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Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

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To the Graduate Council:

I am submitting herewith a dissertation written by Shirleen Denise Chase entitled "Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sadie P. Hutson, Major Professor

We have read this dissertation and recommend its acceptance:

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(Original signatures are on file with official student records.)

Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Shirleen Denise Chase
December 2017

Dedication

I dedicate this work to my husband, daughter, and mother.
To my loving husband, Ernie, who kept me grounded, you are a source of strength and support.
You encouraged me to follow my dream and because of you, this goal is a reality.
To my daughter, Megan, who inspired me to push the boundaries and keep moving forward.
To my mom, Shirley, who taught me to be all I could be even when the chips were down.
To all the cancer survivors I cared for who inspired me to see more, ask more, and do more.

In loving memory of
Ronald Lee Rainwater
Dad, “Boogie made something of herself.”

There is no telling how many miles
you will have to run while
chasing a dream

-Author Unknown

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I want to thank all the melanoma survivor participants in east Tennessee who cared enough to share their stories. I listened and will share your experiences and advocate for your needs.

I would like to acknowledge my family and friends who cared enough to see me through the rough days. A special thank you for my husband Ernie Chase and daughter Megan Chase. I love you both very much.

Abstract

Melanoma is a dangerous form of skin cancer that can spread throughout the body without treatment. The population of melanoma survivors has grown for several reasons including rising melanoma incidence, earlier detection, and treatment advances. The eastern Tennessee area is designated as an Appalachian region of the country where many people still live in abject poverty and lack access to adequate healthcare resources. Eight counties were found to have the highest melanoma incidence rates in Tennessee. Currently, post-treatment melanoma surveillance is disjointed, and falls on a variety of healthcare providers. The health-related experiences and post-treatment needs of melanoma survivors are essentially unknown in Tennessee. While additional resources are needed, there are limited local providers and facilities in rural Tennessee. The purpose of this qualitative interpretive description study was to understand the experiences related to melanoma survivorship from the perspective of the patients themselves.

Thorne's (2008) framework for interpretive description research was used for this qualitative study. Sixteen participants were interviewed from counties in the east Tennessee Appalachian region. Qualitative data analysis using interpretive description recommendations allowed the identification of four themes: 1) S*itting in the driver's seat of follow-up care*, 2) *Living in a skin world*, 3) Once *bitten, twice shy*, and 4) *Watch me like a hawk*. Melanoma survivors living in east Tennessee experience follow-up similarly to other individuals living with cancer who also have specific cultural, geographical, and regional barriers to surveillance. Their implicit needs are basic and consistent with the standard of care we offer other cancer survivors. Future research suggestions include taking a closer look at types of melanoma in other diverse populations, less invasive or less urgent post-treatment management options, and best practice programs that benefit melanoma survivors with psychosocial distress in long-term follow-up.

Key words: melanoma survivors, melanoma follow-up, post-treatment experiences and needs, East Tennessee Appalachian Region (ETAR)

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List of Abbreviations

SF-36	36-item Short Form Health Survey
AIHW	Australian Institute of Health and Welfare
ARC	Appalachian Regional Commission
CDC	Centers for Disease Control and Prevention
CXR	Chest radiography
CITI	Collaborative Institution Training Initiative Program
CAT	Computerized axial tomography
ETAR	East Tennessee Appalachian Region
EORTC	European Organization for Research and Treatment of Cancer
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HRC	Health-related clinic
HRQOL	Health-related quality of life
IOM	Institute of Medicine
IRB	Institutional Review Board
MRI	Magnetic resonance imaging
MHOS	Medicare Health Outcomes Survey
NCI	National Cancer Institute
NCCN	National Comprehensive Cancer Network
NI	Naturalistic inquiry
OS	Overall survival
PET/CT	Positron emission tomography
QLQ-C30	Quality of Life Questionnaire
QOL	Quality of life
SEER	Surveillance, Epidemiology and End Results Program
SI	Symbolic interactionism
TCR	Tennessee Cancer Registry
VR-12	Veterans RAND 12-Item Health Survey
WHO	World Health Organization

Chapter One: Introduction

Melanoma is a form of skin cancer that, without treatment, can spread throughout the body (Nouri, 2008; Levine & Shapiro, 2012). As the most lethal form of skin cancer, melanoma is responsible for 80% of all skin cancer-related deaths despite accounting for only 4% of all skin cancer cases (Guy et al., 2015; SEER, 2017). In fact, this year in the U.S., melanoma is expected to result in more than 10,000 deaths from an estimated 87,000 new cases this year (SEER, 2017, ACS, 2017).

The Centers for Disease Control and Prevention (CDC) report that, unlike that of other skin cancers, melanoma incidence has been steadily increasing for the last 30 years (CDC, 2013; Guy et al., 2015; Siegel, Miller, & Jemal, 2016). While the melanoma incidence rate has doubled since 1976, the overall five-year survival rate has increased significantly in the same period (CDC, 2013; Liu & Soong, 1996). This increased overall survival rate has led to growth in the number of melanoma survivors, estimated at more than one million nationally (DeSantis et al., 2014). In Tennessee, the number of melanoma survivors exceeded 15,500 in 2014 and that number is expected to increase each year through 2024 (American Cancer Society [ACS], 2016; DeSantis et al., 2016; Surveillance, Epidemiology and End Results Program [SEER], 2017).

For this study, the primary investigator (PI) focused on understanding the post-treatment health-related experiences and needs of melanoma survivors residing in a designated underserved area in the East Tennessee Appalachian Region (ETAR) (Appalachian Regional Commission [ARC], 2016). Some ETAR counties are have double the national and state estimates for melanoma incidence (ACS, 2017; NCI, 2017; SEER, 2017) and are designated as lacking adequate healthcare access and resources to meet basic needs (ARC, 2016). Melanoma survivors diagnosed at a later stage of the disease require a variety of healthcare resources and access to tertiary care not available more locally for follow-up (National Comprehensive Cancer Network [NCCN], 2016). Additionally, aging melanoma survivors face side effects from extensive treatments, effects from other chronic conditions, ongoing costly monitoring, and work limitations affecting their livelihood (Livingstone et al., 2011). The effectiveness and quality of care directly for post-treatment melanoma survivors in urban and rural ETAR counties is unknown. Understanding this population's particular experiences with post-treatment uncertainty, recurrence, and follow-up care could help inform treatment changes to improve quality of life (QOL) for individuals, families, and communities in the ETAR (Ludke, 2012; Miller, 2014a; Miller, 2014b). Additionally, research on melanoma survivors in this region is needed to alleviate barriers to ongoing continuity of care and disparities during follow-up care (Ludke, 2012; NCI, 2004; Parikh, Kirch, & Browley, 2015).

Background

For more than a decade, melanoma research has focused mainly on prevention, early detection, and treatment (Little & Eide, 2012; Palesh et al., 2014; Siegel, Ma, & Jemal, 2014; Yang, Barnholtz-Sloan, Chen, & Bordeauz, 2011). Because of such research, approximately 84% of melanomas are diagnosed at a local stage, when they are most curable (DeSantis et al., 2014). Once thin melanomas are detected and surgically removed, ongoing skin examination and symptom monitoring is critical for melanoma survivors (Youl et al., 2011; NCCN, 2016; ACS, 2017; NCI, 2017). Although commonly thought of as cancer that affects only the skin, melanoma is particularly prone to spread (metastasize) via blood or lymphatics to subcutaneous tissues, lungs, brain, and the gastrointestinal tract (Levine & Shapiro, 2012; UpToDate, 2016). Moreover, depending on a melanoma's size and location, removal can be disfiguring (DeSantis et al., 2014).

Generally, melanoma lesions are categorized into four subtypes: acral melanoma (occurs on the palms of the hands, soles of the feet, or nail beds); lentigo melanoma (usually occurs on the face or scalp); nodular melanoma (lumpy, often blue-black in color, and grows rapidly downward toward the dermis); and superficial spreading melanoma (grows outward at first to form an irregular pattern) (ACS, 2017; NCI, 2017). Regardless of type, it is critical to detect and surgically remove melanoma before it grows, when it is small and thin (localized) (NCCN, 2016; National Institutes of Health [NIH], 2016; ACS, 2017; NCI, 2017). The five-year survival rate in patients diagnosed with localized melanoma exceeds 94% and drops to 16% when it spreads (Guy et al., 2015; CDC, 2015; SEER, 2017).

Anyone can get melanoma, but some people have a higher risk. Important risk factors for melanoma include being male or having a fair complexion (fair skin that freckles or burns easily and does not tan; blue or green eyes; red or blonde hair), multiple or large moles, or a family history of melanoma (mother, father, brother, sister) (ACS, 2017). An important modifiable melanoma risk factor is intermittent, intense exposure to sunlight or artificial sunlight (tanning beds), especially on skin usually covered by clothing (Lin, Wang, Li, & Kolker, 2012; ACS, 2017). Experiencing multiple, blistering sunburns, especially as a child or teen also is associated with a higher risk of eventual melanoma development (ACS, 2017). Generally, increased thin melanoma lesions have been associated with patients who have skin cancer awareness, provider skin examinations, and higher socioeconomic status (Liu & Soong, 1996; Balch et al., 2001; UpToDate, 2016; ACS, 2017). However, thicker melanoma lesions are associated with patients with lower socioeconomic status, lower education levels, and healthcare access inequalities. These latter characteristics are common to people in ETAR, especially in more rural Tennessee

(Kirby, Taliaferro, & Zuvekas, 2006; Pollitt, Clarke, Shema, & Swetter, 2008; Zell et al., 2008; Wich et al., 2011, ARC, 2016).

Although there are no universally accepted guidelines that define post-treatment surveillance for individuals diagnosed with melanoma, the National Comprehensive Cancer Network (NCCN) does offer recommendations (Linette & Cornelius, 2013; McCabe & Jacobs, 2012; NCCN, 2016). The NCCN Clinical Practice Guidelines in Oncology consists of multidisciplinary cancer experts and an alliance of leading cancer centers devoted to patient care, research, and education. The NCCN's recommendations are evaluated periodically by NCCN associates who review current research, examine practice, and contribute to cancer care improvement. For example, once diagnosis is confirmed by biopsy, NCCN treatment plan recommendations include referral to a tertiary, multidisciplinary center based on the lesion thickness and pathology specifics (NCCN, 2016) (Table 1.1, Appendix A).

A thin melanoma is defined as a tumor less than 1.0 mm thick and a thick melanoma as a one more than 1.0 mm thick. Individuals diagnosed with thicker lesions and advanced stage disease have a poor prognosis (Geller & Annas, 2003; Levine & Shapiro, 2012; Matzke, Bean, & Ackerman, 2009; ACS, 2017). Once a melanoma lesion has been biopsied, the cancer is staged according to the American Joint Committee on Cancer (2016) as stage I, II, III, or IV. The disease is staged by tumor thickness and/or metastasis: stage IA (1mm or less); stage IB (1–2mm); stage IIA (2–4mm); IIC (>4mm); stage III (any size+lymph node involvement); and stage IV (any size+lymph node involvement+metastasis) (NCCN, 2016; ACS, 2017). Survival is strongly related to melanoma thickness with higher mortality occurring in patients with lesions thicker than one millimeter (mm) (Aitken, Elwood, Baade, Youl, & English, 2010).

Following diagnosis and treatment, NCCN panel experts (2016) suggest lifelong skin examinations and education for melanoma survivors. In 2017, there were more than one and half million melanoma survivors living in the U.S. (Miller, 2017; ACS, 2017). The population of melanoma survivors has grown for several reasons including increased incidence of patients diagnosed with thin melanoma, earlier detection initiatives, and treatment advances (Howlader et al., 2014; Mariotto, Yabroff, Shao, Feuer & Brown, 2011; U.S. Cancer Statistics Working Group, 2014).

Although clear data and varying expert opinions exist regarding appropriate surveillance for melanoma survivors there is a need for ongoing follow-up (NCCN, 2016). Specifically, the NCCN recommends that melanoma patients diagnosed with stage IA (thin lesion) who have no evidence of disease after surgical removal have at least annual skin exams for life; education in regular self-skin and lymph nodal examination; and a history and physical with emphasis on skin and lymph nodes every 6–12 months for the first five years and then annually thereafter. Routine blood tests or radiographic imaging for asymptomatic disease is not recommended. Follow-up for stage IIA patients includes all the recommendations for IA (except the history), and a physical every 3–6 months for two years then every 3–12 months for three years. Recommendations for stage IIB–IV patients include considering the following scans every 3–12 months screening for recurrent or metastatic disease: chest radiography (CXR), computerized axial tomography (CAT) scan, magnetic resonance imaging (MRI), and or positron emission tomography (PET/CT) scans. The recommendations for stage IIB–IV patients also includes no routine radiologic screening for asymptomatic disease after 3–5 years. Melanoma survivors need ongoing monitoring for recurrence and/or new malignancies with regular comprehensive skin exams, nodal assessment, symptom management, as well as psychological evaluation and treatment (DeSantis et al., 2014; Mrazek & Chao, 2014). Patients with disfigurement usually have burdensome progressive symptoms that can affect their quality-of-life (QOL) (Kemp et al., 2012; Chung-Yuan, 2013).

Routine follow-up for patients after treatment for melanoma is standard practice; however, globally there is also debate about appropriate surveillance methods, frequency of exams, or additional testing (Dancey, Rayalt, Courthold, & Roberts, 2005; Franchken, Bastiiaannet, & Hoekstra, 2005; NCCN, 2016). The current plan for melanoma follow-up in the U.S. is fractured, with the burden falling inconsistently on a variety of healthcare providers: primary care physicians, nurse practitioners, physician assistants, dermatologists, medical oncologists, surgical oncologists, general surgeons, and plastic surgeons (Francken, Bastiaannet, & Hoekstra, 2005; Gamble et al., 2010; Mrazek & Chao, 2014; Rueth, Cromwell, & Cormier, 2014). Although most melanoma survivor post-treatment follow-up is provided with dermatologists, the availability of services is unknown. There is insufficient research in some populations regarding melanoma survivors' long-term quality of life needs. Specifically, the threat of recurrence, the meaning associated with recurrence, supportive care, economic constraints, psychological issues, provider availability, symptom control, and/or disfigurement concerns (Francken, Bastiaannet, Hoekstra, 2005; Wheeler, 2006; McLoone et al., 2012; Linette & Cornelius, 2013; Rychetnik, McCaffery, Morton, & Irwig, 2013; Kasparian, 2013; McLoone et al., 2013; Oliveria et al., 2013; Trotter et al., 2013; Tan, Butow, Boyle, Saw, & O'Reilly, 2014; Hamel et al., 2016).

Economic Burden

The continuing cost of follow-up care for melanoma patients is projected to be over $226 billion by 2025, representing a 48% increase from 2010 (Howlander et al., 2014). According to the CDC, melanoma detection, treatment, and recurrence accounts for approximately $4 billion in lost productivity each year (CDC, 2012). The physical, psychological, and socioeconomic impacts along with lost productivity following melanoma treatment depend on many factors including regional incidence rates, available treatment resources, healthcare access, and research investments (Eide, Weinstock, & Clark, 2009; Greenlee & Howe, 2009; Linos, Swetter, Cockburn, Colditz, & Clarke, 2009; Little & Eide, 2012; Reyes-Ortiz, Goodwin, & Freemen, 2005; Youl et al., 2011). More than half of the melanoma survivors in the U.S. (approximately 710,000) are younger than 70 years of age, including 220,000 survivors who are younger than 50 (CDC, 2014; SEER, 2014).

Following a melanoma diagnosis, patients live with a lifetime of monitoring that includes uncertainty and watching for signs of recurrence and/or relapse (Mishel, 1988; Mishel, 1990; McLoone et al., 2012). Melanoma patients and their families face physical, emotional, social, and economic challenges that may result from the diagnosis and treatment (Hetz & Tomasone, 2012; Plescia, Berman, & White, 2011; McLoone et al., 2012; Morton, Rychetnik, McCaffery, Thompson, & Irwig, 2013). Specifically, survivors' experiences include enduring pain and fatigue, declines in physical and emotional functioning, and a decrease in over well-being. (Beutel et al., 2015; Bird, Coleman, & Danson, 2015; Blanchard, Courney, & Stein, 2008; Hamma-Raz & Solomon, 2006; Hamma-Raz, Solomon, Schachter, & Azizi, 2007; Oliveria & Berwick, 2009; Oliveria et al., 2013; Palesh et al, 2014; Tan, Butow, Boyle, Saw, & O'Reilly, 2014; Wheller, 2006). Between 1990 and 2011, the overall cost of melanoma diagnosis and treatment was approximately $932.5 million per year for the general population, with $44.9 million per year for Medicare beneficiaries (Guy, Donatus, Ekwueme, Tangka, & Richardson, 2012).

Regional Differences

Melanoma is now considered the third leading cause of cancer in men and the sixth in women in the U.S. (ACS, 2016; National Cancer Institute [NCI], 2016). The melanoma incidence rate (number of new cases of melanoma per 100,000 people) in the U.S. is 16.9% for women and 28.5% for men (NCI, 2017). Utah has the highest state melanoma incidence rate at 34.6% (CDC, 2012). However, many U.S. counties are burdened with higher incidence rates that exceed the national rates and even approach international incidence rates. Compared to U.S. melanoma incidence rates, Australia and New Zealand have the highest melanoma rates in the world (59.9% and 63.8%, respectively). In fact, Queensland, Australia has an incidence rate of 82.1% for males and 54.8% for women, figures that exceed all other areas nationally and internationally (Australian Institute of Health and Welfare [AIHW], 2016; Queensland Government, 2015).

The melanoma incidence rate is reportable to the state and federal registry (NCI, 2016; USHHS, 2016; NIH, 2017). However, little research is available about where treatment might occur and even less is known about where or by whom survivors are followed long-term. The state of Tennessee has a higher melanoma incidence rate when compared to the overall U.S. rate (20.8% and 19.9%, respectively). Some Tennessee counties, especially those in Appalachia, have melanoma incidence rates double that of the state and national rate (Figure 1.1, Appendix A) For example, Grainger, Hamblen, Hawkins, Jefferson, Sevier, Sullivan, Unicoi, and Washington counties have melanoma incidence rates ranging from 30.8% to 42.4% (Figure 1.2, Appendix A). The Appalachian Region is a 205,000-square-mile area that extends along the Appalachian Mountains from southern New York to northern Mississippi (Figure 1.3, Appendix A). More than 25 million people live in this region, where 42% of the population lives in a rural area, compared with only 20% of the national population (ARC, 2016). Knight (2012) described the Appalachian Region as an area with high levels of unmet basic human needs and insufficient services. The counties with high melanoma incidence rates are considered to be in either economically at-risk areas that include the worst 10–25% of U.S. counties, or transitional areas where the county has moved from having a weak economy to a stronger one (ARC, 2016).

Many counties across the U.S. including rural Tennessee have substantially higher poverty rates or significantly lower income levels than national averages, which may affect melanoma survivors in need of post-treatment follow-up services (Livingstone et al., 2011; Wich et al., 2011; Cromwell et al., 2012; Linette & Cornelius, 2013; CDC, 2015; SEER, 2017; ARC, 2017). The cluster of eight counties with high melanoma incidence in the northeast corner of Tennessee was reported to the state cancer registry but no additional information is available related to where follow-up is obtained or by which provider locally or regionally.

Individuals from Appalachia are more likely to have several risk factors that increase cancer incidence and mortality: tobacco use, a high-fat diet, physical inactivity, and inadequate access to medical care (ARC, 2016). Ludke (2012) explained that health encompasses more than medical care and may be necessary to look at a much broader definition for cancer survivors. The Tennessee Cancer Coalition’s (2016) acknowledges, “There are unmet needs and disparities in knowledge, access, treatment, and survival among some populations in Tennessee” (p. 6). The State of Tennessee’s 2013–2017 cancer plan included skin cancer (melanoma and non-melanoma) initiatives along with initiatives to decrease incidence and improve outcomes by increasing education about prevention, early detection, and treatment.

The National Cancer Institute (NCI) defines cancer health disparities as adverse differences in incidence, prevalence, mortality, cancer survivorship, and the burden of cancer or related health conditions that exist among specific U.S. population groups. From 2005–2009, Tennessee ranked 19th in cancer incidence and third in cancer deaths when all races and sexes were combined. Many factors contribute to the complexity with ranks and ratings varying by race, ethnicity, geography, gender, age, and socioeconomic status. Some differences in rates are known, but the identity of specific factors that cause disparities and how these factors are interrelated is complex and poorly understood.

In general, the entire Appalachian region has a higher mortality rate for all cancers combined compared to the overall U.S. rate (178.6 and 171.4 per 100,000 respectively; Whiteside, 2007; SEER, 2014). For some cancers—such as lung, colorectal, breast, prostate, and melanoma—Appalachian counties have significantly higher mortality rates than non-Appalachian counties (Whiteside, Murray, & Crowley, 2007). In the Appalachian Region, barriers to cancer care include lack of primary and specialty care services at the local and regional levels (ARC, 2016). While the number of providers in the Appalachian Region has grown, many are clustered in urban areas. Other barriers to care include physical distance, mountainous terrain, and lack of public or private transportation to and from healthcare facilities, lack of health insurance, and the inability to pay for prescription cancer drugs. Overall survival (OS) has improved in both black and white populations, although there is disparity in survival rates between these two groups (70.3% for blacks versus 85.3% for whites). Part of the disparity is due to the stage of disease at diagnosis, with 82% of whites diagnosed with melanoma at the early, localized stage compared to only 60% of blacks (Whiteside et al., 2007; ACS, 2017; SEER, 2017). The poorer survival rate among black individuals suggests the need to develop greater melanoma awareness in this population in order to promote early diagnosis and reduce mortality (Friedman, Rigel, Silverman, Kopt, & Vossaert, 1991; Liu & Soong, 1996; Vayer & Lafor, 1993).

Cancer Survivorship

NCI-Office of Cancer Survivorship (2017) defined a survivor as an individual from the time of diagnosis, through the balance of their life. This group includes not only the patients but also their family members, friends, and caregivers. The term “survivor” was not used prior to 1986, but today survivorship begins once cancer is diagnosed (Mullan, 1985; NCI, 2004). Cancer survivorship also has been described as living with, thru, or beyond cancer (the extended, post-treatment stage) (NCI, 2004). Generally, cancer survivorship stages have been identified as acute, extended, permanent, and end-of-life (Mullan, 1985). One of the goals identified by the Tennessee Cancer Coalition (2013) was to coordinate an interdisciplinary effort “involving administration, basic and clinical research, evaluation, health education, program development, surveillance, public policy, clinical services, and health communication” related to cancer surveillance (Whitehead, 2007, p. 6). The Tennessee cancer plan also included the following three specific aims: increasing cancer survivors’ awareness of academic medical center resources, educating selected providers about cancer survivors’ long-term needs, and educating researchers and providers about funding opportunities focused on cancer survivors.

Research within Tennessee focused on the post-treatment phase of survivorship is absent. Cancer survivorship research has been focused on survivors’ experiences such as QOL factors, behavior changes, lack of exercise, decreased motivation for usual activities, fatigue, chronic pain, depression, impaired interpersonal relationships, difficulty coping, and, lack of secondary prevention strategies to preserve function (Earle, 2007; Blanchard, Courneya, & Stein, 2008;

Blanchard, Stein, & Courneya, 2010). Earle offered three questions that could be used in research to focus on improving survivorship care:

- Do disparities exist in the quality of care provided to survivors of different ages, racial and ethnic groups, sexes, socioeconomic status, and diagnosis?
- What is the effect of cancer on a survivor's family and caregivers?
- What is the cost-effectiveness of different survivorship care-plan strategies?

Additionally, the development and validation of instruments to capture important outcomes and quality measures related to survivorship care plans also are also an important area for cancer survivorship research (Hewitt & Ganz, 2006). The HRQoL for long-term cancer survivors in the U.S. is an area about which little is known; consequently, no studies have been conducted that examine any of the common or secondary survivorship issues for individuals in Tennessee or the ETAR.

Hewitt & Ganz (2006) included recommended goals for future cancer survivor research in collaboration with the Institute of Medicine (IOM): "raising awareness; ensuring a plan of care; establishing surveillance guidelines; defining quality cancer survivor care; managing healthcare system challenges; addressing survivorship as a public health concern; providing education and training to healthcare professions; addressing employment challenges and success options; and improving access to adequate and affordable health insurance for continuity of care and follow-up" (pp 485-489). Additionally, research is needed to find ways to increase monitoring of secondary cancers with support from primary care and specialty practitioners to address short- and long-term preventable pain, disability, and psychological distress (NCI, 2004; Jacobs et al., 2009). Hewitt and Ganz (2006) summarized the IOM report as an initiative to "address quality concerns for cancer survivors with an emphasis on what happens following the primary treatment of cancer" (p. 16). However, the specific needs of melanoma survivors in Tennessee or Appalachia have not been addressed.

Philosophical Perspective

Theory is an essential element for framing a problem and guiding research such as efforts to understand follow-up experiences in melanoma survivorship. The philosophical model that informed this research is symbolic interactionism (SI) and naturalistic inquiry (NI). Blumer (1969) provided the groundwork for SI and NI, an approach that ideally explores the interactions of daily life and experience. Stated briefly, SI's basic precepts are that

1. "individuals act based on the meanings objects have for them;
2. interaction occurs within a particular social and cultural context in which physical and social objects (persons), as well as situations, must be defined or categorized based on individual meanings;
3. meanings emerge from interactions with other individuals and with society; and
4. meanings are continuously created and recreated through interpreting processes during interaction with others" (Carter & Fuller, 2015, pp 1–2).

Blumer defined SI as "social products, as creations that are formed in and through the defining activities of people as they interact" (p. 5). Interestingly, in SI, the meaning of experiences is "derived by the person from that interaction," which involves an interpretative process that arrives at their "perspective" (p. 5). Symbolic interactionism is an integral part of research in which an individual (the researcher) interprets another's gestures and acts based on the meaning yielded by that interpretation. In naturalistic inquiry, there is heavy reliance on the human as the instrument. The researcher should be thoroughly familiar with the field site or setting the study will be referenced (Lincoln & Guba, 1985).

Bruner (1986), noted for his cognitive development studies, contended that human beings think in two fundamentally different ways. One way is *paradigmatic* or thinking through a propositional argument; the other is *narrative* or interpreting through storytelling. The difference between these two types of thinking involves how human beings make sense of and explain what they see. Narrative inquiry is viewed as human beings' primary way of making sense of experience through an interpretation of human concerns, intents, and motives (Clandinin & Connelly, 2000). Narrative inquiry and specifically "experience," which was addressed by John Dewey, "grows out of other experiences, and [these] experiences lead to further experiences" (Clandinin & Connelly, p. 2). As human beings, we "move back and forth between the personal and social, simultaneously thinking about the past, present, and future" (p. 3). Only by understanding the meaning people attribute to their illness, their ways of coping, and their sense of future possibilities can sensitive and appropriate care be provided (Barkwell, 1991).

Thorne (2008) encouraged the use of diverse perspectives during data analysis to extend interpretation. The iterative processes of reading, listening, thinking, and writing yields an understanding of the phenomenon that reflects the researcher's thoughts and ideas, not just the specific properties the data possess. To explore the potential for a greater depth of interpretation, this study's data analysis involved questioning what other meanings could be present. Additionally, the naturalistic approach affirms the mutual influence that the researcher, participants, and environment have on each other, creating a deeper understanding.

Nursing Perspective

Although this study was influenced by SI and NI, a nursing perspective also was used throughout the study. The nursing perspective is a reflection of nursing culture, education, professional experiences, and values that influence a nurse's view of a situation (Rodgers, 2005).

Such disciplinary perspective shapes what is observed in the field, what is seen during observation, and what sense is made of the observations (Thorne, 2008). Four defining characteristics of the nursing perspective are that nursing is

1. a human science,
2. a practice-oriented discipline,
3. a caring discipline that encourages relationships between nurses and patients, and
4. a health and wellness-oriented pursuit.

This perspective is useful for establishing general knowledge that can be used within the profession. Professional and advanced practice nurses share a larger role in monitoring cancer survivors and coordinating their care (Schlesinger-Raab, et al., 2010). The focus of nursing on health and health-related experiences fits with the focus of this study (Rodgers, 2005). Moreover, the strong foundation from the PI's 25 years of nursing experience contributed to the quality of inquiry and data analysis of this study's topic.

Insight and understanding are derived from the subjective experience of the participant, expressed in his or her own words. In the SI epistemology, the nursing perspective provided a lens for establishing a relationship with the knower and interpreting or constructing meaning from the contextual surroundings. The nursing perspective helped the PI establish a professional relationship with participants as they shared their health experiences.

Research Question and Definitions

This study's research question was *What are the health-related experiences and post-treatment needs of melanoma survivors living in the ETAR?* Following is an alphabetical list of the terms and definitions used for this study.

Dermatologist – a doctor who specializes in skin diseases (ACS, 2017).

Experience is defined in the dictionary as actually living through an event or events; actual enjoyment or suffering; the effect upon the judgment or feeling produced by personal and direct impressions; or the sum total of the conscious events which compose an individual's life (Oxford Dictionary, 2015).

Healthcare provider – a licensed person or organization that provides healthcare services (NCI, 2017). Specifically, healthcare providers include doctors of medicine or osteopathy, podiatrists, dentists, chiropractors, clinical psychologists, optometrists, advanced practice nurses, or clinical social workers.

Health-related – The World Health Organization (WHO, 2017) defines *health* as "complete physical, mental, and well-being, not merely the absence of disease or infirmity" (p. 1). The dictionary definition of *related* is connected by reason of an established or discernable relation (Oxford Dictionary, 2015). For this research, health-related was defined as toward a state of complete physical, mental, and overall well-being including other connected issues as designated by individuals.

Health-related quality of life (HRQOL) is a construct that measures an individual's level of physical and mental health perceptions, health risks and conditions, obesity, functional status, social support, and socioeconomic status.

Medical oncologist – a doctor who is specially trained to diagnose and treat cancer with chemotherapy and other drugs (ACS, 2017).

Melanoma cancer survivor – an adult from the time of melanoma diagnosis through the rest of his or her life

Melanoma survivorship includes surveillance for cancer spread, recurrence, or second cancers, as well as intervention for cancer treatment effects.

Need – a requirement that is essential or very important to an individual, family, or a community at-large. Needs can be economic, physical, psychosocial, or educational.

Quality of care – the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge and standards.

Quality of life (QOL) – an overall enjoyment of life; an individual's sense of well-being, ability to participate in activities, and functionality.

Surgical oncologist – a doctor who specializes in using surgery to treat cancer (ACS, 201).

Survivorship research encompasses studies related to the physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment, including issues related to healthcare services, access, and follow-up care.

Assumptions

This study was conducted assuming the following six statements were true.

1. People are capable of communicating accurately about their healthcare experiences, within the usual limits of memory.
2. Current melanoma clinical practice guidelines (NCCN, 2016) indicate that following melanoma patients intensively for metastatic disease beyond five years is not cost effective.
3. Melanoma survivors continue to require dermatologic (not dermatology) surveillance commensurate with their recurrence risk throughout their lifetime because of the illness course and the fact that it is already a systemic cancer at diagnosis (NCCN, 2016).
4. Melanoma survivors are monitored following treatment by various local or regional healthcare providers.

5. Most recurrences are detected by patient recognition or provider full-body skin exam findings.
6. Research does not support melanoma surveillance as a way to improve overall survival (NCCN, 2016).

Limitations and Delimitations

When human beings are used as the instrument for gathering data of subjective experiences, steps should be taken to account for potential problems that are beyond the researcher’s control. The potential for biases from the researcher and participant perspectives was a consideration for this study (Creswell, 2009). Interviewers come with “histories and cultural value systems; on many levels, the cultural and social expectations of both the interviewer and interviewee” will affect what is said and what is heard (Streubert & Carpenter, 2011, p. 35). While study limitations can be viewed as weaknesses, the strengths of qualitative research such as gaining historical information along with a subjective perspective can outweigh the conditions that influence the findings.

Participant bias may be introduced when individuals are responding to questions. Consideration was given to the fact that participants may offer responses they think the researcher wants to hear, not what they actually experienced. Awareness of influences, including any cultural or social differences between the researcher and participant can also add to the findings’ credibility. An understanding of the meaning of the experience moved beyond the words and socially acceptable answers toward building trust, triangulating the information, and persistence toward data saturation (Thorne, 2016). While researcher bias may be introduced at any time during a study, the probability increases during the data analysis. Steps were taken to reduce researcher bias for this study using recommended strategies such as reflective journaling, memos in the margin, detailed project notes, and expertise consulting.

The focus of the study was to understand the health-related experiences and post-treatment needs of melanoma survivors. Setting boundaries to achieve this purpose included making decisions regarding the sample, method, and data collection procedures. In addition, the study was conducted in one region in the southeastern United States. Another important attribute for this study included a varied group of men and women with different stages of self-reported melanoma. Private face-to-face semi-structured interviews were conducted to elicit the subjective stories from participants to speak freely without peer pressure that may be present in a focus group setting. This method of data collection provided consistency in the questions asked and allowed participants to give their own story rather than just nodding or agreeing with others. Using specific criteria (inclusions and exclusions) to select the sample further defined the population boundaries.

Purpose of the Study

The problem that prompted this study was a lack of understanding of the post-treatment experiences and needs (physical, mental, and overall well-being) of melanoma survivors living in Tennessee. One observation identified by the PI when caring for melanoma survivors was the amount of travel for follow-up from patients in the eastern part of the state to the central and western parts of the state. Further inquiry identified the eastern part of Tennessee was designated Appalachia by the United States government as part of a protected area where lack of needed resources and basic needs exist alongside the economic constraints of higher poverty and income levels lower than the national average (Ludke, 2012, Roehrich-Patrick & Moreno, 2016). The researcher found no studies that identified health-related experiences or post-treatment needs in

Tennessee or Appalachia. Without this information, it is difficult to establish best practice guidelines for meeting this population's post-treatment needs or help improve health outcomes. Failing to understand the link between the socioeconomic and culture-specific needs in the ETAR may contribute to this region's increased disparities, rising mortality, and a higher economic burden locally, regionally, and statewide.

Based on the significance and lack of understanding about the problem, the purpose of this study was to increase nursing and interdisciplinary knowledge about the follow-up care plans for melanoma survivors' in the ETAR from the patients' perspectives. This purpose included gaining understanding about post-treatment health-related experiences that could affect follow-up care. Insight gained from understanding the link between post-treatment socioeconomic, cultural, and economic factors could be useful for designing or enhancing interventions to address survivors' needs promptly, which in turn could affect their mental, physical, and social conditions. This unique perspective could promote an understanding of how healthcare delivery for melanoma survivor's links across time, place, and settings.

Study Significance

A specific, holistic description of melanoma survivors' health-related experiences and post-treatment needs living in ETAR is not currently available. "Nursing always and inherently requires knowledge about patterns and themes in general, so that it can better inform the care of the unique and distinct individual" (Thorne, 2008, p. 25). A major follow-up component for melanoma survivors is monitoring for recurrence and/or new malignancies with regular comprehensive skin exams, nodal assessment, and symptom and psychological evaluation. This study's findings can be used to help improve care delivery and continuity for this group of survivors. The findings also could be used by clinicians to inform their assessment of patient needs and care planning, and by policy and decision makers to inform decisions about ongoing healthcare system changes and reform.

Chapter Summary

The continuing cost of care for melanoma patients is projected to be over $220 billion in 2020, a statistic that is driving the quest for more efficient and cost-conscious ways of managing this population's care (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). Professional and advanced practice nurses will continue to share a larger role in monitoring cancer survivors and coordinating their care as patient navigators or providers. The findings of this study could support the development of best practices and provide high quality follow-up care for melanoma survivors in the Appalachian region of the southeastern U.S. Based on this study's findings, the researcher plans to continue research on related topics.

Chapter Two: Literature Review

Over the past 20 years, research on the topic of melanoma survivorship has focused more on patients' psychological needs and quality-of-life during diagnosis and treatment, and less on their long-term post-treatment experiences and needs. National and international melanoma studies have provided a broad look at adjustment and support issues during melanoma diagnosis and treatment (AIHW, 2016; Balch et al., 2011; Boyle, 2003; Clarke, McKinley, Keegan, & Glaser, 2014; Hamama-Raz & Solomon, 2006; Hetz & Tomasone, 2012; Linden, Vodermaier, Mackenzie, & Greig, 2012). The few related studies fall into three areas of interest for the current study: post-treatment QOL, examinations of psychological adjustments and the influence of personality, gender, uncertainty, and mental health issues on melanoma survivorship; and melanoma survivors' post-treatment health practices.

Review of the Literature

The electronic databases used in the literature search were CINAHL, ERIC, PubMed, PsycInfo, and Sociological Abstracts. Key search terms were melanoma survivorship, melanoma follow-up, patient experiences with melanoma after treatment, nursing care and melanoma, psychological issues in melanoma survivors, melanoma post-treatment experiences, and melanoma survivor needs. After reviewing the published literature, several additional key terms were added: cancer survivorship, melanoma survivorship outcomes, and Tennessee melanoma survivors. To capture a wide range of national and international studies, publication dates were not limited. Publications found during the search were examined to find those focusing on melanoma survivors' post-treatment care episodes, encounters with healthcare providers, follow-up experiences, and needs. Twenty studies fit this profile with literature excluded that focused on health-related experiences and needs during the diagnostic and treatment period only.

Additionally, after evaluating the literature an additional search was conducted to look for Tennessee cancer survivor-specific studies that involved participants from within the state or the East Tennessee Appalachia Region (ETAR). No additional studies were found in that additional search. The current gap in the research on the health-related experiences and post-treatment needs of melanoma survivors living in the ETAR became the impetus for the current study.

Regional History Literature

The region identified in the current study required some discovery related to the geography of the east Tennessee area and Appalachian culture. The Appalachian region includes 13 states and 420 counties that span 205,000 square miles (ARC, 2016). Although the Appalachian boundaries have changed over the inception in 1890, the region starts at the southernmost mountains of New York and continues south to northern Mississippi. Initially dependent on mining, forestry, and agriculture, Appalachia has become more diverse to include manufacturing, services industries, and tourism. However, because of its sprawling mountainous land, the economic status of the Appalachian region varies from county to county and includes some remote areas with widespread poverty. The Appalachian region includes eastern Tennessee, where the study participants were recruited. Portions of Appalachia continue to have widespread poverty and limited local or regional access to healthcare, which is in stark contrast to other regions of the Tennessee or the US.

