al. 2014).

Current research demonstrates that healthcare oncology providers express negative attitudes toward overweight and obese patients that can be conveyed through weight-related language (Puhl, Peterson, & Luedicke, 2013). Addressing the proverbial elephant in the room, ‘weight’, is difficult subject to broach for any healthcare providers. It is crucial to provide holistic care that includes cultural beliefs and practices as well as medical aspects of care to motivate change rather than stigmatize weight. In this study, the healthcare oncology providers’ judgement related to their patient’s being overweight seemed to overshadow the interaction to the point of negating the value of common sense, basic medical diagnosis and education. One participant states:
But even, um, I guess not acknowledging the weight is a --- I don’t know if that – Yeah. It’s like we’re not going to talk about the elephant in the room, you are overweight and here’s the facts. It doesn’t mean that you’re a bad person, it’s just that, you know when you’re done with treatment, and you can work on getting to a healthier weight.

It is as if oncology providers’ focus on cancer care doesn’t include dealing with weight issues, so blame obesity on something out of one’s control like genetics and hormones. One participant described this blaming type of attitude by stating:

“It’s OK to tell me I’m overweight but do so in a way that couches the issue in non-threatening ways. My obesity is multifactorial and not due to a single cause. Think of me as a holistic being that is more than my estrogen levels.”

Research evidence supports how obesity can alter healthcare oncology providers’ ability to accurately perceive the attitudes of others during interpersonal interactions; (Gudzune, Huizinga, Beach, & Cooper, 2008). Noteworthy, is that all of the study participants admitted to self-seeking life style modification programs and/or weight loss support groups with no encouragement from nurses or healthcare oncology providers. There is no data on whether the participant told their healthcare oncology providers that they sought weight loss support on their own. Additionally, all participants shared a lack of success with weight loss and needed guidance. Perhaps we can deduce that a missing component to their weight loss success is that support/encouragement from their health care professionals.

Positive Experiences

Noteworthy is the emergence of study themes denoting the participants positive experiences associated with their cancer care. One participant experienced a sense of happiness
for the weight loss during chemotherapy treatments even though the treatment side effects included debilitating nausea and neuropathy.

Okay, so, um, at this time, I’m cancer-free and, um, I’m going through radiation. And I went through eight rounds of chemotherapy. The last treatment was on the first of October. I’m getting my energy back. Um, everything’s kind of back to normal. I don’t have nausea. I’m just kind of dealing with a little bit of neuropathy in my feet. Um, my fingernails are kind of weird. But overall, compared to how I felt in treatment, I feel a lot better. I actually lost weight. I wasn’t supposed to lose more than four – five pounds, but I lost about fifteen pounds during treatment.

Being satisfied with their cancer care was defined as positive experiences.

I have – I’ve had very good results with my cancer care. I think I’ve had really good care

So I was very satisfied with my cancer care. It was several years ago, though. You know, as cancer goes, you have to have checkups the rest of your life. So I’m at the annual stage of checkups and, um – but when I was back to where I was going through all of the stuff associated with it like in the acute level, I was very happy with my care at the time.

Another participant described cancer as a happy surprised and feeling blessed as she was going into neck surgery with the potential risk of ending up paralyzed for life and instead finding out everything was “all fixed” but the diagnosis was cancer, equating the cancer diagnosis to a blessing to hear she had cancer and not a debilitating and permanent.

Well, I was very blessed. I went in with an injury to my neck. Um, x-rays showed that there was a bone missing in my neck, and I went into surgery thinking that my outcome would be – I’d be paralyzed or in a brace for the rest of my life. And when I came out of
surgery (laughter), I said – they said, “You’re all fixed, but you have cancer.” And so I said, “Oh, cancer’s not so bad.

Some of the study participants did not experience any blatantly overt forms of weight bias by their healthcare oncology providers and some study participants did not experience weight discrimination during their cancer journey: “No. Not that I can recall.” “No. No, they weren’t. No.” “No, I – I’ve never felt any discrimination whatsoever.” “Not that I can think of. I think so. I haven’t – I haven’t noticed anything or not that I can think of.”

Some study participants did not feel like they experience overt forms of weight bias and quantified this in terms of being able to carry their weight well; participants felt that because they did not have the typical obese body type was why they did not feel weight discrimination. Others described never feeling overt forms of weight bias from her oncologist or nurses during the course of her cancer healthcare.

“I’m not – my body isn’t that big. Somehow I can carry around a big load of weight and my butt can sit in a regular-sized chair. So I did not experience that. I did not feel like, you know, gee, I should’ve been in a bigger – a wider gurney or wider bed or something.”

“I don’t think that they’ve curtailed care for me or treated me any different with the cancer care because of my size. I don’t really think it has, I mean, at least for me. But like I said, I think I’m, you know, in the overweight category, but I think I – you know, if you looked at me, I don’t think that’s your first – like I said, I think I carry it reasonably well. So I really have felt that that’s really been an issue for me.

