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# The Inclusion of the Care of the Cancer Survivor in Undergraduate Nursing Curricula

Mary E. Dietmann



# THE INCLUSION OF THE CARE OF THE CANCER SURVIVOR IN UNDERGRADUATE NURSING CURRICULA

BY

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A dissertation Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree of Doctorate in Education

Southern Connecticut State University New Haven, Connecticut December 2015 ProQuest Number: 10013295

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# Abstract

As the number of individuals surviving cancer continues to rise, short and long term effects of cancer and its treatment that result in physical, psychosocial, and spiritual needs unique to the care of the cancer survivor has not been addressed in nursing curricula. The Institute of Medicine (IOM, 2005) recommends that all health care providers are educated on the care of cancer survivors. Nurses in all areas of practice will provide care for cancer survivors. This descriptive qualitative study explored faculty beliefs and practices regarding the inclusion of caring for the cancer survivor in undergraduate nursing curricula. Faculty knowledge of the term "cancer survivor" and their beliefs and practices regarding the placement of theory and clinical experiences on cancer survivorship were explored. Qualitative content analysis revealed themes and patterns related to the barriers and facilitators for disseminating information on the gap in content on care of the cancer survivor.

Keywords: Cancer Survivor, Cancer Survivorship, Nursing Education on Cancer Survivorship, Nurse Faculty Beliefs on Cancer Survivorship Education, Nurse Faculty Teaching Practices on Cancer Survivorship Education

To my family who have supported me through this journey: my husband Carey for his willingness to do more than his share without complaint, my son Christopher who often studied parallel to me during his own journey through law school and the bar, and my daughter Laura who is currently immersed in doctoral work of her own. This is dedicated to you, my loves, who have believed in me forever.

#### **ACKNOWLEDGEMENTS**

First and foremost, I would like to acknowledge my Committee Chair and Primary Advisor for this dissertation, Dr. Elizabeth Ercolano. Dr. Ercolano's advice and knowledge of the needs of cancer survivors inspired me to immerse myself in this research study. It is with sincere gratitude that I acknowledge the hours of guidance and support in the preparation of this study, her review and guidance during data collection and analysis in order to ensure rigor, and in the diligent preparation of the final document.

My second reader, Dr. Mary Ellen Doherty, must be acknowledged for her expertise as a qualitative researcher who shared the wealth of her research experience in a generous manner with unwavering support. Dr. Doherty's proficiency as a qualitative researcher was instrumental in her role as a research methods expert. Dr. Elaine Martin, my third reader, provided consistent support at any time of the day or night. Her practical resources for doctoral students in the dissertation phase of their education are very much appreciated. I have truly been blessed with a Committee of caring individuals who were instrumental in making this dissertation possible.

I would also like to acknowledge the Program Chairs of the Doctorate in Nursing Education Program (Ed.D.) from Southern Connecticut State University (SCSU) and Western Connecticut State University (WCSU). Dr. Barbara Aronson not only serves as

SCSU's Ed.D. in Nursing Education Program Coordinator but she has also served as my advisor since I began my program of studies at SCSU. Her unwavering support over the last several years means more to me than I can say. Dr. Ellen Abate, who serves as WCSU's Ed.D. in Nursing Education Program Coordinator has also encouraged and supported me through my program of studies and the dissertation process. Dr. Lisa Rebeschi, Chair of the Nursing Department of SCSU is especially recognized for taking the time to read every word of my proposal and to provide expert advice that is so greatly appreciated. I realize how fortunate I am to have had so many highly qualified faculty researchers engaged in the development of my dissertation. Your belief in the importance of this research in nursing education illustrates nursing faculty who are cognizant of the contemporary health care needs of our society.

Acknowledgement of the study participants is essential, even though I am unable to identify who they are. These nurse educators were very generous with their time by agreeing to meet with me and share their experiences. I am humbled by their generosity of spirit and their willingness to share their experiences for the purpose of this study.