Culturally, eastern Appalachia family culture is dynamic, complex, diverse, and rich (Abramson & Haskill, 2006). The family remains an essential component of local and regional society in Appalachia. Some common characteristics include humility, modesty, rugged independence, prideful and having love of family, community, and nature. More rural Appalachians generally are distrustful of outsiders and often are misunderstood and stereotyped as being ‘hillbillies’, ‘mountain folk’, ‘white trash’ or ‘rednecks’ (Shackelford, Weinberg, &Anderson, 1977; Burns, Scott, & Thompson, 2006; Biggers, 2006; Huber, 2008; Presely, 2013). In *Our Appalachia* (Shackelford et al., 1977), a philanthropist doctor from Appalachia was interviewed in 1980,

> One of our congressmen was evaluated by Ralph Nader as ‘typically hillbilly.’ What the hell does that mean? If you are reading that in Ohio it means a whole lot different thing that it does [in Tennessee]…What we have lacked in the mountains is people who can relate to the technically advanced aspect of society but still retain the personal characteristics that are necessary to relate to people down here. You have got to separate people’s minds from people’s way of living. If the way of living means that they are not getting the right kind of food, they don’t have a decent place to live, they don’t have a chance to get an education, to get a job, then I think something has to be done about that. But loving your family, liking your country, [and liking] soup-beans, cornbread, and onions, I don’t think people ought to be put down for having those kinds of ways. (p. 360)

While southern Appalachia was thought to be too mountainous and unsettled, Biggers, (2006) noted that much of the white migration to the eastern U.S. in the 1700s and 1800s were from Europe (British Isles & Ireland) and many settled in the southern portion of rural Appalachia Phipps, 2016). For the many settlers who called rural Appalachia home, there was a sense that the area’s terrain and ruggedness gave them a sense of freedom from the persecution they experienced in their previous lands over religious, social, or economic divergence (Watson, Griffin, Eveleigh, & Shaw, 2008). In modern times, while some changes and modernization have taken place, Appalachia remains a mountainous, rugged region often misunderstood. Rural

Appalachians distrust outside influences, cherish the solitude of their environment, and stay close to family with some maintain a fundamentalist religious doctrine.

The East Tennessee Appalachian Region (ETAR) literature reflects a proud people with strong connections to family and community relationships. Although Appalachia's population has become increasingly concentrated in urban areas, the region's "small towns and communities continue to be inhabited by related families who have sometimes lived there for hundreds of years and have personal connections to local history" (Burns, Scott & Thompson, 2006, p.149).

Melanoma Post-Treatment Literature

The search for research about post-treatment melanoma survivors in Tennessee uncovered a large gap in regional indices. One study from Tennessee about skin cancer from the early 1970s was identified. Zagula-Mally, Rosenberg, and Kashganan (1974) compared epidemiology skin cancer rates (for all types of skin cancer, not just melanoma) with a representative rural population using cluster analysis in West Tennessee's Tipton County. Other than this study, Tennessee melanoma survivors have not been included in the research looking specifically at their experiences or needs.

Quality of Life

Survivors' experiences and care issues were explored in a qualitative study conducted in Sydney, Australia. Morton, Rychetnik, McCaffery, Thompson, and Irwig (2013) completed in-depth interviews with 29 melanoma survivors from a clinic that provided long-term follow-up after melanoma treatment. The impetus for the study was to understand the commitment of time and effort that melanoma survivors invest and practitioners provide. The research aims included capturing patients' perspectives of the value of follow-up care including its benefits, limitations, and potential downsides; survivors' thoughts and feelings about changes to follow-up frequency;

and patient-centered recommendations for improving follow-up care. Enrollment occurred during May and June of 2010 with all ages of stage I and II melanoma survivors (median age 62). Most participants were followed-up by a melanoma unit general physician and the others by a surgeon.

The interview guide questions focused on positive and negative follow-up experiences, such as what happened during follow-up visits, and what the follow-up experience meant to the survivors. Following are examples of typical participant responses: "he checks everything… he checks between my toes… through my hair thoroughly," "he always checks the lymph glands under my arms and in the groin…," and "…those cancer clinics… the doctors are just there to make the dough [money], they want to cut everything out of everyone because they get more money" (Morton et al., 2013).

Participants reported that the benefits of long-term follow-up included reassurance, early detection of recurring or new cancers, education about skin self-examination, an opportunity to ask questions, and reinforcement of sun protection behaviors. Participants also indicated that their anxiety increased as the visit date grew closer, and the inconvenience of traveling to attend visits often included lost work time. Melanoma survivors performed skin self-examinations infrequently and had conflicting views on multiple skin excisions. Access to specialists for unscheduled visits consistently was reported as beneficial (Morton et al., 2013).

Based on Morton et al.'s (2013) study results, the Melanoma Institute in Australia stated that melanoma follow-up could be extended to 12 months for patients with stage I, as long as they could access a melanoma specialist at short notice. The health-related experiences and needs identified in this study included reassurance, early detection of recurrences, education, and anxiety (Morton et al., 2013).

Murchie and colleagues (2010a) conducted a randomized controlled trial in Ireland that demonstrated positive patient satisfaction with general practitioners (GPs) providing post-treatment follow-up versus routine follow-up with specialists. The control group was followed by specialists at the Aberdeen Royal Infirmary in Northeast Scotland from 2005–2006. The participants (n=142) received care from 35 different general practices where the physicians received specialized training and instructions in follow-up for melanoma survivors who were no further than 10 years post-treatment without any recurrence. Baseline satisfaction was measured in both groups at the beginning of the study and at 12 months using a self-completed, mail-in patient questionnaire measuring demographics and socioeconomic status, a patient satisfaction questionnaire, the 36-item Short Form Health Survey (SF-36), and the Hospital Anxiety and Depression Scale (HADS). The participants' medical records were reviewed for information regarding the initial melanoma diagnosis, treatment, and use of primary and secondary care services in the previous 12 months (Murchie et al., 2010a).

As a whole, the physicians, treatment, and control groups followed the protocol without any incident (Murchie et al., 2010a). Participants adhered to the protocol to see a GP first and receive a specialist referral if needed. No statistically significant differences were found between the treatment and control groups' health status and psychological well-being. The researchers also examined within-group differences between baseline and follow-up and found no statistically significant differences (Murchie et al., 2010a).

In a subsequent study, Murchie, Delaney, Campbell, and Hannaford (2010b) interviewed 18 melanoma survivors from the randomized controlled study with the same first author. The treatment group participants were interviewed to explore their practical post-treatment experiences with the study protocol. Generally, participants reported positive experiences, citing the protocol advantages of convenience, less rushed appointments, more thorough examinations, a more pleasant atmosphere, and greater continuity of care from the GPs. The main concern expressed by participants was the awareness that the GPs had less experience. The researchers identified three broad themes: the practicalities of GP follow-up, a comparison of the two systems, and the participants' personalities and feelings. One study limitation was the fact that the interviewer was a GP, which may have affected how he handled negative views about the GP protocol (Murchie, et al., 2010b).

In a nationwide prospective longitudinal descriptive study, Livingstone et al. (2015) examined Germany's follow-up plan for melanoma survivors. The four-year study focused on describing current melanoma treatment and follow-up, the value of this follow-up care for patients without recurrence, and melanoma patients' psychological effects and needs. All patients (1,264 registered in the database) who had been diagnosed with melanoma between April 1, 2008 and June 30, 2008, signed a consent form at the time of diagnosis and completed several self-reported questionnaires. The European Organization for Research and Treatment of Cancer's (EORTC) Quality of Life Questionnaire (QLQ-C30) was administered. The EORTC QLQ-C30 has a Cronbach's alpha coefficient for its quality of life measure ranging from 0.86 and 0.89. Anxiety and depression also were assessed using the German version of the HADS, a widely accepted questionnaire that is designed to "assess clinically relevant symptoms of anxiety and depression in patients with somatic diseases" (p. 655). The instrument's sensitivity (83.3%) and specificity (61.5%) for identifying psychiatric cases was acceptable.

Complete data was available for 668 patients from 67 centers "of whom 96% were in regular melanoma surveillance" (follow-up) at the two-year mark (Livingstone et al., 2010, p. 1982). In addition to the questionnaires, sociodemographic information (sex, age, marital status, educational level, and employment status), disease-specific health information sources, and health-behavior information were "ascertained with self-constructed questions" (Livingstone et al., 2010, p. 1985). Patients with stage I–IIC melanoma were included in the study with a similar number of men (50.9%) and women (49.1%). The men's mean age was 64.3 years and the women's was 59.4 years. Tumor thickness average for men was 1.67mm and 1.55mm for women. Therefore, the study included slightly fewer women, who were younger than were the men, and had thinner tumors. The follow-up frequency included quarterly (35%), half-yearly (40%), and yearly (16%) follow-ups. After four years, 93% of participants were alive. Only 6.6% died, but only 50% of these deaths were caused by melanoma. Prevalent comorbidities included cardiovascular diseases (14.3%), other cancers (9%), and diabetes (4.3%). Autoimmune diseases and depression reported in less than 5% of participants (Livingsone et al., 2015).

Most participants received melanoma follow-ups with surgeons at centers throughout Germany, with 25.3% of the survivors referred to dermatologists, and only 1% referred to GPs or medical oncologists. The researchers calculated the cost of providing follow-up for 550 patients without recurrence for over four years at $257,992.82 (228,155.75€). Through its Commonwealth Fund, Germany provides universal healthcare services for melanoma survivors with surgical follow-up an integrated part of post-treatment care. The researchers' recommendations included decreasing follow-up frequency for low-risk (stage I–IIB) melanoma patients. They also recommended that melanoma surveillance resources be focused on providing patient education and psychosocial support to patients with high psychological stress. The objective of cancer follow-up care is the early detection of tumor recurrence with the aim of improving OS. Many melanoma patients have tumor recurrences within the first three years after diagnosis. While patient-detected recurrences are believed to be as high as 60–70%, this study showed that less than one-third were detected by the patients (Livingsone et al., 2015).

Oliveria et al. (2013) was interested in melanoma survivors' experiences with sun-protection behaviors and follow-up practices. The sample was taken from patients treated at a major cancer center in the Northeast U.S. who were diagnosed with primary cutaneous melanoma (stages I–III) between1996 and 2005. Eight focus groups were assigned from a stratified, random sample based on survivor's age at diagnosis. Two hundred and twenty eligible participants were contacted and 48 individuals participated in the focus groups. Focus groups questions concerned topics identified as important in or absent from the literature: melanoma's impact on patient health behaviors; lifestyle and quality of life issues; practices related to physician skin screening and skin self-examination; patient concerns for family members including their risk for developing melanoma; economic issues arising from diagnosis and treatment; and post-treatment anxieties including recurrence concerns. While most participants did not conduct routine skin self-examinations, some experienced anxiety if caught unprotected in the sun. Many survivors did not discuss risk reduction with family or friends. Findings indicated that the melanoma diagnosis elevated the importance of retaining health insurance and purchasing life insurance for younger survivors (Oliveria et al., 2013).

In a descriptive quantitative study, Palesh and colleagues (2014) explored melanoma survivors' long-term symptoms, sun protection practices, and support needed from their healthcare providers. Melanoma survivors treated at the Pigmented Lesion and Melanoma program at the Stanford Cancer Center in Marin County, California from 1995 to 2011 were asked to complete a health-needs survey with an 18% response rate (N=893). The enrollment period was from July through September of 2012 and 160 surveys were completed and de-identified. The survey was a non-validated online instrument with usability issues. Researchers compared the responses between gender, education, and time since diagnosis (Palesh et al., 2014).

Several outcomes within the Palesh et al. (2014) remained consistent with prior research in melanoma survivors. On average, the participants were highly educated (75%), non-Hispanic whites (94%). Several conclusions were drawn from the health survey data. First, melanoma survivors experience continuing symptoms long after treatment ends, especially anxiety (34%). Next, participants expressed a need for more information about long-term melanoma effects (43%), additional psychosocial support (12%), and ways to prevent recurrence (19%). The researchers recommended greater healthcare provider involvement to address patients' physical and psychosocial needs, increased education to prevent the possible long-term effects of melanoma, and treatment guidelines for clinically relevant levels of post-treatment distress (Palesh et al., 2014).

Although the Marin County, California sample was homogenous—predominantly educated, non-Hispanic whites with a high socioeconomic status—U.S. researchers report consistently that this population is typical of Americans diagnosed with melanoma (Siegel, Ma, Zou, &Jemal, 2014). In 2012, Marin County melanoma incidence rates were 46.2% compared with the state melanoma incidence rate of 21.1%. Stanford University, where the study originated, is a major area provider of post-treatment care for melanoma survivors in the regional area.

McLoone et al. (2012) explored the psychosocial experiences of melanoma survivors at high risk of developing new primary disease. Twenty-two survivors participated in semi-structured telephone interviews in which the researchers explored melanoma-related beliefs, experiences, psychological adjustment, and supportive care needs. Participants were recruited from a high-risk melanoma clinic in Sydney, Australia where the melanoma incidence rate tis three times that of U.S. (CDC, 2015). The researchers used the transactional model of stress and coping (Folkman & Greer, 2000), which predicted that psychological stress will be greater if an individual is at higher risk of developing melanoma and the threat is perceived as severe (McLoone et al., 2012).

Miles and Huberman's (1994) conceptual framework was used to guide the qualitative content analysis and coding of the transcribed text. After sorting the data into hierarchical categories to form organized and meaningful clusters, several themes emerged. The themes were fear, persistent uncertainty, threat perceived as pervasive, causal attributions, controllability and behavioral responses to threat, low confidence in ability to detect melanoma (self-efficacy), specialized medical care, barriers to accessing emotional support, and feeling misunderstood. Although participants reported adjusting to their melanoma risk using an active coping response, the researchers commented, "it is concerning that a substantial proportion also reported concurrent and persistent uncertainty, anxiety, and fears regarding recurrence" (McLoone et al., 2012, p. 1110).

McLoone et al.'s (2012) study questions were designed to elicit responses that would help the researchers understand melanoma survivors' experiences. Survivors were asked to discuss their thoughts, beliefs, and experiences regarding melanoma and its cause, their level of risk, health behaviors, and general beliefs about moles (skin). The researchers commented that although the participants reported specific psychological issues, "none of the survivors in this study reported seeking or receiving professional emotional support, despite a desire for such support on the part of some individuals" (McLoone et al., 2012, p. 1110). One explanation given for this finding was “patients’ perceptions that—because melanoma is a visible cancer, and therefore detectable at an early, curable stage—the term cancer survivor” may not apply to them, a perception that could impose considerable issues in follow-up (McLoone et al., 2012, p. 1110).

Psychological Impact

Hetz and Tomasone (2012) focused their study on understanding the supportive care needs of a sample of 31 Canadian melanoma survivors. For this cross-sectional, descriptive, correlational, quantitative study, patients were selected from the Melanoma Network of Canada, a patient-led organization providing melanoma information and resources. Participants completed the *Supportive Needs Questionnaire–Melanoma Supplementary Module*. Most survey questions dealt with initial diagnosis and treatment; only one addressed post-treatment needs. Results revealed unmet needs related to lack of information, particularly among individuals with less formal education. Descriptive statistics using ANOVA and Pierson Chi-square found a statistical correlation between individuals without a post-secondary education and the need for more information in the diagnosis and treatment phases (Hetz & Tomasone, 2012).

Participants without post-secondary education had a higher need for information about surgical treatment of the skin (p=.04), surgical removal of lymph nodes (p=.004), non-surgical treatments (p=0.1), melanoma spreading from the skin (p=.0001), and pain control (p=.01) (Hetz & Tomastone, 2012). The only post-treatment question on the online survey was, “Do you conduct regular self-checks to screen for melanoma, skin cancers, or a recurrence?” Results showed that the individuals who performed more regular self-checks generally were college educated and felt comfortable asking for information. Melanoma patients were referred more often from dermatology offices for psychological support in the Netherlands (Korner & Fritzshe, 2012).

Bird, Coleman, and Danson (2015) explored melanoma survivors' experiences, support needs, and the processes that met their needs. The study focused on a follow-up program for melanoma survivors conducted by advanced practice nurses in the United Kingdom. A grounded theory approach was used with in-depth interviews that examined melanoma-related worry. This worry was identified as a need to have their concerns believed by others prior to and after diagnosis, the desire to avoid being a burden, and lack of self-reassurance. The purposive sample was from melanoma clinics at a specialist cancer center in England where the incidence of melanoma is 26.7% (cancerresearchuk.org, 2016). Initially, open-ended questions were asked with some probing, and then additional questions about melanoma-related worry from earlier interviews were added (Bird et al., 2015).

Interview responses were organized into categories and subcategories of melanoma-related worry. The researchers noted that "regardless of whether patients experienced a recurrence, the thought that the melanoma could come back" was identified as a concern or worry (Bird et al., 2015, p. 941). Additionally, being believed was identified as the need to have "someone verify that their concerns were real or justified" (p. 941), a need that continued throughout the patients' experience. For example, patients felt that because "melanoma was not seen as being as serious as other cancers" (p. 941), other cancer patients, family, and friends did not acknowledge their fears. Self-assurance stemmed from "a need to actively do something to prevent recurrence" (p. 944), to offset melanoma-associated worry (Bird et al., 2015).

The eleven patients interviewed in this study were evenly distributed between females and males with a mean age of 61 and averaging from one to 11 years from initial diagnosis (Bird et al., 2015). The stage at diagnosis was between II–IIIB (thick lesion). Patients had between two to seven surgeries, and two had radiotherapy, interleukin, or interferon. Researchers concluded that participants viewed their needs as unique from those of people with other types of cancer. Participants described the uncertainty of the future and the possibility of disease recurrence, "… it was hard. I just felt as if I were a bit out on a limb" or "… then it meant the 40% chances of… it spreading further…" (p. 942). This research's relevance to clinical practice is related to its findings about the lack of public awareness of melanoma, and how it differs from other types of cancer. This study answered some questions about melanoma survivors' post-treatment experiences and needs in England. The melanoma-related worry, concern, or anxiety fits with patients' psychological need for information, reassurance, and validation of melanoma as a cancer diagnosis. Nurses can help identify such worry, concern, or anxiety when they interact with melanoma survivors in a variety of settings. Patients will choose "whomever they feel best able to talk to at that time, whether this is a specialist nurse or someone independent of their cancer care" (Bird et al., 2015, p. 945).

McLoone et al. (2013) interviewed 22 Australian melanoma survivors who had at high risk for recurrence. Semi-structured interviews were conducted via telephone to determine their satisfaction with post-treatment care. Miles and Huberman's qualitative framework was used to develop study themes (Denzin & Lincoln, 2000). This study was the first to assess patients' satisfaction with a particular follow-up model—The Health-Related Clinic [HRC]—that was designed specifically for melanoma survivors at high risk of developing new primary disease. This specialized clinical facility provides expert care, including dermoscopy imaging, sequential digital imaging, and total body digital photography to patients at least bi-annually, and free of charge. Patients' satisfaction with their clinical care was high. Several contributing factors were identified including rapid and regular access to physicians who were perceived as experts, and the development of confidence, trust, and a sense of being cared about and understood. While the melanoma survivors did not seek formal psychological support, many expressed long-standing melanoma-related fears and concerns. The importance of "accessible, expert medical attention, delivered in a patient-centered manner was integral to melanoma survivors' satisfaction with clinical management" (McLoone et al., 2013, p. 1994).

Many patients felt they needed more education and training to perform skin self-examination adequately (McLoone et al., 2013). Participants frequently reported being satisfied with the clinics' continuity of care. Patients also expressed a clear need to be informed of changes to their prognosis as well as advances in melanoma treatment. Researcher suggestions included developing best practice protocols for the management of depression and anxiety to offer more referrals.

Health and Well-being

In their quantitative study, Zucca, Boyes, Linden, and Girgis (2012) examined whether multiple concurrent symptoms (clusters) exist in long-term cancer survivors and made comparisons to global QOL. The researchers' aims were to assess patient-reported QOL and identify of clusters of physical cancer-related symptoms by cancer type among long-term breast, prostate, colorectal, and melanoma cancer survivors. The researchers used a population-based cross-sectional random sample of 863 adult cancer survivors from Australia's Central Cancer Registry who were five to six years post-diagnosis. The survivors completed the EORTC QLQ-C30. The results showed this sample had higher global QOL scores than general population norms, and a majority did not report any cancer-related physical symptoms across cancer types (71%). Melanoma survivors represented 15% (n=131/863) of the study's participants. The results from a comparison between pre-treatment and long-term melanoma survivors showed a higher global QOL for the latter group. The physical symptom frequency in melanoma survivors was largely no symptoms at 89%, with one symptom at 6.6%, and multiple symptoms at 4%. The two major symptoms reported were insomnia and memory trouble. The limitations of such large-scale population-based studies are revealed in its one-dimensional examination of physical effects or symptoms frequency that does not assess symptom severity or distress (Zucca et al., 2012).

Kent and colleagues (2014) conducted a large population-based study examining health outcomes in older adult cancer survivors. Cancer survivor was defined as an individual with any history of cancer. Researchers selected less frequently occurring cancers for this study including those of the kidney, bladder, pancreas, UGI, oral cavity and pharynx, uterus, cervix, and thyroid as well as melanoma (19% or 3,019 survivors), leukemia, non-Hodgkin's lymphoma, and multiple myeloma. The researchers identified a gap in the literature regarding the QOL indicators for older adult survivors who had cancer in less frequently occurring sites. Ten cohorts, beginning in 1998 and ending in 2009, were included in the data set from the SEER National Cancer Registry System linkage with the Medicare Health Outcomes Survey (MHOS). The heterogeneous data set included 16,095 survivors along with 1,224,549 individuals without a cancer history for comparison. The results showed poorer health outcomes among older adult cancer survivors (Kent et al., 2014).

Melanoma survivors scored similarly on the SF-36 and Veterans RAND 12-Item Health Survey (VR-12) as individuals without a cancer history (Kent et al., 2014). For *vitality*, individuals with no cancer history scored 49.4%, and melanoma survivors scored 49.6. For *social functioning*, individuals with no cancer history scored 48.0%, and melanoma survivors scored 47.6%. For *emotional well-being,* individuals with no cancer history scored 45.2%, and melanoma survivors scored 45.7%. Finally, for *mental health*, individuals with no cancer history scored 51.4%, and melanoma survivors scored 51.8%. Although the SF-36 and the VR-12 instruments lack cancer-specific measures, they were used for this study because they are widely accepted and have been evaluated in multiple disease and treatment contexts allowing for comparisons between SEER-MHOS subgroups. This study has several limitations including its lack of data related to fee-for-service and Medicare HMO older adults in the cohorts. The authors' research recommendations included the need to address sociodemographic, biological, and clinical factors that may contribute to overall health status impairments along with longitudinal data to examine changes in health status over time. The SEER-MHOS data set contains essential information collected at the time of diagnosis that cannot be extrapolated in identifying post-treatment experiences or needs in melanoma survivors (Kent et al., 2014).

Chapter Summary

Post-treatment melanoma survivors' have received less attention in the body of research about melanoma and cancer survivorship. For more than a decade, melanoma research mainly has focused on prevention, early detection, and treatment. Although ongoing follow-up is critical for cancer survivors, there are currently no accepted guidelines defining best practice, post-treatment care for individuals diagnosed with melanoma or the healthcare providers who care for them. A major component of melanoma survivors' follow-up is monitoring for recurrence and/or new malignancies with regular comprehensive skin exams, nodal assessment, along with symptom and psychological evaluation and treatment. Currently, the responsibility for follow-up with melanoma survivors falls inconsistently on a variety of healthcare providers. Research is needed to understand this group of survivors and their needs within their community.

Chapter Three: Methods

For this study, the PI employed the *interpretive description* method, the preferred strategy when "new knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience is needed" to inform understanding that can guide future decisions that "apply evidence to the lives of real people" (Thorne, 2008, p. 356). The understanding gained from this study could help inform and guide future decisions about how to apply evidence to improve the lives of melanoma survivors. In this chapter, the study's method, participant sample, and ethical considerations are discussed. Next, data collection techniques and in-depth analysis processes are covered along with the steps used to maintain the study's rigor and trustworthiness.

Interpretive Description Method

The interpretive description method is a qualitative method with the flexibility to fit a variety of disciplinary perspectives (Thorne, 2008). One aim of interpretive description, a relatively new qualitative methodology, is to "generate knowledge relevant for the clinical context of applied health disciplines" (Hunt, 2009, p .1). This method involves seeking patterns and themes within "subjective human experience, not so much as to grasp its essence, as to understand what (practitioners) are likely to encounter in future clinical practice and to have some meaningful sensitivity around it" (p. 79).

By selecting analytical techniques from other qualitative methods, interpretive description promotes a deep understanding of study data through a rich, diverse, and robust process. An interpretive description qualitative method is the most appropriate and effective method for addressing the research question guiding this study and producing an "analysis of discovering associations, relationships, and patterns" within the post-treatment melanoma survivor population (p. 33). Whereas the focus of phenomenology is to understand the essence of an experience (Creswell, 2013), interpretive description focuses more on generating new knowledge about clinically relevant human phenomena (Thorne, 2008). Generally, a qualitative research approach involves an interpretive, naturalistic approach to the world (Denzin & Lincoln, 2000). A qualitative design is holistic and looks at the larger picture, which leads to a better understanding of the whole (Denzin & Lincoln). Interpretive description is the preferred strategy when new knowledge pertaining to the "subjective, experiential, tacit [implied], and patterned aspects of the human health" experience is needed (Thorne, 2008, p. 36). The interpretive description approach described by Thorne guides the researcher in moving beyond a straight description of the phenomenon to an analysis that seeks to discover associations, relationships, and patterns within the focus topic (Thorne, 2008).

Understanding the experiences of melanoma survivors through an interpretive approach can create visibility and meaning for individuals and the community at large (Denzin & Lincoln, 2000). Interpretive description is an applied disciplinary approach that uses theoretical influences from naturalistic and narrative inquiries and to look at broader clinical problems or populations where the focus is to describe and interpret "patterns of experience, action, or expression" (Thorne, 2008, p. 68). As an applied science, nursing research pulls from many disciplines when "different approaches to discovery are needed" (p. 95). Qualitative researchers attempt to make sense of, or interpret phenomena in terms of the meanings people bring to them in a naturalistic setting rather than a laboratory (Denzin & Lincoln, 2000). In an interpretive description approach, an ongoing engagement with the data will "confirm, test, explore, and expand on the conceptualizations that begin to form" (Thorne, 2008, p. 99).

To gain a better understanding of what melanoma survivors experience after treatment, they should be asked. Interpretive description is an “applied qualitative research approach that contributes to better understandings of complex experiential clinical phenomena” within nursing to establish rapport and field questions from within the industry (Thorne, 2008, pp. 26–27).

In qualitative research, the role of the researcher includes describing participant biases and ideological preferences in an “effort to get inside their world of meaning” (Denzin & Lincoln, p. 76). This task includes recording anything specific about the participant that would be pertinent in transcription, things that stands out about the interview, possible interruptions or unusual occurrences, and the researcher’s reactions. Additionally, specific notations about rapport, environment, flow of communication, and participants’ and researchers’ emotional responses should be recorded. Consistent with the interpretive description process, data collection and data analysis occur simultaneously. To gain knowledge of patients’ previously unexplored experiences, this method allows going beyond descriptions or essences in that interpretations are made relative to the patients’ perspective and to the group as a whole, noting clinical implications (Thorne, Kirkham, & MacDonald-Emes, 1997).

Data Collection

Data was collected from participants within a 45-county area of eastern Tennessee designated part of Appalachia by the Appalachian Regional Commission (2016). The researcher has lived and worked in Tennessee for more than 20 years in both Appalachian and non-Appalachian regions.

Setting

The ETAR was the area of focus for this study, which included counties where the melanoma incidence is higher than state and national rates (Grainger, Hamblen, Hawkins, Jefferson, Sevier, Sullivan, Washington, and Unicoi). The PI travelled to the eastern Tennessee Appalachian Region to distribute flyers and to engage in the interviews with participants. East Tennessee is a name given to a third of Tennessee, representing one of three grand divisions that has legal and economic implications for the state (West, 1998). East Tennessee is entirely located within the Appalachian Mountains with landforms that range from densely forested mountains to broad river valleys (Abramson & Haskell, 2006). The focus on the ETAR melanoma survivors is important for a number of reasons including the area's higher melanoma incidence rate. Several indicators are important consideration for the focus on this area of Tennessee for this study, which includes the large income disparity in Appalachia versus non-Appalachian counties; the area's relatively high unemployment, low educational attainment, and isolation due to lack of transportation access; and the outmigration of people (and workers) from the region (ARC, 2016).

Sample

A purposive convenience sample of melanoma survivors living in the ETAR was the participant focus area. Information on individuals diagnosed with melanoma was self-reported. The PI made efforts to achieve gender balance and diversity in age and race/ethnicity in the sample. This study was conducted with melanoma survivors age 18 and older. Individuals were invited to participate if they were diagnosed with melanoma (stages I–IV), were post-treatment or post-partial treatment; or had a melanoma recurrence and currently receiving treatment or in a clinical trial; were English speaking, and had access to a phone or computer. Participants were excluded if they were receiving treatment following primary or an initial melanoma diagnosis; were receiving ongoing treatment for cancer other than melanoma; were unable to communicate verbally; had acute emotional or physical distress from any cause; or were cognitively impaired.

Sample Size

Thorne (2008) stated that any sample size could be appropriate for interpretive description, as the size is best justified by generating a rationale consistent with the research question. She concluded that most studies are relatively small with five to 30 participants. Considering the lack of current research with post-treatment melanoma survivors and the scant health-related research in the ETAR, the PI had a goal of a minimum of 15 participants.

Recruitment

Flyers were distributed to cancer centers, cancer support groups, primary care providers, and dermatology practices in numerous counties within the eastern Tennessee Appalachian target area. The flyer invited study participation and included the study criteria along with the PI's contact information. Interested melanoma survivors who were contacted by the PI (via mail, email, or phone) and were screened for inclusion criteria over the phone. After melanoma survivors indicated their desire to participate, the PI brought a consent form to the interview, where the PI reviewed the form with the participants and a copy was given for their future reference. After obtaining consent, the demographic information was collected and later recorded on a spreadsheet: age, gender, ethnicity, education, zip code, and employment status.

Interviews

The interviews were scheduled in a location agreed upon with the participant. The PI indicated that the interviews should take no more than 90 minutes. The PI allowed 20–30 minutes for participants to review the informed consent document in her presence, complete the demographic date worksheet, and one hour for the interview. The PI also informed participants of their right to be notified of the study results. Once the consent was signed, the PI proceeded with the interview. Primary data collection included audiotapes from face-to-face interviews with individual participants. Interviews were recorded using a voice or audio recorder; no video was recorded. The PI used semi-structured interviews with field notes to collect important data. Participants' recorded interviews were transcribed. Participants were asked to contact the researcher to request a copy of the results.

Ethical Considerations

This study was submitted to and approved by the University of Tennessee–Knoxville's Institutional Review Board (IRB). Interview participation was voluntary and participants have the opportunity withdraw at any time. A detailed consent form was given to each participant and interviews were not conducted until it was signed. A copy of the consent form was given to the participant to keep. Each participant was given a pseudonym and no real name appeared anywhere except on the original consent form. Consent forms are stored separately in a secure, locked location. All interviews were digitally recorded and transcribed verbatim by a reliable transcriber who signed a confidentiality form.

Participants faced three minimal potential risks: they could experience a loss of confidentiality, become emotionally upset, or feel some sense of coercion. Several strategies were used to minimize to protect confidentiality. First, the PI completed the Collaborative Institution Training Initiative Program (CITI) for research ethics education and was the only person with access to the data. Additionally, all data was stored in a locked cabinet in the PI's home office and on a computer with a digital access code known only to the PI. The PI de-identified all data and separated the consent forms and lists of contacts from other research materials.

Another risk was that participants could become upset because of the sensitivity about their health experiences or illness narratives, and the difficulties associated with cancer as a fatal illness. To prevent participants from feeling coerced or anxious about participating, the PI assured them they could end their participation or terminate an interview at any time, and decline to answer any individual questions. To promote participants' comfort, breaks were offered every 20 to 30 minutes and whenever participants requested one. The PI planned for the interviews to last approximately 90 minutes, but allowed more time when a participant had more to say. Interviews were scheduled in a location agreed upon by the participant. These results will be used for practice and scholarly purposes, and the results will be reported only in the aggregate. Particular quotes that might identify the participant based on specific or regional details were disguised.

Data Analysis

To become engaged with the interview data—including developing an understanding of the nuanced meaning of words, sounds and silent moments—the PI transcribed the initial three interviews and initiated the coding process manually (Throne, 2008). The PI did guard against any bias related to familiarity with the first three transcripts differently than the other transcripts. The review of all interviews and written transcripts were reviewed numerous times with the same level of scrutiny. The PI used NVivo software for data management. The remaining interviews were transcribed by a transcriptionist, which the PI reviewed closely which included listening to the interviews several times while simultaneously reviewing the written transcripts. The PI entered the study data and stored it on a password-protected computer on a secure research network housed in the PI's locked office. Data will be maintained for three years after the study, and then destroyed. Any written and audio notes will be shredded. Audio files will be permanently deleted, as voices are identifiable.

One of the most essential elements of a credible interpretive description study is the intensive process of analyzing the data to generate new constructions that are meaningful and relevant (Thorne, 2008). Interpretive description requires the researcher to see beyond the obvious questioning and test what is observed in the data. The initial analytic process began with a broad sorting of the data from individual transcripts. Words and phrases that reflected meaningful responses were underlined, circled, and highlighted. For this interpretive description study, inductive analysis continued through an iterative (repeated) process of formulating categories, themes, and recognizing patterns from the data.

Initial Analysis

In the early phase of analysis, Thorne (2008) suggested organizing the data using few permanent labels. First, pieces of data that attracted attention and caused a reaction were noted by the PI. Thorne (2008) described this part of the analysis as an act of contrasting the expected with the unexpected, which stimulates the senses. For each transcript, the PI engaged in confirming an accurate recording of the transcripts and immersing herself in the data. As she analyzed the data, the PI also developed a sense of the whole, as this method requires the researcher to focus attention consciously in a sequential manner from the individual participant “cases” to the whole data set, and from groups of similarity among certain cases to various overall differences among other cases. This iterative process increased the level of clarity in understanding what relationships existed among and between instances within the data. Seeing the bigger picture is essential in qualitative research as the researcher looks for relationships and tensions within systems, cultures, and subcultures. Data analysis was deemed complete when the research question had been answered, questions that emerge during the study had been addressed adequately, and a clear picture had developed regarding the subjective health-related experiences and needs of post-treatment melanoma survivors. Additional notes, such as the PI's reflection journal entries and memos, were incorporated into similar categories and linked patterns or groupings were identified.

Coding Process

Interpretive description requires a broad-based, generic coding process (Thorne, 2008) that allows groups to be established such as age categories, or participants diagnosed in similar medical settings or under similar circumstances. Thorne recommended generic identifiers be used to prevent assigning meaning too early and guiding the interpretation into false findings. The initial coding process was followed by descriptive coding (i.e., topic coding), which involves summarizing a qualitative data passage using a word, short phase, or basic topic rather than the content (Saldana, 2013). This approach is appropriate for qualitative studies and is particularly useful for novice researchers. Descriptive coding can help the researcher answer general questions aligned with the interpretive description design: *What exactly is being shared here?* and *What does this mean within the scope of the study?* Such questions were asked during the iterative process that included reading, listening, thinking, and writing and the responses were captured though journaling and memos (Thorne, 2008).

Thorne (2008) does not promote the idea of data saturation. Rather, she endorses an analytic process of probing data for outliers to identify predictable and rare but relevant findings not present in current literature. Probing for outliers is described as a method of moving beyond typical questions that one might ask when testing the data. Looking for new possibilities or topics not previously discussed leading the researcher to look beyond the obvious for the undiscovered. This process requires analytical thinking that goes beyond the original findings or the state of the science. This method can be used to determine if there is anything else to be known prior to ending data collection.

Memos

The use of marginal memos involved categorizing text previously coded as potentially meaningful into categories using colored markers to represent thematic similarities (Thorne, 2008). This method is consistent with the analytic thought process facilitated through interpretive description. Memos and short biographical sheets were initiated for each participant during analysis and expanded upon for use in findings.

Evaluation Criteria for Findings

The steps taken to ensure a study's rigor and trustworthiness can influence its overall quality. A qualitative study's relevance and value ultimately should be determined by its rigor (Thomas & Polio, 2002). This study's value is toward the scientific knowledge about an understudied population in a way that has the potential to help inform clinical practice. This study's relevancy is found in the information it provides for promoting improved outcomes for regional melanoma survivors—information that has possible national and global implications, as well.

Several kinds of evaluative criteria can be applied to an interpretive description research approach. The first consideration Thorne described is *epistemological integrity*, which follows the line of reasoning from the assumptions regarding the nature of knowledge and the methodological decisions used. A second consideration is *representative credibility* that compares whether the theoretical claim remains consistent with the phenomenon under study. An inductive reasoning process also should include an audit trail to demonstrate the reasoning pathway. To ensure that the interpretations are free of bias, reflective journaling, memos in the margins, and recorded field notes were employed by the PI and become part of the findings and discussion (Thorne, 2008). *Analytic logic* makes explicit the reasoning of the researcher based on what was learned. The audit trail, which included all conversations with faculty and consultants as well as the project journal with refinement of ideas and reflections during the entire process, is an important aspect of the transparency.

Interpretive authority included a strategy where members of the dissertation committee reviewed aspects of the data and findings for consistency (Thorne, 2008). The dissertation committee members—experts in research, nursing, and public health—were part of the ongoing rigor and trustworthiness process. The committee's faculty chair advisor is a researcher with several NIH RO1 funded studies using mixed and qualitative research methods with skills in critically reviewing transcripts. The PI has a basic understanding of the research process and a good reading and working knowledge of qualitative analytic techniques.

Chapter Summary

The generic nature of the interpretive descriptive approach can be both a challenge and an asset to a novice researcher. On one hand, its lack of prescribed methods can leave novices to question their research choices. On the other hand, it gives researchers the flexibility to explore the data in various ways in order to answer specific research questions. The use of the interpretive description approach allowed the PI to reflect on clinical experiences as participants described their personal experiences. This was important as the participants reflected on such experiences as physical limitations, emotional concerns, social constraints, and/or economic hardships. While the use of this disciplinary lens also introduced potential biases, the strategies of PI reflective journaling, recording of memos and field notes, along with the involvement of the dissertation committee members' added validity to the findings. The understanding gained from this research can help inform nursing care and guide future decisions in the care of melanoma survivors.