Discussion
Teachman and Brownell (2011) asserted that obese patients’ population are crossing the boundaries of mainstream clinical and hospital-based care throughout America as more specialty clinics emerge. This is demonstrated within the clinical oncology settings. What is also know, is weight bias permeates healthcare with subtle forms of provider weight bias including; prejudice, stigmatization, and discrimination (Dovidio, Major, & Crocker, 2003; Puhl & Heuer 2011; Rudd Center for Food Policy and Obesity, 2008; Rudolph, 2008; Teachman & Brownell, 2001). Believing and accepting these common forms of weight bias promotes an environment of intolerance and prejudice, which can ultimately leads to the unfair treatment of the overweight and obese individual (Puhl, 2014). With oncology care, weight bias can lead to inadequate or even improper care. By removing the weight stigma-related barriers to receiving cancer screenings and treatments, may help diminish the relationship between higher body weight and cancer mortality (Puhl & Heuer, 2009). Some questions can be asked. Are healthcare oncology providers giving-up on the survivor by not addressing weight loss, life style modifications or prior gastric bypass? Do oncologists, by virtue of their specialty practice, solely deliver cancer care, thereby, leaving the comorbidity of obesity to other health care providers to manage? These question warrants further research.

In essence, weight bias discrimination is when there is a decision made to treat a person or groups differently based on their size, and deny them access to the treatment or care to which they are entitled (Farlex, 2012). In this study, illuminated were participants’ many positive experiences in the overall aspects of their cancer care. However, the study’s findings also revealed and illuminated the need to change current oncology practice to include evaluation and support for the survivors’ efforts in weight loss and life style modification. A holistic approach to achieving care outcomes and improving overall cancer-related quality of life is optimal.
Another hot button issue related to how weight is addressed at the clinic appointment was participants’ hatred of the weight scale. There is an interesting paradox between being weighed at every appointment to obtain the current data on the patient at the beginning of every clinic appointment, with what one participant referred to sarcastically as, “a lovely reminder” of their obesity. Overweight or obese survivors being weighed in the middle of the publicly open hallway immediately puts up a barrier to wanting to ever return to their clinical appointments. This can also shut down communication and decrease trust in the doctor/nurse and survivor relationship and forms negative feelings and memories regarding going to the clinic appointments. The survivor has internally motivated feelings regarding weight bias discrimination and poor self-image regarding their weight which can derail the clinic appointment and put up barriers to future medical care. This is in part due to negative feelings and emotions that are conjured up based on experiences with weight bias discrimination. Case in point; in a study on the impact of weigh bias on healthcare utilization, study findings revealed participants reported barriers leading to delaying their healthcare was due to; (a) disrespectful treatment and negative attitudes from their healthcare oncology providers, (b) embarrassment about being weighed, (c) not having the proper sized equipment such as gowns and exam tables to be functional for their size, and (d) receiving unsolicited advice to lose weight (Amy, Aalborg, Lyons, & Keranen, 2006).

The key in providing quality, patient-centered care to obese patients is to include sensitive care and respect (Bejciy-Spring, 2008). Changing clinical practice to a holistic frame of practice by changing practice guidelines would entail anticipating and responding to the explicit needs of overweight or obese cancer survivors. A few suggested remedies include adding more privacy when getting weighed or weighing in at the end or middle of the
appointment and having appropriately-sized gowns ready for the patient visit to minimize exposure. Case in point, a study examining cervical cancer screening of obese patients reported embarrassment about their size or discomfort with the procedure and healthcare oncology providers, as the primary reason for not undergoing screening (Wee, McCarthy, 2005).

**IMPLICATIONS**

**The Clinical Environment**

Being sensitive to cancer survivors includes assessing the clinical room, equipment, and facility for equipment and supplies that accommodate overweight and obese patients. Being proactive and anticipating the needs of the survivor who is overweight or obese helps to decrease the perception of being different, in a negative way, as well as decrease feelings of embarrassment and humiliation by having to ask for larger sized items. Not every cancer survivor with the BMI of 25 or greater in this study had the body size that requires special oversized equipment such as chairs, beds, or exam tables. For those that did, findings were positive in that participants searched out and found clinical settings that provided appropriate sized equipment and supplies. However, there was no data to indicate how hard it was and how long it took them to find adequate accommodations to fit their needs.

Social stigmatization is characterized by dehumanization, aversion, marginalization, prejudice and stereotypic depersonalization, bringing with it consequences of deep-seated, negative personal, interpersonal and social costs (Dovidio et al., 2003). Oncologists and nurses have a responsibility to listen carefully to the cancer survivor to understand fully and gather all data for assessment purposes by reflecting on and adjusting their own beliefs and biases. Overweight and obese cancer survivors that face overt and subtle forms of weight bias are reluctant to seek medical care ignoring potentially life threatening symptoms and cancer
checkups (Gallagher, Brannan, & Davis, 2008; Huizinga, Cooper, Bleich, Clark, & Beach, 2009; Merrill & Grassley, 2008; Schwartz et al., 2003; Teachman & Brownell, 2001).

Recognizing that weight bias exists within a broader context of healthcare can help prevent weight bias discrimination that may be unintentionally communicated between the cancer survivor and the healthcare oncology providers (Rudd Center for Food Policy and Obesity, 2008). Current research demonstrates that health oncology providers express negative attitudes toward overweight and obese patients that can be conveyed through weight-related language (Puhl, Peterson, & Luedicke, 2013). A prime example of communicating weight-related language is by using either motivating or stigmatizing language. Findings from a national study indicate the terms weight and ‘unhealthy weight’ were rated most desirable and the term overweight rated as the most motivating to lose weight and the terms obese, morbidly obese and fat rated as the most undesirable, stigmatizing, and blaming language used by doctors and nurses (Puhl, Peterson, & Luedicke, 2013).