Finally, I would like to acknowledge my family and friends for their unending support during this process. A special acknowledgement to my dear friend Mary Ellen Baus, who lost her courageous battle with breast cancer during the writing of this dissertation and who encouraged me to keep writing as the unimaginable occurred. Lastly, I must acknowledge my faithful canine companions, Molly and Meadow. Not one word of this dissertation has been written without their presence at my side.

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# **CHAPTER I**

## INTRODUCTION

## **Statement of the Problem**

While more people are being diagnosed with cancer at earlier stages and surviving cancer for longer periods of time than ever before, nurses are ill prepared to deal with the unique concerns that cancer survivors face on a daily basis. It is estimated that there are nearly 14.5 million cancer survivors in the United States who require follow-up for the detection of recurrences and new primary tumors, diagnosis and treatment for the late effects of cancer treatments (Chubak et al., 2012; DeSantis et al., 2014). Additionally, cancer survivors require nursing interventions for the maintenance of appropriate selfcare for residual impairments that result from cancer treatments, address health problems unrelated to cancer, and promote healthy behaviors, especially those that reduce cancer risks (Chubak et al., 2012). This growing population of cancer survivors with their unique health care needs must be addressed in the education of nurses. The Institute of Medicine's (IOM) report (2005) From Cancer Patient to Cancer Survivor: Lost in Transition recognizes the need for research in care that is provided to cancer survivors by health professionals. The IOM identified cancer survivorship care as content that should be included in the education of nurses as well as other disciplines including physicians, rehabilitation specialists, and psychosocial and mental health providers. Most nursing students receive little or no education on the specific health care needs of cancer

survivors in their undergraduate curricula (Klemp, Frazier, Glennon, Trunecek, & Irwin, 2011).

In 1986, the National Coalition for Cancer Survivorship (NCCS) was formed by 23 founding members who redefined the term *cancer survivor* from an individual who remained cancer free for five years to an individual who is a survivor from the moment of diagnosis throughout their lifespan (Rowland, Hewitt, & Ganz, 2006). It was the intent of the founders of the NCCS to give recognition to survivorship as a continuum of cancer control and recognize that different needs may be experienced during the "seasons of survivorship" (Rowland et al., 2006).

The definition of a cancer survivor is now widely recognized as an individual who has been diagnosed with cancer and is still living. The individual is a "survivor" from the day that they are diagnosed, as they are surviving their disease (Morgan, 2009). Three distinct phases of survivorship have been identified. The acute stage is the time surrounding initial diagnosis where staging is done and treatment decisions are made and initiated. The extended stage begins when intense treatment is completed and the patient enters possible remission. The permanent stage of survivorship is defined as achievement of a cure or extended or long-term survival (Morgan, 2009). Within each stage the individual experiences physical and psychosocial effects that result from their cancer diagnosis and treatment.

# The Purpose

The purpose of this study was to explore faculty beliefs and teaching practices regarding the inclusion of cancer survivorship care in nursing curricula. This study identified and validated a gap in content in the care of cancer survivors in undergraduate

U.S. nursing programs. The exploration of faculty beliefs regarding the importance of teaching students about the unique needs of cancer survivors provided insight into the curricular gap on cancer survivorship content in nursing education.

The literature has provided research on the health care needs of cancer survivors and studies related to the lack of knowledge among nurses regarding survivorship issues. There was a need to investigate whether the health care needs of cancer survivors were being addressed in nursing curricula, both in the classroom and clinical settings. As a profession, nurses are uniquely qualified to care for cancer survivors who are coping with a variety of issues unique to survivorship. Ferrell, Virani, Smith, and Juarez (2003) describe the need for nurses to address physical burdens (fatigue, menopausal symptoms, nutrition, sleep disturbances, short and long-term physical sequelae of treatment), psychological concerns (fear, anxiety, depression, uncertainty), social concerns (sexuality, fertility, appearance, and counseling of partners and children, economics and employment), and spiritual care (respect for diversity, hope, uncertainty, and meaning in illness).