Chapter Four: Findings

The purpose of this study was to explore the post-treatment health-related experiences and needs of melanoma survivors in the ETAR. This chapter presents the research findings beginning with participant demographics. Sixteen participants were interviewed using an in-depth, semi-structured format. The sample included participants who self-identified as melanoma patients living in the ETAR. These participants offered their perspectives of their experiences during melanoma diagnosis, treatment, and post-treatment periods. The transcribed interviews were coded systematically—manually and with NVivo® software—as guided by Thorne's (2016) recommendations for analysis of interpretive description data. The survivorship trajectory (timeframe) includes the diagnosis and treatment periods that informed post-treatment experiences. The post-treatment needs were identified implicitly from participant dialogue and narratives. Four thematic patterns, supported by participant experiences as represented by essential summative quotes, are presented along with summaries of participants' implicit needs.

Overview

Participant Demographics

Participants were recruited from the ETAR, which includes 54 counties. All participants (N=16) who self-identified as melanoma survivors willing to share their experiences were invited to participate. All participants spoke fluent English as their first language. Interviews were conducted in a private location chosen by the participant, typically a work setting or a familiar community location. The researcher collected the demographic data of age, gender, ethnicity, educational attainment, residential zip code, and employment status. Additional participant information collected during the interviews included specifics about the diagnosis, treatment, and post-treatment periods. Of the 16 participants, nine were females and seven were males, with a mean age of 54.4 years. Twelve participants were from rural areas and four were from more urban areas. Participants identified as non-Hispanic or Latino with one listed as unknown. The education level was split evenly with eight college graduates and eight non-college graduates. Eleven participants worked full-time, two were retired, two were on disability, and one was unemployed (Table 4.1, Appendix A).

The investigator analyzed the interview data to determine similarities and differences among participants along the cancer trajectory. The PI recorded such information as length of time since diagnosis, treatment type, melanoma location, family history, recurrence, travel time, and yearly follow-up schedule (Table 4.2, Appendix A). Twelve participants were diagnosed within the past 10 years and three were diagnosed more than 15 years ago. One participant was diagnosed 29 years ago. Regarding treatment type, seven participants had a wide excision with a negative sentinel lymph node biopsy (SLB). Two participants had a wide excision only without a SLB. Six participants had a wide excision and a positive SLB, and five had additional treatment removing all lymph nodes from the specific area (lymphadenectomy). One participant did not return to the clinic for additional recommended surgery. When she returned three months later, her disease had advanced to the point where surgery was no longer recommended. One participant diagnosed because of lymph node swelling without any metastasis had a wide excision of the mucosal lesion and lymphadenectomy. The location of the melanoma at diagnosis included five (n=5) on the back, three (n=3) on the forearm, two (n=2) on the thigh, one (n=1) on the abdomen, two (n=2) on the face, two (n=2) on the chest, and one (n=1) from a mucosal area.

Participant recurrences (n=8) included two on the back, two on the abdomen, one on the arm, one on the neck, and two as metastasis. Five participants with a negative SLB had a family history of melanoma. Eight college graduates had negative SLBs except for one, while the eight non-college graduates had positive SLBs. Regarding travel time to healthcare providers, 14 participants reported traveling one to two hours' round trip, three traveled four hours round trip, and one traveled eight hours roundtrip. For follow-up, 12 traveled at least once or twice a year, and four traveled up to four times a year (Table 4.3, Appendix A).

Melanoma Survivorship Trajectory Experiences

Participants told stories that went beyond their demographic information. Gaining a detailed description of each participant allowed the PI to set the stage for describing their collective narrative. Pseudonyms were assigned to each participant to protect their privacy. From some survivors' perspectives, early sun-related experiences that may have placed them at risk of melanoma seemed important and relevant. Participants' pre-diagnosis, diagnosis, and treatment experiences informed their post-treatment narratives.

Typical Trajectory

Greta is a 42-year-old nurse practitioner who went to see her primary care provider for a biopsy after several friends at a conference told her a spot looked "funny." She had a family history of melanoma in that her mother and cousin had the disease. She was sent to a surgical oncologist who performed a wide excision without an SLB. She was diagnosed with melanoma 14 years ago and has not had a recurrence. She also has dysplastic nevus syndrome, a condition that causes her to have numerous moles that can become cancerous. Her follow-up consisted of seeing a photo dermatologist (one that photographs the moles and compares the photos to detect changes each visit) every three months, which has required her to make a two-hour roundtrip, four times a year for 14 years.

Robyn is a 56-year-old health educator who went to a dermatologist after a beach trip with friends. She had never seen a dermatologist and procrastinated in making the appointment.

Once she found out a friend's husband had been diagnosed with melanoma, she made an appointment. After having 12 biopsies in the office, she was told to return four days later for the results. Three of the biopsies were melanoma, one each on her nose, cheek, and arm. She promptly called her plastic surgeon friend who saw her in the office four days later and performed surgery the following week. Her surgery consisted of a wide excision without a SLB on the three areas. For follow-up, she has seen her local dermatologist every six months for the last four years. While she has had no recurrence, she has had several biopsies and lesions excised since her diagnosis.

Heidi is a 60-year-old registered nurse (RN) whose husband noticed a "funny" area on her back before she noticed another on her abdomen. She decided to make an appointment with a surgeon who removed the abnormal areas. The pathology indicated melanoma. She then saw a surgical oncologist to have a wide excision and SLB, which was negative. Except for a two-year period when she cared for her elderly parents in Florida, her follow-up over the last five and a half years has included seeing a photo dermatologist every six months (a two-hour round trip).

Ethan is a 57-year-old civic engineer who once worked with city municipalities, but now works from home in his own business. His wife found a black spot on his back and he was seen by a dermatologist who removed the spot, and the pathology revealed melanoma. He was referred to a surgical oncologist who did a wide excision and a SLB that was negative. He has followed up yearly with a dermatologist. Some suspicious areas have been removed but none was melanoma.

Rosie, a 29-year-old physician resident who was initially diagnosed at the age of 18, first went to the dermatologist at the insistence of her mother. After a biopsy of a lesion on her chest indicated melanoma, she was referred to a surgical oncologist who performed a wide excision without an SLB. One year later she had a suspicious area on her abdomen removed that also turned out to be melanoma. Another surgical oncologist did a wide excision and SLB, which was negative. For 11 years, her follow-up has consisted of seeing a dermatologist yearly. When changing healthcare providers she may have gone more than a year without an appointment.

Darron is a 61-year-old man and former pilot military who now works as a supervisor and park ranger. Twenty years ago, he developed a freckle on his chest that the general practitioner aboard a military ship in a U.S. harbor watched for a period. His wife also was in the service and was stationed in Puerto Rico. Eventually, the suspicious area was removed and tested positive for melanoma. A surgeon did a wide excision and SLB, which was negative. Five years later, he had a recurrence behind his ear and an additional SLB was done, which was negative. His follow-up care over the past 20 years has consisted of seeing a dermatologist every one to two years. His occasional breaks in visits happened when he was finding a new healthcare provider when he and his wife relocated during their time in the service.

Arlene is a 43-year-old woman who works as a therapist for individuals and families in crisis. Two years ago, she noticed a mole on her back and saw a dermatologist who did a biopsy. Two weeks later, she received a voicemail reporting that she had melanoma, and would be referred to an oncologist. She did not want to wait to speak with the dermatologist and made an appointment with her aunt’s surgeon who treats breast cancer and melanoma. She had an appointment within three days and surgery a week later with a wide excision and an SLB, which was negative. Her follow-up over the past two years has consisted of being seen by a dermatologist and surgical oncologist every three months initially, then every six months. A few weeks before the interview, she was being evaluated for breast cancer after her mammogram showed a small lesion.

Linda is a 46-year-old real estate agent whose husband noticed an unusual area on her thigh. She saw her primary care doctor who referred her to a dermatologist. She had two biopsies: one on her thigh and one on her back, both of which were melanoma. She was referred to a surgical oncologist two hours from her home that performed a wide excision with SLB to both areas, which were negative. After she recovered from the surgery, her surgical oncologist moved the practice further away, which made her twice-yearly follow-up require a four-hour round trip. She continues to follow-up with her local dermatologist twice a year. She also continues to see the medical oncologist she initially saw after surgery once a year at a cancer center two hours from her home.

Taylor is a 64-year-old retired electrician. His wife noticed something on his back that seemed to be getting bigger. He saw the dermatologist and his biopsy showed melanoma. His surgical oncologist performed a wide excision and SLB, which was negative. His twin sister was diagnosed with melanoma a year before his diagnosis. Initially, his follow-up with a dermatologist was every three months, then every six months, and now yearly.

Complicated Trajectory

Griffin is a 49-year-old who works as a computer programmer. Five years ago during tax season, his wife noticed a "funny looking" mole on his thigh. She made him an appointment with her dermatologist an hour away because he could not get a local appointment. The biopsy done in the office indicated he had the "bad kind of skin cancer," and he was referred to a cancer center in central Tennessee. He saw a surgical oncologist and had a wide excision with an SLB, which was positive. He met with a medical oncologist after surgery and had a PET scan and MRI of his brain, which were negative. He then had further treatment with a lymphadenectomy and one year of Interferon therapy. His follow-up has consisted of seeing the surgical oncologist yearly and the dermatologist twice yearly. The medical oncologist follows him once yearly close to home, but he travels two hours round trip to see the surgical oncologist and dermatologist.

Randall is a 94 year-old retired farmer who scratched his cheek in the barn and the area started bleeding. His son took him to the emergency room because it kept bleeding. The mole was removed and after the pathology showed melanoma, he was sent to a local plastic surgeon. A wide excision with skin graft and SLB was done on his neck, which tested positive for melanoma. Additional treatment was required, a lymphadenectomy to remove the lymph nodes on one side of his neck. For the last 10 years, he has been followed by his local primary care physician and dermatologist.

Karen is a 65-year-old RN who practices full-time. Twenty-nine years ago, she went to her primary doctor after a mole on her abdomen started bleeding. A biopsy was done in the clinic that day and the next day she was diagnosed with melanoma. She was admitted to the hospital and had a wide excision with SLB, which was positive. After a lymphadenectomy, she was fitted for a stocking to prevent lymphedema in her leg. Two years ago, she had a lesion on her back. After a wide excision with SLB, the results again were positive for melanoma. She required an additional lymphadenectomy. Her follow-up was complicated by a lesion identified on her kidney following a PET scan and MRI of the brain. She had a partial nephrectomy and after her recovery, her medical oncologist decided that she did not qualify for a clinical trial or any other immune therapy treatments. During the period after her initial diagnosis, she was followed by her primary provider each year. She sees a dermatologist and medical oncologist now for twice-yearly follow-up.

Jeanie is a 58-year-old who worked in sales prior to going on disability for melanoma. Three years ago, her boyfriend saw a “funny” place on her arm. He pushed her to get it evaluated even though she was hesitant because she had no insurance. She went to the health department for the biopsy. Although it "took a while" to get the biopsy results back, she finally had an appointment with a surgical oncologist at the cancer center two hours away. She had a wide excision, skin graft, and SLB, which was positive. No other melanoma was found internally on imaging. She then had a lymphadenectomy and additional surgery because the skin graft to her arm became infected. She saw a medical oncologist who recommended a clinical trial, but she was not able to tolerate the medication. She developed a local recurrence just above the incision area and had another excision and radiation treatment after the area healed. She now follows up with the medical oncologist and surgical oncologist every three months.

Clifton is a 60-year-old man retired from military service who now works as a paramedic. A mole was found on his back during a military physical 18 years ago and the biopsy indicated melanoma. A surgical oncologist at a Veterans Administration (VA) facility performed a wide excision with SLB, which was positive. He had a lymphadenectomy and, after recovering from surgery, met with a medical oncologist. After a year of Interferon therapy, his follow-up consisted of seeing a dermatologist and medical oncologist every three months initially and then every six months. He retired from the military last year and has continued his follow-up with either the medical oncologist or a dermatologist. Recently, his chest radiography showed a suspicious area in his lung. He then had a lung CT and a PET scan and MRI of the brain. These scans showed he had melanoma in his lung and brain.

Daisy is a 26-year-old who worked as a cashier before her melanoma diagnosis. Her obstetrician found a suspicious mole on her arm when she was six months pregnant. She had some difficulty getting the biopsy, as she did not have comprehensive insurance. Once she had the biopsy that verified she had melanoma, she was referred to the cancer center in central

Tennessee to see a surgical oncologist. The recommendation was to do the surgery after she delivered her baby. When her daughter was two months old, she had a wide excision and SLB, which was positive. She was told she needed additional surgery and to see a medical oncologist, and gave scans to make sure she did not have melanoma anywhere else. She admitted that hearing about more surgery and looking after her two-month old kept her from coming back for about three months. When she returned to talk about the surgery and the scan results, she was told that the melanoma was in her lungs and bone and that would need to be enrolled in a clinical trial or placed on systemic treatment. She was started on a systemic treatment, but she could not tolerate the medication as it made her very sick. She had an appointment to return to the medical oncologist a week after her interview for follow-up.

Hayden is a 61-year-old who worked repairing computers until he went on disability after melanoma treatment. Swelling in his thigh, leg, and foot prompted a visit to his primary care provider. A surgeon performed a biopsy and the pathology was positive for melanoma. He was referred to the cancer center in central Tennessee. The surgical oncologist examined him and initially concluded that he may have had a skin lesion but it was not identifiable at the time of exam. Upon conducting a more detailed assessment, a dark area near his anal sphincter was detected. Colonoscopy and biopsy of the dark area revealed mucosal melanoma. He had two separate surgeries: lymphadenectomy and rectal surgery. His recovery was complicated by wound problems and permanent lymphedema that keeps him from sitting for long periods.

Pre-Diagnosis Experiences

During interviews, most participants recalled their pre-diagnosis sun-related activities and the identification of their suspicious lesions. Participants seemed to view these experiences as a way to introduce information about the diagnosis period. Growing up, most participants spent a great deal of time in the sun boating or participating in other outdoor activities and sports. Suspicious lesions often were described by participants or their family and friends as a "funny-looking area." Further conversations during the interview regarding this period revealed that even though the area was discovered by someone else, participants often knew the area was there and they and/or healthcare providers had been monitoring its growth.

Sun-related Activities

Most participants shared early sun-related experiences. For instance, Heidi and Linda spent their adolescent and early adult years on a houseboat during summers and weekends. Rosie, who described herself as fair-skinned and freckled, explained, "Mom kept me lathered with sunscreen as a child." Rosie added, "I was outside all the time playing softball in the summer wearing sunscreen, but still, I mean, when you're in the sun 15 hours a day, you know, how much does it really help?" Ethan shared sentiments similar to those of the other men interviewed by stating, "I did not use sunscreen and I still don't care much for [it]." Taylor, who was adopted, described his sun exposure mainly came from activities with his dad during the summer and weekends. He said, "I grew up around it [the sun]" because his dad owned a body shop and often had his shirt off while working in the sun. Robyn had the most to say about her sun-related activities as a teenager and how that extended into her early adulthood. She elaborated:

> I'm the generation of… no sunblock, only iodine and baby oil and holding up aluminum reflective out on the deck at college… so we could get the maximum. I'm ah, an outdoors person and… grew up, spending all summer long—Memorial to Labor Day—on the water, in the lake, lifeguard, swim instructor, sailing instructor, water skiing, so I was maximum exposure to the sun with no protection at all. I was really bad to my skin. I…

> just went out in the sun and didn't put anything on it and maybe I'd throw aloe on it… I was a lifeguard all through college, too. I gauged the summer by the number of layers that came off my nose, like how many times it would burn and peel, burn and peel, burn and peel, that was a hot summer. Gosh, I think I had eight noses that summer.

Suspicious Areas

Most participants identified a spouse, family member, significant other, or friend who initially recognized the unusual area. Fewer participants identified the areas themselves, and two participants named providers who found the areas incidentally. Clifton explained that during his yearly routine military physical exam, "a mole was found on my back and was removed by the surgeon at [the base hospital]." Two participants noticed an unusual mole and went for evaluation after some bleeding occurred. Karen, an RN, explained, "I had a mole on my lower abdomen and one day I noticed that it bled a little bit, just out of the blue, and went to my family doctor."

More commonly, the mole or unusual area was identified by the spouse, significant other, family member, or friend (n=10). Heidi stated, "My husband thought the one on my back looked funny," and Ethan reported, "My wife found it on my back and she said that the black spot did not look right." A few women interviewed reported being very upset, scared, and in shock at being diagnosed with melanoma. For example, Heidi stated, "I was mad, I cried and then I was mad, and then I wanted it out of me... I thought this can kill you." Arlene had similar reaction, "I just felt um, pretty scared and alone… I needed any and all cancer out of me and off of me as soon as possible." Karen responded with "I was in shock." However, Rosie (a physician resident who was 19 when diagnosed) commented, "I wasn't scared then but now, knowing everything I know, I'm a lot more nervous about it." Robyn explained, "I didn't go down the panic rabbit hole" but she also elaborated that she received the news from a healthcare provider in a calm and encouraging manner. Robyn offered another explanation for her calm response, "I tend to look [at] the silver lining, like well this is going to be great 'cause I know a plastic surgeon who can… [fix me up] so, so I wasn't scared or worried."

Darron (military retiree who does administrative work for the National Forest) had a very different take, "Well, you just go in there [and] have it removed" and "let's get it done." Clifton (military retiree now working as a county paramedic) shared that his mom died of pancreatic cancer when he was a young child and so he kept in shape, ate a balanced diet, and had regular check-ups in order to "avoid" what his mom had suffered. He remarked, "I can honestly say that melanoma was the last thing I thought I needed to worry about." Jeanie, whose melanoma was discovered by her boyfriend, commented about getting a skin exam, "I wanted to go, but was scared it was skin cancer, you know from the sun." As participants shared their stories about the initial recognition of the suspicious area, they often revealed that they had seen or been aware of the area.

Diagnosis Experiences

Initial Biopsy

Most participants were diagnosed by either a dermatologist or their primary care provider. All participants described their initial biopsy and diagnosis in detail, many even remembering the date and time they received the results. Randall, a 94 year-old retired farmer, explained, "It (mole) came off by accident when I was out in the barn, but it sure did bleed all over the place." My son took me to the ER to get it sewed up, but a piece was left, so when the doctor called me, he said, "you'll need to go see the surgeon in town". Even 29 years later, Karen (RN) remembered,

> I went to the doctor right away [after the mole on her abdomen bled] and he did… a[n] office biopsy and removed it. I'll never forget what he said after he got it out, as he handed the specimen to the nurse he said, get this to lab stat, and as soon as he said that I, I was… kind of drained out, it's like, oh my gosh this is serious, you know, 'cause I just thought it was gonna' be a little mole.

Three participants had more than one melanoma when the initial diagnosis was made. Heidi had six biopsies and two were melanoma, while Robyn had 12 biopsies and three were melanoma. The process of recognizing a suspicious mole, getting a biopsy, and receiving a diagnosis can be complicated by issues of insurance coverage or care access. Griffin, a computer programmer with insurance said, "I really never noticed it [the mole] before, and she [his wife] said that it was not there [before]. So, she made me a[n] appointment to see her doctor [two hours away] because it would be… three months before I could get a[n] appointment with a dermatologist close to where we lived." Jeanie, who was unemployed and without insurance at the time of diagnosis, explained, "I had to have lots of biopsies and the one on my arm had melanoma in it. My arm is still not right. I had to drive all over [Tennessee] to get a biopsy and the biopsy results took forever… too." Most biopsies were done by dermatologists and patients were referred to surgeons who performed the excision surgeries, as recommended in the National Comprehensive Cancer Network's (NCCN, 2016) guidelines.

Hearing the Diagnosis

Hearing the melanoma diagnosis directly from a healthcare provider was very important for some participants. Robyn explains how she was told,

> She [the dermatology physician assistant] was very um, matter of fact and very transparent and very calm about it like okay, this is gonna' be a scary word. Yes, you

> have melanoma. Yes, it's the bad kind, but we've caught it early… you know, that kind of thing. So it was very reassuring and um, empowering 'cause I… didn't feel like oh, I don't know what this is or what does this mean.

Arlene, a clinical psychology therapist, heard the news on her voicemail two weeks after the biopsy and could not contact the dermatologist to get any specifics. Greta, a nurse practitioner, stated, "I went to my little PCP and he biopsied it and he said he knew right away it was melanoma." Hayden's story is a little unusual, as his melanoma is categorized as unknown because no actual skin lesion was identified initially, highlighting the complicated nature of this disease. He said,

> I started having… lots of swelling in my right leg. I went to see my primary doctor and he sent me to another doctor that took a biopsy in my groin… and sent me to Dr. [T], he's a surgeon, and then they sent me to a cancer doctor [surgical oncologist] in [major cancer center in central Tennessee] because it was melanoma. New to me, I thought melanoma was skin cancer; you know moles and… stuff… The cancer doc said again that the other doctor found melanoma in my lymph nodes… so, my colon checked out, but the biopsy from the dark area [near the anus]… was melanoma… [I] just did not want to hear that. Valentine's Day last year… I remember when they called me to come to the office, after the biopsy and checking my colon… my phone showed Happy Valentine's Day when the phone rang…

Treatment Experiences

Participants described the treatment period in as much detail as they did the initial recognition and diagnosis periods. The PI elicited details about their healthcare providers, where care was obtained, and whether they participated in a clinical trial. For most participants, surgery was the initial treatment once the diagnosis was made. The surgery generally included a wide excision of the melanoma and most participants had an SLB to check for any cancer cells in the first area of lymphatic drainage. Except for three participants, surgery was performed by a surgical oncologist, plastic surgeon, or general surgeon in outpatient settings. Two participants had surgery at military base hospitals and another spent nine days in the hospital after her surgery 29 years ago (Table 4.4, Appendix A).

Driven by prior experiences and emotions from their diagnosis, participants working in the healthcare field often called on friends to expedite the treatment process. In addition, participants and their friends and family members were concerned about ensuring they went to the best available facility and surgeon for their care. For example, Heidi reported that her dermatologist could have referred her to a local surgeon, but "I didn't feel like… it was the best place to go, so I went to the [cancer referral center in Central Tennessee]." She told the dermatologist who she wanted to see and described the surgeon as "a surgeon/oncologist/general surgeon… he's the works."

Griffin explained that his wife looked up the specialist at the cancer center in Central Tennessee and made me an appointment "because it was the bad kind of skin cancer, that's where they told my wife I needed to go, [to] see the melanoma doctor." Griffin saw the surgical oncologist and was scheduled for surgery two weeks later. When asked about traveling for the surgery, he commented, "it is a drive from here [two-hour round trip], and [I] wish [I had] someone closer… we had to make arrangement for our daughter, she was in middle school at the time." Linda—who was referred to a surgical oncologist at an East Tennessee cancer center—said, "She was very nice and prepared me for the worst, but hoped for the best." Rosie was referred to a local surgical oncologist and reported that "He said he was gonna' take care of it, so

I thought, okay, he's gonna take care of it." This experience inspired Rosie to become a doctor to help other people. Not all participants were treated by a surgical oncologist. Randall, who was diagnosed after a trip to the Emergency Room with bleeding from a mole that had come off partially, was referred to a general surgeon who referred him to a plastic surgeon. He laughingly said, "My son says he is a plastic surgeon, like I need plastic surgery, didn't before, but now I do."

After finding out she had melanoma on her arm and two areas on her face, Robyn called a friend who is a plastic surgeon. She had an appointment three days later and surgery within two weeks. One month after being diagnosed, she was back in the dermatologist office for follow-up. That same day, she received a call from the plastic surgeon to which her dermatology office had referred her. Robyn further explained:

> I wasn't sitting around for six weeks waiting for somebody's office to call me to schedule a consult to talk about the surgery we might be having in the future. I felt I could be in charge of, of how I was gonna' handle [it]. And… it quite frankly, naively, never occurred to me that I wouldn't be in charge of how I handled it… I'd been waiting for somebody to call me for weeks on end and not hearing anything and wondering, you know, when am I gonna' get this taken care of? The most disconcerting thing was I wasn't anticipating… they took about an ice cream scoop's worth of flesh out of my arm. So, I have a real indent, even two years later, it still hasn't filled in.

Arlene initiated her visit with the dermatologist when she noticed an area on her back was changing. When she received a voicemail about the diagnosis two weeks later, she took matters into her own hands for fear it would spread. She called her aunt, who had been treated for breast cancer, to discuss her feelings about her diagnosis. Her aunt called her surgical oncologist who treated patients with breast cancer and melanoma. After telling her dermatologist whom she wanted to see, Arlene was scheduled with the surgical oncologist three days after her Aunt made the initial call. Arlene described her encounter with the surgical oncologist:

> I saw him the first day, then um, I had an educational video that was very scary. But he came in and he looked at [my mole], and he felt very confident that um, he could take care of it and I would be okay. And that's really what I wanted to know.

After being notified of her diagnosis via voicemail, Arlene informed the surgical oncologist that she wanted direct communication with him,

> "… Please, you know, if you could not repeat that [leaving a voicemail with bad news]. Just… tell me and not leave [me] dangling… 'cause… information is power and so I want to know what was going on, and I want to know what to do about it. And I didn't know what it meant [when the dermatologist left the message]. I knew um, [that] melanoma kills people, that's what I know."

Two participants received care through the VA and follow-up in East Tennessee. Clifton stated he had "the best care and treatment the VA could offer, but ahh the wheels move slower in the government." He remembered specifically that the surgeon was "very precise about making sure I understood about melanoma and how serious it could be. He told me that I would need to be followed after treatment regularly. As I recall, that was the bottom line." Darron left the service after four years but had his melanoma removed at a Veterans facility when his wife (an RN) was serving in Puerto Rico. His understanding was "whether the mole was melanoma or skin cancer, it seemed to be, well, you just go in there [and] have it removed."

Daisy's melanoma was found when she was six months pregnant. She was seen by a local dermatologist who confirmed the diagnosis, and then was sent to a surgical oncologist who performed her surgery after her daughter was born. She explained that finding a surgeon who accepted her insurance was difficult. She and her Dad traveled two hours round trip to the cancer center each time. Her dad came with her for the surgery and cared for the baby, “it was hard, my Dad had to come with me and took care of [my baby] each time I had to go. After all the time traveling back and forth, after I had the first surgery, we were tired of all that”.

Jeanie reported that it took time to get her biopsy information and to see a surgeon:

> It took a while to find out anythin’, crazy really. After I had the biopsy, then it seemed like so many weeks before they could get it out… it took a long time to get… that surgery… [My surgical oncologist] said I would be okay once when we get it out. Glad for that first, but it came back again, not so glad. Let’s see, he cut a long place here on my arm and deep, wow, and looked under my arm for cancer there, I had to go to the cancer center to get everything. I didn’t have any way to get anything. Medicine and stuff they helped me with. I see a lot more people now …cancer doctors, social workers, nurses, radiation doctors…

Karen’s diagnosis and treatment was the standard-of-care care in 1988. She was urgently admitted to the hospital, stayed nine days, and did not leave the hospital without her leg stocking fitted to prevent lymphedema. Karen recalled that the local general surgeon was very well known and she had a lot of respect for him, “I really… think he did me good.” She remembered one incident in particular that helped her after the surgery:

> I remembered the doctor referred me to… another person that had a melanoma removed, and she was about my age. And I just met her briefly, but she was, uh, very encouraging and… made me feel better about myself, you know, that hopefully my life was gonna go

> on, and things were gonna be okay, [that] it wasn't a death sentence at this point so, so I appreciated him doing that, he got me in touch with her.

Ethan's story included two surgeries because additional tissue needed to be removed. A dermatologist initially removed the melanoma from his back, but because the margins were still positive, he was referred to a surgical oncologist two hours from his house. He offered a humorous take on the additional surgery, "I guess [they] had to kind of take a big pork chop out of my back. It was probably like, four or five inches wide." Taylor—who was adopted and had a twin sister who had a melanoma removed a year before—reported, "The doctor said that I was going to be okay once he removed the melanoma. My sister was telling me that all would be fine, and that's the way things went."

Integrated Health-related Experiences and Post-Treatment Needs

In this study, the PI explored the essence of survivorship in melanoma participants living in the ETAR. Recurrent experiences and specific patterns and began to emerge during the interview, transcription, and coding processes. The researcher brought her nursing perspective and expertise as a healthcare provider for melanoma survivors to the analytic process. While the interpretive description method was used during the entire analytic process, the PI relied on it especially during the iterative phase as she was making sense of the findings. Thorne (2008) stated that "we desperately need new knowledge [in nursing and other applied disciplines] pertaining to the subjective, experiential, tacit, and pattered aspects of human health evidence" (p. 36). The contextual understanding gained from the new perspectives presented in this study can help guide future decisions by cancer care providers and clinicians related to melanoma surveillance and survivorship.

Thematic Overview

Four major themes regarding melanoma survivors' post-treatment health-related experiences were derived inductively from the interview data. Participants' post-treatment needs were tacit or implicit within their stories and from their perspectives as people from Appalachia and melanoma survivors. Theme and subthemes are described in detail with supporting participant quotes and narratives, and are followed by summaries of identified implicit needs (Table 4.5, Appendix A).

Theme 1: Sitting in the Driver's Seat of Follow-up Care

The first theme represents how participants were forced to commit to direct their own post-treatment follow-up care. Participants described driving across the state, negotiating follow-up terms with providers, and involving others in their journey. Additionally, participants described the time involved in going to follow-up appointments, the responsibility of coordinating their own care, and the implied signaling to family and friends when they needed help (Table 4.6, Appendix A). The following three recurrent subthemes supported theme 1:

- Subtheme 1A – On the road again;
- Subtheme 1B – I steer my care; and
- Subtheme 1C – Hazards on for help.

Subtheme 1A – On the road again. Participants covered subtheme 1A when they talked about traveling across the state and the time involved in their follow-up activities. Many participants had to make one- or two-hour round-trip visits two or three times a year. Many traveled from East to Central Tennessee to see a melanoma specialist or visit a cancer center. While some participants, like Robyn (age 56) were lucky enough to have local providers, "appointments are 10 miles maybe round trip" this was not a common occurrence. Hayden (age

61) stated, “It takes about two hours to get… to the cancer clinic… so my mom drives.” Taylor (age 64) said, “Lots of driving is the problem,” while Greta (age 42) reported, “When I drive there (two hours to the photo dermatologist), my friends go too sometimes to have an excuse to go shopping with me.”

In addition to the miles driven for appointments and check-ups, participants expressed other implicit needs such as transportation to and from appointments, pain and symptom management, and overnight accommodations needed when tests were done one day and results given the next. Jeanie (age 58) said, “So, he [boyfriend] has been bringing me to the doctor, I’m… too nervous to drive right now.” Additionally, Jeanie, who did not have local access to pain and symptom management, added, “The nurse practitioner helped me when I was having so much pain, but I had to come and see her every month and so a two-hour drive.” Hayden (age 61) said, “We got through it [by driving to the cancer center to see the nurse practitioner for pain medication monthly], but for a few months it drove me batty, and my mom would get real tired.” Daisy (age 26) reported, “We get to stay in the resource housing area, so that’s great, my Dad and [daughter] can stay, too.”

The amount time participants spent traveling across the state also was an important aspect of their follow-up experiences. Linda, (age 46), who had an eight-hour round trip, explained:

> After a year, the [surgical oncologist] moved her practice to [another major city in Central Tennessee two hours away] and so we go there now. I don’t want to see another surgeon and so we started going there, she knows me, so we go see her there. We usually try to stay overnight and visit friends sometimes.

Greta (age 42), reported, “He [photo dermatologist] said that I was very high risk, and that I would have to come every three months, and I’ve gone to him every three months now for 14 years [a two-hour round trip].”

The time involved in each follow-up visit, also affected the participants. Griffin (age 49) reported, “I come and see the skin cancer doctor [medical oncologist] now every six months, some blood work and x-rays too.” Rosie (age 29) said, “I do feel like I’ll be seeing a dermatologist for the rest of my life… as far as [medical] oncology… I go once a year and then he said… after a couple of years of once a year if everything looks good, you know maybe we’ll touch base in a decade.” Greta (age 42) said, “I go every three months now, like clockwork to [Central Tennessee], to my melanoma guy [photo dermatologist] and that’s pretty much it.” Robyn (age 56) explained, “I had a sense this is gonna be the rest of my life, whether it’s semi-annually or annually.” Often, post-treatment follow-up visits were more frequent and then tapered off, as reported by Taylor (age 64), “I was followed the first three months, you know, in the office, the doctor would see me for three months, uh, I think for about a year, and then I think they tapered off to six months, and then, once a year.” Similarly, Ethan (age 57) said. “It may have been more frequently in the beginning, but it became every six months and then every year.”

Follow-up visits could take half the day if something new was found or biopsies were required, as noted by Heidi (age 60), “I did have another place show up, but it was a different kind of skin cancer and he cut it out.” Robyn (age 56) noted, “Waiting to be seen… I don’t know if it’s that particular practice… or… just dermatology in general, oh my gosh, half a day’s adventure.” Participants also reported spending time making appointments for a new suspicious area and finding a new dermatologist when one left or they moved to another city. Ethan (age 56) said, “Well, I’ve been through or seen a few dermatologists, they move and new ones start, this last one I have seen three times, and [it’s] hard sometimes to get an appointment if something comes up.” Some healthcare providers have advanced practice nurses who provide follow-up care and alternate seeing patients, as reported by Jeanie (age 58), “I see the skin cancer doctor [medical oncologist] or… the nurse practitioner every six months.”

Subtheme 1B – I steer my care. Subtheme 1B is the umbrella category that explains participant experiences related to coordinating or navigating follow-up care. Participants viewed roadblocks and delays as a necessary part of the healthcare process and would find ways to handle the problems that arose. For example, Ethan (age 57) said, “Nobody recommends it [yearly follow-up with a dermatologist, because the dermatologist told him that he could follow-up yearly with his primary care and primary care does not look at his skin] but I do it anyway,” while Greta (age 42) emphasized, “I got an appointment and I keep everyone”. Participants’ strong commitment to follow-up was evident. Robyn (age 56) stated, “I have to force myself to make appointments, those aren’t appointments that are set up for me, those are appointments I have to make…,” while Darron (age 61) said, “I mean… it’s got to start from the…patient.” Individual responsibility played a key role in guiding follow-up, as Darron (age 61) noted, “I think that… it’s the patient’s… responsibility to identify the areas and then seek… the help… for getting it done.” Clifton (age 60) noted, “In the service, things work slow, but eventually it all gets done. I retired after 25 years in the military two years ago and I still have been following up in the same manner.” Self-directed care included asking questions and being informed, as illustrated by Rosie’s (age 29) comments, “New research came out and showed that the bloodwork actually wasn’t helpful, and so we stopped doing that, then I said… I don’t really want to keep getting chest x-rays.”

Subtheme 1C – Hazards on for help. Subtheme 1C reflected the survivors' implicit need for help following treatment. The participants did not ask for help, but communicated their life events with family, friends, and others (including fellow church members) who would organize and provide what the individual or their family might need. Individuals in the healthcare field might help a survivor by calling or texting a provider to get assistance in the form of a providing advice or scheduling an appointment. For example, Linda (age 46) reported, "A few times when my husband was so nervous [about a new area], he took me to the doctor's office without an appointment, and the dermatologist worked me in." Participants found talking with someone else with melanoma was helpful, as relayed by Clifton (age 60), "She had melanoma, too and that was very helpful, I don't know how, but maybe… talking to others out there that have been through it." The implicit need for transportation by participants who lacked an automobile or were unable to drive was noted by Jeanie (age 58) who said, "I have to get to [the cancer center in] Central Tennessee every time… and wait for medicine, and have someone drive me home".

Participants' assumptions about sun effects and family activities showed their implicit need for more information on the subject. Linda (age 46) said, "I think it's too much staying inside, but after what I put [my husband] through, we stick to shade and inside." Sometimes participants talked about the implicit need for companionship during long car rides. Greta (age 42) said, "Everybody's always been real supportive, ride with me for two hours there 'cause it's so boring every three months." Family, friends, and healthcare professionals were helpful starting with the diagnosis and treatment periods and continuing into the post-treatment period. Daisy (age 26) noted, "My aunt has been the best help, especially my dad too." The implicit need for help with meals and pet care during follow-up visits also was described by Linda, "My friends at church were extremely helpful with fixing meals and helping with my dogs, I have two large poodles that needed some attention with me gone sometimes."

Even tough love was appreciated, as noted by Robyn (age 45), "My family, you know are helpful, you could have your arm chopped off and they would say like, well, buck up." Participants also discussed getting help with day-to-day issues such as putting on leg stockings and handling work pressure. Hayden (age 61), said "My mom helps me get it on (fitted stocking for lymphedema)," while Griffin (age 49) noted, "My work, too, they just said take as much time as you need." Family and friends also helped with follow-up visit and sunscreen reminders. Robyn (age 56) reported, "My eldest daughter will say, okay, isn't that about time for that check-up?" and Heidi (age 61) noted, "I do have friends who every… three or four months… say 'so have you gone back for your follow-up, yet?'" Ethan (age 57) said, "My wife is… kind enough to remind me that I need to use it [sunscreen]." Participants also needed financial help in many forms. For example, Hayden (age 61) reported, "Now I'm on disability with some income, um but the first two years I had to keep asking people to pay for gas." Daisy (age 26) noted, "The social worker helps us stay nearby when I come to town." Participants who, like Hayden (age 61), cared for family members also needed help, "When we would be gone all day, nobody was with my dad, so sometimes the neighbor or people from church looked after him."

Summary of implicit needs. The implicit needs communicated by this study's participants inform several important aspects of melanoma surveillance. One need is to provide local resources for melanoma survivors who now have to travel across the state to obtain post-treatment care. The PI also noted an important omission: most participants were not given a specific survivorship care plan linking them with cancer resources. While the need for regular, complete skin exams is important, linking survivors with providers is equally important to ensure they are reassessed periodically for cancer risk, reevaluated after any updated family history, and monitored for ongoing post-treatment effects like lymphedema, chronic pain, depression, anxiety, or a change in social resources. The PI also uncovered participants' implicit need to involve their family and friends in their journey. Finally, participants had an implicit need for their healthcare providers to be aware of the role Appalachian culture plays in their care. The need included and how that culture may differ from the provider's culture, especially if care is provided outside a participant's local community.