Weight bias can be conveyed overtly or subconsciously and can include a number of different forms of social stigmatization characterized by dehumanization, aversion, marginalization, prejudice and stereotypic depersonalization, bringing with it consequences of deep-seated, negative personal, interpersonal and social costs (Dovidio, et al., 2003). Many of the study participants reported some type of weight bias discrimination related to their experiences within medical care practices. These biases include feelings of prejudice and stereotyping. Participants’ described healthcare oncology providers as having preconceived notions, being pre-judgmental and putting a stigmatizing label on them. Discrimination has been shown as a major causal factor in health disparities (Crawley et al., 2008).

Clinicians
This descriptive phenomenologic study resulted in explicating the experiences of overweight and obese cancer survivors’ interactions with their oncologist and oncology nurses. This study advances the state-of-nursing-knowledge in providing a better understanding of why cancer survivors who are overweight and obese find dissatisfaction with care once a cancer patient, but reluctant to go to cancer screenings as well as feeling dissatisfied with their oncologist and nurses. One participant summed it up by stating:

*Like maybe I didn’t follow up for my annual checkup, you know, quite on time because I felt the need to like – I don’t know – exercise for a week before I went in. I think that if I were to be honest with myself, I think that it (referring to being overweight and weight bias) may subtly inform my wanting to go in for my follow-ups.*

Dissatisfaction included the use by oncology providers of stigmatizing language, both spoken and inferred through body language. As one participant stated; “*I really think weight bias does – it goes beyond that. It goes into all of the things that are never said, but that – but that someone who is overweight feels.*”

Additionally, the experiences of the study participants illuminates the effects of the power differentials between the healthcare oncology providers and cancer survivors related to weight bias discrimination. A power differential is the role difference between the health care professional’s authority and patient’s vulnerability; this directly affects the well-being of the patient (Baca 2011; Benjamin, 2004). Healthcare oncology providers must have an understanding of the therapeutic relationship between oncology providers and patient which is difficult without comprehending the dynamics of power in a therapeutic relationship (Benjamin, 2004). Within healthcare, the power differential is amplified by the physical, verbal, and psychological aspects of practice and at times is related to one’s own beliefs and biases; it can
include stereotyping, prejudice, and discrimination (Benjamin, 2004; Fore, 2006; Puhl et al., 2008).

The findings of this study provide several implications for clinical practice for the oncology providers that included (a) addressing education and resources not only for the survivor’s cancer but for their weight issues, (b) not rushing the appointment time with the survivor, (c) being cognizant of the non-verbal language that can look like non-caring behaviors, (d) avoiding stereotyping and depersonalization, (d) being sure to make statements regarding weight bias at the beginning of the clinical appointment to set the tone that the oncology providers are open to feedback and it is important that they make the visit as comfortable and trusting as possible, (e) treating the cancer survivor holistically while remaining sensitive their cultural needs, and (f) picking the right time to talk about weight and add a personal touch during their clinical appointment.

Theoretical Framework

The resounding single overarching theme is the lack in receiving sensitive, holistic care; addressing both the cancer diagnosis and weight issues. This thematic statement is supported by the theoretical framework guiding the process of inquiry for this research study; Leininger’s Theory of Culture Care: Diversity and Universality, also known as the Transcultural Care Theory (Sitzman & Eichelberger, 2011) and the Sunrise Model (see Figure 1). The current state of oncology practice needs to include a holistic approach to care for cancer survivors with BMI’s of 25 or greater. Oncologists and oncology nurses must incorporate self-evaluation of their beliefs and biases about weight and caring for the overweight and obese cancer survivor. Leininger’s theory validates practitioners’ assessing their beliefs and biases while incorporating the patient’s beliefs, values, and culture, in providing sensitive and culturally congruent care. This theory
reminds healthcare providers of the value in assessing one’s beliefs and biases while incorporating the patients’ beliefs, values, and culture in providing sensitive and culturally congruent care. Not only is this framework fitting for the oncology specialty but could be generalized and extend to overweight and obese patients seeking medical care. The study findings found the cancer survivors with BMI’s of 25 or greater have common beliefs, values, and rituals which are congruent with the structure of Leininger’s theory. Operationalizing Leininger’s theory as an approach in clinical oncology practice, would solidify a holistic and culturally sensitive approach to improving the care for the cancer survivor, who does not fit the norm for weight.

Epidemiologic studies have repeatedly confirmed the risk factors for incidence of cancer, cancer recurrence and higher mortality (Ligibel & Strickler 2013; Schmitz et al., 2013). Known barriers to satisfaction in health care are hostile behaviors including stereotyping, labeling, and stigmatizing patients, also identified as affecting the oncology providers’ clinical judgments (Fore, 2006; Friedman & Puhl, 2012). The healthcare oncology providers’ judgment about weight could overshadow their interactions with their cancer patients to the point of negating treatment plans and patient education related to their weight.