There are many implications of care of the cancer survivor's current status of development on nursing practice, research, and knowledge development. Cancer survivorship care plans (CSCPs) are utilized in nursing practice to address the cancer survivor's long-term care needs that are related to the type of cancer the individual had, the treatment received along with its potential side effects, and recommendations for follow-up (Morgan, 2009). While patients are actively being treated for cancer nurses are cognizant of treatment side effects, however, long-term side effects of treatment are less likely to be addressed by nurses in practice. This is an area of research that has been

identified by the IOM (2005) as one that is necessary to increase knowledge development not only in nurses but also in other health professions that care for cancer survivors. Other components of the CSCP address preventive practices, how to maintain health and well being, information on legal protections related to employment and health insurance, and psychosocial concerns (Morgan, 2009). Nurses are in a unique position to counsel cancer survivors on the beneficial effects of exercise in reducing breast cancer recurrence or dietary choices that may reduce one's risk of certain types of cancers. Nurses are qualified to lead a multidisciplinary team approach to cancer survivorship care with a variety of healthcare providers.

The IOM report (2005) included the following recommendations, which have implications for nursing practice, research, and knowledge development: healthcare providers must increase awareness of the needs of cancer survivors, establishing and providing appropriate care to cancer survivors as a distinct stage of cancer care; providers should coordinate a survivorship care plan that is reimbursed by third-party payers to provide to all patients; evidence-based clinical practice guidelines for healthcare providers should be used, developed, and refined to assist in identifying and managing late effects of cancer and cancer treatment; expansion and coordination of educational efforts for providers by the National Cancer Institute (NCI), professional associations, and voluntary organizations will increase quality of care to cancer survivors; there is an urgent need for new research initiatives that are focused on cancer survivorship care.

# **Research Questions**

The following research questions were explored in this qualitative descriptive study:

- 1. How do faculty describe the concept of cancer survivorship care?
- 2. How do faculty describe the inclusion of cancer survivorship care within the undergraduate nursing curriculum?
- 3. What academic or clinical literature about cancer survivorship care is included in the nursing program?
- 4. What types of clinical sites are used to provide nursing students with learning opportunities regarding cancer survivorship care?
- 5. What do faculty believe are barriers and facilitators to the inclusion of curriculum on care of the cancer survivor?

# **Significance**

As of January 1, 2014 nearly 14.5 million Americans were identified as cancer survivors. This number is expected to increase by January, 2024 to nearly 19 million cancer survivors (DeSantis et al., 2014). Due to the increasing numbers of cancer survivors and the unique short and long-term health care needs of this population, it is essential that nurses are provided with education beginning at the undergraduate level. Nurses in all areas of practice will provide care for a patient who is a cancer survivor. Recognizing that individuals have concerns that may be physical, psychosocial, and spiritual that is related to cancer survivorship is essential in providing comprehensive nursing care. Nurses are in a unique position to help survivors cope with physiologic and psychological well being (Ferrell et al., 2003).

Early effects of cancer treatment that survivors may experience include acute physical side effects from treatment along with anxiety and fear of death. Physical side

effects can include acute and chronic pain from surgical interventions, hair loss, nausea and vomiting as well as other gastrointestinal symptoms from chemotherapy.

Chemotherapy can also cause bone marrow suppression placing the patient at risk for life threatening sepsis, anemia, and thrombocytopenia. Fatigue can result from surgical interventions, chemotherapy and radiation therapy. Radiation and surgery may also cause physical disfigurement that may change body image early on and continue to be problematic as a late effect of cancer treatment. Social isolation and sexual dysfunction may result from physical disfigurement (Morgan, 2009).

Late effects of cancer treatment that survivors, particularly of childhood cancers, may experience include cognitive impairment after treatment to the central nervous system, changes in hearing or vision, impairment in growth and development, thyroid dysfunction, respiratory or cardiac problems, second malignancies, and impaired fertility (Lally, 2007). Late effects that may occur in adults or children include fear of recurrence, anxiety, lymphedema, development of secondary cancers, body image disturbance and infertility.