Theme 2: Living in a Skin World

The amount of information available to participants and the public regarding the risk factors for developing melanoma or a recurrence can make the disease seem like a secret ailment. One participant even commented that "melanoma is secret," illustrating the implicit need to share such information with others because his melanoma developed in an area unexposed to the sun. Additionally, participants said they and others avoid using the "C word" (cancer) when discussing melanoma, instead referring to it as a spot, bump, or skin lesion, almost as a form of covert language. The conflict created from having just enough information to understand the serious nature of melanoma, while simultaneously minimizing this seriousness caused some confusion among participants. Throughout the interviews, participants communicated their implicit need to receive more information about their disease from their healthcare providers. Most participants had post-treatment follow-up in dermatology offices, while those with more advanced disease had to be seen by melanoma experts in medical and surgical oncology practices (Table 4.7, Appendix A). The following three subthemes supported theme 2:

- Subtheme 2A – Melanoma is not a secret;
- Subtheme 2B – Call it cancer; and

- Subtheme 2C – Defer to dermatology.

Subtheme 2A – Melanoma is not a secret. Subtheme 2A covers how participants spoke about their understanding of melanoma-related information and risk factors. Heidi (age 60) commented on how melanoma can be unrelated to sun exposure, “There was one [suspicious area] that came up on my stomach that hadn’t seen the sun in 20 years.” One participant spoke about melanoma as separate from skin cancer and not in the cancer family, “Melanoma is a secret sometimes… when you hear about skin cancer, it’s about the sun and getting old and all.” Arlene (age 43) made the same point and touched on the public’s lack of knowledge about the disease, “I would say the average person does not realize that it’s a soft tissue disease, and it’s not just on your skin, and it’s not just from being in the sun. Mine was on my lower back that was as white as white could be.” Similarly, Taylor (age 64) said, “half of it is your heritage; it’s not all the sun.” Hayden (age 61) also spoke of the need for more information, “People with melanoma need to know about other types of it, just wish I had more to say about it, but anyway, maybe this will help…”

One aspect of the treatment period that affected participants’ post-treatment experiences was scarring. For some participants, the visible reminder of their experiences became show and tell sessions during interviews. Many participants spoke about their physical scars from treatment and the pain they have caused. While some participants wanted to conceal them, most wanted to talk about their scars as well as the dipping tissue deformities left after surgery. Many participants reported that their scars were painful and felt numb at the same time, while others described the feeling as an annoying sensation. Those with permanent swelling or lymphedema described pain that ran down the extremity making the area very touch sensitive. Areas where skin was removed for grafts also left scars and areas of decreased sensation and/or hypersensitivity.

While participants were told what to expect after surgery, including how the incision would look, they were not shown before and after pictures as examples. Participants described their scarring in different ways. After pulling up his shirt to show his scar, Ethan (age 57) said, “I guess he had to kind of make a big pork chop out of my back.” Rosie (age 29) pointed to her chest just below the scapula and reported, “It was probably like, maybe four or five inches wide.”

In addition to scarring from excision, participants also mentioned skin graft scars and the unexpected pain from the dye tracer used to check for melanoma in the lymph nodes. Arlene (age 43) said of her scar, “It looks like they… took my kidney out and took about seven inches off my back um, but… that wasn’t the worst part. The dye tracer… was probably the worst thing that I initially experienced because they can’t give you anything for it, and they do… four shots of dye around your cancer spot.” Linda (age 46), relayed that “[the surgical oncologist] took some skin from my thigh, which was really painful after surgery, worse than anything, and now it looks like I have alligator skin”.

Several other aspects of melanoma miscommunication also were discussed: surgery as treatment, treatments for recurrences, and the role of clinical trials. For example, Ethan (age 57) noted, “There were two surgeries but… no real treatment.” Karen (age 65), who was followed for 29 years by her primary care provider, reported, “There was no chemo available… specifically for melanoma and radiation wasn’t called for back then… they were just gonna’ watch me because no other treatments were available… I had one positive lymph node, then the second one [recurrence] was just here recently…” Arlene (age 43) noted, “I could not believe it, of all the things to be told, that you have melanoma and a surgeon would have to remove the area and make sure it stays away."

Subtheme 2B – Call it cancer. Subtheme 2B incorporates how participants viewed communication about melanoma as a "real" cancer. Participants described family and friends implying that melanoma may not be one of the real cancers like breast or colon cancer. Many participants were familiar with these other cancers from experiences with family and friends. The implication was that unless they are undergoing major surgery and weeks or months of chemotherapy or radiation, their melanoma is not really cancer. Taylor (age 64) stated, "I think of colon cancer as cancer." Robyn (age 56) elaborated, "It's funny, I don't really think of it [melanoma] as cancer like breast cancer or like my dad has lung cancer now… I guess because you know he [my dad] went for radiation and chemo from lung cancer, and then with breast cancer my friend… had a full double mastectomy. I mean I think of those things of cancer… and I… thought of this [area on her nose] as…I have this spot, or these spots."

Participants described these cancer-labeling experiences in different ways. Darron (age 61) said, "Melanoma or skin cancer seemed to be… you just go in there have it removed… I look at…this little bit of skin cancer [scar from melanoma removal] on the skin, I don't call that melanoma." Robyn (age 56), noted, "It always jogs my memory… when you fill out any history [form] and they say, *check this box if… you had cancer*, and I have to remind myself to check *Yes*… [my friends say]… you have cancer, and I'm like, I had a spot on my nose, so again, a little bit…of the denial…" Taylor (age 64) emphasized the seriousness of the diagnosis, "It was… not… you have skin cancer… it was more, you (pause) Have (pause) Skin (pause) Cancer."

Participants shared experiences in which healthcare providers minimized the seriousness of melanoma recurrence or surveillance. For example, Rosie (age 29) said, “The surgeon [surgical oncologist] said it’s no big deal. We’re gonna’ take care of it, and it’s gonna’ be done.” Heidi (age 60) noted, “One time, they [the photo dermatologist and office nurse] saw something that changed, and they didn’t tell me they were concerned, and they cut it off and they were worried about it, but it came back fine.” Ethan (age 57) said, “Some [dermatologists] have been good, the one I have now is ah, one of those who just wants to get you in and out just as quickly as possible.”

One participant described her melanoma experience as a spiritual journey. During the interview with Arlene (age 43), it seemed for a moment that we were not talking about melanoma, but rather a personal growth experience.

> I think cancer for me was something that was always, I wonder if I’ll ever get it? And I did, and I’ve survived and… it continued… my relationship with God a lot… and so I just… don’t see it as a bad thing. I see it as something that was really scary, but… I met a lot of really great people… I did a lot of personal growth in it, and so, I wouldn’t wish it on anybody because I don’t know what the future is, but… I learned a lot.

Some participants looked at having melanoma from the practical perspective of educating other types of healthcare providers. After her dermatologist told her to tell the gynecologist what to look for, Rosie (age 29) said, “I never thought about [how] you should tell your gynecologist to check for melanoma, so that when they do your pap smear, they can look for spots on your cervix.” Similarly, Arlene (age 43) noted that when her surgical oncologist told her what to have the dentist to look for, “I did share it with my dentist, and so he does track it when he does my exams, he looks for spots.”

Leaving the words cancer and melanoma completely out of the narrative worked for Robyn (age 56),

> … I don’t call it cancer. I don’t call it melanoma. I will say… I had something removed. Someone will say, ‘Oh, I went to the dermatologist and, oh my gosh, I had this spot removed’ and I’ll say yes, when I went, oh my gosh, I found out I had to have all these things removed. I don’t… really say I had melanoma… I’ll say well it turned out I had a skin issue.

Subtheme 2C – Defer to dermatology. Subtheme 2C refers to participant experiences of being referred to a dermatologist by primary or specialty care providers for any suspicious or unusual skin lesions. Arlene (age 43) said, “Anything that looks funny, we biopsy immediately.” Robyn (age 56) noted, “She (dermatologist) just wanted to take ‘em [abnormal looking moles] off.” Similarly, Greta (age 43) said, “I knew they’d have to be cut off.”

Often the dermatologist defined the follow-up process for the participant after treatment. Greta (age 43) reported, “The dermatologist let me know about follow-up, I then had a sense that this is gonna’ be the rest of my life.” Robyn noted that melanoma follow-up visits are treated like any other appointment, “It’s just like any other office visit, it’s not a special like whoa, you get the special VIP treatment… It’s go and sit in the waiting room for hours on end.” Heidi (age 60) emphasized the amount of time involved, “You might as well block out your day. I mean, it… doesn’t matter what time of day I’m there (dermatology), it seems like if I go for a 9 am appointment, I’m finally out by 1:30 pm.”

A few participants talked about the stressful experience of anticipating a biopsy or excision. For example, Robyn (age 56) said, “I know every time I go back… it’s gonna hurt… it’s not like she’s happy to cut me… but it’s just… [that] I know every time I go, I’m gonna have stitches.” Jeanie (age 58) reported, “My dermatologist checks my skin extra careful now, and I worry about another biopsy, they hurt, and I get real nervous.”

Generally, primary care providers refer patients to the dermatologist for melanoma follow-up. Darron (age 61) said, “she’ll [primary care provider] say something like, so are you going back to see the dermatologist? I mean she’ll kind of do an inquiry about when I go.” Griffin (age 49) reported, “I told my doctor about it [a new area of concern] and he sent me to a dermatologist to take it off, and see if some of the other areas on my back needed attention.” Taylor (age 64) noted, “The dermatologist sometimes checks it [skin]… [and] asks if I have any new moles.”

The type of exam done in the dermatologists’ office varied among participants. Taylor (age 64) reported, “The dermatologist looks at my arms and face, and asks if I have any problems, stuff like that.” Arlene (age 43) noted, “Anytime I see the dermatologist, I just ask, is there anything you want to cut off?” Greta was committed to her follow-up, emphasizing, “I just religiously go to him.”

Summary of implicit needs. One implicit need identified from the data was for timely information, preferably face to face or via phone conversation when getting biopsy results. Additionally, participants needed information about long-term treatment effects and access to resources for managing physical complaints such as lymphedema and chronic pain. Participants also indicated that they have benefited from talking and sharing stories with other survivors who have had similar experiences.

Theme 3: Once Bitten Twice Shy

Participants explained that all new suspicious areas on their skin resulted in anxiety and the implicit need to have them evaluated quickly—waiting was not an option. The Chinese proverb about a person who has been bitten by a snake feeling suspicious, even when seeing a piece of rope (Oxford Dictionary of Proverbs, 2015) depicts the essence of this theme; however, the American version seemed more appropriate for this research section. Participants found strength within themselves and by sharing with others. This process, which began in the diagnosis and treatment periods and continued post-treatment, gave participants a sense of hope and camaraderie that helped them get through the rough periods (Table 4.8, Appendix A). The following three subthemes provided a way to think about these experiences:

- Subtheme 3A – Waiting is not an option;
- Subtheme 3B – Everything looks like melanoma; and
- Subtheme 3C – Sources of strength.

Subtheme 3A – Waiting is not an option. Subtheme 3A pertains to participants already being aware of a suspicious lesion at the time they were told it should be removed. Participants recalled that their primary care provider or dermatologist watched the lesion change, but most did not remember being told that the area could be or become melanoma. Due to guilt at having waited before their initial diagnoses and/or the desire to take better care of themselves in the future, most participants were determined not to wait when they found another suspicious lesion. Worry, anxiety, and distress about possible recurrence played a role in their sense of urgency. Arlene (age 43) said, “I noticed a new mole that I thought looked darker.” Darron (age 61) also noted, “Right now… I’ve got a couple spots that need to get checked.” Robyn (age 56) noted, “Something came up on my face, over here by my cheek.” Griffin (age 49) reported, “Something new showed up a couple of years ago, and my wife said, ‘We are not waiting.’” Arlene (age 43) told her dermatologist, “If you think it could turn, take it now!” Any suspicious area felt like a threat until the results were known. Although not explicitly termed ‘I did self-skin examinations’, the participants reported examining their skin or designating a spouse or close friend to do so. Most participants could identify areas of concern or areas that were recently removed.

Subtheme 3B – Everything looks like melanoma. Subtheme 3B reflects the participant experience of feeling that any new suspicious area could be a melanoma recurrence. Because the suspicious areas looked either similar or different from the original melanoma, each participant had to make a decision based on their previous experiences. Heidi (age 60) noted, “I thought it looked the same,” while Jeannie (age 58) said, “I wanted to go, but was scared it was melanoma again.” Robyn (age 56) reported, “Another new area resulted in a frenzy to get someone to address it.” For example, Greta (age 42) said she had “a few things removed, but no more melanoma… he’ll see me the next day and cut it off.”

Subtheme 3C – Sources of strength. Subtheme 3C represents participants developing skills to cope with melanoma and continue to live their lives. The sources of strength were relationships with family, friends, and the community within the Appalachian culture. Many participants found strength in talking with other melanoma survivors. Clifton appreciated being able to “talk to other people with melanoma,” while Jeanie (age 58) noted, “It was helpful talking with someone with melanoma in the hospital.” Faith also was a source of strength for some participants. Karen (age 65) emphasized, “My faith has been a constant, my friends have prayed, I prayed, my husband has prayed… double.” Karen also demonstrated optimism, “It wasn’t a death sentence at this point,” while Greta (age 42) said, “I hope I don’t die.”

Summary of implicit needs. Participants explained that all new areas resulted in anxiety and the implicit need to have them evaluated quickly without waiting. Like the Chinese proverb, once melanoma survivors were bitten by the disease, they were suspicious of any area that could be a recurrence. The participants' sources of strength—including family, friends, and their community—were able to meet many immediate needs. This source of strength may be connected to the Appalachian culture of close-knit bonds and the tendency not to ask for help from outsiders.

Theme 4: Watch Me like a Hawk

Participants responded to interview questions about their physical exam experiences with dermatology, primary care, and specialty providers. They described in detail experiences in which healthcare providers gave them reassurances to help ease their worry or anxiety. In fact, participants often sought out providers who empowered them and gave them confidence. The participants also shared their experiences during uncertain times when they were worried about melanoma coming back, having more surgery, needing new treatments, and dealing with life-long issues as they age. This theme incorporates participants' expectations going forward as they continue living with melanoma (Table 4.9, Appendix A). The following subthemes supported theme 4:

- Subtheme 4A – Follow-up visits;
- Subtheme 4B – Reassurance offered; and
- Subtheme 4C – Uncertain times.

Subtheme 4A – Follow-up visits. Subtheme 4A highlights specific visit details of participants' primary care, dermatology, specialty, and cancer care visits. Participants described what was done during visits when providers were aware of their melanoma history. While these findings suggest that most of the participants' routine follow-up checks were conducted by dermatologists, the participants implicitly expected all providers to be able to identify anything that looked like a recurrence or validate they did not have one. Overall, participants were healthy, had little comorbidity, and were not on routine medications. Participants indicated that they see few if any specialists who would be assessing them regularly besides dermatologists. Melanoma follow-up was crucial for these participants, as they acknowledged that any symptoms they have could be related to melanoma and would need to be ruled out as such before being treated. Most primary care providers have not been trained in cancer surveillance, and therefore generally do not provide this type of care to other cancer survivors. Taylor (age 64) was one of the few participants reporting that his primary provider does a more comprehensive yearly exam, "I see the primary doctor [at a clinic] once a year for blood work, chest x-ray. [He] listens to my lungs, checks everything out, checks my blood pressure, you know, the drill. In the primary clinic they do check the lymph nodes in my neck and armpit."

Most participants do not put on a gown for either their primary care or dermatology office visits. From the participant's point-of-view, wearing a gown signals a more thorough examination by a clinician. In addition, from a practical perspective, having a patient put on a gown for a complete skin examination adds approximately 20 minutes to the visit, while primary care visits in a busy clinic are scheduled every 10 to 15 minutes. A skin exam can be done by lifting clothes, an approach more fitting a post-operative check. For the participants, their melanoma journey started with their skin and therefore it makes sense to continue with their skin, while most know the disease goes beyond it. Providers generally did not discuss their decision-making process in determining which type of examination to perform. Participants described their primary care provider office visit experiences. Heidi (age 60) noted, "All the doctors say the same thing, you go to him [dermatologist], why would I look [at your skin]?" When asked if his primary care provider had him put on a gown for a skin check, Ethan (age 57) said, "Not routinely, that'… something they only do at… annual checkups. But I haven't had one in two or three years." Griffin (age 49) reported, "He listens to me with the stethoscope, front and back, listens to my gut, listens to my neck, checks my blood pressure, [does] lab work, then I'm done."

Linda (age 46) stated, "I don't put on a gown when I see my PCP and usually that appointment is pretty quick, I've changed a few times." While smiling at me and pointing to his cheek, Randall (age 94) said, "When I see my primary doctor, I do not put a gown on, the melanoma was on my cheek." In contrast, Arlene (age 43) remarked, "I put a gown on for everybody except my eye doctors, so anyone who would look at a part… I'm at least half-naked, if not fully, and they all look for cancer… I am just naked all the time now, I do put on a gown and she checks me." Darron (age 61) noted, "No… the primary doesn't [have me put on a gown]… which it kind of surprises me that… the primary doesn't do an assessment for… skin." Robyn (age 56) said, "I did see my primary care provider right after it was diagnosed, but no taking off… my clothes or putting on a gown in… their office, no that wouldn't be appropriate for why I was there."

Participants also described physical exams performed by their dermatologist, the provider participants viewed as the front line in recurrence prevention. Heidi (age 60) described her visits, "My dermatologist checks my skin extra careful now, and I am always asking about this, and I have had a few more things removed but no cancer, thank goodness." Sometimes the visits are short, as Taylor (age 64) reported, "The dermatologist looks at my arms and face, and asks if I have any problems, stuff like that." Griffin (age 49) said, "The dermatologist checks my skin, asks if anything new has shown up, [and] I have had small things removed from my back, but all have been benign." Taylor (age 64), who sees a local dermatologist while his wife wants him to see a one an hour away, said, "There's nothing anybody can do except what he does, which is just look at 'em." Greta (age 42), who sees a photo dermatologist and has exams that can last up to an hour, stated, "I said this is not the photoshoot that I was looking forward to (laughing), and then he takes… pictures of everything the first time, and… he compares them every time."

Of her visits to the gynecologist, Greta (age 42) said, "My gynecologist checks everything… I mean everything; she always has including lymph nodes under my arms and groin." Arlene (age 43) also spoke of her gynecologist visits, "He has to check for stuff in places that my surgeon doesn't feel he needs to check every time, and he encourages me to have him check all those places." In contrast, Robyn (age 56) reported, "No skin checks, she (gynecologist) doesn't do anything that's not specific to why I'm there to see her."

Surgical oncologists also see patients for follow-up, as noted by Linda (age 46), "He [surgical oncologist] checks lymph nodes under my arms and in my groin." Griffin (age 49) stated, "I put a gown on and you know the typical cancer questions, and then they check my skin and ask me if I'm having any symptoms. My lymph nodes are always checked all the time." Hayden (age 61) said, "Yes, they look at my skin and feel and check my lymph nodes under my arms and groin area too, they check both." Arlene (age 43) appreciated her provider's responsiveness, "I mean the doctor's amazing, seriously… like when I texted this week and I had something else that I found… he just said come in Monday."

Subtheme 4B – Reassurance offered. Subtheme 4B serves as the label for participant experiences in communicating with their healthcare providers and clinicians. Reassurance is a therapeutic intervention that has origins in the field of medicine. Reassurance can be defined as a statement or comment than removes someone's doubts or fears and has the intent to help another feel less worried or anxious. Participants implicitly reported positive experiences when they received information from professionals who were confident about melanoma recurrence monitoring. Many participants received reassurance from their providers. For example, Heidi's dermatologist told her, "You know this one on your stomach looks kind of weird, it's probably nothing." Rosie (age 29) reported, "I went to a new dermatologist, and she kind of opened my eyes to some other things, she said… not only should you be wearing sunscreen, you really shouldn't be in the sun at all." Jeanie (age 58) stated, "The surgeon [surgical oncologist] said I would be okay once we get it out. Glad for that, but it came back again, not so glad." Greta, (age 42) said, "Every now and then my primary care provider will say… he thinks I need to have PET scan, and then my [photo dermatologist] always disagrees." Speaking of his primary care provider, Ethan (age 57) stated, "He was surprised, it seemed. He looked at the area on my back and asked if someone was following me for that." Arlene (age 43) spoke at length about the assurance she received:

> He [surgical oncologist]… was just amazing… very… caring, very… personable, and was very reassuring, and wanted to make sure at every step of the way that I knew exactly what he was doing, and what he was saying. And so he clarified, clarified, clarified. Yeah, I can't actually imagine not going to see him, too [surgical oncologist], because actually, [I] feel like when I'm seeing him, I don't have cancer. They [PCP, surgical oncologist, medical oncologist, and dermatologist] all knew [about each other and that I had melanoma]… they all communicate; they are one big, happy, faxing-each-other family.

The participants also spoke about the reassurance they received from office nurses and radiological staff. Arlene (age 43) described, "They explained to me the whole time what was happening um, so that was very humbling because even while I was there, I knew that other people went through this and that was hard… I was very appreciative of his nursing staff to really walk me through.” Friends and family also offered words of encouragement, as that noted by Taylor (age 64), “My sister was telling me that all would be fine, and that’s the way things went.”

Of his surgical oncologist, Ethan (age 57) said, “He was gonna take care of it, so I thought okay, he’s gonna take care of it.” Arlene (age 43) commented,

> The surgeon [surgical oncologist] was very precise about making sure I understood about melanoma and how serious it could be. He told me that I would need to be followed after treatment regularly. As I recall, that was the bottom line, he wanted me to know exactly what was happening at all points, and he does that ‘till this day.

For some participants, the precedent set during the diagnosis and treatment periods extended into post-treatment as well. For example, Arlene (age 43) emphasized, “It was very reassuring and… empowering ‘cause…I didn’t feel like oh, I don’t know what this is, or what does this mean, and he still treats every visit like that.”

Subtheme 4C – Uncertain times. Subtheme 4C describes participant comments related to insecurity and worry about recurrence. Many participants offered suggestions to other melanoma survivors based on their own experiences. For example, Darron (age 61) advised, “Make sure you go to the best dermatologist you can find… continuity is important, so if you can stay with the same provider and you like that person, then you should do that” Arlene (age 43) emphasized, “It’s your body, if you care about it, you fight for it, don’t wait for someone else to fight for it.” Greta (age 42) said, “If I had quit following up, then I’d have a metastatic melanoma, and I might… not be here now.”

About a suspicious area that turned out not to be melanoma, Arlene said "I was safe with that, because I knew that if he did it, he would do it like a melanoma cut, and I would never have to worry about that spot again." Clifton (age 60) reported,

> Recently, they found new areas in my lungs and brain… No problems for 18 years, I have… stayed in shape, healthy. Then they saw something new on the chest x-ray, and that started this ball rolling. No symptoms, no symptoms at all. That's the unbelievable part, really [sigh]. I am going to Bethesda to participate in a clinical trial.

Robyn (age 56) advised, "Force yourself to make the appointment, force yourself to stay on top of it because had I… not had…what I think… is that God moment, that guardian angel, that discussion with my friend, had we not been talking about that, I probably still wouldn't have gone."

Summary of implicit needs. Participants need access to local resources that can help with overall long-term melanoma effects and related psychosocial issues. Survivors need assurance and access to local primary care providers and cancer specialists to coordinate their melanoma surveillance plans. Moreover, they also need a more streamlined appointment follow-up system and access to current, relevant melanoma resources for recurrences. Additional information regarding the specifics of self-skin examination as well as the appropriate roles in melanoma surveillance of the dermatologist, primary care physician, and other specialists also would be helpful.

Chapter Summary

The four themes and accompanying subthemes that emerged from data analysis are important findings. Noteworthy experiences included the need to drive across the state for follow-up appointments. Another finding was that dermatology served as the front line for melanoma follow-up, with very little coordination with cancer surveillance plans or resources. Primary care played a small role in melanoma follow-up, with providers deferring skin exams and recurrence monitoring to dermatology. Inconsistent monitoring of melanoma surveillance increased the burden for survivors who many not have the resources to continue traveling for follow-up access.

The Appalachian culture seemed to influence the way some participants responded to interview questions. These survivors are self-sufficient, self-directed individuals who rely on family, friends, and community resources for transportation needs, meals, and help with family obligations. Often the help provided to meet essential needs was unsolicited and came from a robust support system. Most participants experienced post-treatment follow-up in dermatology offices, while participants with advanced disease required melanoma experts in medical and surgical oncology practices.

Chapter Five: Discussion

Sixteen melanoma survivors living in the ETAR shared their health-related experiences that occurred during the diagnosis, treatment, and follow-up periods of their cancer journeys. Interestingly, the post-treatment needs were not explicitly shared in the interviews, but rather implied from participant discussions. In this chapter, findings are compared and contrasted to those of other melanoma survivorship studies, and implications from the Appalachian kinship and social literature are discussed. Implications are presented for registered and advanced practice nurses, nursing education, primary care, dermatology, and cancer specialist providers working with melanoma survivors in Eastern Tennessee and surrounding regions. Healthcare policy and research suggestions also are presented.

Toward An Interpretive Explanation

This study's research question was *What are the post-treatment health-related experiences and needs of melanoma survivors living in the ETAR?* While further analyzing the data, the PI sought interpretive explanations of the whole while continuously looking back as the individual participant data. Interpretive explanation is the "most fully integrated of qualitative analytic products" (Thorne, 2008, p. 165). The goal of an interpretive explanation is to "create a thematic structure for showcasing the main elements of a phenomenon in relationship with one another, if not within a conceptual or thematic schema" (Thorne, 2008, p. 164). The connections and linkages constructed from this study's data—the interpretive explanations—provide new knowledge that helps advance this field of study.

For this study, the current literature related to melanoma survivors' post-treatment experiences and needs was divided in three areas: research related to QOL measures, psychological impacts, and health and well-being practices. The post-treatment health-related experiences and needs of melanoma survivors from the ETAR share some similarities with melanoma survivors in the U.S. Pacific Northwest, Texas Panhandle, and Northeast regions. Common experiences between this study's participants and other U.S. survivors included sun-protections behaviors, satisfaction with providers, worry about recurrence, and psychosocial factors (more common among younger survivors and those with limited financial resources). Additionally, melanoma survivors in this study share several commonalities with those from the UK, Australia, Germany, Netherlands, Ireland, and Canada: sun-protection behaviors, anxiety, and feelings of uncertainty.

The ETAR melanoma survivors used self-directed behaviors to coordinate their own follow-up treatment without a specific surveillance plan. Many of these participants travel numerous miles for the assurance their providers and clinicians provide. Their knowledge about melanoma and commitment to stay cancer free keep them coming back. While the uncertainty the participants experienced is similar to that of sufferers of other systemic cancers, melanoma survivors are not followed within the cancer healthcare system unless they have advanced stage disease. The threat of recurrence caused some participants to experience ongoing stress and anxiety, which lead to urgency when new suspicious areas developed. They managed these situations by receiving care that was self-directed or coordinated by a designated person, and being determined to stay ahead of the disease through frequent follow-up, travel to experts across the state, and/or finding a support group where they could be seen and heard. The four major themes identified in this study provide an organized way to discuss the findings and the melanoma survivorship literature about health-related experiences, post-treatment needs, and Appalachian cultural influences.

Theme 1: Sitting in the Driver's Seat of Follow-up Care

From the ETAR, participants drove across the state to follow-up visits in Central Tennessee and locations in between. The terrain across Tennessee involves major highways as well as many small cities and rural towns. Once melanoma survivors established a relationship with a provider during either the diagnosis or the treatment periods, those bonds remained. Even if a practice moves, survivors generally will continue to follow-up the same provider. From the interviews, the PI concluded that the survivor-provider relationship usually is survivor-directed and collaborative. This commitment to guide their own follow-up care is driven by several factors within participants' narratives. Survivors wanted to continue partnerships with providers who adhered to a realistic and confident assurance that they would take care of the survivor, provided direction about care, and/or kept them informed. Survivors' care management extended to coordinating any needs including transportation to appointments along with help from family and friends and when choosing which providers— local or distant—to see. In one Australian study, Morton (2013) briefly mentioned participants reporting "inconvenience of travel." However, these participants had a more advanced disease stage than the study participants discussed in chapter four making travel very difficult and confounding.

In addition to travel, many participants mentioned the amount of time they spent in office visits. A dermatologist visit could take a whole morning or afternoon and require work release. A medical or surgical oncologist visit with labs or scans could take two days to complete. Often family and friends would drive and/or accompany participants depending on resources like owning a car or having gas money for the trip. Participants did not report traveling to any visit alone. As seen in typical close-knit family relationships in Appalachia, support for the participant included accompanying them on the trip, and depending on participant resources, making a day of it by stopping to visit, shop, or have a picnic. Only two participants said they would not travel to see the doctor when a local doctor could do the job. In their literature review, researchers Murchie and Delaney (2010) noted that melanoma survivors appreciated a less rushed appointment that included a more thorough examination. However, that study involved melanoma survivors who saw either a primary care provider who had received additional melanoma surveillance education or a melanoma specialist for post-treatment follow-up.

The personal and social support expressed from participants was familiar within the Appalachian culture discussed earlier. Abramson & Haskell (2006) discuss the rural Appalachian people who refer to their family members and neighbors as *kin*. Communities within close proximity to one another support each other during illness and turmoil (Biggers, J., 2006). Extended family living locally or those moved out of the Tennessee Appalachian region return to provide support depending on the need.

Theme 2: Living in a Skin World

This study's participants often avoided using the word "cancer" when communicating with friends and family members. Many also avoided having serious conversations about melanoma with their family members, especially their children because the stigma related to cancer and dying. While more than half of the participants reported having family members with cancer, many did not know if they had a family member who died from melanoma. Some participants expressed that they had melanoma, a cancer that can spread anywhere, anytime, and then talked about what they have done to avoid recurrence. Participants did not offer reasons for not referring to melanoma as cancer, but the choice seemed to be a culturally influenced behavior to keep some health issues private. Although some participants did not grow up in the Appalachian region but migrated there, the area's customs may have influenced them. While

Palesh et al. (2014) reported that melanoma survivors from Northern California did not discuss ways to reduce recurrence with family or friends but they did not specifically mention avoidance of the word cancer.

Participants described avoiding the word cancer when they spoke about whether melanoma was considered a real cancer. Some participants reported that they and their family members did not consider melanoma a real cancer such as colon or breast cancer. The rationale given by participants was that colon or breast cancer involves a large surgery and weeks or months of chemotherapy or radiation, as well as the symptoms associated with these treatments. McLoone et al. (2012) reported that many of the Australian melanoma survivors in their study did not see themselves as cancer survivors because melanoma is visible and can be detected and cured at an early stage.

Two participants traveled up to two hours round trip to the regional cancer center for pain management because local facilities or providers were unavailable. Only one study in the literature specifically addressed pain management for melanoma survivor’s post-treatment. Kuo et al. (2012) investigated physical scars and pain in 19 melanoma outpatient clinics in the UK. This study is an example of the implicit identification of needs in the post-treatment period. The pain scores were recorded using a survey that asked about pain from any cause. Kuo et al. (2012) concluded that melanoma patients in the outpatient setting commonly experience chronic and undertreated pain. Half of the patients suffered from pain from non-cancer sources, often with a neuropathic component, and many could benefit from better management. Similarly, participants in the current study need local pain management resources so they do not have to drive two hours round trip every month to get help with their pain.

Stavia et al. (2006) conducted a large cohort study at MD Anderson in Texas with patients from a melanoma specialty clinic (N=996). These researchers examined melanoma survivors' quality of life compared to that of other cancer survivors. Survivors who had surgery as their sole treatment (N=577) reported their only health problems were arthritis, osteoporosis, cataracts, and heart problems, but they had them much more frequently than did other cancer survivors. Similarly, the participants from the current study were generally heathy with few quality of life issues except for arthritis and hypertension.

Talking about cancer remains a stigma within the overall narrative of participants in this study. The dichotomy between privacy and Appalachian folklore, participants spoke about the difficulty of not only sharing their diagnosis with others as 'melanoma' but also hesitancy about using the word 'cancer'. The 'cancer' stigma also involved participants meeting resistance when asking or probing relatives to share specifics of the 'cancer' or 'melanoma' history to understand their risk.

Theme 3: Once Bitten, Twice Shy

Participants were very vocal about their urgency to continue following-up even when they knew a biopsy would involve pain if a new area was identified and a biopsy had to be done. Many participants wanted any newly identified suspicious area resected the next day, often texting the surgeon to get in urgently. Some called a friend who was a plastic surgeon or family practice provider to see if they had time to do a biopsy. Others described moving themselves to the front line by dropping by the dermatologist office without an appointment in order to be worked in. Participants reacted to a new suspicious area as if it were melanoma. No studies in the literature mentioned survivors having a sense of urgency with new suspicious areas or what level of familiarity they had with their providers or clinicians.

Participants reported worry and anxiety about melanoma recurrence. In a study of the benefits of long-term follow-up, Morton et al. (2013) reported anxiety among melanoma survivors as the follow-up date drew near. Livingstone et al. (2015) looked at the first two years after diagnosis and found that some survivors had high psychological stress (anxiety and uncertainty) and might benefit from additional education and psychosocial support. Palesh et al. (2014) found that melanoma survivors with anxiety could benefit from greater health provider involvement to address psychosocial needs and develop treatment guidelines for managing clinically relevant levels of post-treatment distress. McLoone et al. (2012) reported that melanoma survivors from a high-risk clinic in Australia suffered from fear and persistent uncertainty. Bird et al. (2015) reported that melanoma survivors viewed their needs as unique compared to other people with cancer, often speaking about continuing follow-up to avoid dying.

Many participants described the strength needed to live with melanoma and continue follow-up for a lifetime. Some participants spoke about how their personal growth contributed to inner strength, while others referenced their faith. The religious roots within the Appalachian culture extended to an even deeper expression of faith created by the collective ‘power of prayer’ during illness and stressful time. Participants appreciated friends and family members providing friendly follow-up reminders and asking them how their visit went, if a biopsy was done, or how things were going. Again, these participant experiences and needs may be influenced by the Appalachian culture milieu.

Theme 4: Watch Me like a Hawk

Skin examination was a major focus of many participants’ narratives. Most participants regularly saw a dermatologist who examined their skin and evaluated any new or suspicious areas. Some participants remembered their initial diagnosis in which a mole that had been watched closely was finally biopsied and turned out to be melanoma. After this kind of experience, participants often wanted suspicious areas removed right away to avoid recurrence. The data indicated that primary care providers generally do not have participants remove their clothes and put on a gown or examine their skin. Instead, most primary care providers refer anything skin related to the dermatologist. Occasionally, a physical exam would include the standard assessments of listening to the lungs, heart, and abdomen and recording any new symptoms. Many participants described specialists, such as gynecologists, who perform a thorough exam to look for other places melanoma may develop, and check lymph nodes in the axilla or groin. Participants expressed puzzlement regarding why providers did not look at their skin during their office visit and made concessions for this with statements such as, “he did not have time” or “that’s not why I am there.”

Studies focused on sun-protection behaviors and self-skin examinations were abundant in the literature. Oliveria et al. (2013) examined sun-protection behaviors, follow-up practices, and psychological concerns. Bowen et al. (2012) studied melanoma risk-reduction behaviors in survivors among the general population in the Pacific Northwest. Most survivors saw a dermatologist who checked their skin thoroughly and many reported doing regular self-skin examinations. Individuals reported wearing long sleeve shirts, sunscreen, or a hat when necessary. The topic of sun protection behaviors did come up in the interviews with participants from ETAR when they were asked if they did anything now that they did not do before being diagnosed with melanoma. Most women reported changing many sun-related behaviors including wearing more sunscreen and avoiding direct sun. Men reported wearing a hat or reluctantly using sunscreen if prompted by a loved one.

Most participants (or significant others) had direct lines of communication with needed providers from either familiarity or community connections. Small towns and family connections often facilitated a path for making a phone call to be seen soon regarding a new area to the skin or new symptoms causing worry or anxiety. Provider action during an office visit where concern about the new area, the sense of touch, inquiry regarding new symptoms, and facilitating appointments, or answering questions provided assurance for survivors faced with ongoing psychological distress and uncertainty.

Recommendations

Nursing Practice

This study has several implications for nursing practice. Overall, nurses need a heightened awareness of the experiences melanoma survivors to inform their conversations with these patients about survivorship and follow-up care. Several strategies could be incorporated into practice, such as including nursing history and assessment questions about survivorship for cancer survivors. Further, the addition of a patient navigator (identify barriers to follow-up or the type of follow-up) for melanoma survivors could improve long-term patient outcomes. Finally, nurses could help identify and provide resources needed by melanoma survivors during transitions and across the life span.

Nursing Education

The National League of Nursing (2015) identified a comprehensive list of priorities in nursing education, one of which was fostering inter-professional practice. One challenge within nursing education is to gauge the effectiveness of approaches to foster development of clinical reasoning in situated patient care contents (simulation). Advanced practice nurses need to be able to examine patients effectively and make critical decisions based on those assessments.

Additionally, knowledge and critical thinking skills are needed to treat problems, make referrals, and coordinate follow-up care. An undergraduate nursing student should be able to perform a basic skin examination, while a student in a graduate nursing program focusing on clinical practice should be able to perform a full-body skin examination. Advanced practice nurses are uniquely qualified to step-up and provide additional care for melanoma survivors in primary care, specialty care, and inter-professional practice settings. The American Cancer Society recommends melanoma survivors have full-body skin examinations at least yearly. However, such surveillance also includes monitoring long-term issues, providing education, and screening for psychosocial needs.

Primary Care, Specialty Care, Advanced Practice

The National Cancer Institute's (2015) cancer survivorship goals focus on the role healthcare provider's play in establishing a care plan for cancer survivors. Although melanoma survivors need regular skin exams and dermatology follow-ups, survivorship should include access to the *cancer circle* where resources and ongoing information are available. Melanoma survivors need accurate, consistent information regarding melanoma post-treatment survivorship. At least one visit to a medical oncologist or nurse navigator could allow survivors discuss their issues, receive information and resources, and a referral to someone the survivor and/or family can call if cancer-related issues arise. Survivors also need opportunities to talk with other survivors and develop support that may not be available through family or friends. Additionally, survivors need access to relevant, up-to-date information as new melanoma research findings or breakthroughs develop that relate to their current health status.

Programs that use a team approach to melanoma surveillance could give survivors more care continuity and assurance. Clinicians need more knowledge about melanoma surveillance to create local community networks for Tennessee survivors across the state. Local facilities providing cancer care could offer a contact person who could answer general questions and provide information about genetic links between melanoma and other cancers.