Appropriate strategies to minimize cultural issues that may impact barriers to healthcare must address race, gender, religion, age, language, and cultural issues unique to the population (Gelhert, Haozous, & Henry-Tillman, 2014). The population of cancer survivors with BMI’s of 25 or greater fit the definition of a culture in and of itself. Changing the current state of oncology practice means the current study’s participants would have an enhanced oncological clinical experience throughout their cancer care continuum that may also result in better overall outcomes.
Specifically, oncology nurses can operationalize this theory in their clinical practice to enhance the patient experience by providing culturally sensitive and holistic care. The theory is conceptualized in four quadrants with the first including the environment and culture of care, the second is the population, the third is the health/education and the fourth is nursing care. The concept of weight bias can be further operationalized by using the R-E-S-P-E-C-T conceptual framework that is based on Leininger’s model of holistic cultural care (Bejciy-Spring, 2008). Implementing this framework as an approach to care is one way to begin changes in oncology practice (Bejciy-Spring, 2008). Being proactive with the care of this patient population holds the key for positive outcomes and includes:

R - Having good rapport
E - Environment /equipment that is size appropriate
S- Safety practices in place due to size of the patient
P- Privacy for communication and exams/treatments that are size appropriate
E- Encouragement to include weight issues not only cancer related
C- Caring/compassion including discussion and planning for life long weight loss modification plans to enhance their quality of life
T- Tact by choosing the right time and approach to discuss the underlying health issues related to weight

The Mindful Attention Awareness Scale (MAAS) is another tool that can be operationalized into the oncologic clinical setting. The MAAS is a 15-item scale designed to assess mindfulness that lends itself to open or receptive awareness and attention to what is taking place in the present (Brown & Ryan, 2003). Higher scores reflect higher levels of dispositional mindfulness. If healthcare oncology providers include the use of MAAS in their clinical practice
and increased the use of mindfulness, they would become more cognizant to their biases, attitudes and behaviors they possess related to weight and over time, mood disturbances and stress of their cancer patients would decline (Brown & Ryan 2003). This tool would also be useful with the overweight cancer patients as well.

Considering best practices for healthcare oncology providers’ training and education related to the overweight or obese cancer survivors requires the knowledge of the evidence provided by this study. These findings further the knowledge and advance nursing science and clinical practice by providing incite and practical tools for changing the current oncology practices that will enhance the experiences and interactions with overweight and obese cancer survivors and increase their satisfaction with their cancer care and overall quality of life.

CONCLUSIONS

Anyone who struggles with weight knows that it’s not just about the weight. It’s about the psychosocial and emotional elements that run so deep that they block progress in the fight to get healthy and lose weight. Attempts to lose weight can fail and leave lasting negative impressions that lead to poor-self-image, negative self-talk, and in some cases, depression. For both men and women, there are many times they look in the mirror and feel like they cannot recognize themselves, buried in the weight they carry. Always contemplating the next weight loss program, diet fad, and asking the question; if not now, when?

The study findings demonstrated that meeting the holistic needs of overweight cancer patients is crucial from the first oncology appointment to the last. Barriers to care can be broken down to allow for the exploration of all phases of cancer diagnosis, treatment, and recovery. Starting with the first oncology encounter, cancer survivors with BMI’s of 25 or greater need to be viewed as a whole person and not just a cancer diagnosis. There must be a holistic plan in
place for their cancer care that also involves the open discussion of and plan for managing their weight. The current study found overweight and obese cancer survivors perceived barriers to healthcare, weight bias discrimination, threats to quality of life, and potential diminution of health outcomes.

A common theme emerged in which the underlying issue of being overweight or obese most threatened a survivors’ health status due to the associated comorbidities. Cancer was perceived as the most emergent and immediate issue, while getting to a healthy weight was the long agonizing journey. Perhaps oncologists and nurses perceive cancer as the most emergent and life threatening issue, allowing them to place weight loss in the background rather than foreground. Yet most healthcare providers are pretty centered on their specialty making it difficult to think about or address co-morbid illnesses.

Sadly, the evidence from this study found oncologists simply do not “want to get involved” in the weight-related implications of cancer. One participant called it a disservice and others simply described it as ignoring the “elephant in the room.” Cancer is treated more like a business that negates the weight issues; as if the obesity is someone else’s problem. Cancer survivors with BMI’s of 25 and greater expressed their desire to be seen as a whole person. Cancer treatment plans need to include avenues and resources for planning and implementation of a wellness program and life style modification plan in order for the survivors to be successful with weight loss during and following the completion of their cancer treatments.

The findings of this research study have advanced our understanding of provider weight bias related to overweight and obese cancer survivorship. The interviews conducted with survivors identified patient-centered tactics to lessen health burdens and barriers to care due to the impact of weight bias. The study findings offer a deeper understanding of the complex
medical and psychological factors related to the co-occurrence of being overweight and obese and being diagnosed with cancer.

Limitations of the Study

There were a few limitations identified in this study. For this study, of note was that when interviewing the study participants, the investigator should have probed further in gaining a better understanding of the nurses’ role in improving patient satisfaction and forms of weight bias.

Using the term *obese* in the title of the research study appeared to greatly impair the first round of study participant recruitment. The terminology of the study’s title was subsequently scrutinized due to the lack of participants recruited after several months of effort. By using only the word *obese* as a quantifier, a negative message was sent to potential cancer survivor participant that was undesirable, stigmatizing, and blaming. This investigator quickly found that there is power in words. For example, one participant described how a simple word like *beautiful* can make an everlasting and positive impact on the encounters between the oncologist, nurse, and survivor who is overweight or obese; the opposite is true for words with negative connotations such as *obese* and *fat*.

The recruitment materials were revised to reflect a larger cancer survivor population from breast cancer survivors to all cancer survivors. The inclusion requirements changed from obese cancer survivors to overweight and obese cancer survivors. Additionally, due to issues with obtaining approvals to recruit in hospitals, clinics, and weight loss centers, recruitment efforts also changed to include all social media and circle of influence. Recruitment flyers were edited to reflect the new research title and inclusion criteria for participants, and emailed to many area
cancer survivor support groups in Arizona and Washington as well as to the investigator’s circle of influence.