Physical effects that most commonly occur are pain and fatigue. Psychosocial concerns such as uncertainty about the future and difficulty in making long-term plans is common, along with changes in body image that are often permanent. Employment and insurance problems may persist as survivors find it impossible to purchase a life insurance policy for their families, or are passed over for a promotion at work, as they may be perceived as not being "up for the challenge". This is a form of discrimination that cancer survivors have described which make them feel vulnerable long after they have been told that their treatment has been successful and their cancer is in remission

(Morgan, 2009). Uncertainty is a major area of concern for cancer survivors, which can affect many areas of daily life including anxiety that can affect quality of life. Quality of life issues specific to cancer survivors that have been identified include issues related to fertility, genetic counseling, and testing for hereditary cancer genes that may influence treatment decisions (Morgan, 2009). To care for these effects across the continuum, Morgan (2009) identifies four essential components of care of the cancer survivor that are prevention, surveillance, intervention and coordination. This further supports that nurses must be educated at the undergraduate level on care of the cancer survivor.

Placing the cancer experience into the context of one's life includes coming to terms with the changes that have resulted from the disease or treatment. Examples include ongoing or new symptoms such as pain or numbness in a body part from surgical intervention, sexual dysfunction resulting from cancer treatment, alterations in body image which impact lifestyle, employment, relationships, and self-concept (Klimmek & Wenzel, 2012). The strain on intimate relationships and marriages from sexual dysfunction can cause a significant amount of conflict in the relationship. Friendships and family relationships may change, as the cancer survivor feels socially isolated from others who have not experienced the same life-altering changes. To friends and loved ones, the survivor often looks like the same person he or she was prior to cancer. To the survivor, they may describe feeling forever changed by the experience of having cancer and have difficulty expressing these thoughts to family and friends who have moved on from the cancer experience. Returning to work after treatment may be difficult due to fatigue and difficulty in concentrating (Klimmek & Wenzel, 2012).

# **Definition of Terms**

Cancer survivorship- "Survivorship encompasses the time of diagnosis through the balance of life and includes family, friends, and caregivers" (Edgington & Morgan, 2011, p. E3).

Survivorship care-includes 4 components 1) prevention and detection of new or recurrent cancers; 2) surveillance for cancer spread, recurrence, or second cancers, 3) intervention for consequences of cancer and its treatment and 4) coordination between professionals to ensure the survivor's health care needs are met (IOM, 2005).

Curriculum on care of the cancer survivor- Content areas in undergraduate BSN nursing program that includes "a description of the population of cancer survivors, primary care, short-and long-term complications, prevention of secondary cancer, detecting recurrent and secondary cancers, treatment of recurrent cancer, quality-of-life issues, rehabilitative services, palliative and end-of-life care, and quality of care" (Ferrell et al., 2003, E1).

Nursing faculty-A nurse educator who teaches undergraduate nursing students.

Nursing student-A student who is enrolled in an undergraduate baccalaureate nursing

*Inpatient clinical placements*-A facility where patients are admitted for health care, this includes acute and long-term care facilities.

program.

Community clinical placements-A setting where health care is delivered to patients in the community. This includes a home care setting or outpatient services delivered in a cancer center

# **Delimitations/Assumptions**

The time frame for this study was from March 2015 through May 2015. The study was conducted through face-to-face interviews of baccalaureate nursing faculty who agreed to participate in the study after receiving a Letter of Information To Consent To Participate In Research. The study sample consisted of fourteen undergraduate nursing faculty who were identified by the principal investigator as non-administrative faculty. Participants also consisted of faculty who taught in undergraduate baccalaureate nursing programs by the College or University website for all nursing programs searched in two northeastern states within a two hour driving radius for the principal investigator. Faculty members who taught only in graduate nursing programs or who were identified as administrators were not included to receive a Letter of Information to Consent To Participate In Research for this study.

This study assumed that cancer survivorship is a necessary area of content for inclusion in undergraduate nursing curricula. In addition, care of the cancer survivor requires specialized care, knowledge, skills, and attitudes. This study assumed that student beliefs regarding care of the cancer survivor can be transformed with nursing education. There are barriers and facilitators faculty may face around inclusion of cancer survivorship care in the curriculum.