Dermatology and primary care providers can play a larger role in melanoma survivorship, by focusing on melanoma as a systemic cancer rather than a skin disorder during patient visits. Additionally, dermatologists and primary care providers and clinicians could refer melanoma patients to survivorship programs, whether or not these patients are seen by a medical oncologist. The standards and goals for cancer survivorship are focused on cancer survivors in general. Unfortunately, melanoma survivors may not be referred to or see a cancer care provider or nurse navigator who can help facilitate care and follow-up.

Policy Implications

Recognizing the challenges of providing cancer care in resource-constrained settings, the National Cancer Policy Forum (2017) convened to make recommendations to help communities build networks. Additionally, the NCI (2015) reported that some of the most basic psychological and social issues affecting cancer patients are not being addressed, including support and ongoing follow-up and monitoring for recurrence. Patients need to be relieved of the burden of coordinating their own melanoma surveillance, whether doing so improves outcomes or not. Melanoma survivors need the same standard-of-care that other cancer survivors concede, before they have a recurrence or develop metastasis. Nurses are uniquely qualified to provide a voice to improving public awareness and applying public pressure to encourage government actions to improve cancer care. Regionally, the ARC addresses critical infrastructure (transportation) and ready workforce (health of residents) issues within Tennessee and other Appalachian states.

Future Research

The results of this study introduce opportunities for future qualitative and quantitative research on the topic of interest. Other researchers should consider conducting research with melanoma survivors from other Appalachian areas and making comparisons with other rural groups. Studies exploring information provided to post-treatment melanoma survivors could give insight into current clinical practice. In addition, measuring patients' understanding of recurrence symptoms before and after an intervention could validate a program's effectiveness.

Researchers also could investigate the role of reassurance versus assurance in cancer survivorship, along with the struggle for power seen in some patient-provider relationships. Another important aspect of cancer survivorship is better understanding the perspectives and needs of caregiver survivors, persons who cared for a melanoma patient who died. Additional information about melanoma survivorship in diverse populations and situations also is needed. Research is needed to examine community resources and regional access options for surveillance in areas lacking local hospitals or regional cancer center services. Responsible melanoma surveillance care needs to move beyond offering reassurance and into providing a solid foundation and confidence to help survivors deal with the real threat of recurrence.

Limitations

While this study is limited by its geography, it is enhanced by a PI with experience as an advanced practice nurse providing care for melanoma survivors. None of this study's participants was cared for by the PI. Instead, the PI traveled the east Tennessee region visiting public areas like libraries, local diners, and community centers to become more familiar with the setting. Participants often contacted the PI after seeing having someone give them a flyer. Although, the PI sent numerous flyers to dermatology and primary care practices in the geographical area, no direct office referrals were made. To meet study recruitment requirements, the initial eight-county recruitment area was expanded to include all 45 counties in the ETAR. Therefore, only limited information regarding where participants live (including the specific counties) will remain connected with the confidential research documents. The shared social and cultural backgrounds among the study population strengthened the study findings with the consistency found in the state of the science and important implications locally and regionally. The participants in this study do not represent all melanoma survivors living in Tennessee or the ETAR. However, the research results can provide a new perspective for all who serve cancer survivors generally, or melanoma survivors specifically.

Significance

This addresses a gap in the literature regarding the post-treatment health-related experiences and needs of melanoma survivors in the ETAR. Before this study, little was understood about melanoma survivorship for those who live in this region. Data from participant narratives provided important links to the current body of knowledge as well as new insights for future exploration. This work is important in light of increases in the number of cancer survivors, including those with melanoma, who will need resources related to surveillance and life-long follow-up. Additionally, lack of resources for melanoma survivors in this geographical area poses barriers to care for this population.

Conclusion

Melanoma survivor's experiences reflected a dynamic process of disjointed care and a lifetime of worry and uncertainty in this study, which is consistent with the extant literature, related to post-treatment survivorship. The needs within the melanoma survivors interviewed were implicit which may reflect cultural influences or their acceptance for self-directing their own survivorship care with the help of family, friends, and providers that accommodate. Participants in this study were found to live with the guilt of feeling they or providers may have 'watched the cancer grow', suffer the agony of frequent biopsies, sometimes excessive appointments, disfigurement from treatments, and ongoing side-effects only to find follow-up consisting of trying to procure a complete skin exam traveling across the highways in Tennessee. The interpretive description method and the naturalistic paradigm provided an appropriate lens for discovery of new knowledge in this study. Exploring and describing participants' narratives gave voice to and understanding of a previously unheard population. The goal was not to generate an exhaustive list of all topics that might be linked to melanoma survivorship, but rather to create a thematic structure for highlighting the main elements of interest.

These findings contribute to the body of knowledge related to cancer survivorship generally, melanoma survivorship specifically, health research within Appalachia generally, and within the ETAR specifically. These findings also identified the important experiences and needs of melanoma survivors from an area in the U.S. where melanoma incidence is higher than state and national rates. The study findings provide important insight into the support needed for melanoma survivors from a local and state perspective and implications for all clinicians who care for cancer survivors. The overarching goal of this study was congruent with current federal and state healthcare goals regarding cancer survivors. The participants interviewed represent a small sample of the many individuals who live with melanoma. Using their words, the PI described and interpreted some ways healthcare can improve general practices when following melanoma survivors over time. These suggestions offer practitioners opportunities to take action and make a difference for this population. While it is easy to become complacent within healthcare practice, this study was conducted in the hopes that others can view the results as a challenge to become more sensitive to the needs of all the patients they serve.

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Appendices

Appendix A

Figures and Tables

Figure 1.1. Tennessee Appalachian recruitment area

Map of Tennessee Appalachian and Non-Appalachian regions. Appalachian Region Commission (2008). Retrieved from
https://www.arc.gov/images/appregion/AppalachianRegionCountiesMap.pdf
Used with permission from the Appalachian Region Commission

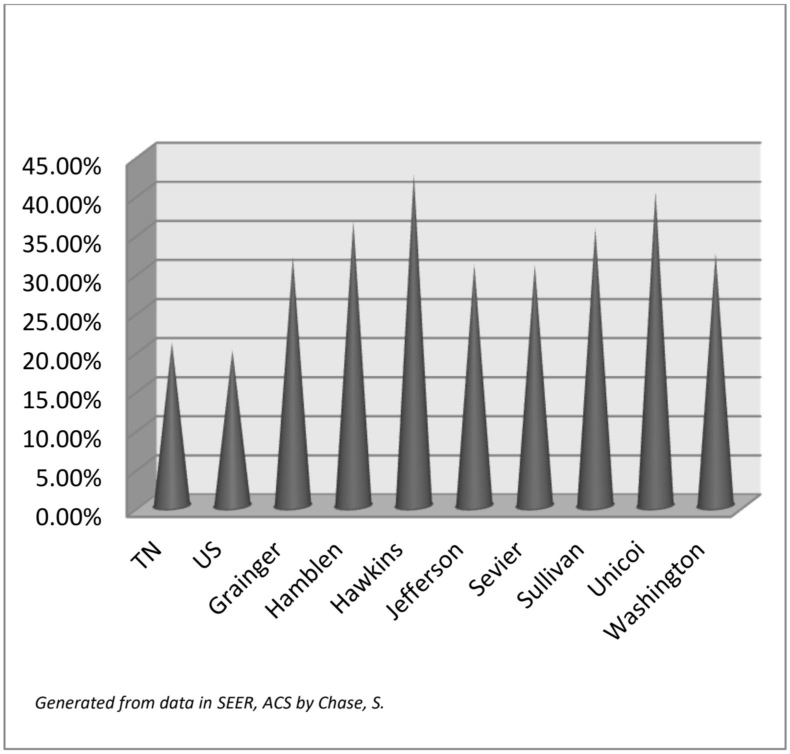


Figure 1.2. Cluster of eight ETAR counties with high melanoma incidence rates

Generated from data with Surveillance, Epidemiology, and End Results (SEER, 2017). Retrieved from http://seer.cancer.gov/csr/1975_2014 and
American Cancer Society (ACS, 2017). Retrieved from http://cancerstatisticscenter.cancer.org

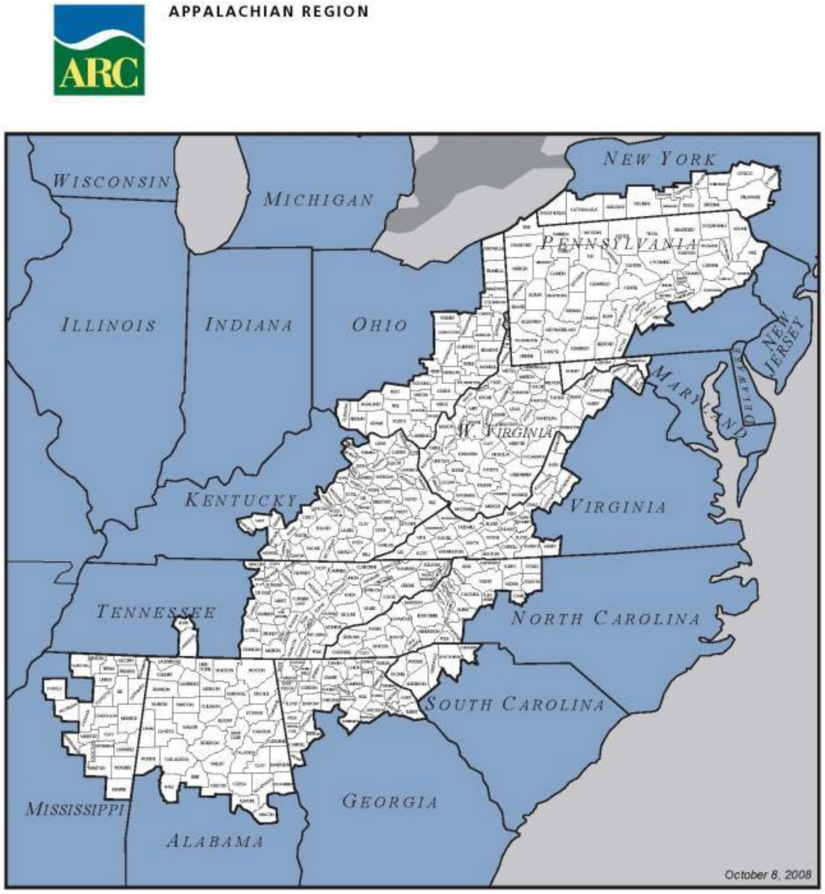


Figure 1.3. Appalachian Region States and Counties

From the Appalachian Region Commission (ARC, 2017) Retrieved from
https://www.arc.gov/images/appregion/appalachianRegionCountiesMay.pdf
Used with permission from the Appalachian Region Commission

Table 1.1. NCCN Clinical Practice Guidelines in Oncology for Melanoma

	Thin Lesion Treatment	Thick Lesion Treatment	Thicker Lesion / Recurrence Treatment
Initial Treatment	Wide excision Sentinel node biopsy (+/-) (negative)	Wide excision Sentinel node biopsy (+/-) (positive) Lymphadenectomy (+/-) Clinical trial (+/-)	Wide excision (+/-) Sentinel node biopsy (+/-) Lymphadenectomy (+/-) Clinical trial (+/-)
Scans		CT scan, PET/CT, MRI (+/-)	CT scan, PET/CT, MRI (+/-)
Adjunctive Therapy		Observation Nodal basin ultrasound (+/-) Interferon alpha (+/-) Immune therapy	Immune therapy (+/-) Radiation (+/-) Chemotherapy (+/-)

Created with information from NCCN Version 3.2016

Table 4.1. Individual Participant (n=16) Characteristics

Participant Pseudonym	Age	Gender	Education Completed	Usual work/Employment Status	Years Since Dx/ Recurrence (Y/N)
Arlene	43	Female	Master's	Psychology Therapist/Working	2 years/N
Clifton	60	Male	Technical	Paramedic/Working	18 years/Y
Daisy	26	Female	11th Grade	Cashier/Unemployed	1 year/Y
Darron	61	Male	Bachelor's	Park Ranger/Working	20 years/Y
Ethan	57	Male	Master's	Engineer/Working	8 years/N
Greta	42	Female	Master's	Nurse Practitioner/Working	14 years/N
Griffin	49	Male	Some college	Computer Programmer/Working	5 years/N
Hayden	61	Male	10th Grade	Computer Repairs/Disability	5 years/N
Heidi	60	Female	Bachelor's	Registered Nurse/Working	51/2 years/N
Jeanie	58	Female	High School	Sales/Disability	3 years/Y
Karen	65	Female	Some college	Registered Nurse	29 years/Y
Linda	46	Female	Bachelor's	Real Estate Agent/Working	4 years/N
Randall	94	Male	10th Grade	Farmer/Retired	10 years/N
Robyn	56	Female	Master's	Health Educator/Working	2 years/N
Rosie	29	Female	Master's	Medical Resident/Working	11 years/Y
Taylor	64	Male	GED	Electrician/Retired	9 years/N

Table 4.2. Group Participant (n=16) Demographics

Characteristic	n	%
Age at time of interview (years)		
20-40	2	13%
41-60	9	56%
61-80	4	25%
>81	1	7%
Ethnicity		
Non-Hispanic or Latino	15	94%
Unknown	1	6%
Highest education level completed		
Less than 12th grade	3	19%
High School, GED, or equivalent	2	12%
Some college	3	19%
College graduate	4	25%
Graduate School	4	25%
Employment status		
Unemployed	1	6%
Disability	2	13%
Working	11	69%
Retired	2	13%

Table 4.3. Participant (n=16) Melanoma Information

Characteristic	n	%
Length of time since diagnosis (years)		
0–5	8	50%
6–10	3	19%
11–15	2	13%
16–20	2	13%
>20	1	6 %
Family member with melanoma	5	31%
Travel time for follow-up (hours round trip)		
<1 hour	7	44%
2 hours	8	50%
4 hours	1	6%
Current follow-up schedule		
At least once a year	5	31%
Twice a year	7	44%
Four times a year	4	25%

Table 4.4. Participant (n=16) Treatment Information

Characteristic	n	%
Melanoma location		
Abdomen	1	6%
Forearm	3	19%
Back	5	30%
Chest	2	13%
Face	2	13%
Thigh	2	13%
Mucosal	1	6%
Recurrence (n=8)	8	50%
Location		
Abdomen	2	25%
Arm	1	13%
Back	2	25%
Metastasis	2	25%
Neck	1	13%
Length of time since diagnosis (years)		
0–5	8	50%
6–10	3	19%
11–15	2	13%
16–20	2	13%
>20	1	6%
Family member with melanoma	5	31%
Surgical treatment type		
Wide excision only	2	13%
Wide excision w/negative SLB	7	44%
Wide excision w/positive SLB	7	44%
Lymphadenectomy	6*	
Systemic Treatment type		
Interferon	2	13%
Immune therapy	1	6%
Clinical trial participation	2	13%
Current yearly follow-up		
At least once	5	31%
Twice a year	7	44%
Four times a year	4	25%

**One participant with a positive SLB did not have a lymphadenectomy due to metastasis*

Table 4.5. Themes and Subthemes in ETAR Melanoma Survivors

Theme	Subthemes
Theme 1: Sitting in the Driver's Seat of Follow-up Care	Subtheme 1A: On the road again Subtheme 1B: I steer my care Subtheme 1C: Hazards on for help
Theme 2: Living in a Skin World	Subtheme 2A: Melanoma is not a secret Subtheme 2B: Call it cancer Subtheme 2C: Defer to dermatology
Theme 3: Once Bitten, Twice Shy	Subtheme 3A: Waiting is not an option Subtheme 3B: Everything looks like melanoma Subtheme 3C: Sources of strength
Theme 4: Watch Me like a Hawk	Subtheme 4A: Follow-up visits Subtheme 4B: Reassurance offered Subtheme 4C: Uncertain times

Table 4.6. Theme 1 and Subthemes

Theme 1: Sitting in the Driver’s Seat of Follow-up Care	
Subthemes	Essential Quotes
1A: On the Road Again	*Distance* • “Appointments are 10 miles maybe round trip…” • “It takes about 2 hours to get there” • “Lots of driving is the problem.” • “No problems just a long drive, Umm, I haven’t been working so coming up with gas money sometimes... We get to stay in the resource housing area so that is great, my Dad and Sarah can stay too.” • “So, he (my boyfriend) has been bringing me to the doctor, I’m um, ah, too nervous to drive right now.” • “They found a surgeon but I had to drive a few hours to get it done… with a new baby it was hard, my dad had to come with me and took care of my daughter each time….” • “Usually I set the appointment up when I leave, sometimes I had to change it. My wife would drive and I’d work…” • “Uum, well, getting to the cancer clinic is a two hour drive, so my mom drives.” • “When I drive there (2 hours away to the photo dermatologist), my friends go too sometimes to have an excuse to go shopping with me.” • “Yes the nurse practitioner helped me when I was having so much pain but I had to come and see her every month and so a two-hour drive, we got through it but for a few months it drove me batty and my mom would get real tired.” • “Yes, well after a year, she (surgical oncologist) moved her practice to [another major city in Middle Tennessee, 4 hours away] and so we go there now. I don’t want to see another surgeon and so we started going there, she knows me so we go see her there. We usually try to stay overnight and visit friends sometimes.” *Time* • “He (photo dermatologist) said that I was very high risk and that I have to come every 3 months… I’ve gone to him every 3 months… for 14 years (2 hours each way).” • “He (surgical oncologist) followed me close for a while because of the problems with getting things healed. I did see the medical oncologist (at the cancer center) about the interferon and then once it was started then another doctor (medical oncologist) here (near home) was the one taking care of me. I still see him (medical oncologist) near home every six months.” • “He (surgical oncologist) said, you know this isn’t something to take lightly. Um, this is something you’ll deal with and ah, take care of the rest of your life.” • “I come and see the skin cancer doctor (medical oncologist) now every 6 months, some blood work and x-rays too.” • “I go every 3 months now, like clockwork to [middle Tennessee], to my melanoma guy [photo dermatologist] and that’s pretty much it.” • “I had a sense of “this is gonna be the rest of my life,” whether it’s semi-annually or annually.” • “So I went every three months, so I did it four times last year and I’m on my every 6 months follow-up now.” • “Waiting to be seen is the only thing. That particular, I don’t know if it’s that particular practice that or if it’s just dermatology in general, oh my gosh, half a day’s adventure.” • “Well, um, I see the skin cancer doctor [medical oncologist] or yea the nurse practitioner every 6 months and I get a x-ray and blood work next time.” • “You have to schedule a new patient appointment and it takes 8 months to get in (dermatology).”

Table 4.6. Continued

Theme 1: Sitting in the Driver’s Seat of Follow-up Care	
Subthemes	Essential Quotes
Subtheme 1B: I steer my care	• “Every time I’ve gone, she (dermatologist) cuts on me, she freezes me and I appreciate it and understand that.” • “I actually went to a big skin cancer group down in Georgia and I have seen them um, a few times in the past couple years. There were a couple of others (dermatologists) locally (Tennessee) but I wasn’t super excited about going to them either.” • “I figure it (follow-up) was forever.” • “I go to a (support) group now.” • “I got an appointment and I kept it and then I kept, I keep everyone.” • “I have to force myself to make appointments (dermatologist). Those aren’t appointments that are set up for me, those are appointments I have to make you know.” • “I have to force myself to make those appointments because I know every time I go, at least so far, she cuts on me every time.” • “I just ah, make an appointment ah, when I go you know.” • “I mean it um, ah, it it’s got to start from the, it’s got to start from the patient.” • “I think that ah, you know it’s the patient’s um, responsibility to identify the areas and then seek the, you know, you know, seek the help for, for getting it done.” • “I think the people around me were a little bit more um, in tune or intense, than I was, cause I was like “you know we’ve found it. It’s coming out. It’s a spot,” and my friend’s like “no, you’re a cancer survivor now.” • “I was alternating seeing him (dermatologist) and seeing the oncologist (surgical oncologist) so I was seeing somebody every 6 months.” • “It starts with the patient…” • “My dermatologist checks my skin, extra careful now and I am always asking, ‘what about this?’ and I have had a few more things removed but no cancer, thaaank goodness.” • “My wife has tried to get me to see someone in a bigger city or cancer center but I’m not driving all over to just get my skin looked at, he…my wife can do that (check my skin), you know what I mean?” • “Right now, there are, you know, I’ve got a couple spots that need to get checked.” • “You just don’t cancel.”
Subtheme 1C: Hazards on for help	• “A few times when my husband was so nervous he took me to the doctor’s office without a appointment and the dermatologist worked me in…” • “Another paramedic, she had melanoma too and that was very helpful, I don’t know how but maybe uuh, others out there that have been through it.” • “At the cancer center, well, they have umm, helped me a lot for sure. I have to get to middle Tennessee every time, ahh, and wait for medicine, and have someone drive me home.” • “Friends who had gone through this, who are cancer survivors, so that support was an, an encouragement.” • “I just felt um, pretty scared and alone and so I called my aunt who had breast cancer. She immediately, just linked me in with her surgeon and so before my doctor (dermatologist) pretty much had done anything, I had already kind of started my path within a couple hours after finding out.” • “Everybody’s always been real supportive, rides with me for two hours there ‘cause it’s so boring every 3 months.” • “I was helping my dad and now he helps me.”

Table 4.6. Continued

Theme 1: Sitting in the Driver’s Seat of Follow-up Care	
Subthemes	Essential Quotes
Subtheme 1C: Hazards on for help	• “The good thing is she (my aunt) lives in Kentucky and came to help us after my surgery.” • “Most of my friends understood about the times when…uum… I just wanted to keep to myself.” • “My aunt has been the best help especially my dad too.” • “The social worker helped us stay near-by when I come to town.” • “My good friend asks the church to help when I have to go for appointments.” • “My daughter was like ‘mom’, 'cause it was right after Thanksgiving. She’s like ‘I’m just staying after Thanksgiving. I’m not going back to D.C.’ I’m like “Why, it’s so, it’s I’m gonna be ok.” She’s like “mom, you’re gonna have surgery on your face for cancer, I’m staying.” • “My family, you know are helpful, you could have your arm chopped off and they would say like, “well, buck up.” • “My husband is retired from the service and worked from home with consulting work when I was recuperating, thank goodness.” • “My mom helps me get it (fitted stocking for lymphedema) on.” • “My wife changed the dressings.” • “My wife is ah, kind enough to remind me that I need to use it (sunscreen).” • “My wife, my daughter, wow! My work too, they just said take as much time as you need.” • “Now I’m on disability with some income, um but the first two years I had to keep asking people to bring me.” • “Well my husband has been here the whole time with me.” • My sister lives near-by and she helps too.

Table 4.7. Theme 2 and Subthemes

Theme 2: Living in A Skin World	
Subthemes	Essential Quotes
Subtheme 2A: Melanoma is not a secret	• “Ah, no care. Just been check-ups.” • “There was one that came up on my stomach that hadn’t seen the sun in 20 years.” • “Melanoma is a secret sometimes and I wanted to help with the study. When you hear about skin cancer, it’s about the sun and getting old and all. Melanoma is melanoma it seems when people talk about it.” • “Well, at least it’s not breast cancer!” • “I could have had it done here but I didn’t feel like you know it was the best place to go so I went to the [cancer center].” • “Injection in my lymph nodes and none of that came back cancer.” • “Actually when I went in for my surgery, they were laughing because they were saying ‘you’re one of the healthiest people we’ve ever seen except for that cancer right there’.” • “Man, my mom has diabetes and my dad had melanoma and I got em both.” • “I’ll tell you what has been more helpful has been talking with someone who has had melanoma too.” • “I said ‘no, it’s not just skin cancer, you dumb…’.” • “I was mad, I cried and then I was mad and then I wanted it out of me, out of me.” • “I thought ‘this can kill you’.” • “I didn’t talk about it around the kids.” • “I had a good friend who said ‘oh my god. I’m sorry, what are you gonna’ do? where you gonna go’?” • “Half of it is your heritage; it’s not all the sun.” • “I was afraid to go out.” • “Not sure I have any advice but talk to other people with melanoma.” • “New to me, I thought melanoma was skin cancer, you know, moles and sh…stuff…” • “All you hear about skin cancer is sun, sun, sun… No sun gets back there for sure…” • “Other people with melanoma need to know about other types of it, just wish I had more to say about it, but anyway, maybe this will help…” • “He [PCP] asks if anybody is following me for my melanoma.” • “I guess he had to kind of make a big pork chop out of my back. It was probably like, what you think, maybe 4 or 5 inches wide.” • “There were 2 surgeries but ah, I mean there was no real treatment.” • “My twin sister had melanoma and she was diagnosed about a year before me. I guess that’s why my wife was looking at things a little closer…” • “There was no chemo available that was out there, uh, specifically for melanomas and radiation wasn’t called for, and um, they were just gonna' watch me, I did have uh, and I had one positive lymph node. The second one [recurrence], was just here recently uh, it’s been 29 years.” • “I’ve had no recurrences in 29 years, and then just, um, I noticed a little mole again on my back and it was hard for me to see because it was on my back, but I noticed a mole that I thought looked darker.” • “I knew enough people that I knew I had resources to go to the best places” • “I had the big-wide excision to my leg or rather my thigh and also to my back. The needles to put the dye in to check my lymph nodes in my neck and my groin were very painful if I remember right.”

Table 4.7. Continued

Theme 2: Living in A Skin World	
Subthemes	Essential Quotes
Subtheme 2A: Melanoma is not a secret	• “She [surgical oncologist) took some skin from my thigh which was really painful after surgery, worse than anything.” • “I had a couple of drains that my husband had to help me with” • “It’s been four years now but I get swelling in my left leg all the time now, lymphedema, and wear a stocking every day.” • “I know I’m very fortunate. Had I not gone, I mean I know this is as sure I’m sitting here because I know of what, what kind it was, had I not gone in, I might not have, it might not have been caught before mine metastasized.” • “My aunt had some kind of skin cancer when she was young but nobody mentioned it until after I was diagnosed. I always thought she died of brain cancer.” • “I don’t know anyone with melanoma or at least that has had this, all this kind of surgery, so really just to help someone else maybe…” • “Well you know my mom died of it. Um, ah so it seems like there’s um, ah, there’s history in the family.” • “I knew um, melanoma kills people, that’s what I know.” • “It looks like they just went and took my kidney out and took about 7 inches off my back um, but it, that wasn’t the worst part. The dye tracer that was probably the worst thing that I initially experienced because they can’t give you anything for it and they do um, 4 shots of dye around your cancer spot.” • “The only thing that was kind of the intimidating thing about melanoma is it’s not just like a skin cancer, it’s a system like cancer so it can show anywhere, anytime and so that was a bit um, humbling as well.” • “So knowing and you know when they took the lymph nodes, it could be anywhere in my body beside just that little mole that I’ve had my whole entire life on my back. Um, it was pretty scary.” • “Yeah, he was very clear. He said you know this isn’t something to take lightly. Um, this is something you’ll deal with and ah, take care of the rest of your life.” • “I had a couple moles removed when I was 28 and they weren’t concerned they were cancer, but they were concerned that maybe at some point they could turn. I have had all of them my whole life and I knew that one was my darker one.” • “I called my friend [plastic surgeon], he was on his way to a game and I said ok, I have this is on my face and it’s on my arm and my nose and my forehead, yeah, every place and he said, ‘I’ll see you next Monday’ and I went in he saw it and then I had surgery a week later.” • “I got the cancer plan from my friends.” • “She (my aunt) said she’d talk me off the ledge anytime 'cause she said ‘once you get that word’ she said ‘unless you have had that word, you don’t fully wrap your head around what it means to hear it’.” • “I did start a clinical trial later after the melanoma came back. I was real sick from the medication and they had to stop it.” • “It’s very scary is what it is in retrospect.” • “After they took the lymph nodes under my arm, umm, more cancer came back to my arm above this scar, then I had radiation, too.” • “It did influence me though to go into medicine I will say.” • Something that I think made me realize how fortunate I am because I had a plastic surgeon friend, because I was able to kind of get to the front of the line, because I met with him the next week and he scheduled surgery the next week, I had the surgery, had the recovery, had already gone back for my follow-up with dermatology and then received a call from the office of the plastic surgeon that they normally do work with.”

Table 4.7. Continued

Theme 2: Living in A Skin World	
Subthemes	Essential Quotes
Subtheme 2A: Melanoma is not a secret	• “The surgery, they went, they went, as far as, clear margins which resulted in a lot more, which was a lot more um, invasive than I thought it was gonna be. I have a whole new nose it’s a totally different shape now.” • “It’s important to follow-up because you just never know…” • “If I had quit following up, then I’d have a metastatic melanoma and I might, may not be here now.” • “After I called and talked to you about the interview, I realized I could help someone maybe think about melanoma more and take it serious.” • “Follow-up is important and can keep you from dying, ahh, that simple really.” • “Whenever I do hear a story about melanoma, it’s usually not good. It’s usually a very bad story and that’s very scary to me but it’s also scary to me for people who will never go to a dermatologist or whose primary care physician will never look at their skin.” • “People need to talk more about it [melanoma].” • “So, finally my wife got me a appointment with a doctor at the cancer center because it was the bad kind of skin cancer, that’s where they told my wife I needed to go, to see the melanoma specialist.” • “It was a while before I could have the surgery because the place on my thigh just would not heal, took forever, my wife had to pack it and change all that and she does not like blood or anything like that, she was a trooper for sure. That took several months and then I went for the lymph node surgery in my groin area and that would not heal either.” • “Nothing showed up on there but degenerative disc disease in my back and my wife saw x-rays of my brain so we had a good laugh about that…” • “Well you know my mom died of it [melanoma]. Um, ah so it seems like there’s um, ah, there’s history in the family.” • “I didn’t really say anything to my friends or people at work, not really the thing to do.”
Subtheme 2B: Call it cancer	• “Yeah and the last time I went, oh my gosh in September, I had some spots ah, just, I thought it was chapped lips.” • “I did not have any melanoma in my lymph nodes.” • “I wanted to go but scared it was skin cancer, you know from the sun.” • “I had to go to part time work but I was off for 7 months all together. • “I have a lot of numbness to this area on my thigh that bothers me sometimes. You know you think a numb area would not hurt but yes it does.” • “So anyone who would look at a part, yeah, I’m at least half naked, if not fully.” • “It always jogs my memory, it always does because when you fill out any history and they say ‘have you, have you had cancer’ and I have to remind myself to check ‘yes’.” • “I look at you know this little bit of skin cancer on the skin, I don’t call that melanoma.” • “I was told to check my lymph nodes in between visits.” • “The spot looked just this. It looked no different than that. It didn’t have any of the markers. It wasn’t rough. It wasn’t um, odd shaped. It wasn’t… but I mean it looked like an age spot.” • “I did see a medical oncologist after the surgery and I go back once a year for follow-up. I get x-rays sometimes and blood work to look for cancer.” • “Work gave me time off, I sell real estate, and I had to cut back. I just did not have the stamina to work the hours that I was.”

Table 4.7. Continued

Theme 2: Living in A Skin World	
Subthemes	Essential Quotes
Subtheme 2B: Call it cancer	• “The clothes I wear are completely different. I wore skirts and sleeveless shirts in summer and not anymore.” • “I check my skin, my husband checks my skin, I even ask Mary and Molly if they see anything (loud laughter)…those are my fur babies…” • “High blood pressure is the main one and I have some arthritis in my hands, I am pretty healthy except for all this with the melanoma.” • “I told my gynecologist about the melanoma. She has done surgery for the endometriosis since I had this all done (pause)…She took biopsies but no signs of any cancer.” • “I had to have some physical therapy with my leg and they were soo great, they really helped me with the stiffness and all the tightness every time I walked, I do exercises that help too.” • “I never thought about, ‘you should tell your gynecologist so that when they do your pap smear, they can look for spots on your cervix’.” • Yes, um I did share it with my dentist and so he does track when he does my exams. He looks for spots. • “Well and it’s interesting too because I um, I don’t call it that. I don’t call it melanoma. I will say ‘oh yeah, I had something removed…’ Someone will say ‘oh, I went to the dermatologist and oh my gosh, I had this spot removed’ and I’ll say yes, when I went, oh my gosh, I found out I had to have all these things removed. I don’t, I don’t really say I had melanoma. .. I’ll say well, it turned out I had skin cancer.” • “I just thought it was gonna be a little mole.”
Subtheme 2C: Defer to dermatology	• “Now I’m much more aware of my skin.” • “Anything that looks funny, we biopsy immediately.” • “She just wanted to take em [abnormal looking moles] off.” • “I knew they’d have to be cut off.” • “My dermatologist checks me” • “I said this is not the photoshoot that I was looking forward to.” • “I got an appointment and I kept it and then I kept, I keep everyone.” • “The dermatologist let me know about follow-up, I then had a sense that this is gonna be the rest of my life, whether it’s semi-annually or annually.” • “My friend who’s a cancer survivor ironically, so here’s the thing I go and do this [get a skin assessment with the dermatologist] and then she made her husband go cause she’s like ‘you know what, that spot looks like hers’. Turned out he had the same thing.” • Seen different ones [dermatologist] over the years. • “It’s just like any other office visit. It’s not a special like whoa, you get the special VIP treatment, um, you know. It’s go and sit in the waiting room for hours on end.” • “You might as well block out your day. I mean, it, it doesn’t matter what time of day I’m there [dermatology], it seems like if I go for a 9 a.m. appointment, I’m finally out by 1:30.” • “She’ll [primary care] say something like, so are you going back to see the dermatologist? I mean she’ll kind of do a inquiry about follow-up.” • “I’ll go in and, and the first thing I’ll say is ‘now, I have something new….’ She said, stop. Do not tell me what you’re worried about. Let me do the full body look and I’ll tell what I’m worried about. I’m like ‘ok’. And then when she’s all done, she’ll say ‘now, I’m not worried about anything but you show me what you’re worried about.” • “Typically, I think when people think about melanoma, they think about a dermatologist.”

Table 4.7. Continued

Theme 2: Living in A Skin World	
Subthemes	Essential Quotes
Subtheme 2C: Defer to dermatology	• "Ahh, it took a long time to get me to get that surgery. I had to drive all over to just get a biopsy. The biopsy results took forever…too." • "Well, that did come up a few times [needing to see someone when a new area came up] and it did take a while to get it checked out. Between my work and dermatologist appointments backed up, it did take about 2-3 weeks each time." • "I told my primary doctor about the melanoma, other than the dermatologist, that's all I see." • "See the dermatologist every year. I did have another place show up but it was a different kind of cancer and he cut it out." • "No, they (dermatology office) take me in just to wait you know, wait on late people." • "The biopsy was done by the dermatologist." • "Well, the dermatologist looks at my arms and face and asks if I have any problems, stuff like that." • "I had a mole on my back and I went to see the dermatologist." • "I got a voicemail about 2 or 3 weeks later and the voicemail said that I had melanoma and would be referred to a [surgical] oncologist." • "You have to schedule a new patient appointment and it takes 8 months to get in." • "I just religiously go to him."