Additional limitations included not meeting the anticipated sample size due to the recruitment issues stated above. Once the inclusion criteria for participants were changed to include all cancer a survivor with BMI’s of 25 or greater, recruits began to come forward. Though many varieties of cancers were represented in the sample, the majority of the sample consisted of women and the majority of the overall sample population ethnicity was Caucasian, limiting any significance in findings regarding ethnicity and heterogeneity.

**Future Research**

The current study advanced the understanding of how overweight and obese cancer survivors experience oncology healthcare. Furthermore, this study served to further the state-of-the-knowledge by informing healthcare oncology providers of tactics to change their current practice to include culturally sensitive, holistic, and respectful delivery of care for the medically overweight or obese cancer survivor. Findings of this study did not specifically address the oncology nurses and their role in the overall cancer care of the survivor. A next step to address the science in the field of oncology would include a study of oncology nurses to explore their role in the holistic approach to sensitive care for the overweight and obese cancer survivor. This could be achieved by operationalizing the conceptual framework R-E-S-P-E-C-T into the oncology nursing practice. Patient satisfaction outcomes would be determined by conducting a study of oncology nurse participants who operationalized this concept in their oncology nursing practice with survivors with BMI’s greater than 25, with those who did not. Future research is warranted in several areas, including the exploration of the culture of obesity, providers’ weight
bias discrimination in other medical specialty areas, and best practices for educating clinicians towards being more culturally congruent and sensitive care for overweight and obese individuals.

**Investigators Final Remarks**

Finding of this study has provided insight into the culture of overweight and obese cancer survivors within the oncology healthcare setting. Moreover, this study has provided a glance of the psychosocial ramifications of living as an obese or overweight person who faces multiple forms of prejudice and discrimination and is highly stigmatized because of their weight. Though some participants reported ambivalent or somewhat positive attitudes about their oncology healthcare experiences, all of the participants expressed suggestions for needed improvements in the clinical practice setting related treatment of overweight and obese patients.

There are serious and catastrophic implications for public health practice regarding the obesity pandemic that warrants addressing obesity through a comprehensive approach across multiple specialty medical settings. Overweight and obese patients may delay or forgo essential preventive care, cancer screenings, treatments, and follow up medical appointments when experiencing weight bias and stigmas. These findings revealed the need for changes in clinical practice standards in order to diminish the barriers to healthcare; as expressed from the participants lived experiences. With the prevalence of weight discrimination increasing by 66% over the past decade, this study and future research in the field of this study are extremely relevant and warranted (Phul & Heuer, 2009).

By understanding the impact provider weight bias has on overweight and obese cancer survivors, oncology providers can begin to evoke changes in their practice to include culturally congruent, sensitive, respectful care. These changes will be more cost-effective, and decrease perceived barriers when seeking preventative cancer screenings and treatments, ultimately
increasing the quality of life and rate of survival. The significance of the current study findings benefits society by contributing evidence supporting change to make weight bias an unacceptable form of prejudice within healthcare and all specialty healthcare areas.
REFERENCES


Centers for Disease Control (2010). Vital signs: State specific obesity prevalence among adults. Retrieved from CDC website: [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5930a4.htm?s_cid=mm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5930a4.htm?s_cid=mm)


Creswell, J. W., Hanson, W. E., Clark, V. L., & Morales, A. (2007). Qualitative research


PARTICIPATE IN A RESEARCH STUDY:
Support the education of nurses and physicians!

Washington State University College of Nursing research PhD student is conducting a research study for dissertation regarding weight bias experiences within the oncology healthcare setting

I am interviewing adult cancer survivors who are overweight or obese regarding experiences related to weight bias

SHARE YOUR EXPERIENCES WITH ME!

Qualified participants will receive a $20 gift card upon the completion of the interview

IF YOU ARE INTERESTED IN PARTICIPATING:
CALL ME: 425-478-0779 EMAIL ME: sandra.wyrick@wsu.edu

Thank you for your consideration!

This study has been reviewed and approved exempt for human subjects participation by WSU Institutional Review Board

To Qualify You Must Be:
- An adult 18 years or older
- Have a diagnosis of Cancer
- Have a BMI between 25 and greater (don’t know, don’t worry, I can figure this out for you)
- Experienced weight bias, prejudice, and/or stigmatization as a cancer survivor
APPENDIX B

Interview Questionnaire

Early warm-up questions:

1. How would you describe your overall health at this time?
2. Describe your satisfaction with your cancer care?

Warmer questions:

1. Describe what it was like to be diagnosed with cancer?
2. What is living with being overweight or obese and having cancer like for you personally?
3. When you hear the term weight bias, what thoughts come to mind?
4. Describe the experience(s) you have had in interactions with your cancer physician(s) and/or nurse(s) related to weight bias (probe for both providers).
5. Describe what the physician and/or nurse did or said that made you feel uncomfortable due to your size (probe for both providers).
6. Describe if the physician and/or nurse made any negative comments, displayed negative body language, or non-caring behavior related to your size (probe for all three types).
7. Describe what the physician and/or nurse might have done to make you feel discriminated against due to your size (probe for both providers).
8. Describe what the physician and/or nurse might have done to be more accepting of your size.
9. Describe if there was adequate equipment such as chairs, beds, wheelchairs, and weight scales that accommodated your size comfortably?
10. Overall, describe how the weight bias you have experienced might have influenced your cancer care, if at all.
11. Thinking back on what we’ve talked about, how would you define the term, weight bias?