# **Organization of the Study**

The remainder of the study contains four additional chapters which include the Literature Review, Methodology, Results and Findings, and a Summary with Conclusions, Implications, and Recommendations. References and Appendixes will follow the chapters.

## **Theoretical Framework**

The theoretical framework that guides this study is Jack Mezirow's transformational learning theory. Transformational learning is an adult learning theory that describes how adults learn to reason for themselves by making their own judgments (Mezirow & Taylor, 2009). For example, many individuals may believe that cancer is an illness, that once treated, resolves the problem and that the patient requires the same routine health care needs of those who are not cancer survivors. Studies support that cancer survivors have unique physical, psychosocial, and spiritual needs that must be addressed by health care professionals. Educators must provide learning opportunities to transform beliefs of students as to the essential needs of cancer survivors. These transformations involve reframing points of view through objective means such as critical reflection and problem solving or by subjective means such as self-reflection. When adults critically reflect on a problem it transforms the frame of reference once critical reflection occurs (Mezirow & Taylor, 2009). It may change the way educators present the care of the patient who is a cancer survivor, from the day of diagnosis throughout their life's journey. Many educators may not believe the inclusion of care of the cancer survivor is critical to undergraduate nursing content, which is why it was important to investigate nurse faculty's beliefs about teaching cancer survivorship content. In this case, the nurse educator must look at their own frame of reference in regard to the needs of cancer survivors and the inclusion of this content in undergraduate nursing curriculum.

Mezirow's transformational learning theory was used to explore one's frame of reference or prior experience with individuals who are cancer survivors and to learn if

these experiences have transformed their teaching practices. Prior experiences of the learner is the core element "individual experience" in transformative learning that describes what each learner brings to the classroom as a starting point. Discourse leads to critical examination of these prior experiences. Educators will stimulate and create classroom activities that will cause the learners to reflect on new ideas based on the experiences that the educator brings to the classroom. For example, the educator will define the cancer survivor as one who is diagnosed with cancer and that they are considered a survivor from the moment of diagnosis throughout the lifespan. The degree of life experience is significant in transformative learning as the more experiences an individual has to draw on the more the learner is able to engage in dialogue and reflection (Mezirow & Taylor, 2009). The educator must develop learning activities for the classroom that are both individual and group experiences in order to foster critical reflection and dialogue. The learning activities should be experiential in nature and should provoke a "disorienting dilemma" which, in turn, provokes critical reflection and transformative learning. For example, many people still believe that a cancer survivor is someone who has "beat cancer" and is considered "cured". Critical reflection and dialogue in the classroom are provided by the prior experiences of the learners as well as classroom activities, readings, and relationships (Mezirow & Taylor, 2009). New perspectives will be gained from the interdependency between experience and critical reflection.

Promoting critical reflection among learners is another core element essential to transformative learning and widely recognized in adult learning theories. Critical reflection is evoked when learners become aware of conflicting thoughts, feelings and

actions. It causes the learner to question their previously held assumptions and beliefs that they have built on previous experiences. Transformation of meaning perspectives can occur through three forms of reflection: "content (reflecting on what we perceive, think, feel, and act), process (reflecting on how we perform the functions of perceiving), and premise (an awareness of why we perceive)" (Mezirow & Taylor, 2009, p. 7). Critical reflection of assumptions (CRA) plays a major role in transformational learning theory and is vital to adult learning (Mezirow, 1998). CRA can mean different things to adult learners but ultimately results in awareness of one's self. This awareness includes thoughts, perceptions, and feelings that involve how adults have built their assumptions (Mezirow, 1998). The environment must be supportive to enhance reflection, which is an active process. Since clinical settings are often fast paced and unpredictable, it can be difficult to engage in critical reflection and problem solving. The support of faculty and resources such as computer programs for medication and policy information is necessary in order for learning experiences to be valuable (Plack, Dunfee, Rindflesch, & Driscoll, 2008). The ability to dialogue in post-conference in addition to reflective journaling about the learning activities can assist students in fully appreciating the learning that has occurred during clinical experiences. Nurses are encouraged to critique, understand, and value new learning experiences that relate to their practice in a way that is personally and professionally meaningful (Matthew-Maich, Ploeg, Jack, & Dobbins, 2010).