Table 4.8. Theme 3 and Subthemes

Theme 3: Once Bitten, Twice Shy	
Subthemes	Essential Quotes
Subtheme 3A: Waiting is not an option	• I could not deal with it…at the time. I stayed away for three months I think and then went back. • I didn't look at it too closely • I've had this mole my whole entire life • it looked totally normal • I think that over time, I've definitely gotten a little more lax • If I had quit following up, then I'd have metastatic melanoma • Whenever I do hear a story about melanoma, it's usually not good • It was the bad kind of skin cancer • Size was on the thicker side • Melanoma is in my lymph nodes • I waited too long after my surgery so it come back again. • Never been to dermatologist, never had a baseline screening, na, never had done anything • It looked no different than that. It didn't have any of the markers. • "Wow, if hadn't…" • Went to see the surgeon to cut it out. • I wanted to go but scared it was skin cancer • Don't wait, don't wait, I might have waited too long, maybe
Subtheme 3B: Everything looks like melanoma	• Yes, I could not believe it. Of all the things to be told that, you have melanoma • Oh my gosh this is serious, you know, cause I just thought it was gonna be a little mole. • I wanted to go but scared it was skin cancer • Anything that looks funny, we biopsy immediately. • I have had these moles forever and no one ever told me to get them removed, well except the one on my leg, I didn't remember it at all, umm, no I don't remember seeing it. • Had a few times when my husband was so nervous he took me to the office without a appointment • It did take about 2-3 weeks each time. • I have all of them my whole life and I knew that one was my darker one. • They look at my skin and feel it, check my lymph nodes • Follow-up is important and can keep you from dying • They saw something new on the chest x-ray and that started this ball rolling. • Good luck," getting a, an appointment • It's the patient's um, responsibility to identify the areas • At the end of that appointment, she had taken 12 biopsies, done 6 freezes • They took about an ice cream scoops worth of flesh out of my arm

Table 4.8. Continued

Theme 3: Once Bitten, Twice Shy	
Subthemes	Essential Quotes
Subtheme 3B: Everything looks like melanoma	• The path for this melanoma sometimes is um, to the lungs The revisits to (tapping) ah, the dermatologist and she cuts on me every time • I had some spots ah, it just I thought it was chapped lips • I've had two episodes of melanoma • I've had several biopsies since then • Anything that looks funny, we biopsy immediately. • Everybody's awful ah, hypersensitive about my moles. • It's just opening Pandora's box. • He'll see me the next day and cut it off • They wanted to do some genetics or genetic testing on my sister and me but when they found out we were adopted, we uum didn't qualify.
Subtheme 3C: Sources of strength	• It happened to me • I just felt um, pretty scared and alone • It's very scary is what it is in retrospect • I know a plastic surgeon who can," you know so, so I wasn't scared or worried • This experience is well…can, ahh change things, it did for me. • "I need something to calm me down." • I would need to be watched like a hawk. • I don't know anyone with melanoma • My faith has been a constant. My friends have prayed, I prayed, my husband has prayed…double • Felt um, pretty scared and alone • Melanoma kills people, that's what I know. • It continued um, my relationship with God a lot um, and so I just, I don't see it as a bad thing. • My daughter said she was scared • Took a while to get my mind cleared up after the Interferon. I cannot run like I did • I can honestly say that melanoma was the last thing I thought I needed to worry about • Talk to other people with melanoma. • She died from it • I guess I was more disappointed because I thought it was over • It wasn't a death sentence at this point • I hope I don't die • There's nothing anybody can do…just look at them • I thought melanoma was skin cancer… found melanoma in my lymph nodes • Just did not want to hear that. • I still have swelling in my leg, never goes down… • It made me real sick and more nervous • I have pain sometimes and get pills • Have someone drive me home • I go crazy worryin' about all this • Starting to have some female problems • I still wear my cover over my scar • Other people need to know about, about this…melanoma

Table 4.9. Theme 4 and Subthemes

<table>
<tr><th colspan="2">Theme 4: Watch Me like a Hawk</th></tr>
<tr><th>Subthemes</th><th>Essential Quotes</th></tr>
<tr><td>Subtheme 4A: Follow-up visits</td><td>• It looks a little abnormal, so we’re gonna biopsy it and so he did and it came back as melanoma
• Well, we’d rather go to an oncologist 'cause it seems like they know more about cancer.
• Yeah, we’re taking care of those six right now.
• You should tell your gynecologist so that when they do your pap smear, they can look for spots on your cervix.
• I just hadn’t heard any great things about any, ar any dermatologists around here at the time
• He (surgical oncologist) set me up for surgery which I had two weeks later.
• He (photo dermatologist) thinks I have malignant nevus syndrome and so he tells me to stay out of the sun as much as I can but it’s probably gonna' come back.
• I don’t want to see another surgeon, she [surgical oncologist] knows me so we go see her there (4 hours round trip).
• She said [dermatologist] I’m 60% not concerned and I thought that was really interesting, instead of saying I’m 40% concerned.
• Anytime I see the dermatologist or my surgeon [surgical oncologist], I just ask is there anything you want to cut off.
• If I text, like when I texted this week and I had something else show up that I found um, he just said come in on Monday.
• Follow-up is important and can keep you from dying.
• You know if you see something, go get it checked out.
• We’re gonna’ take care of it and it’s gonna’ be done.
• He’s older and he [photo dermatologist] has told me that probably if something happens to him, that he, you know, he will have a plan for his high-risk people. Um, I, ah, I feel better, I, I trust him.
• I had some spots ah, it just, I thought it was chapped lips.
• I know surgeons better than he does.
• Well give me whatever you take.
• I could have had it done here [locally] but I didn’t feel like, you know, it was the best place.
• He’s the works.
• I’ve been going there probably at least 5 years every 6 months.
• He (photo dermatologist) compares them every time.
• He looks me over and chops things off here and there.
• Prepared me for the worst but hoped for the best.
• I get x-rays sometimes and blood work to look for cancer.
• I would need to be watched like a hawk.
• My dermatologist checks my skin, extra careful now and I am always asking, what about this and I have had a few more things removed but no cancer, thaaank goodness.
• He’s an oncology surgeon so he’s my follow-up
• I see the dermatologist or my surgeon (surgical oncologist); I just say is there anything you want to cut off?
• When she does my lab work, they do um, a blood test to look for tumors.
• I said well what about that one and they (doctors in general) would say it looks fine. So now, when they say it looks fine for now, I don’t like that word. I’m like if you think it could turn, take it now. I don’t want it to turn again.</td></tr>
</table>

Table 4.9. Continued

Theme 4: Watch Me like a Hawk	
Subthemes	Essential Quotes
Subtheme 4A: Follow-up visits	• We found out about him (surgical oncologist), and he went and we loved him from the first time so we just kept going back to him. • The surgeon (surgical oncologist) said I would need to follow-up with him and dermatology. The [medical oncologist] checks my x-rays and blood work, not sure how long, uum so far I'm still here and want to keep it that way. • Not much, just asked me who follows me for melanoma and how often. He was going to get the records. • The dermatologist checks my skin, asks if anything new has shown up.
Subtheme 4B: Reassurance offered	• Actually they took it out (melanoma) and ah, then they had to redo it because they didn't take out enough the first time [needed wider margins] • Surgeon told me he was gonna' take care of it so I thought ok, he's gonna' take care of it. • He's the works • They did scans and could see that it didn't spread anywhere so that was a good thing. • They [surgical oncologist] were highly efficient. They had me in the office in about 3 days. Um, when I saw him the first day, then um, I had an educational video that was very scary, but he came in and he looked at it and he felt very confident that um, he could take care of it and I would be ok and that's really what I wanted to know. • Very well known and I've got a lot of respect for him, I really, I really… think he did me good. • Yeah, he (surgical oncologist) just immediately um, he was just amazing. I mean very um, caring, very um, personable and was very reassuring and wanted to make sure at every step of the way that I knew exactly what he was doing and what he was saying and so he clarified, clarified, clarified. • Yeah, I can't actually imagine not going to see him (surgical oncologist), because I actually feel like when I'm seeing him, I don't have cancer • I went in and saw him [plastic surgery friend] on Monday and then I had surgery two weeks later. • I'll see you next Monday and I went in saw him [plastic surgeon friend] the next Monday and then I had surgery two weeks later. • She (surgical oncologist) specifically said I would need to be watched like a hawk. • The ideal plan is I'm supposed to try to scatter my doctors so that they are throughout, so that I'm technically being seen around the year, so as much as I can do that with the insurance allowing, I do. • The surgeon (surgical oncologist that removed the melanoma) said, do not take her to the Emergency Room, please bring her to the office in the morning. • She [her aunt] just linked me in with her surgeon and so before my doctor pretty much had done anything, I had already kind of started my path within a couple hours. • I mean the doctor's amazing, seriously. Um, if I text, like when I texted this week and I had something else that I found um, he just said come in Monday • My doctor was very clear that I will always be a cancer patient. • I had the surgery, had the recovery, had already gone back for my follow-up with her [dermatology PA) and then received a call from the office of the plastic surgeon that they normally do work with. • I had to go to the cancer center to get everything. I didn't have any way to get anything. Medicine and stuff they helped me with it all. • So it was very reassuring and um, empowering cause I, it, it ah, I didn't feel like oh, I don't know what this is or what does this mean

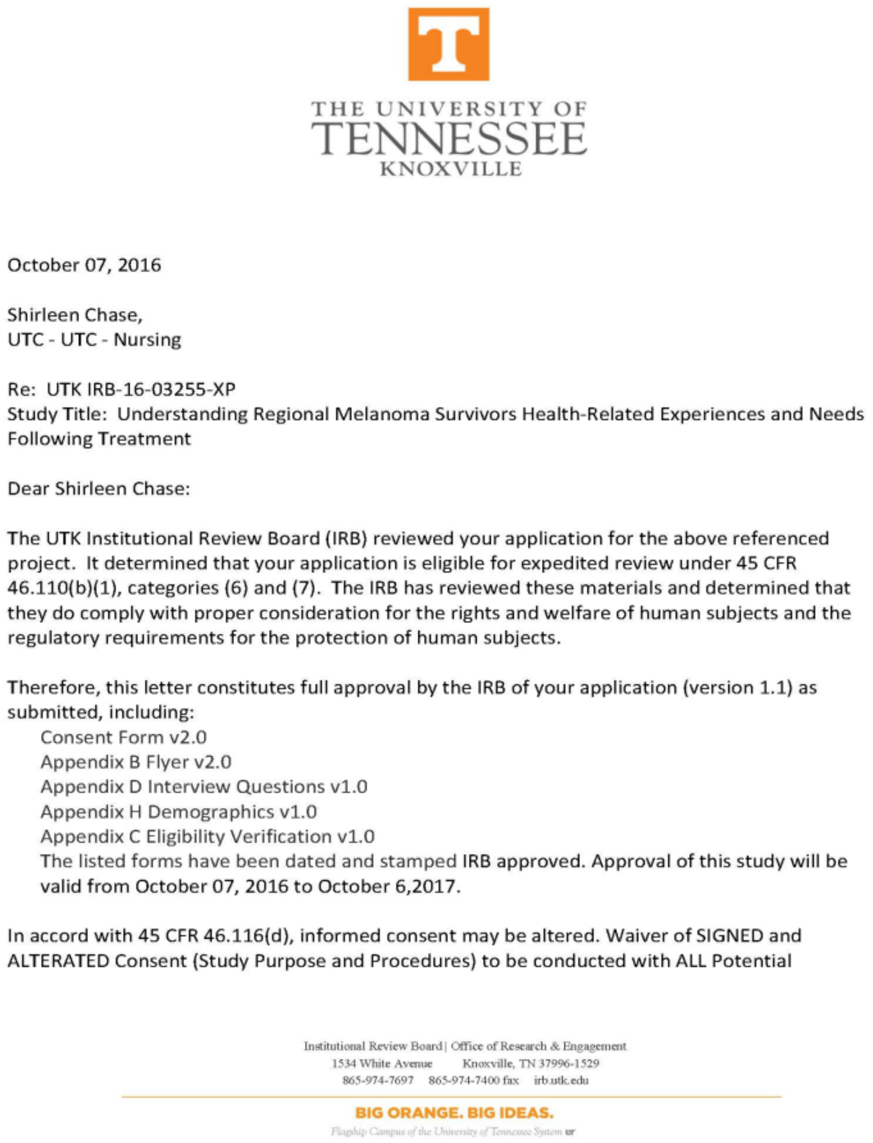
Table 4.9. Continued

Theme 4: Watch Me like a Hawk	
Subthemes	Essential Quotes
Subtheme 4B: Reassurance offered	• So she [dermatologist] gave me information and the option rather than just this is what we are going to do and did it in person. I like better than over the phone. After she scheduled the appointment…I called my sister I'm like, it was really great she scheduled an appointment the same week to come back.... • I felt I could be in charge of, of how I was gonna handle and it never, it quite frankly, naively never occurred to me that I wouldn't be in charge of how I handled it but if I'd been waiting for somebody to call me for weeks on end and not hearing anything and wondering you know when am I gonna get this taken care of, I think I would have felt really different. • I felt very comfortable that I had good um, clinician's diag ah, diagnosis, good doctors. • I wasn't sitting around for 6 weeks waiting for somebody's office to call me to schedule a consult to talk about the surgery we might be having in the future. • I was safe with that because I knew that if he did it, he would do it like a melanoma cut and I would never have to worry about that spot. • I mean the doctor's amazing, seriously. • She was very nice and prepared me for the worst but hoped for the best. • It's not she's so, so happy to cut into to me but it's just so I know every time I go, I'm gonna' have sti, stitches. • I just felt safe with that. • They ah, referred me to another dermatologist. He's a photo dermatologist. • He looks me over and chops things off here and there but there hadn't been any more melanoma. • Once they know that I'm going to somebody, they don't really touch on it. • I tell the eye doctor too. • Oh, I have endometriosis too I forgot, I told my gynecologist about the melanoma. She has done surgery for the endometriosis since I had this all done…She took biopsies but no signs of any cancer. • So because I have melanoma, they um, check my eye so I have eye people. I have a freckle on my eye and it's never changed or anything like that. • My primary care just asked me who follows me for melanoma and how often. He was going to get the records. Meantime, my knee settled down after I took a week of steroid pills to get the swelling down. I go back to see him in three months. • All the other people are very hypersensitive to it and always want me to ah, have all these tests done. • I feel like he's been the, the most supportive and anytime I've ever called him and said oh this thing started bleeding on my face, he'll see me the next day and cut it off. • No but my primary doctor asks if I have had any swelling or anything. • My [dermatologist] is very informative. • It's no big deal. We're gonna' take care of it and it's gonna' be done. • Um, but yeah, I still don't really think of it and it's funny, I don't really think of it as cancer like breast cancer or like my dad has lung cancer now. • The cancer doctor and cancer surgeon were…helped me…talked to me. The nurses and folks were always nice and called me back. • I think it made me realize how fortunate I am because I had a plastic surgeon friend, because I was able to kind of get to the front of the line. • I was going to have the surgery to take more nodes but my x-rays showed the melanoma somewhere else.

Table 4.9. Continued

Theme 4: Watch Me like a Hawk	
Subthemes	Essential Quotes
Subtheme 4C: Uncertain times	• I was referred to an [medical] oncologist. Um, uh, and he recommended just, he said there was no chemo available that was out there, uh, specifically for melanoma and radiation wasn't call for, and um, they were just gonna watch me. • It looks a little abnormal, so we're gonna biopsy it and so he did and it came back as melanoma • Well, we'd rather go to an oncologist 'cause it seems like they know more about cancer. • Yeah, we're taking care of those six right now. • You should tell your gynecologist so that when they do your pap smear, they can look for spots on your cervix. • I just hadn't heard any great things about any, ar any dermatologists around here at the time • I remembered the doctor referred me to, uh, another person that had a melanoma removed, and she was about my age, and I just, met her briefly but she was, uh, very encouraging and, and just made me feel better about myself, you know, that hopefully my life was gonna go on, and things were gonna be okay, um, it wasn't a death sentence at this point so, so I appreciated him doing that, he got me in touch with her. • My doctor [surgical oncologist] was very clear that I will always be a cancer patient. • Anytime I see the dermatologist or my surgeon [surgical oncologist], I just ask is there anything you want to cut off. • If I text, like when I texted this week and I had something else show up that I found um, he just said come in on Monday. • I could have had it done here [locally] but I didn't feel like, you know, it was the best place. • He's the works. • I've been going there probably at least 5 years every 6 months. • He (photo dermatologist) compares them every time. • I mean very um, caring, very um, personable and was very reassuring and wanted to make sure at every step of the way that I knew exactly what he was doing and what he was saying and so he clarified, clarified, clarified. • When she does my lab work, they do um, a blood test to look for tumors. • Not much, just asked me who follows me for melanoma and how often. He was going to get the records. • The dermatologist checks my skin, asks if anything new has shown up. • I was just getting to know where I was about every 6 months then I had something else come up last year and it was precancerous and so he [surgical oncologist] took it off versus my dermatologist just because I asked him what he preferred and he said that he would prefer to remove it and I was safe with that because I knew that if he did it, he would do it like a melanoma cut and I would never have to worry about that spot.

Appendix B1



THE UNIVERSITY OF
TENNESSEE
KNOXVILLE

October 07, 2016

Shirleen Chase,
UTC - UTC - Nursing

Re: UTK IRB-16-03255-XP
Study Title: Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

Dear Shirleen Chase:

The UTK Institutional Review Board (IRB) reviewed your application for the above referenced project. It determined that your application is eligible for expedited review under 45 CFR 46.110(b)(1), categories (6) and (7). The IRB has reviewed these materials and determined that they do comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects.

Therefore, this letter constitutes full approval by the IRB of your application (version 1.1) as submitted, including:

Consent Form v2.0
Appendix B Flyer v2.0
Appendix D Interview Questions v1.0
Appendix H Demographics v1.0
Appendix C Eligibility Verification v1.0
The listed forms have been dated and stamped IRB approved. Approval of this study will be valid from October 07, 2016 to October 6,2017.

In accord with 45 CFR 46.116(d), informed consent may be altered. Waiver of SIGNED and ALTERATED Consent (Study Purpose and Procedures) to be conducted with ALL Potential

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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Participants for Eligibility Screening Activities as noted in the PI Review Response Form (v 2.0) for Consent Waiver.

In the event that subjects are to be recruited using solicitation materials, such as brochures, posters, web-based advertisements, etc., these materials must receive prior approval of the IRB. Any revisions in the approved application must also be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

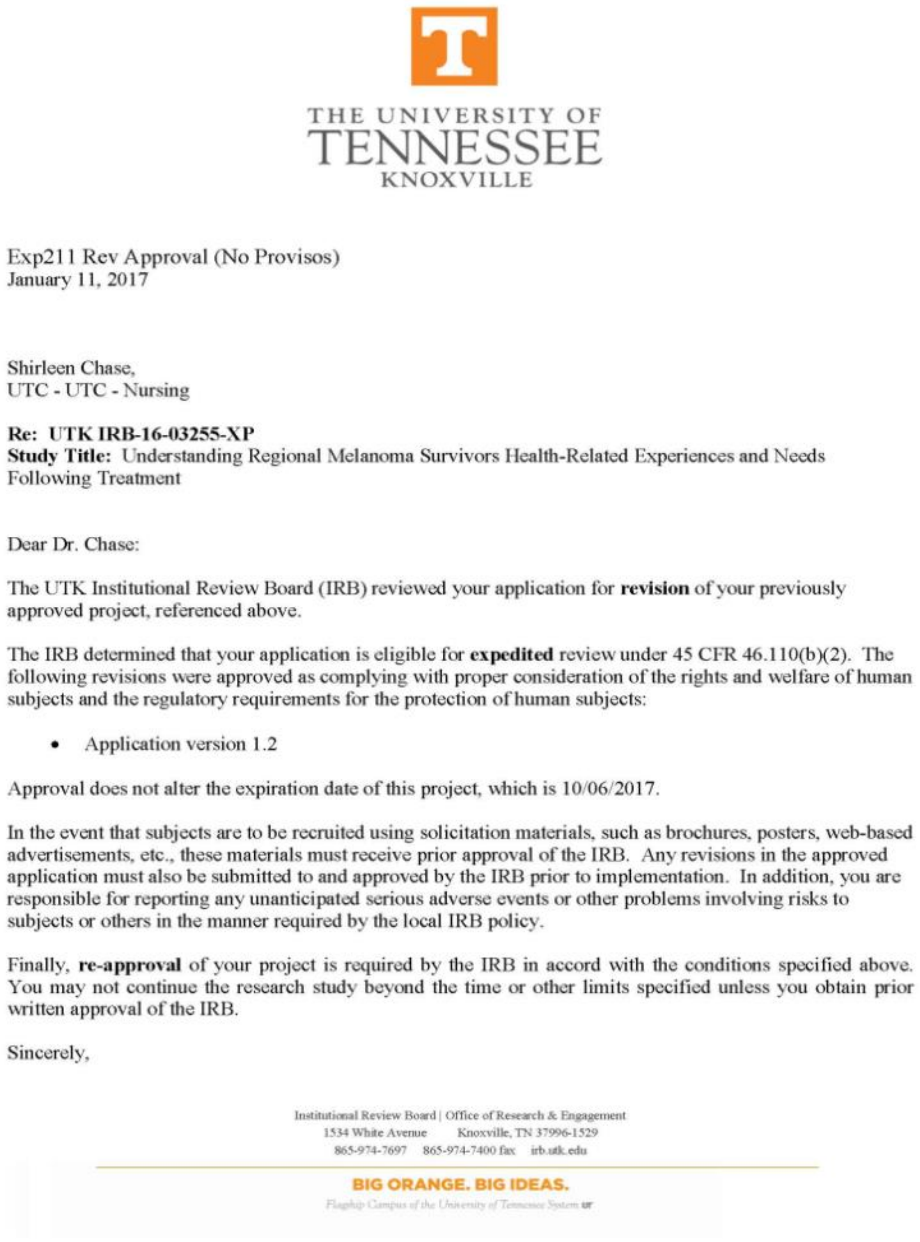
Finally, re-approval of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,

Colleen P. Gilrane

Colleen P. Gilrane, Ph.D.
Chair

Appendix B2



THE UNIVERSITY OF
TENNESSEE
KNOXVILLE

Exp211 Rev Approval (No Provisos)
January 11, 2017

Shirleen Chase,
UTC - UTC - Nursing

Re: UTK IRB-16-03255-XP
Study Title: Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

Dear Dr. Chase:

The UTK Institutional Review Board (IRB) reviewed your application for **revision** of your previously approved project, referenced above.

The IRB determined that your application is eligible for **expedited** review under 45 CFR 46.110(b)(2). The following revisions were approved as complying with proper consideration of the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects:

- Application version 1.2

Approval does not alter the expiration date of this project, which is 10/06/2017.

In the event that subjects are to be recruited using solicitation materials, such as brochures, posters, web-based advertisements, etc., these materials must receive prior approval of the IRB. Any revisions in the approved application must also be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

Finally, **re-approval** of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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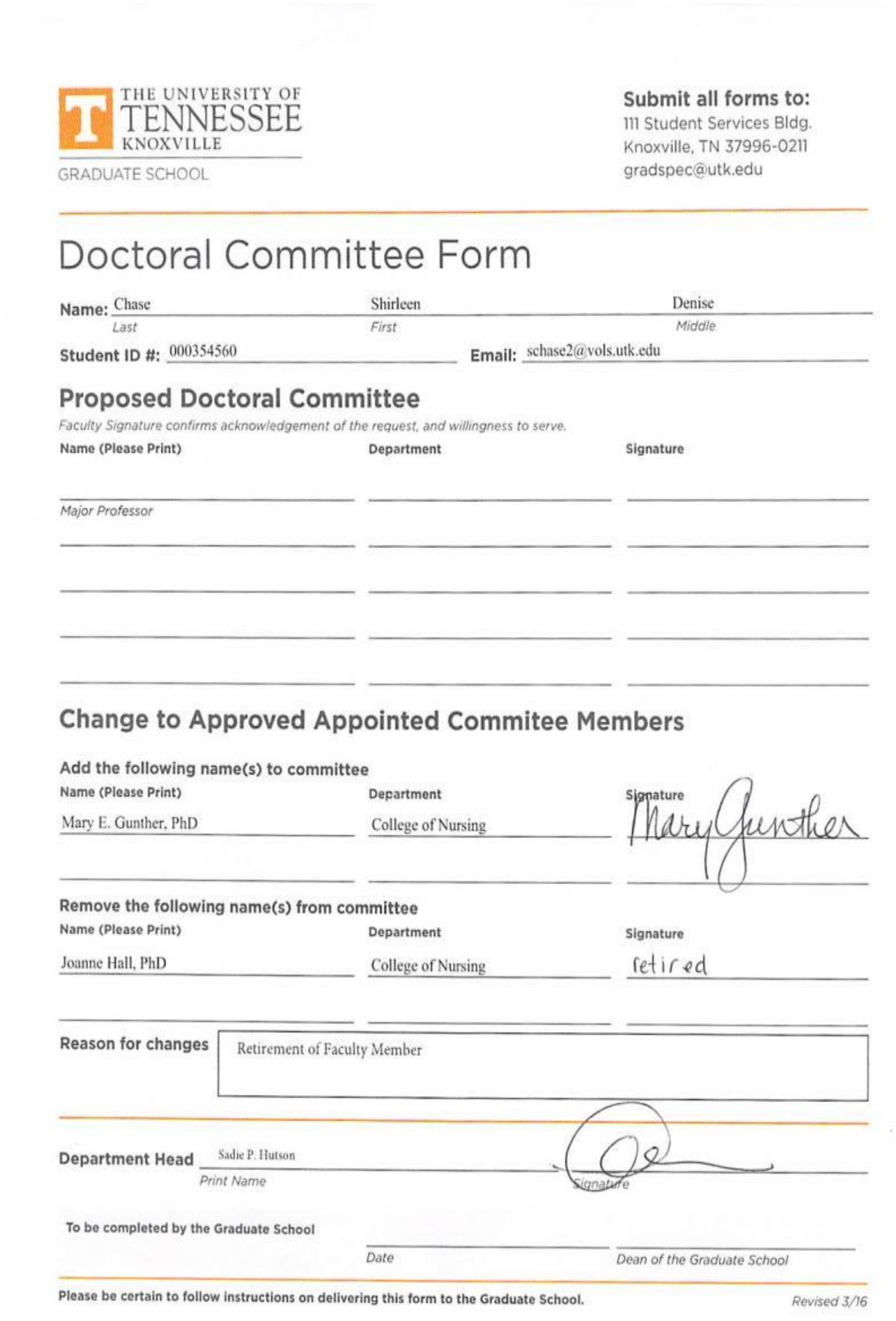
Colleen P. Gilrane

Colleen P. Gilrane, Ph.D.
Chair

Appendix B3



THE UNIVERSITY OF
TENNESSEE
KNOXVILLE
GRADUATE SCHOOL

Submit all forms to:
111 Student Services Bldg.
Knoxville, TN 37996-0211
gradspec@utk.edu

Doctoral Committee Form

Name: Chase (*Last*) Shirleen (*First*) Denise (*Middle*)

Student ID #: 000354560 **Email:** schase2@vols.utk.edu

Proposed Doctoral Committee

Faculty Signature confirms acknowledgement of the request, and willingness to serve.

Name (Please Print)	Department	Signature
Major Professor		

Change to Approved Appointed Commitee Members

Add the following name(s) to committee

Name (Please Print)	Department	Signature
Mary E. Gunther, PhD	College of Nursing	Mary Gunther

Remove the following name(s) from committee

Name (Please Print)	Department	Signature
Joanne Hall, PhD	College of Nursing	retired

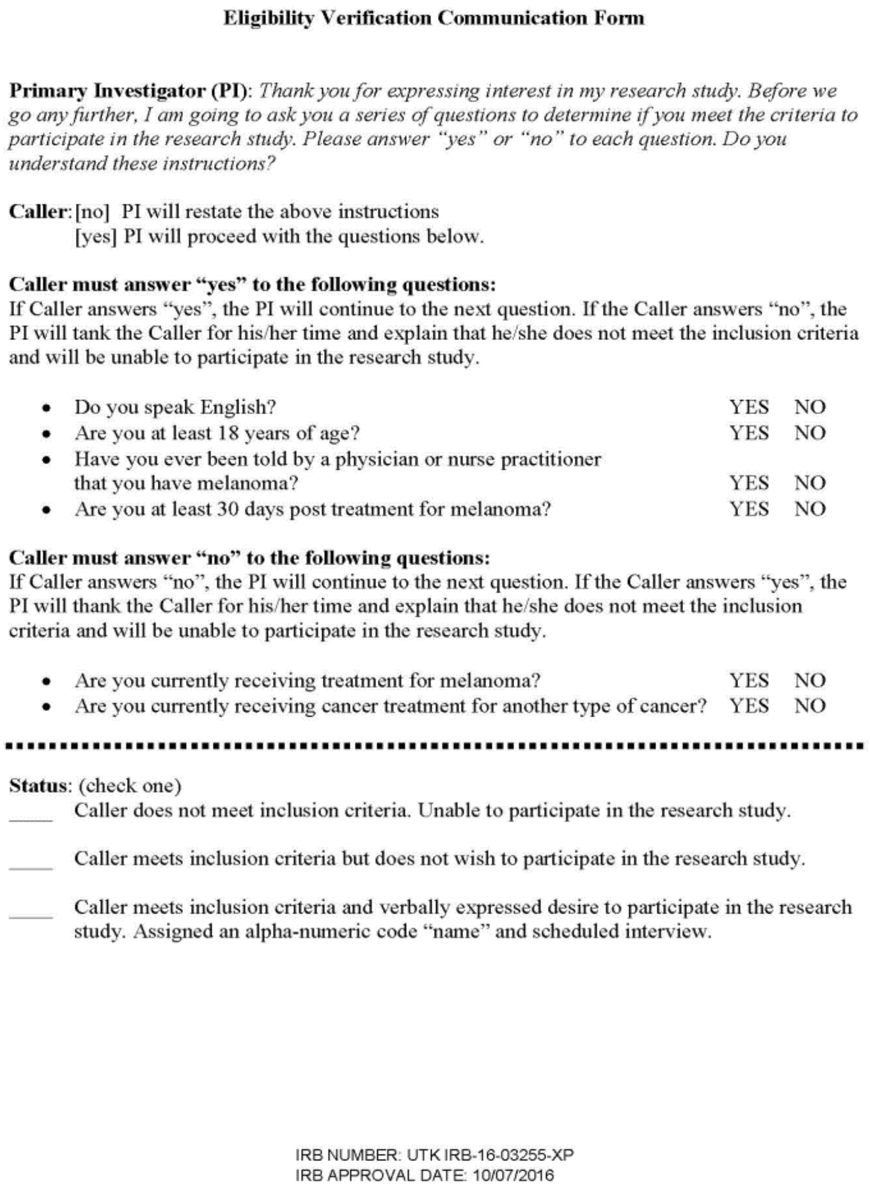
Reason for changes Retirement of Faculty Member

Department Head Sadie P. Hutson (*Print Name*) *Signature*

To be completed by the Graduate School *Date* *Dean of the Graduate School*

Please be certain to follow instructions on delivering this form to the Graduate School. *Revised 3/16*

Appendix C1



Eligibility Verification Communication Form

Primary Investigator (PI): *Thank you for expressing interest in my research study. Before we go any further, I am going to ask you a series of questions to determine if you meet the criteria to participate in the research study. Please answer "yes" or "no" to each question. Do you understand these instructions?*

Caller: [no] PI will restate the above instructions
[yes] PI will proceed with the questions below.

Caller must answer "yes" to the following questions:
If Caller answers "yes", the PI will continue to the next question. If the Caller answers "no", the PI will tank the Caller for his/her time and explain that he/she does not meet the inclusion criteria and will be unable to participate in the research study.

- Do you speak English? YES NO
- Are you at least 18 years of age? YES NO
- Have you ever been told by a physician or nurse practitioner that you have melanoma? YES NO
- Are you at least 30 days post treatment for melanoma? YES NO

Caller must answer "no" to the following questions:
If Caller answers "no", the PI will continue to the next question. If the Caller answers "yes", the PI will thank the Caller for his/her time and explain that he/she does not meet the inclusion criteria and will be unable to participate in the research study.

- Are you currently receiving treatment for melanoma? YES NO
- Are you currently receiving cancer treatment for another type of cancer? YES NO

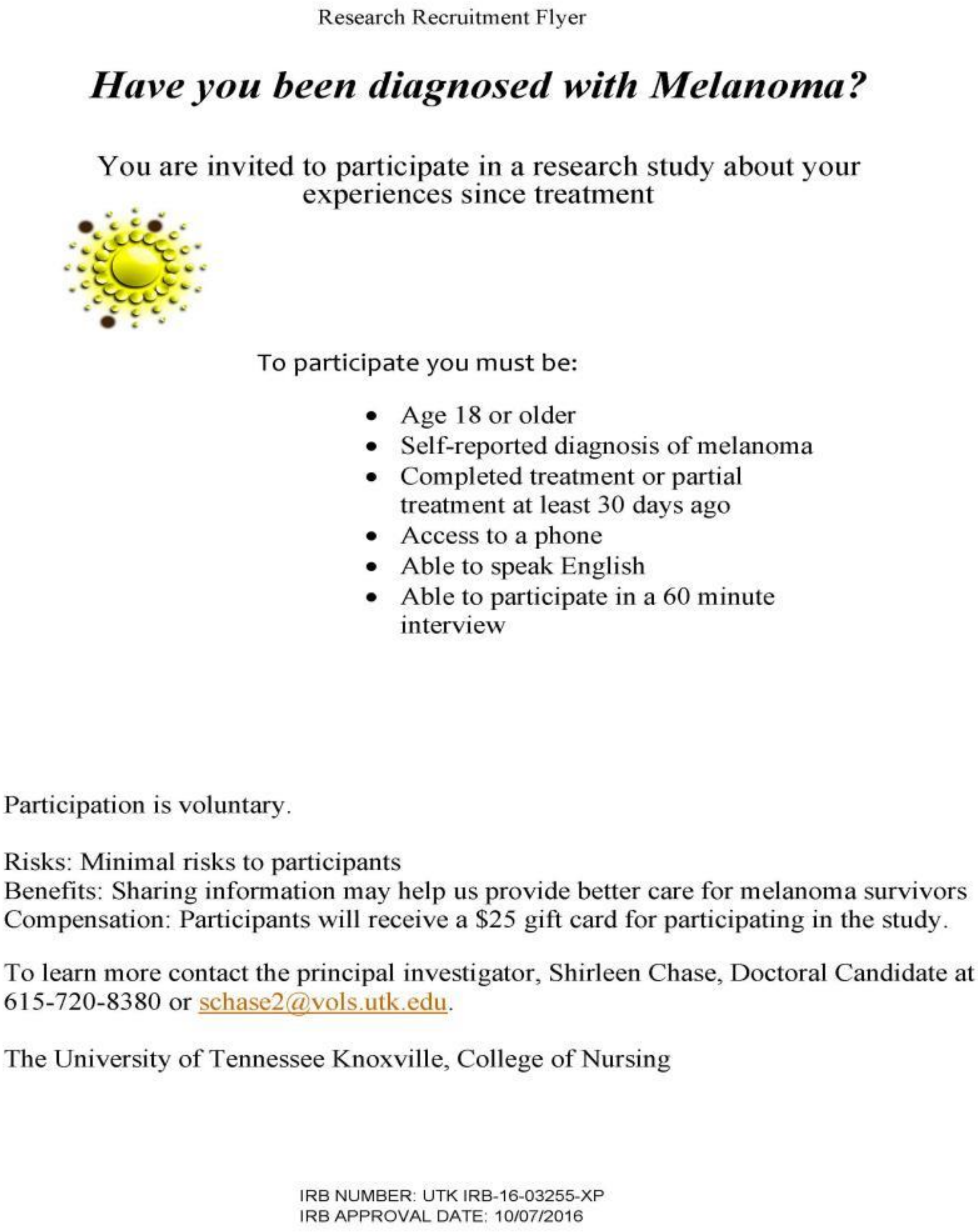
Status: (check one)
____ Caller does not meet inclusion criteria. Unable to participate in the research study.

____ Caller meets inclusion criteria but does not wish to participate in the research study.

____ Caller meets inclusion criteria and verbally expressed desire to participate in the research study. Assigned an alpha-numeric code "name" and scheduled interview.

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016

Appendix C2



Research Recruitment Flyer

Have you been diagnosed with Melanoma?

You are invited to participate in a research study about your experiences since treatment

To participate you must be:

- Age 18 or older
- Self-reported diagnosis of melanoma
- Completed treatment or partial treatment at least 30 days ago
- Access to a phone
- Able to speak English
- Able to participate in a 60 minute interview

Participation is voluntary.

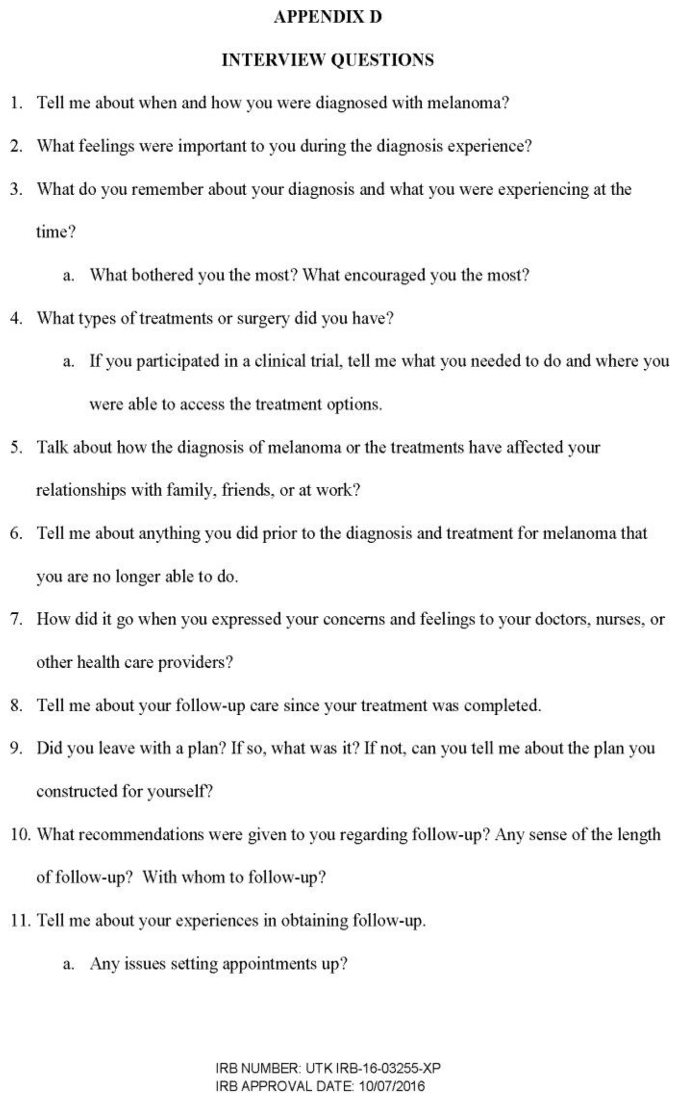
Risks: Minimal risks to participants
Benefits: Sharing information may help us provide better care for melanoma survivors
Compensation: Participants will receive a $25 gift card for participating in the study.

To learn more contact the principal investigator, Shirleen Chase, Doctoral Candidate at 615-720-8380 or schase2@vols.utk.edu.

The University of Tennessee Knoxville, College of Nursing

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016

Appendix D



APPENDIX D

INTERVIEW QUESTIONS

1. Tell me about when and how you were diagnosed with melanoma?
2. What feelings were important to you during the diagnosis experience?
3. What do you remember about your diagnosis and what you were experiencing at the time?
    a. What bothered you the most? What encouraged you the most?
4. What types of treatments or surgery did you have?
    a. If you participated in a clinical trial, tell me what you needed to do and where you were able to access the treatment options.
5. Talk about how the diagnosis of melanoma or the treatments have affected your relationships with family, friends, or at work?
6. Tell me about anything you did prior to the diagnosis and treatment for melanoma that you are no longer able to do.
7. How did it go when you expressed your concerns and feelings to your doctors, nurses, or other health care providers?
8. Tell me about your follow-up care since your treatment was completed.
9. Did you leave with a plan? If so, what was it? If not, can you tell me about the plan you constructed for yourself?
10. What recommendations were given to you regarding follow-up? Any sense of the length of follow-up? With whom to follow-up?
11. Tell me about your experiences in obtaining follow-up.
    a. Any issues setting appointments up?

IRB NUMBER: UTK IRB-16-03255-XP
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    - b. Getting to and from visits
    - c. Paying for medications related to melanoma?
    - d. Office visit payments or co-pays?