Cool down and closing questions:

1. If you could tell an oncology physician or nurse caring for medically obese cancer survivor’s one thing, what would you say? (Probe for both).

2. If you could tell another cancer survivor who is medically obese one thing, what would you say?

3. Is there anything else you’d like me to know about you experience(s) with weight bias?

Thank you for your time and willingness to take part in my research study. As a reminder, your answers are confidential and your name will never appear in any of the documents associated with my study. If you would like a summary of my findings, please provide the following contact information.

Name

Address
APPENDIX C

Phone Scripting

Hello, my name is Sandra Wyrick. I’m a Registered Nurse and PhD student at Washington State University College of Nursing. I am conducting a research study for my dissertation. I am interviewing adult breast cancer survivors with medical obesity. I am interested in the experiences of breast cancer survivors with medical obesity and their interactions with their medical oncology nurses and physicians related to weight bias. I need to confirm that you fit the study subject criteria so I will ask you 4 questions:

5. Are you 18 or older?
6. Please provide me with your height and weight (to calculate BMI)
7. Have you been diagnosed with Cancer?
8. Have you had any experience(s) regarding weight bias during your interactions with cancer care physicians and/or nurses that you perceived as prejudice, stigmatization or non-caring behavior due to your size?

If the applicant does not qualify for all 4 criteria: Unfortunately you do not qualify for this study, thank you for your time. (will explain why...)

You qualify for participation in this study. May I explain what your participation will entail? My study will involve you completing a questionnaire about your cancer history and background information (5 minutes) and completing an interview with me about your experiences with weight bias (45 minutes). OR USE BELOW. Would you like to participate?

Obtain Verbal Informed Consent at this point.

If yes: Do you have time now to answer a questionnaire and to participate in the interview? This interview will be recorded. Are you ok with that?

If yes, I will conduct the questionnaire by phone.

If no: Please provide me with a better time for you to call back to complete this preliminary questionnaire.

We need to set up a time/date to meet for the in-person interview. This will take place in a private, safe mutually agree upon setting. Please let me know what dates/times work best for you. Thank you for your time today. I look forward to our next meeting.

Benefits:

✓ Supporting the continuing education of oncology nurses and physicians regarding weight bias
✓ Self-healing, by sharing your experiences that may still be causing psychosocial health issues such as depression or post-traumatic stress
✓ Empowered in knowing that someone wants to listen to your experiences and that you are not alone
✓ Receiving resources for breast cancer survivor and bariatric support
✓ Receive a $20 gift card

Potential Risks:

✓ Highly emotional topic could cause feelings of anxiety, stress, anger, depression, and/or sadness
✓ Risks will be minimized as the researcher remains sensitive to the participants’ emotional and physical well-being and energy level during the interview process, by being alert to nonverbal cues he or she may be offering, and will be conscious of time during the interview. The researcher will periodically ask the participant how they are doing and offer time for breaks if needed.

Thanking the Participant:

✓ Bottled water will be provided to the participant during the interview and a small honorarium in the form of a $20 gift card, will be provided to the study participants’ following the conclusion of the interview. Potential risks and benefits will be explained up front upon the initial communication with the participants
✓ The study participants’ will receive a reference list for cancer survivorship support groups within geographic area of Arizona (see Appendix E, cancer survivor support groups).

The researcher will provide each study participant with my WSU Business Card with phone and email address and will be informed that they can have a copy of the summary of findings upon request.
APPENDIX D

ID No. __________

Demographic, Diagnosis and Treatment Questionnaire

The following questions will provide me with information about your personal characteristics and background information. Please answer each question to the best of your ability. Thank you!

1. Age_______
2. Female_____ Male______
3. Height_______ Weight_______ BMI_______ (will be calculated by the investigator)
4. Ethnicity (circle one): Caucasian (white) African American Native American Asian/Pacific Islander Hispanic/Latino Russian Other ________________
5. When did you receive the initial diagnosis of cancer? _____Month _____Year____
6. Stage of cancer upon diagnosis: Stage I ___ Stage II___ Stage III___ Stage IV___ Unstageable___
7. Have you participated in the past in professional counseling for issues related to your weight? (Include weight-loss support groups) _____Yes _____No
8. Do you have any other diagnosed chronic illnesses? _____Yes _____No
   If yes, please list: __________________________________________________________
   ____________________________
9. Have you had any bariatric surgical procedures? _____Yes _____No
10. If so, what type? Gastric By-Pass _____ Gastric Sleeve_______ Gastric Pouch_______
    Other__________________________
11. Have you had any reconstructive surgeries related to weight loss? _____Yes _____No
    If so what type?___________________________________________________________
12. Has your oncologist prescribed that you attend a lifestyle modification program due to your medical obesity? _____Yes _____No
13. How would you rate your overall physical health at this time? (Circle one number)

Very Poor 1 2 3 4 5 6 7 8 9 10 Excellent

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14. How would you rate your overall emotional health at this time? (Circle one number)

Very Poor     1   2   3   4   5   6   7   8   9   10   Excellent

15. How would you rate your overall quality of life at this time? (Circle one number)

Very Poor     1   2   3   4   5   6   7   8   9   10   Excellent

Thank you for this information!
APPENDIX E

Bariatric Support Resources and Breast Cancer Survivor

Greater Phoenix Arizona Area

**Obesity Action Coalition » Arizona Support Groups**
www.obesityaction.org/advocacy/support-groups/arizona-support-groups