Dialogue with self and others promotes and develops transformative learning while building on critical reflection. Dialogue is the process for which critical reflection occurs by emphasizing "relational and trustful communication" that is often times "highly personal and self-disclosing" (Mezirow & Taylor, 2009). The process of

engagement in dialogue involves a revelation and resulting change in attitudes, feelings, and preferences (Mezirow & Taylor, 2009). Trust is developed during this process with others. When what is communicated to us conflicts with our assumptions a "dialectical process of discourse" is engaged with others to share their experiences. Critical reflection of the evidence presented and assumptions regarding the arguments leads to a new meaning perspective (Mezirow, 1996). Ensuring that students have opportunities to reflect on the care of cancer survivors in the clinical area will transform their perceptions on the needs of cancer survivors.

One does not need to place a nursing student in an inpatient oncology unit or outpatient cancer center to provide exposure to cancer survivors. Cancer survivors are present in all health care settings. Consider the patient who comes into the outpatient suite for a routine colonoscopy and the nurse notes an elevated blood pressure, pulse, and symptoms of anxiety. The patient has a history of breast cancer treated six years ago and when taking a health history tells the nurse that besides breast cancer she has no other significant health history. Upon critical reflection, one would hope that the nurse would open a discussion with the patient regarding her elevated blood pressure, pulse, and anxiety which could very likely lead to a conversation about routine screenings and the anxiety that results from any type of routine cancer screenings in this population of patient. This patient may relay her story of how her cancer was diagnosed after a routine mammogram and how she has read that there is a correlation between people who have had breast cancer and an increased incidence of colon cancer.

Application of Mezirow's transformational learning theory to the inclusion of the care of cancer survivors is nonexistent in educational literature. However, Such Lockhart

et al. (2013) explored the depth of oncology nursing content taught in prelicensure nursing curricula, the perceived importance of oncology nursing content, barriers to providing oncology-related content, and use of resources that were oncology-related (Such Lockhart et al., 2013). In this national survey of prelicensure nursing faculty, cancer survivorship content was rated amongst the lowest in relation to depth and importance of oncology content (Such Lockhart et al., 2013). Some faculty responses indicated that lack of time to include survivorship content was a barrier. Having faculty reflect on what is currently being taught in their curriculum on cancer survivorship and what they believe should be taught in the curriculum on this concept as directed by a framework such as Mezirow's allows for an opportunity for critical reflection to change meaning perspectives and increase the amount of time given to this important curricular content

# Summary

Cancer survivors are a growing population of individuals who require unique follow up care that includes physical, psychosocial and spiritual components of health. Nurses in all areas of practice will be involved in the care of cancer survivors. However, it is not known the extent to which faculty include content on cancer survivorship (Such Lockhart et al., 2013). Therefore, this study's purpose was to explore nursing faculty beliefs and practices regarding the inclusion of care of the cancer survivor in undergraduate nursing curricula. Potential barriers to the inclusion of care of the cancer survivor content in undergraduate nursing curricula were also explored. Mezirow's theoretical framework served as a guide in transforming views of the healthcare needs of

cancer survivors, and the role that nurses in all areas of practice have in caring for these patients (Matthew-Maich et al., 2010; Mezirow, 1998; Plack et al., 2008).

# **CHAPTER II**

# REVIEW OF LITERATURE

## Introduction

The literature review began with a search of EBSCO and CINAHL for keywords that included "cancer survivor", "cancer survivorship", "cancer survivorship and nursing education", and "educating nurses on cancer survivorship". Results revealed a significant amount of studies on nursing and interprofessional care and cancer survivorship but there is a paucity of information in the literature on inclusion of care of the cancer survivor in nursing education curricula. A ProQuest Dissertation search of "nursing education and cancer survivorship" revealed no results.