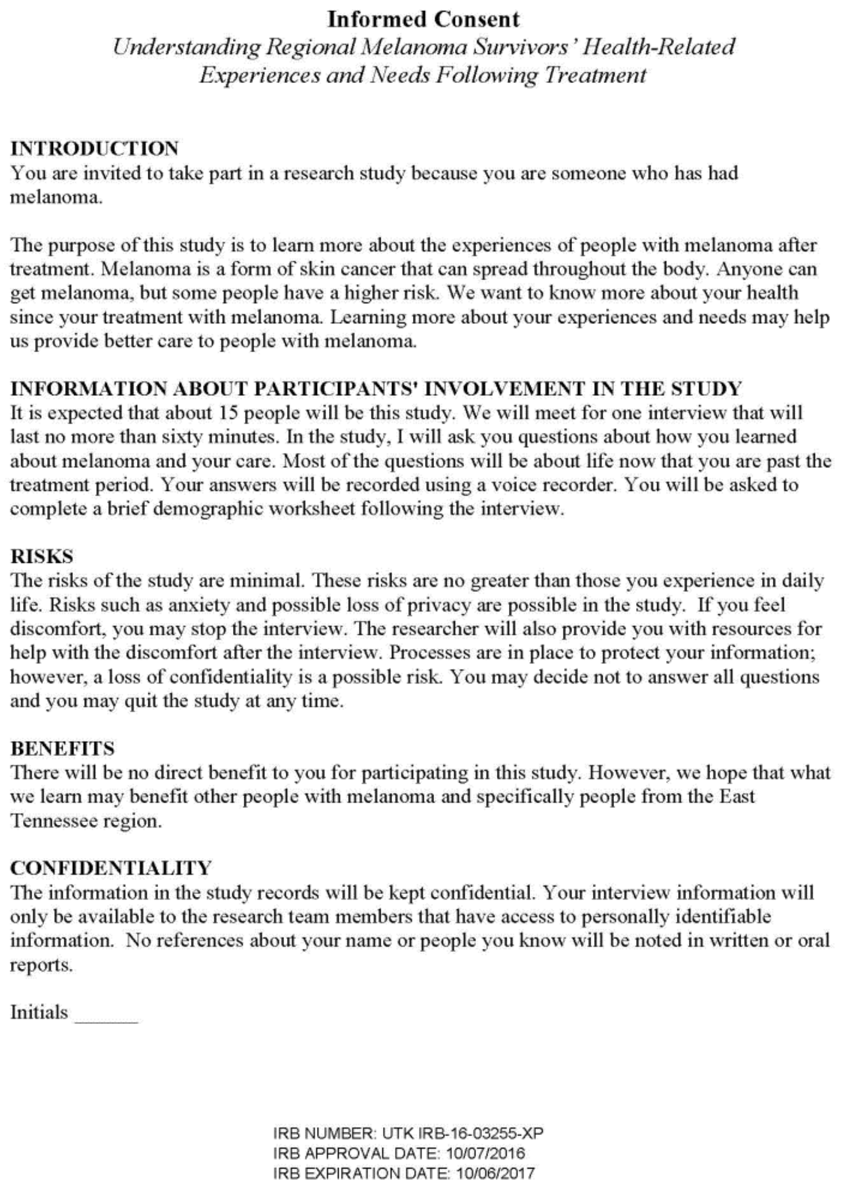
12. Tell me about any support you receive from:
    - a. Family?
    - b. Friends?
    - c. Community?
    - d. Or from health care providers?
13. Have you been seen for any health problems since treatment?
    - a. What kind of physical exam did you have?
    - b. Did they check your skin?
    - c. Your lymph nodes?
14. What other health problems do you have?
15. How often are you seen? What type of provider(s) do you see for any health-related issue?
    - a. Do your providers ask about melanoma follow-up?
16. Which health care providers do you share information with about your melanoma history?
17. What do you do when you see a suspicious lump or bump on your skin or an unusual symptom?
    - a. Do you have an example of this happening since your initial diagnosis?
    - b. Tell me more about that.

18. Is there anything about your experiences or your interactions with health care providers that have helped you more? Or less?
19. Why did you choose to participate in this study?
20. What advice would you give to other patients with melanoma?

Anything additional you want to share?

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016

Appendix E



Informed Consent

Understanding Regional Melanoma Survivors' Health-Related Experiences and Needs Following Treatment

INTRODUCTION

You are invited to take part in a research study because you are someone who has had melanoma.

The purpose of this study is to learn more about the experiences of people with melanoma after treatment. Melanoma is a form of skin cancer that can spread throughout the body. Anyone can get melanoma, but some people have a higher risk. We want to know more about your health since your treatment with melanoma. Learning more about your experiences and needs may help us provide better care to people with melanoma.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

It is expected that about 15 people will be this study. We will meet for one interview that will last no more than sixty minutes. In the study, I will ask you questions about how you learned about melanoma and your care. Most of the questions will be about life now that you are past the treatment period. Your answers will be recorded using a voice recorder. You will be asked to complete a brief demographic worksheet following the interview.

RISKS

The risks of the study are minimal. These risks are no greater than those you experience in daily life. Risks such as anxiety and possible loss of privacy are possible in the study. If you feel discomfort, you may stop the interview. The researcher will also provide you with resources for help with the discomfort after the interview. Processes are in place to protect your information; however, a loss of confidentiality is a possible risk. You may decide not to answer all questions and you may quit the study at any time.

BENEFITS

There will be no direct benefit to you for participating in this study. However, we hope that what we learn may benefit other people with melanoma and specifically people from the East Tennessee region.

CONFIDENTIALITY

The information in the study records will be kept confidential. Your interview information will only be available to the research team members that have access to personally identifiable information. No references about your name or people you know will be noted in written or oral reports.

Initials ______

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016
IRB EXPIRATION DATE: 10/06/2017

COMPENSATION

A $25 Walmart gift card will be provided for your time in this study. You will be given the gift card even if you quit the study.

CONTACT INFORMATION

If you have questions at any time about the study you may contact the researcher, Shirleen Chase, MSN, RN at the College of Nursing, The University of Tennessee 1200 Volunteer Blvd. Room 203, Knoxville, TN 37996, phone number: (865) 974-7606 or Faculty Advisor, Dr. Sadie Hutson College of Nursing, The University of Tennessee, 1200 Volunteer Blvd., Knoxville, TN 37996, phone number: (865) 974-7585.

If you have questions about your rights as a participant, you may contact the University of Tennessee IRB Compliance Officer at utkirb@utk.edu or (865) 974-7697.

PARTICIPATION

Your participation in this study is voluntary; you can decline to participate. If you decide to participate, you may withdraw from the study at any time without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be destroyed.

CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's Name (printed) ____

Participant's Signature ________________________________ Date __________

CONSENT FOR AUDIO RECORDING

I understand that my participating in the study will be recorded. I agree to allow the researcher to make an audio recording of my interview for the purpose of this study.

Participant's Name (printed) ____

Participant's Signature ________________________________ Date __________

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016
IRB EXPIRATION DATE: 10/06/2017

Melanoma Survivor Resources

American Cancer Society
www.cancer.org/cancer/skincancer-melanoma

The American Melanoma Foundation
www.melanomafoundation.org

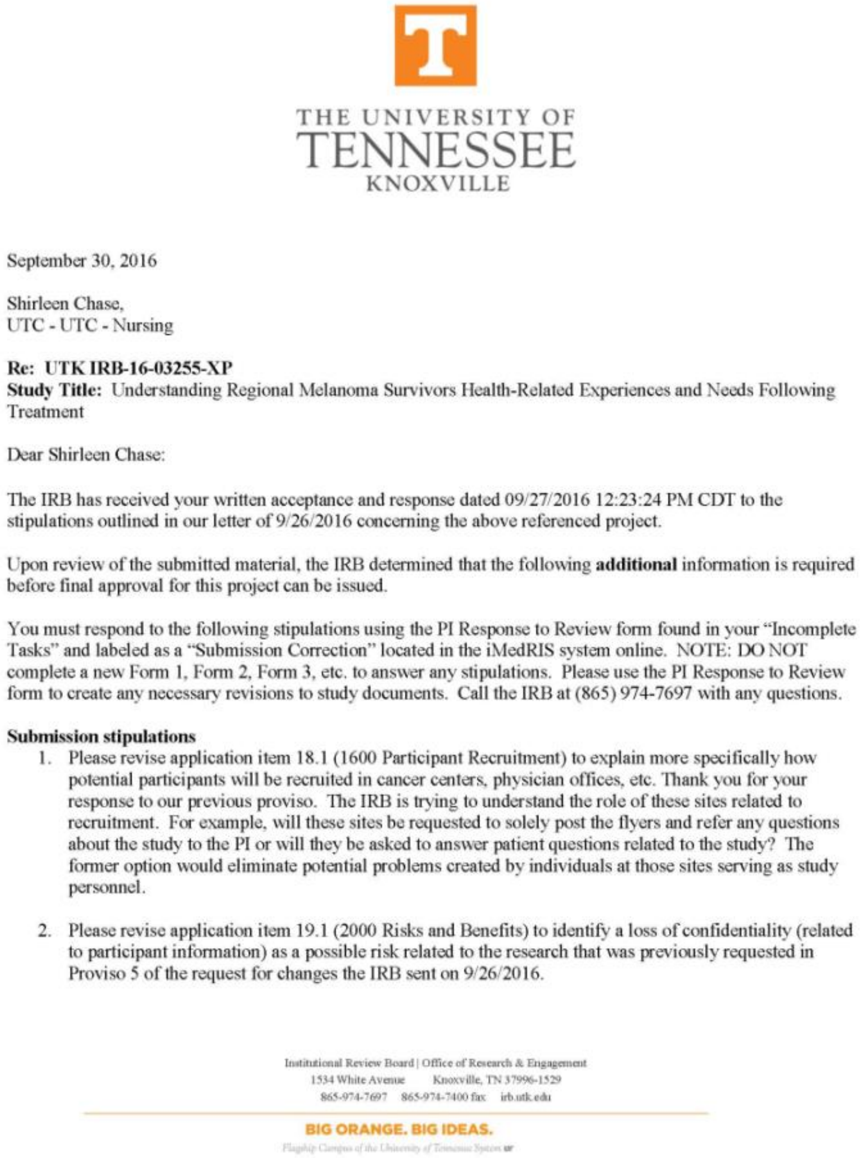
CancerCare 1-800-813-HOPE (4673)
www.cancercare.org

The Wellness Community
1-888-793-9355
www.thewellnesscommunity.org

The Melanoma Patients Information Page (MPIP) is the oldest and largest community of people affected by melanoma hosted through the Melanoma Research Foundation. It is designed to provide support and information to caregivers, patients, family and friends.
www.melanoma.org

IRB NUMBER: UTK IRB-16-03255-XP
IRB APPROVAL DATE: 10/07/2016
IRB EXPIRATION DATE: 10/06/2017

Appendix F



THE UNIVERSITY OF
TENNESSEE
KNOXVILLE

September 30, 2016

Shirleen Chase,
UTC - UTC - Nursing

Re: UTK IRB-16-03255-XP
Study Title: Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

Dear Shirleen Chase:

The IRB has received your written acceptance and response dated 09/27/2016 12:23:24 PM CDT to the stipulations outlined in our letter of 9/26/2016 concerning the above referenced project.

Upon review of the submitted material, the IRB determined that the following **additional** information is required before final approval for this project can be issued.

You must respond to the following stipulations using the PI Response to Review form found in your "Incomplete Tasks" and labeled as a "Submission Correction" located in the iMedRIS system online. NOTE: DO NOT complete a new Form 1, Form 2, Form 3, etc. to answer any stipulations. Please use the PI Response to Review form to create any necessary revisions to study documents. Call the IRB at (865) 974-7697 with any questions.

Submission stipulations

1. Please revise application item 18.1 (1600 Participant Recruitment) to explain more specifically how potential participants will be recruited in cancer centers, physician offices, etc. Thank you for your response to our previous proviso. The IRB is trying to understand the role of these sites related to recruitment. For example, will these sites be requested to solely post the flyers and refer any questions about the study to the PI or will they be asked to answer patient questions related to the study? The former option would eliminate potential problems created by individuals at those sites serving as study personnel.

2. Please revise application item 19.1 (2000 Risks and Benefits) to identify a loss of confidentiality (related to participant information) as a possible risk related to the research that was previously requested in Proviso 5 of the request for changes the IRB sent on 9/26/2016.

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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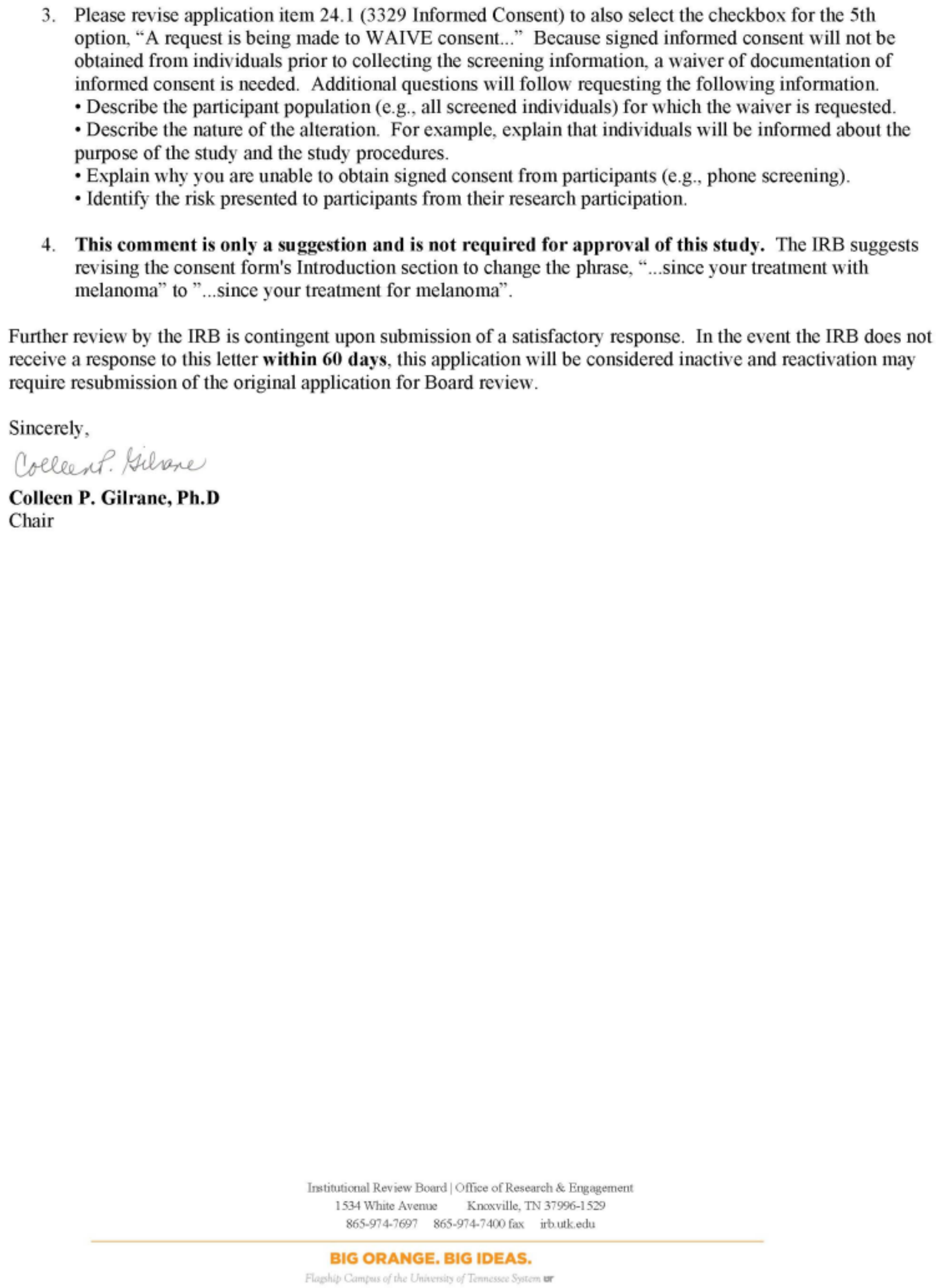


3. Please revise application item 24.1 (3329 Informed Consent) to also select the checkbox for the 5th option, “A request is being made to WAIVE consent...” Because signed informed consent will not be obtained from individuals prior to collecting the screening information, a waiver of documentation of informed consent is needed. Additional questions will follow requesting the following information.
   • Describe the participant population (e.g., all screened individuals) for which the waiver is requested.
   • Describe the nature of the alteration. For example, explain that individuals will be informed about the purpose of the study and the study procedures.
   • Explain why you are unable to obtain signed consent from participants (e.g., phone screening).
   • Identify the risk presented to participants from their research participation.

4. **This comment is only a suggestion and is not required for approval of this study.** The IRB suggests revising the consent form's Introduction section to change the phrase, “...since your treatment with melanoma” to ”...since your treatment for melanoma”.

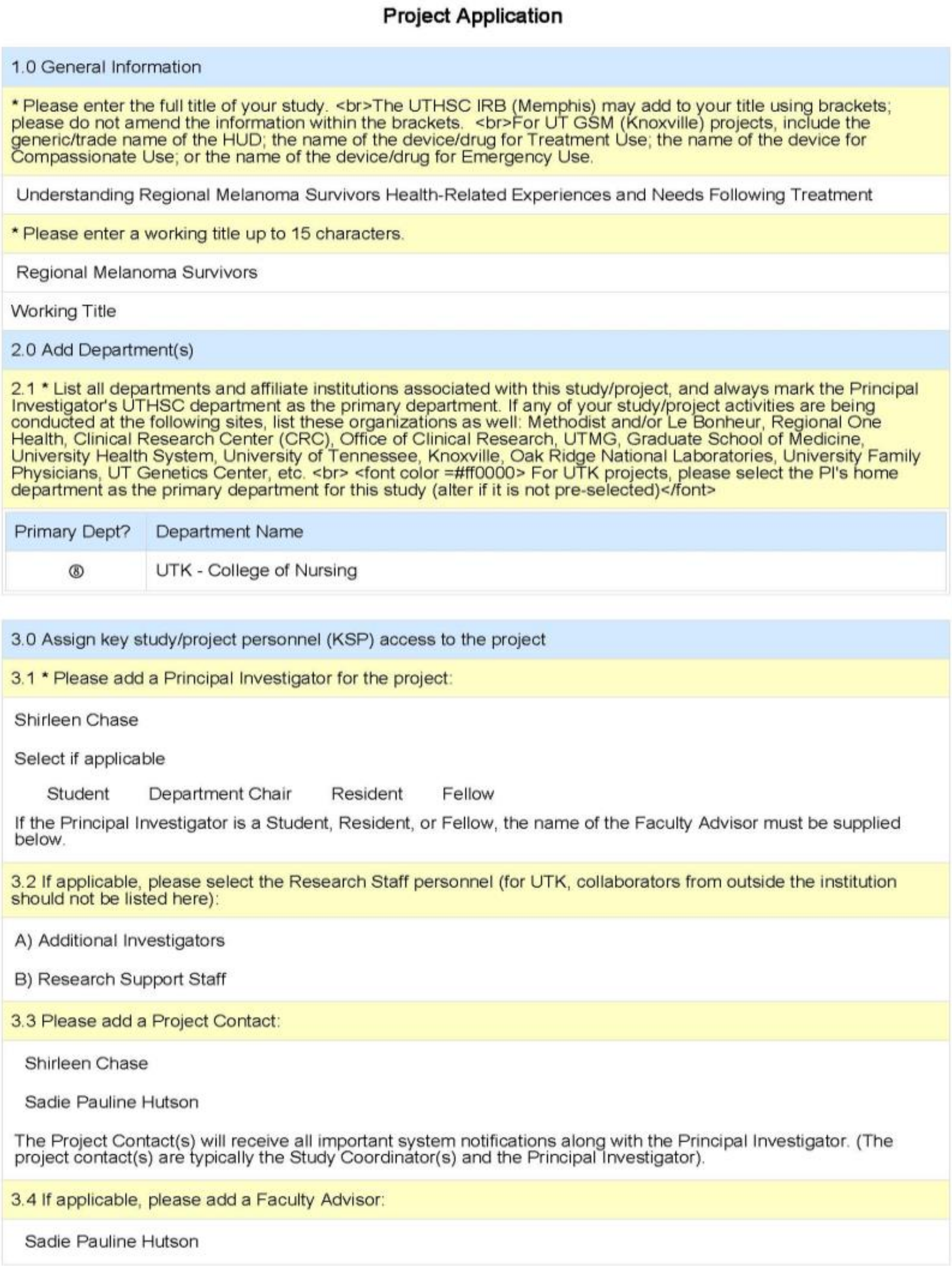
Further review by the IRB is contingent upon submission of a satisfactory response. In the event the IRB does not receive a response to this letter **within 60 days**, this application will be considered inactive and reactivation may require resubmission of the original application for Board review.

Sincerely,

Colleen P. Gilrane

Colleen P. Gilrane, Ph.D
Chair

Appendix G



Project Application

1.0 General Information

* Please enter the full title of your study.
The UTHSC IRB (Memphis) may add to your title using brackets; please do not amend the information within the brackets.
For UT GSM (Knoxville) projects, include the generic/trade name of the HUD; the name of the device/drug for Treatment Use; the name of the device for Compassionate Use; or the name of the device/drug for Emergency Use.

Understanding Regional Melanoma Survivors Health-Related Experiences and Needs Following Treatment

* Please enter a working title up to 15 characters.

Regional Melanoma Survivors

Working Title

2.0 Add Department(s)

2.1 * List all departments and affiliate institutions associated with this study/project, and always mark the Principal Investigator's UTHSC department as the primary department. If any of your study/project activities are being conducted at the following sites, list these organizations as well: Methodist and/or Le Bonheur, Regional One Health, Clinical Research Center (CRC), Office of Clinical Research, UTMG, Graduate School of Medicine, University Health System, University of Tennessee, Knoxville, Oak Ridge National Laboratories, University Family Physicians, UT Genetics Center, etc.
  For UTK projects, please select the PI's home department as the primary department for this study (alter if it is not pre-selected)

Primary Dept?	Department Name
●	UTK - College of Nursing

3.0 Assign key study/project personnel (KSP) access to the project

3.1 * Please add a Principal Investigator for the project:

Shirleen Chase

Select if applicable

Student Department Chair Resident Fellow

If the Principal Investigator is a Student, Resident, or Fellow, the name of the Faculty Advisor must be supplied below.

3.2 If applicable, please select the Research Staff personnel (for UTK, collaborators from outside the institution should not be listed here):

A) Additional Investigators

B) Research Support Staff

3.3 Please add a Project Contact:

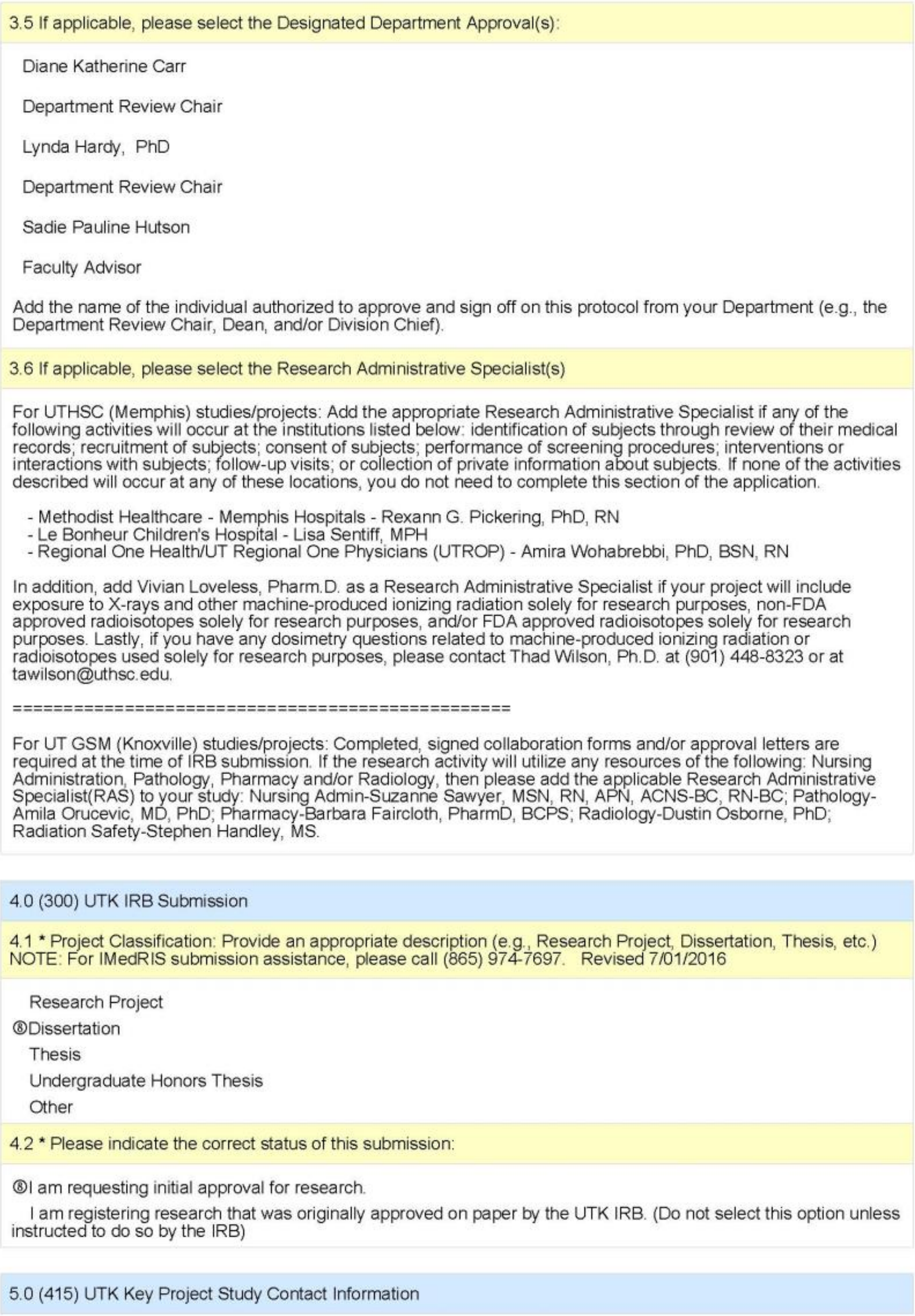
Shirleen Chase

Sadie Pauline Hutson

The Project Contact(s) will receive all important system notifications along with the Principal Investigator. (The project contact(s) are typically the Study Coordinator(s) and the Principal Investigator).

3.4 If applicable, please add a Faculty Advisor:

Sadie Pauline Hutson



3.5 If applicable, please select the Designated Department Approval(s):

Diane Katherine Carr

Department Review Chair

Lynda Hardy, PhD

Department Review Chair

Sadie Pauline Hutson

Faculty Advisor

Add the name of the individual authorized to approve and sign off on this protocol from your Department (e.g., the Department Review Chair, Dean, and/or Division Chief).

3.6 If applicable, please select the Research Administrative Specialist(s)

For UTHSC (Memphis) studies/projects: Add the appropriate Research Administrative Specialist if any of the following activities will occur at the institutions listed below: identification of subjects through review of their medical records; recruitment of subjects; consent of subjects; performance of screening procedures; interventions or interactions with subjects; follow-up visits; or collection of private information about subjects. If none of the activities described will occur at any of these locations, you do not need to complete this section of the application.

- Methodist Healthcare - Memphis Hospitals - Rexann G. Pickering, PhD, RN
- Le Bonheur Children's Hospital - Lisa Sentiff, MPH
- Regional One Health/UT Regional One Physicians (UTROP) - Amira Wohabrebbi, PhD, BSN, RN

In addition, add Vivian Loveless, Pharm.D. as a Research Administrative Specialist if your project will include exposure to X-rays and other machine-produced ionizing radiation solely for research purposes, non-FDA approved radioisotopes solely for research purposes, and/or FDA approved radioisotopes solely for research purposes. Lastly, if you have any dosimetry questions related to machine-produced ionizing radiation or radioisotopes used solely for research purposes, please contact Thad Wilson, Ph.D. at (901) 448-8323 or at tawilson@uthsc.edu.

==

For UT GSM (Knoxville) studies/projects: Completed, signed collaboration forms and/or approval letters are required at the time of IRB submission. If the research activity will utilize any resources of the following: Nursing Administration, Pathology, Pharmacy and/or Radiology, then please add the applicable Research Administrative Specialist(RAS) to your study: Nursing Admin-Suzanne Sawyer, MSN, RN, APN, ACNS-BC, RN-BC; Pathology-Amila Orucevic, MD, PhD; Pharmacy-Barbara Faircloth, PharmD, BCPS; Radiology-Dustin Osborne, PhD; Radiation Safety-Stephen Handley, MS.

4.0 (300) UTK IRB Submission

4.1 * Project Classification: Provide an appropriate description (e.g., Research Project, Dissertation, Thesis, etc.) NOTE: For IMedRIS submission assistance, please call (865) 974-7697. Revised 7/01/2016

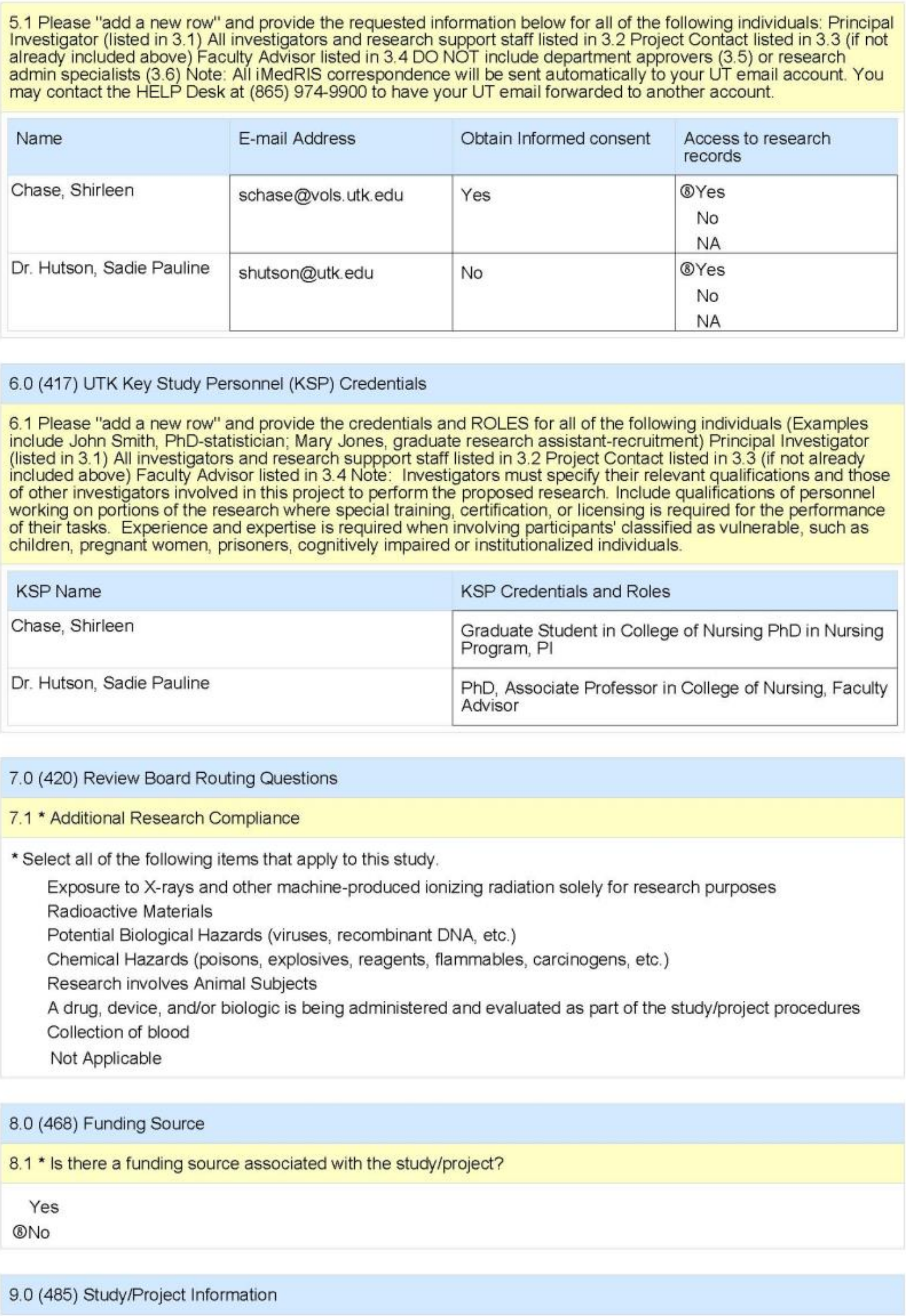
Research Project
●Dissertation
Thesis
Undergraduate Honors Thesis
Other

4.2 * Please indicate the correct status of this submission:

●I am requesting initial approval for research.

I am registering research that was originally approved on paper by the UTK IRB. (Do not select this option unless instructed to do so by the IRB)

5.0 (415) UTK Key Project Study Contact Information



5.1 Please "add a new row" and provide the requested information below for all of the following individuals: Principal Investigator (listed in 3.1) All investigators and research support staff listed in 3.2 Project Contact listed in 3.3 (if not already included above) Faculty Advisor listed in 3.4 DO NOT include department approvers (3.5) or research admin specialists (3.6) Note: All iMedRIS correspondence will be sent automatically to your UT email account. You may contact the HELP Desk at (865) 974-9900 to have your UT email forwarded to another account.

Name	E-mail Address	Obtain Informed consent	Access to research records
Chase, Shirleen	schase@vols.utk.edu	Yes	●Yes No NA
Dr. Hutson, Sadie Pauline	shutson@utk.edu	No	●Yes No NA

6.0 (417) UTK Key Study Personnel (KSP) Credentials

6.1 Please "add a new row" and provide the credentials and ROLES for all of the following individuals (Examples include John Smith, PhD-statistician; Mary Jones, graduate research assistant-recruitment) Principal Investigator (listed in 3.1) All investigators and research suppport staff listed in 3.2 Project Contact listed in 3.3 (if not already included above) Faculty Advisor listed in 3.4 Note: Investigators must specify their relevant qualifications and those of other investigators involved in this project to perform the proposed research. Include qualifications of personnel working on portions of the research where special training, certification, or licensing is required for the performance of their tasks. Experience and expertise is required when involving participants' classified as vulnerable, such as children, pregnant women, prisoners, cognitively impaired or institutionalized individuals.

KSP Name	KSP Credentials and Roles
Chase, Shirleen	Graduate Student in College of Nursing PhD in Nursing Program, PI
Dr. Hutson, Sadie Pauline	PhD, Associate Professor in College of Nursing, Faculty Advisor

7.0 (420) Review Board Routing Questions

7.1 * Additional Research Compliance

* Select all of the following items that apply to this study.

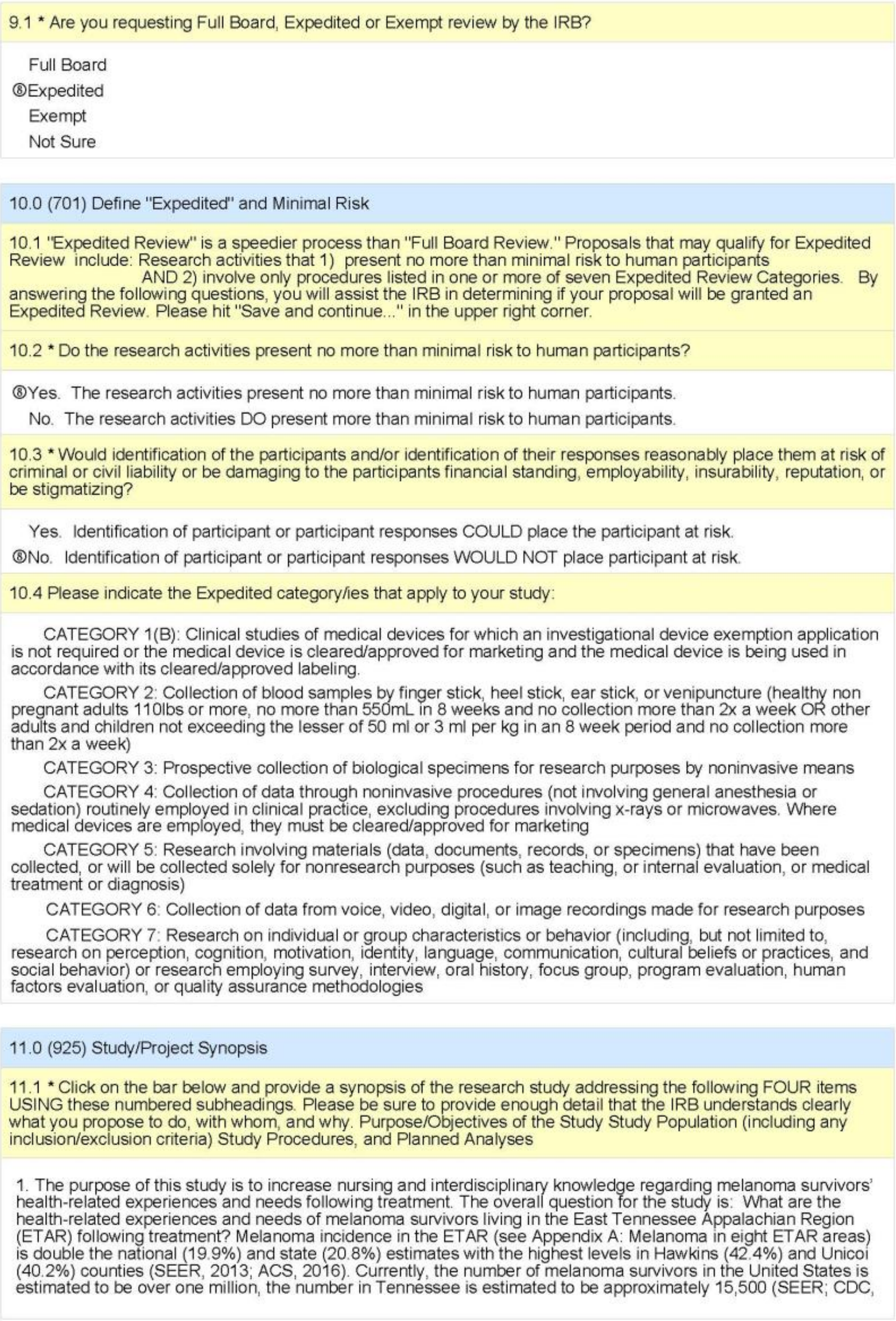
Exposure to X-rays and other machine-produced ionizing radiation solely for research purposes
Radioactive Materials
Potential Biological Hazards (viruses, recombinant DNA, etc.)
Chemical Hazards (poisons, explosives, reagents, flammables, carcinogens, etc.)
Research involves Animal Subjects
A drug, device, and/or biologic is being administered and evaluated as part of the study/project procedures
Collection of blood
Not Applicable

8.0 (468) Funding Source

8.1 * Is there a funding source associated with the study/project?

Yes
●No

9.0 (485) Study/Project Information



9.1 * Are you requesting Full Board, Expedited or Exempt review by the IRB?

Full Board
● Expedited
Exempt
Not Sure

10.0 (701) Define "Expedited" and Minimal Risk

10.1 "Expedited Review" is a speedier process than "Full Board Review." Proposals that may qualify for Expedited Review include: Research activities that 1) present no more than minimal risk to human participants AND 2) involve only procedures listed in one or more of seven Expedited Review Categories. By answering the following questions, you will assist the IRB in determining if your proposal will be granted an Expedited Review. Please hit "Save and continue..." in the upper right corner.