**Bariatric Support Group | AmericanBariatrics.Org**

**Bariatric Support Groups - Bariatric Support Groups.**
Bariatric.SurgeryOperations.com

**Bariatric Support Group (FREE) - Weight Loss Surgery ...**

**Mayo Support Groups in Arizona - Patient and Visitor Guide ...**
www.mayoclinic.org/patient-visitor-guide/support-groups/arizona

**Flagstaff Medical Center - Bariatric Support Group**
www.flagstaffmedicalcenter.com/.../Bariatric_Support_Group

**Life After Bariatric Weight-Loss Surgery | Scottsdale ...**
Bariatricsurgeryaz.com/after-bariatric-surgery-support

**Support Groups | University of Arizona Cancer Center**
azcc.arizona.edu/patients/support/support-groups

**Bosom Buddies of Arizona Ahwatukee Chandler Breast Cancer ...**
www.bosombuddies-az.org/category/support-groups/ahwatukee-chandler

**Home - Arizona Breast Cancer Resource Guide**
azbreastcancer.org

**4HER Patient Support**
itunes.apple.com
Breast Cancer Support Groups in Phoenix, Arizona
www.jcl.com/.../breast-health/breast-cancer-support-groups

Breast Cancer Awareness
WarriorsInPink.Ford.com - 660,200+ followers on Twitter

Metastatic Breast Cancer | hcpmetastaticbreastcancer.com
www.hcpmetastaticbreastcancer.com

Breast Cancer Support
www.advanced-breast-cancer.com
Participant Pseudonym:________________________

Date:________________________

Verbal Informed Consent Obtained:_____________Date__________________Time

Interview Script

I am interviewing adult breast cancer survivors with medical obesity. I am interested in the experiences of overweight and obese cancer survivors interactions with their medical oncology nurses and physicians related to weight bias.

This is a study of weight biases experienced by persons who are overweight or obese and have cancer at any time during their treatment and survivorship. Weight bias is defined as prejudice, discrimination, and stigmatization, expressed by an oncology physician or nurse. It could also be related to not having appropriate accommodations in the clinic or hospital to fit the larger sized person.

I am going to ask you some questions regarding weight bias and interactions with your oncology nurses and physicians, as well as questions about; your cancer diagnosis, treatments, medical obesity condition, and overall health and quality of life.

There is no right or wrong answers.

Do not name any of your providers but refer to them by their role, e.g., physician or nurse.

You may choose not to answer any of the questions or end the interview at any time.

The information you share is confidential and your providers will never be told any of your responses to questions.

Your opinions and experiences are important to me.

The interview will last between 45-90 minutes. The interview is recorded for transcription purposes.

Do you have any questions?
APPENDIX G

Informational letter

Date: 7-10-2015

Study information letter

Phenomenon of Provider Weight Bias

Title of the research study: Provider Weight Bias: A Phenomenological Study of Overweight and Obese Cancer Survivors

Dear Sir or Madam,

Sandra Wyrick, an Oncology Registered Nurse Education Specialist and PhD candidate, is conducting a research study about the experiences of overweight and obese cancer survivors in their interactions with their medical oncology nurses and physicians related to weight bias.

This is a study of weight biases experienced by persons with cancer at any time during their treatment and survivorship. Weight bias is defined as demonstrating behavior that is prejudice, discriminates, belittling, negative attitude or stigmatization towards the medically obese person.

What will I be asked to do?

You will be asked to complete a short demographic and health survey and then participate in a 45-90 minute interview. During the interview I will be asking you some questions regarding weight bias and interactions with your oncology nurses and physicians, as well as questions about; your cancer diagnosis, treatments, medical obesity condition, and overall health and quality of life.

There is no right or wrong answers and you will not be asked to name any of your providers but refer to them by their role, e.g., physician or nurse. This is a completely confidential interview. Your name will not be identified anywhere on the study documents.

You may choose not to answer any of the questions or end the interview at any time.
The information you share is confidential. Your providers will never be told you are in the study and will never be told any of your responses to questions.

Your opinions and experiences are important to me.

The interview will last between 45 and 90 minutes and will be conducted at a mutually agreed upon private location. This interview will be recorded for transcription purposes.

**What are the risks and benefits of the study?**

The level of risk related to the study is very minimal. There is a minimal risk that participating in a group, audio recording or identifying with some of the questions may make you feel uncomfortable. The results of this project could help the research study lead understand the phenomenon of provider weight bias and to help inform oncology healthcare nurses and physicians of tactics to change their current practice to include culturally sensitive, holistic, and respectful delivery of care for the medically obese breast cancer survivor.

**Will I be compensated for my time?**

*Upon completion of this study, you will be provided with a $20 gift card* by the Research Study Lead

**Is the study confidential?**

Yes, the decision to participate or not is voluntary and kept confidential. You can withdraw from the study at any time without an explanation or consequences. Your name will never be used to ensure privacy. You will be asked to use a pseudonym (false name) so that none of the demographic information or typed notes from the interview will have your name on them. All of the notes that are collected from our interview will be kept on a safe computer and access to the computer will be secured by a specific password that nobody except me knows. The written data and audio tapes will be kept in a locked file cabinet in an assigned area. After the notes are typed up from the taped interview, all of the audiotapes will be destroyed. If at any time while we are talking during the focus group interview, you feel you have said something that you do not want to be used for the study, that part will be removed when the notes are typed.