The initial emergence of the concept of cancer survivorship, while probably rooted in the signing of the National Cancer Act in 1971 which was aimed at progress in cancer prevention and control, is thought to have been launched in the U.S. in the 1980's related to two events. The first event occurred in 1985 when a young physician named Dr. Fitzhugh Mullan published a description of his journey with cancer in the *New England Journal of Medicine* titled "Seasons of Survival." In 1986, the National Coalition for Cancer Survivorship (NCCS) was created by Mullan and two dozen founding members who proposed a new definition for the term cancer survivor (Rowland et al., 2013). Prior to the formation of the NCCS, the accepted definition of a cancer survivor in the medical community was one who had been disease-free for a minimum of

five years since diagnosis. The members of the NCCS rationalized that patients with cancer could not wait five years to make decisions regarding treatment choices that might affect them with long-term outcomes such as infertility, or treatments that alter lung capacity or cause peripheral neuropathies (Rowland et al., 2013). Thus, the founders of the NCCS proposed that an individual with cancer should be considered a cancer survivor from the time of diagnosis onward. It was thought that this change in definition would promote hope and the realization that treatment decisions should be made with the patient's awareness of unique needs that may be necessary once initial treatment for the cancer is completed.

Growth has occurred in the field of cancer survivorship in the U.S. through the establishment of the Office of Cancer Survivorship (OCS) at the National Cancer Institute (NCI) in 1996 to increase research on long-term effects of cancer. The American Cancer Society (ACS), President's Cancer Panel, and many private foundations have also dedicated resources to researching the unique needs of cancer survivors (Rowland et al., 2013).

The sample of literature to be analyzed includes literature obtained from the disciplines of nursing, medicine, physical therapy, and psychology. The time frame for the literature search is articles published within the last ten years to ensure that current beliefs about care of the cancer survivor are summarized. The care of cancer survivors is interprofessional, requiring literature from multiple disciplines. The care of cancer survivors requires involvement from disciplines that include, but are not limited to nursing, medicine, social work, psychology, physical rehabilitation, complementary

modality therapists and nutritional therapists. Involvement of interprofessional care provides for a holistic approach to care of cancer survivors.

The format for this literature review will be organized based on three themes that are relevant to this study. The themes include Nursing Implications in Cancer Survivorship Care, Interprofessional Care of Cancer Survivors, and Implications for Nursing Faculty.

# **Nursing Implications in Cancer Survivorship Care**

Cancer survivorship care encompasses four components: prevention and detection of new and recurrent cancers; surveillance for cancer spread, recurrence, or second cancers; intervention for consequences of cancer and its treatment; and coordination between specialists and primary care providers to ensure that the health needs of the survivor are met (Chubak et al., 2012; IOM, 2005). The attention that cancer survivorship care has been receiving is due in large part to the numbers of individuals surviving cancer. Boyle (2006) identifies psychosocial correlates of surviving cancer, which include loss and grief, recurrence anxiety, isolation and abandonment, transitional crisis, difficulty with reentry and work, reevaluating life priorities, and family coping difficulties. Long-term psychosocial and physical needs of adult and childhood cancer survivors are being addressed in practice as post-treatment sequelae research advances (Rowland, Hewitt, & Ganz, 2006). Rowland et al. (2013) reviewed the history of cancer survivorship research in the United States (U.S.) and Europe. This review noted many accomplishments in both the U.S. and Europe along with many challenges to increase research on cancer survivorship. Of note is the authors' recommendation to increase

collaborative efforts between the U.S. and Europe in the hope of implementing interventions that will improve the health and well being of cancer survivors globally.

The nursing role in the care of cancer survivors is critical. Ferrell et al., (2003) collected data on the inclusion of content areas for cancer survivorship in nursing. Ten areas of cancer survivorship content were considered critical for data synthesis and analysis. These areas include: describing the population of cancer survivors, primary care, complications that are short-and long-term, preventing secondary cancers, detection of a recurrent or second cancer, treatment of a recurrent cancer, issues related to quality-of-life, rehabilitative services, palliative and end-of-life care, and quality of care (Ferrell et al., 2003). Sociocultural concerns for the cancer survivor addressed by Ferrell et al. (2003) include sexuality, fertility, appearance, and counseling of partners and children. In addition, the financial burden of cancer treatment and employment concerns may extend into a prolonged adjustment period.