10.2 * Do the research activities present no more than minimal risk to human participants?

● Yes. The research activities present no more than minimal risk to human participants.
No. The research activities DO present more than minimal risk to human participants.

10.3 * Would identification of the participants and/or identification of their responses reasonably place them at risk of criminal or civil liability or be damaging to the participants financial standing, employability, insurability, reputation, or be stigmatizing?

Yes. Identification of participant or participant responses COULD place the participant at risk.
● No. Identification of participant or participant responses WOULD NOT place participant at risk.

10.4 Please indicate the Expedited category/ies that apply to your study:

CATEGORY 1(B): Clinical studies of medical devices for which an investigational device exemption application is not required or the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

CATEGORY 2: Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture (healthy non pregnant adults 110lbs or more, no more than 550mL in 8 weeks and no collection more than 2x a week OR other adults and children not exceeding the lesser of 50 ml or 3 ml per kg in an 8 week period and no collection more than 2x a week)

CATEGORY 3: Prospective collection of biological specimens for research purposes by noninvasive means

CATEGORY 4: Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing

CATEGORY 5: Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as teaching, or internal evaluation, or medical treatment or diagnosis)

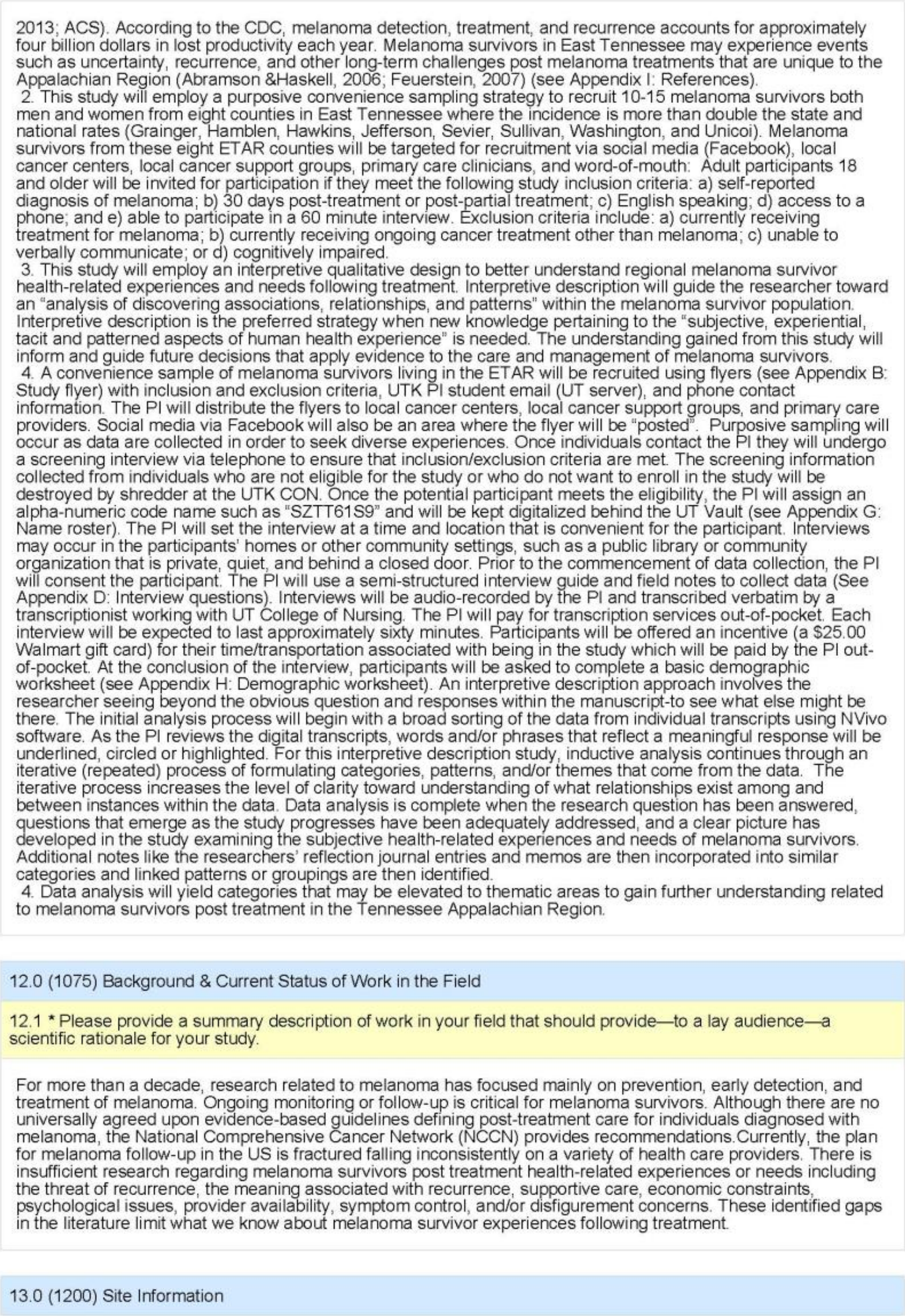
CATEGORY 6: Collection of data from voice, video, digital, or image recordings made for research purposes

CATEGORY 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

11.0 (925) Study/Project Synopsis

11.1 * Click on the bar below and provide a synopsis of the research study addressing the following FOUR items USING these numbered subheadings. Please be sure to provide enough detail that the IRB understands clearly what you propose to do, with whom, and why. Purpose/Objectives of the Study Study Population (including any inclusion/exclusion criteria) Study Procedures, and Planned Analyses

1. The purpose of this study is to increase nursing and interdisciplinary knowledge regarding melanoma survivors' health-related experiences and needs following treatment. The overall question for the study is: What are the health-related experiences and needs of melanoma survivors living in the East Tennessee Appalachian Region (ETAR) following treatment? Melanoma incidence in the ETAR (see Appendix A: Melanoma in eight ETAR areas) is double the national (19.9%) and state (20.8%) estimates with the highest levels in Hawkins (42.4%) and Unicoi (40.2%) counties (SEER, 2013; ACS, 2016). Currently, the number of melanoma survivors in the United States is estimated to be over one million, the number in Tennessee is estimated to be approximately 15,500 (SEER; CDC,



2013; ACS). According to the CDC, melanoma detection, treatment, and recurrence accounts for approximately four billion dollars in lost productivity each year. Melanoma survivors in East Tennessee may experience events such as uncertainty, recurrence, and other long-term challenges post melanoma treatments that are unique to the Appalachian Region (Abramson &Haskell, 2006; Feuerstein, 2007) (see Appendix I: References).

2. This study will employ a purposive convenience sampling strategy to recruit 10-15 melanoma survivors both men and women from eight counties in East Tennessee where the incidence is more than double the state and national rates (Grainger, Hamblen, Hawkins, Jefferson, Sevier, Sullivan, Washington, and Unicoi). Melanoma survivors from these eight ETAR counties will be targeted for recruitment via social media (Facebook), local cancer centers, local cancer support groups, primary care clinicians, and word-of-mouth: Adult participants 18 and older will be invited for participation if they meet the following study inclusion criteria: a) self-reported diagnosis of melanoma; b) 30 days post-treatment or post-partial treatment; c) English speaking; d) access to a phone; and e) able to participate in a 60 minute interview. Exclusion criteria include: a) currently receiving treatment for melanoma; b) currently receiving ongoing cancer treatment other than melanoma; c) unable to verbally communicate; or d) cognitively impaired.

3. This study will employ an interpretive qualitative design to better understand regional melanoma survivor health-related experiences and needs following treatment. Interpretive description will guide the researcher toward an "analysis of discovering associations, relationships, and patterns" within the melanoma survivor population. Interpretive description is the preferred strategy when new knowledge pertaining to the "subjective, experiential, tacit and patterned aspects of human health experience" is needed. The understanding gained from this study will inform and guide future decisions that apply evidence to the care and management of melanoma survivors.

4. A convenience sample of melanoma survivors living in the ETAR will be recruited using flyers (see Appendix B: Study flyer) with inclusion and exclusion criteria, UTK PI student email (UT server), and phone contact information. The PI will distribute the flyers to local cancer centers, local cancer support groups, and primary care providers. Social media via Facebook will also be an area where the flyer will be "posted". Purposive sampling will occur as data are collected in order to seek diverse experiences. Once individuals contact the PI they will undergo a screening interview via telephone to ensure that inclusion/exclusion criteria are met. The screening information collected from individuals who are not eligible for the study or who do not want to enroll in the study will be destroyed by shredder at the UTK CON. Once the potential participant meets the eligibility, the PI will assign an alpha-numeric code name such as "SZTT61S9" and will be kept digitalized behind the UT Vault (see Appendix G: Name roster). The PI will set the interview at a time and location that is convenient for the participant. Interviews may occur in the participants' homes or other community settings, such as a public library or community organization that is private, quiet, and behind a closed door. Prior to the commencement of data collection, the PI will consent the participant. The PI will use a semi-structured interview guide and field notes to collect data (See Appendix D: Interview questions). Interviews will be audio-recorded by the PI and transcribed verbatim by a transcriptionist working with UT College of Nursing. The PI will pay for transcription services out-of-pocket. Each interview will be expected to last approximately sixty minutes. Participants will be offered an incentive (a $25.00 Walmart gift card) for their time/transportation associated with being in the study which will be paid by the PI out-of-pocket. At the conclusion of the interview, participants will be asked to complete a basic demographic worksheet (see Appendix H: Demographic worksheet). An interpretive description approach involves the researcher seeing beyond the obvious question and responses within the manuscript-to see what else might be there. The initial analysis process will begin with a broad sorting of the data from individual transcripts using NVivo software. As the PI reviews the digital transcripts, words and/or phrases that reflect a meaningful response will be underlined, circled or highlighted. For this interpretive description study, inductive analysis continues through an iterative (repeated) process of formulating categories, patterns, and/or themes that come from the data. The iterative process increases the level of clarity toward understanding of what relationships exist among and between instances within the data. Data analysis is complete when the research question has been answered, questions that emerge as the study progresses have been adequately addressed, and a clear picture has developed in the study examining the subjective health-related experiences and needs of melanoma survivors. Additional notes like the researchers' reflection journal entries and memos are then incorporated into similar categories and linked patterns or groupings are then identified.

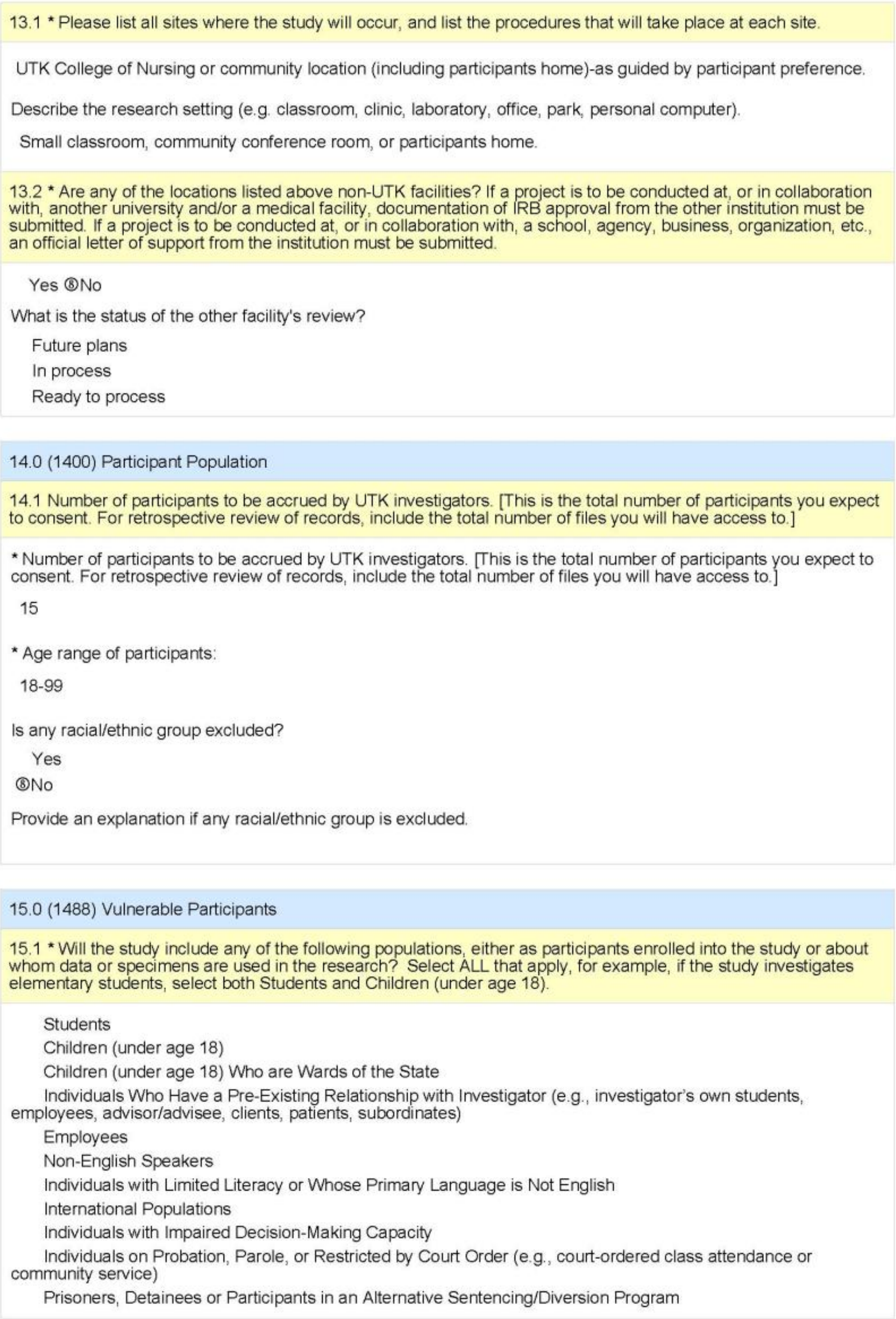
4. Data analysis will yield categories that may be elevated to thematic areas to gain further understanding related to melanoma survivors post treatment in the Tennessee Appalachian Region.

12.0 (1075) Background & Current Status of Work in the Field

12.1 * Please provide a summary description of work in your field that should provide—to a lay audience—a scientific rationale for your study.

For more than a decade, research related to melanoma has focused mainly on prevention, early detection, and treatment of melanoma. Ongoing monitoring or follow-up is critical for melanoma survivors. Although there are no universally agreed upon evidence-based guidelines defining post-treatment care for individuals diagnosed with melanoma, the National Comprehensive Cancer Network (NCCN) provides recommendations.Currently, the plan for melanoma follow-up in the US is fractured falling inconsistently on a variety of health care providers. There is insufficient research regarding melanoma survivors post treatment health-related experiences or needs including the threat of recurrence, the meaning associated with recurrence, supportive care, economic constraints, psychological issues, provider availability, symptom control, and/or disfigurement concerns. These identified gaps in the literature limit what we know about melanoma survivor experiences following treatment.

13.0 (1200) Site Information



13.1 * Please list all sites where the study will occur, and list the procedures that will take place at each site.

UTK College of Nursing or community location (including participants home)-as guided by participant preference.

Describe the research setting (e.g. classroom, clinic, laboratory, office, park, personal computer).

Small classroom, community conference room, or participants home.

13.2 * Are any of the locations listed above non-UTK facilities? If a project is to be conducted at, or in collaboration with, another university and/or a medical facility, documentation of IRB approval from the other institution must be submitted. If a project is to be conducted at, or in collaboration with, a school, agency, business, organization, etc., an official letter of support from the institution must be submitted.

Yes ●No

What is the status of the other facility's review?

Future plans
In process
Ready to process

14.0 (1400) Participant Population

14.1 Number of participants to be accrued by UTK investigators. [This is the total number of participants you expect to consent. For retrospective review of records, include the total number of files you will have access to.]

* Number of participants to be accrued by UTK investigators. [This is the total number of participants you expect to consent. For retrospective review of records, include the total number of files you will have access to.]

15

* Age range of participants:

18-99

Is any racial/ethnic group excluded?

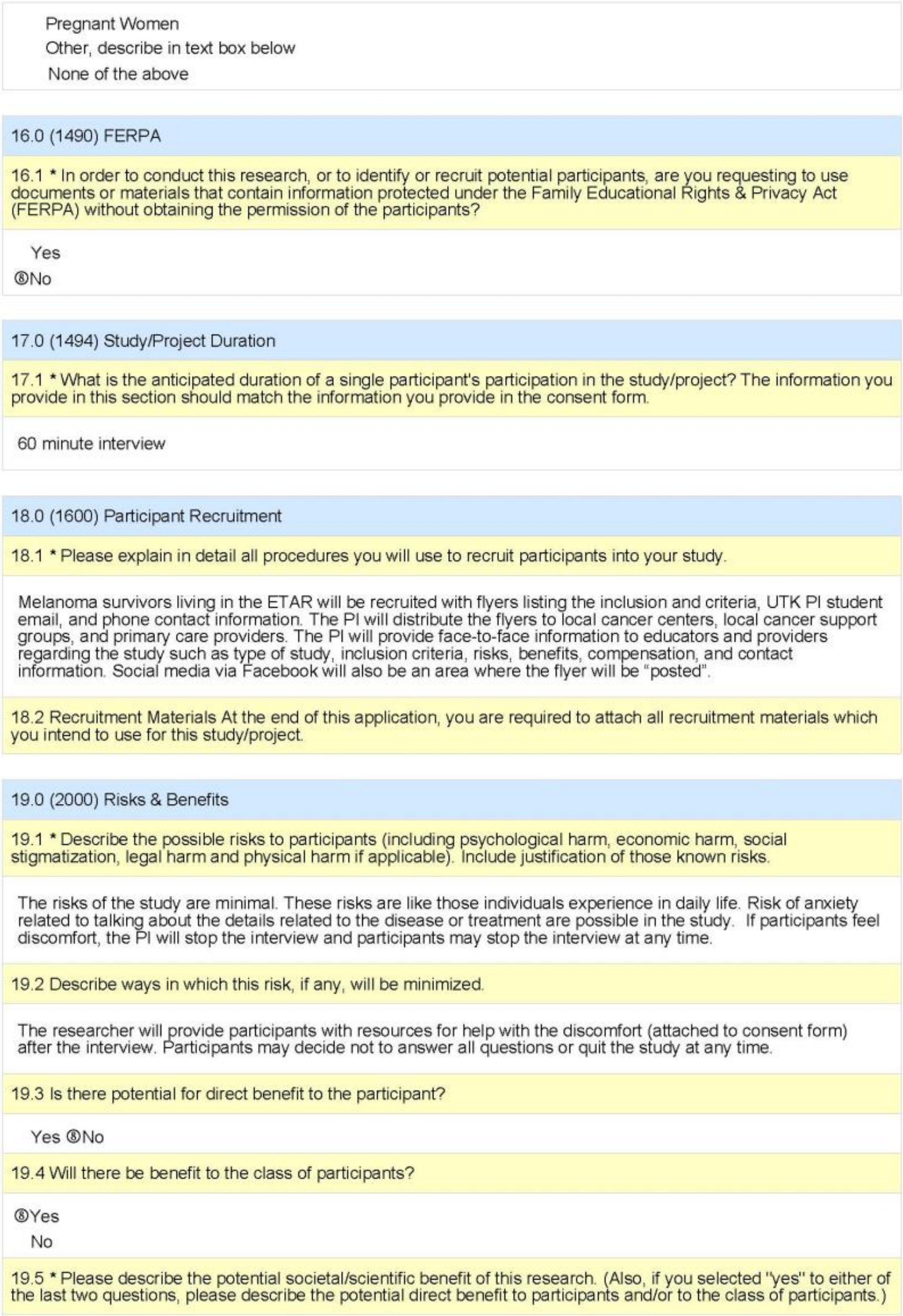
Yes
●No

Provide an explanation if any racial/ethnic group is excluded.

15.0 (1488) Vulnerable Participants

15.1 * Will the study include any of the following populations, either as participants enrolled into the study or about whom data or specimens are used in the research? Select ALL that apply, for example, if the study investigates elementary students, select both Students and Children (under age 18).

Students
Children (under age 18)
Children (under age 18) Who are Wards of the State
Individuals Who Have a Pre-Existing Relationship with Investigator (e.g., investigator's own students, employees, advisor/advisee, clients, patients, subordinates)
Employees
Non-English Speakers
Individuals with Limited Literacy or Whose Primary Language is Not English
International Populations
Individuals with Impaired Decision-Making Capacity
Individuals on Probation, Parole, or Restricted by Court Order (e.g., court-ordered class attendance or community service)
Prisoners, Detainees or Participants in an Alternative Sentencing/Diversion Program



Pregnant Women
Other, describe in text box below
None of the above

16.0 (1490) FERPA

16.1 * In order to conduct this research, or to identify or recruit potential participants, are you requesting to use documents or materials that contain information protected under the Family Educational Rights & Privacy Act (FERPA) without obtaining the permission of the participants?

Yes
● No

17.0 (1494) Study/Project Duration

17.1 * What is the anticipated duration of a single participant's participation in the study/project? The information you provide in this section should match the information you provide in the consent form.

60 minute interview

18.0 (1600) Participant Recruitment

18.1 * Please explain in detail all procedures you will use to recruit participants into your study.

Melanoma survivors living in the ETAR will be recruited with flyers listing the inclusion and criteria, UTK PI student email, and phone contact information. The PI will distribute the flyers to local cancer centers, local cancer support groups, and primary care providers. The PI will provide face-to-face information to educators and providers regarding the study such as type of study, inclusion criteria, risks, benefits, compensation, and contact information. Social media via Facebook will also be an area where the flyer will be "posted".

18.2 Recruitment Materials At the end of this application, you are required to attach all recruitment materials which you intend to use for this study/project.

19.0 (2000) Risks & Benefits

19.1 * Describe the possible risks to participants (including psychological harm, economic harm, social stigmatization, legal harm and physical harm if applicable). Include justification of those known risks.

The risks of the study are minimal. These risks are like those individuals experience in daily life. Risk of anxiety related to talking about the details related to the disease or treatment are possible in the study. If participants feel discomfort, the PI will stop the interview and participants may stop the interview at any time.

19.2 Describe ways in which this risk, if any, will be minimized.

The researcher will provide participants with resources for help with the discomfort (attached to consent form) after the interview. Participants may decide not to answer all questions or quit the study at any time.

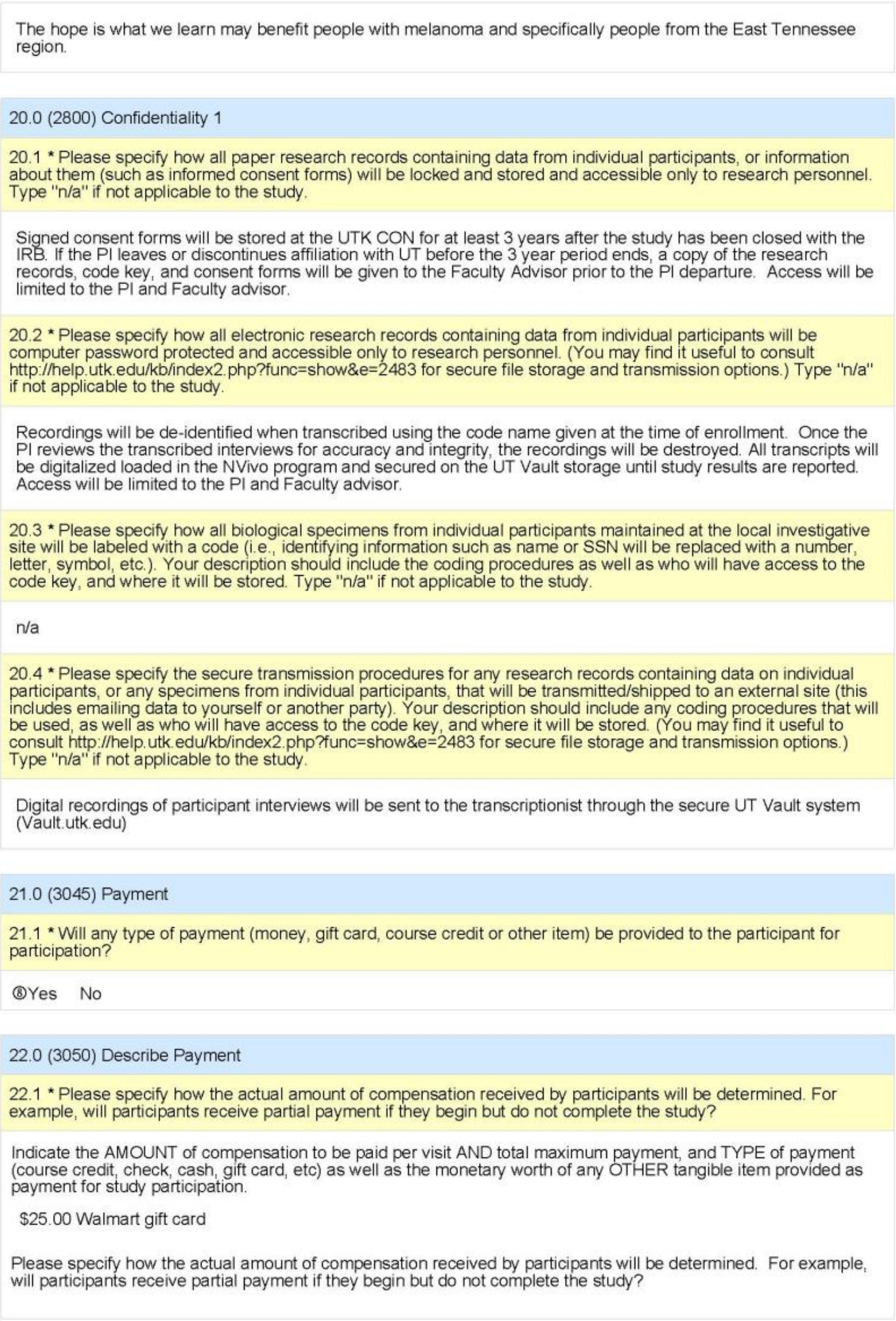
19.3 Is there potential for direct benefit to the participant?

Yes ● No

19.4 Will there be benefit to the class of participants?

● Yes
No

19.5 * Please describe the potential societal/scientific benefit of this research. (Also, if you selected "yes" to either of the last two questions, please describe the potential direct benefit to participants and/or to the class of participants.)



The hope is what we learn may benefit people with melanoma and specifically people from the East Tennessee region.

20.0 (2800) Confidentiality 1

20.1 * Please specify how all paper research records containing data from individual participants, or information about them (such as informed consent forms) will be locked and stored and accessible only to research personnel. Type "n/a" if not applicable to the study.

Signed consent forms will be stored at the UTK CON for at least 3 years after the study has been closed with the IRB. If the PI leaves or discontinues affiliation with UT before the 3 year period ends, a copy of the research records, code key, and consent forms will be given to the Faculty Advisor prior to the PI departure. Access will be limited to the PI and Faculty advisor.

20.2 * Please specify how all electronic research records containing data from individual participants will be computer password protected and accessible only to research personnel. (You may find it useful to consult http://help.utk.edu/kb/index2.php?func=show&e=2483 for secure file storage and transmission options.) Type "n/a" if not applicable to the study.

Recordings will be de-identified when transcribed using the code name given at the time of enrollment. Once the PI reviews the transcribed interviews for accuracy and integrity, the recordings will be destroyed. All transcripts will be digitalized loaded in the NVivo program and secured on the UT Vault storage until study results are reported. Access will be limited to the PI and Faculty advisor.

20.3 * Please specify how all biological specimens from individual participants maintained at the local investigative site will be labeled with a code (i.e., identifying information such as name or SSN will be replaced with a number, letter, symbol, etc.). Your description should include the coding procedures as well as who will have access to the code key, and where it will be stored. Type "n/a" if not applicable to the study.

n/a

20.4 * Please specify the secure transmission procedures for any research records containing data on individual participants, or any specimens from individual participants, that will be transmitted/shipped to an external site (this includes emailing data to yourself or another party). Your description should include any coding procedures that will be used, as well as who will have access to the code key, and where it will be stored. (You may find it useful to consult http://help.utk.edu/kb/index2.php?func=show&e=2483 for secure file storage and transmission options.) Type "n/a" if not applicable to the study.

Digital recordings of participant interviews will be sent to the transcriptionist through the secure UT Vault system (Vault.utk.edu)

21.0 (3045) Payment

21.1 * Will any type of payment (money, gift card, course credit or other item) be provided to the participant for participation?

●Yes No

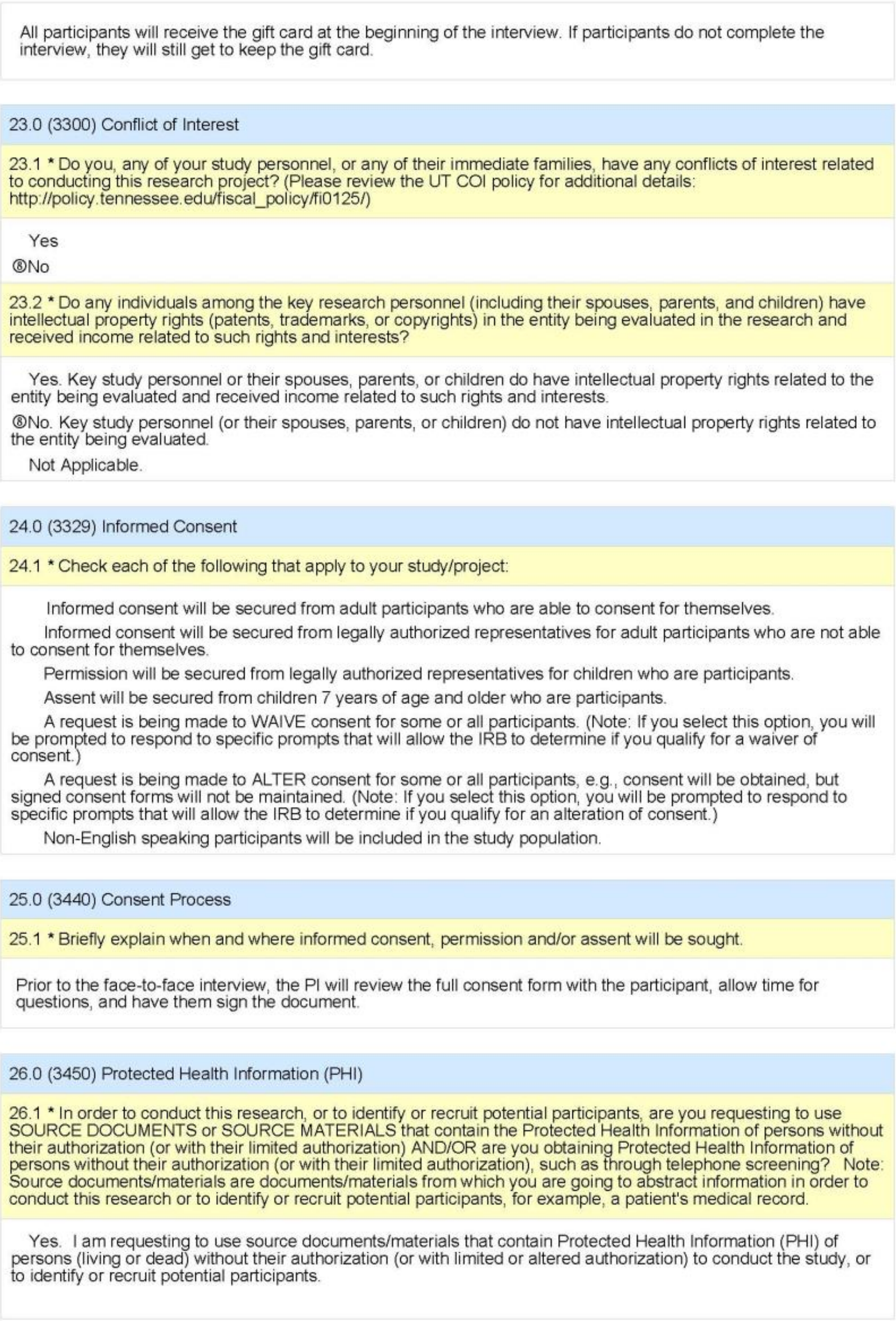
22.0 (3050) Describe Payment

22.1 * Please specify how the actual amount of compensation received by participants will be determined. For example, will participants receive partial payment if they begin but do not complete the study?

Indicate the AMOUNT of compensation to be paid per visit AND total maximum payment, and TYPE of payment (course credit, check, cash, gift card, etc) as well as the monetary worth of any OTHER tangible item provided as payment for study participation.

$25.00 Walmart gift card

Please specify how the actual amount of compensation received by participants will be determined. For example, will participants receive partial payment if they begin but do not complete the study?



All participants will receive the gift card at the beginning of the interview. If participants do not complete the interview, they will still get to keep the gift card.

23.0 (3300) Conflict of Interest

23.1 * Do you, any of your study personnel, or any of their immediate families, have any conflicts of interest related to conducting this research project? (Please review the UT COI policy for additional details: http://policy.tennessee.edu/fiscal_policy/fi0125/)

Yes

● No

23.2 * Do any individuals among the key research personnel (including their spouses, parents, and children) have intellectual property rights (patents, trademarks, or copyrights) in the entity being evaluated in the research and received income related to such rights and interests?

Yes. Key study personnel or their spouses, parents, or children do have intellectual property rights related to the entity being evaluated and received income related to such rights and interests.

● No. Key study personnel (or their spouses, parents, or children) do not have intellectual property rights related to the entity being evaluated.

Not Applicable.

24.0 (3329) Informed Consent

24.1 * Check each of the following that apply to your study/project:

Informed consent will be secured from adult participants who are able to consent for themselves.

Informed consent will be secured from legally authorized representatives for adult participants who are not able to consent for themselves.

Permission will be secured from legally authorized representatives for children who are participants.

Assent will be secured from children 7 years of age and older who are participants.

A request is being made to WAIVE consent for some or all participants. (Note: If you select this option, you will be prompted to respond to specific prompts that will allow the IRB to determine if you qualify for a waiver of consent.)

A request is being made to ALTER consent for some or all participants, e.g., consent will be obtained, but signed consent forms will not be maintained. (Note: If you select this option, you will be prompted to respond to specific prompts that will allow the IRB to determine if you qualify for an alteration of consent.)

Non-English speaking participants will be included in the study population.

25.0 (3440) Consent Process

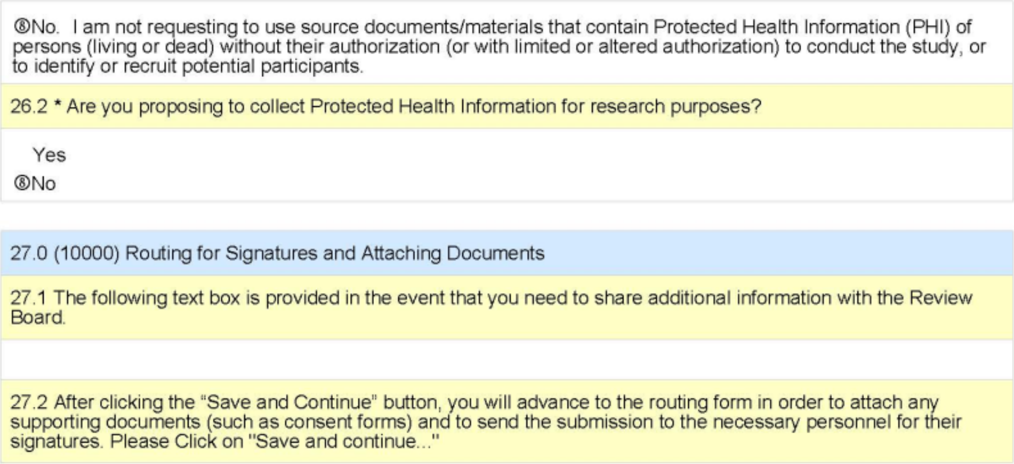
25.1 * Briefly explain when and where informed consent, permission and/or assent will be sought.

Prior to the face-to-face interview, the PI will review the full consent form with the participant, allow time for questions, and have them sign the document.

26.0 (3450) Protected Health Information (PHI)

26.1 * In order to conduct this research, or to identify or recruit potential participants, are you requesting to use SOURCE DOCUMENTS or SOURCE MATERIALS that contain the Protected Health Information of persons without their authorization (or with their limited authorization) AND/OR are you obtaining Protected Health Information of persons without their authorization (or with their limited authorization), such as through telephone screening? Note: Source documents/materials are documents/materials from which you are going to abstract information in order to conduct this research or to identify or recruit potential participants, for example, a patient's medical record.

Yes. I am requesting to use source documents/materials that contain Protected Health Information (PHI) of persons (living or dead) without their authorization (or with limited or altered authorization) to conduct the study, or to identify or recruit potential participants.



● No. I am not requesting to use source documents/materials that contain Protected Health Information (PHI) of persons (living or dead) without their authorization (or with limited or altered authorization) to conduct the study, or to identify or recruit potential participants.

26.2 * Are you proposing to collect Protected Health Information for research purposes?

Yes

● No

27.0 (10000) Routing for Signatures and Attaching Documents

27.1 The following text box is provided in the event that you need to share additional information with the Review Board.

27.2 After clicking the "Save and Continue" button, you will advance to the routing form in order to attach any supporting documents (such as consent forms) and to send the submission to the necessary personnel for their signatures. Please Click on "Save and continue..."

Vita

Shirleen Denise Chase was born in California and has spent over 20 years living and practicing as a Registered Nurse in Tennessee. She began her career in nursing after obtaining a nursing degree from the LAC/USC School of Nursing in Los Angeles. Her education endeavors took her to California State University in Fullerton where she obtained an undergraduate degree and a Master's degree as an Adult Clinical Nurse Specialist from the University of Tennessee Chattanooga. With over 33 years of experience in healthcare, nursing, and education, Shirleen's experience spans a variety of settings. She has worked with oncology services caring for patients across the spectrum of care in both the inpatient and outpatient environments as an advanced practice nurse.

Shirleen's love of teaching and practicing nursing in Tennessee was the catalyst for her journey and doctoral work. She started in the PhD program at the University of Tennessee, Knoxville in 2012, receiving a post-maters certificate in nursing education in 2016. This doctoral dissertation fulfills the completion of a doctoral degree in nursing from the University of Tennessee, Knoxville in 2017.