**What will this information used for?**

Some of the information that you share in the interview, observation, and survey may result in projects that become talks, reports, presentations and publications by the research study
lead or author. Your name will never be used in these talks, reports, presentations and publications. In addition, a brief summary of the results will be submitted to all participants. Your participation is important in helping the research study lead better understand the phenomenon of provider weight bias and to help inform oncology healthcare nurses and physicians of tactics to change their current practice to include culturally sensitive, holistic, and respectful delivery of care for the medically obese breast cancer survivor.

Thank you for your interest in this research study.

If you have any questions concerning the project, please contact Sandra Wyrick, Research Study Lead, at 425-478-0779. Thank you again for your willingness to participate!

Sincerely yours,

Sandra Wyrick, PhD Candidate, MN, RN
Oncology Nurse Education Specialist
APPENDIX H

Table 5

Table 5 defines the study questions, major themes by questions and all sub-themes of major themes by question. Identified are 14 major themes and 83 sub-themes.

<table>
<thead>
<tr>
<th>STUDY QUESTIONS</th>
<th>MAJOR THEMES BY QUESTIONS</th>
<th>SUB-THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. Please describe your overall health at this time?</td>
<td>1. Perceptions of Health</td>
<td>Not healthy, healthy, cancer free and feeling fantastic, the biggest perceived health issue</td>
</tr>
<tr>
<td>Q2. Describe your satisfaction with your cancer care?</td>
<td>2. Satisfaction with Overall Cancer Care</td>
<td>Satisfied, not satisfied, adequate care</td>
</tr>
<tr>
<td>Q3. Please describe what it was like to be diagnosed with cancer?</td>
<td>3. Reactions to Cancer Diagnosis</td>
<td>Frightening, I don’t want to die, not surprised, surprised, blessed, surreal, self-blame, defiant, not feeling vulnerable to cancer</td>
</tr>
<tr>
<td>Q4. When you hear the term “weight bias”, what thoughts come to mind?</td>
<td>4. Self-Reflections on the Meaning of Weight Bias</td>
<td>Discrimination, assumptions, pre-judging, stereotyping, be prepared, feeling vulnerable, accept and deal with it, obese people are biased too, lack of control, not treating the underlying cause of obesity, never heard of that the term weight bias</td>
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<td>Q5. Describe what the physician and/or nurse did or said that made you feel uncomfortable due to your size.</td>
<td>5. Actions by Physicians/Nurses in Response to Personal Size</td>
<td>Unhealthy, fitting the society norm for beauty and weight, just business-as-usual, crushing my spirit, oncology physicians insinuations, pulling the wool over their? eyes, I’m not handicapped,</td>
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<tr>
<td>Q6. Describe if the physician and/or nurse made any negative</td>
<td>6. Non-caring Behavior, Negative Verbal and Non-Verbal Language</td>
<td>Fearing treatments, I felt unsafe, no overt weight bias gestures or language</td>
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<td>Comments</td>
<td>Q7. Describe what the physician and/or nurse might have done to make you feel discriminated against due to your size.</td>
<td>7. Lack of Support</td>
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<td>Q8. Describe what the physician and/or nurse might have done to be more accepting of your size.</td>
<td>8. 1st Major theme: The Clinical Appointments</td>
<td>I hated with the weight scale, providing the appropriate size exam gowns, talk about the weight issues, provide sensitive care, addressing education and resources, don’t rush the appointment, body language speaks volumes, labeled as obese by the provider, negative self-talk, I didn’t experience overt forms of weight bias</td>
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<td>Q9. Describe if there was adequate equipment such as chairs, beds, wheelchairs, gowns, BP cuffs and scales that accommodated your size comfortably.</td>
<td>9. Inappropriate Sizes</td>
<td>Poor self-image, desire for life and young motherhood, altered self and body image, needing to take back control of my life,</td>
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<td>Q10. Overall, describe how the weight bias you have experienced might have influenced your cancer care, if at all.</td>
<td>10. Labeled as Overweight or Obese</td>
<td>Stereotyped as being a women more than being overweight, barriers to care, lose the weight, discrimination is a fact of life, societal weight bias, seeking the right</td>
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<td>Q11. Thinking back on what we’ve talked about, how would you define the term “weight bias”?</td>
<td><strong>11. Weight Bias</strong></td>
<td>Not being proactive in the care of large sized survivors, bias is not just overt actions, barriers to care, causing more pain and distress than gain, lumping us into one patient population, not a motivator for weight loss, I don’t see a lot of very overweight people</td>
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<td>Q12. If you could tell an oncology physician or nurse caring for an overweight or obese cancer survivor one thing, what would you say?</td>
<td><strong>12. Changing the Current State of Oncology Practice</strong></td>
<td>Being treated as a whole person, picking the right time for this talk about weight, add a personal touch, be more sensitive, ignore the stereotypical weight related labelling, weight bias self-perceptions and assumptions</td>
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<tr>
<td>Q13. If you could tell another cancer survivor who is overweight or obese one thing what would you say?</td>
<td><strong>13. Honor Thy Self</strong></td>
<td>Survivorship validation, love and focus on yourself, focused on my body size, societal perspective on weight and cancer,</td>
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<td>Q14. Is there anything else you’d like me to know about your experience(s) with weight bias?</td>
<td><strong>14. No Additional Comments</strong></td>
<td></td>
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</tbody>
</table>
FIGURES

Figure 1. Sunrise Model: Derived by Madeline Leininger’s theory of Culture Care: Diversity and Universality, also known as the Transcultural Care Theory
Figure 2. Obese Patient Transcultural Nursing Model derived from Madeline Leininger’s theory of Culture Care: Diversity and Universality