Ferrell et al. (2003) acknowledged how critical nursing care is to the quality of care a cancer survivor experiences. The article recognized the contributions made by nurses as significant but states that the gaps in care are serious and must be addressed to ensure the quality of care required to meet the needs of cancer survivors. This study supports the role of the nurse and the importance of nursing care that is specific to the needs of the cancer survivor. This study was limited to adult survivorship; there are significant additional needs to be addressed in survivors of childhood cancers. The authors acknowledged that support is needed for expansion on education and research to ensure quality care for future survivors (Ferrell et al., 2003).

Holistic needs following treatment for colorectal cancer were assessed to identify cancer survivors physical, emotional and spiritual needs (Taylor, Cummings, & McGilly, 2012). The authors identified common physical complaints after treatment for colorectal cancer such as fatigue, gastrointestinal problems, urinary incontinence or sexual dysfunction, as well as psychological complaints including fear of recurrence, anxiety, depression or change in body image. This study examined all aspects of a cancer survivor's life through the administration of a holistic needs assessment tool, which consisted of two parts. The first part of the tool measured distress on a visual scale from 0 to 10 (0 equal to no distress, 10 equal to high distress), while the second part was a standard checklist, which asked if the patient had experienced any of 14 concerns on the list within the past week. Data analysis revealed seventeen different types of identified needs by patients, with the most commonly listed as bowel function (diarrhea), pain, fear of recurrence, diet, fatigue, and concentration/memory. Referrals to dieticians, primary health care providers, educational programs, sexual therapists, support groups, physical therapists and counselors were made based on the results of the holistic needs assessment (Taylor et al., 2012).

In a study of prostate cancer survivors, Colella and Gejerman (2013) reported that as prostate cancer survivors who have undergone radiation treatment increased, those who will experience the chronic side effects associated with radiation therapy will also increase. These side effects usually included urinary incontinence, bowel dysfunction, and sexual dysfunction. This study examined if the use of survivorship discharge health information counseling that included patient health information preferences improved satisfaction when compared to usual discharge health information. Fifty-two patients

participated in the study. Thirty-two men did not receive the survivorship intervention but received the usual care and health counseling given at the end of radiation treatment followed by a Patient Satisfaction Questionnaire. Twenty men received the survivorship intervention through attendance at a 45-minute individual counseling session with an advanced practice registered nurse (APRN) during their last week or radiation treatment. The patients also received health information fact sheets on "Managing Symptoms after Prostate Cancer", along with a copy of a written survivorship health information packet with community resources. This group also completed the Patient Satisfaction Survey. The Patient Satisfaction Questionnaire was supported for content and construct validity. Findings showed significantly higher satisfaction scores for those who received the survivorship discharge health information counseling program, which included patient health information preferences. Colella and Gejerman (2013) recommended health information discharge counseling as a strategy to meet the IOM recommendations for cancer survivorship care.

Cancer survivorship and breast cancer has been studied as a complex disease that affects survivors, requiring customized survivorship care plans (Singh-Carlson, Wong, Martin, & Nguyen, 2013). This study examined South Asian women with breast cancer living in Canada, where there is a large population of South Asians. Sixty eligible participants were chosen from 127 potential participants to examine social and cultural aspects of South Asian women's survivorship experience. This qualitative descriptive study explored participants' experiences with breast cancer survivorship in relation to cultural, religious, social and individual practices and beliefs after treatment for their breast cancer in relation to the context of personal meanings for health and illness. Data

was gathered through interviews that were semi structured, including group and one-toone interviews. The following themes were identified as "universal" from the data
collected by Singh-Carlson et al. (2013): physical sequelae including fatigue, changes in
cognition, loss of libido, nerve damage and pain, reproductive or pregnancy issues,
psychosocial impact including altered sexuality or body image, depression, fear of
recurrence, intimacy and difficulties with relationships. The themes that were identified
as "unique" to South Asian women by Singh-Carlson et al. (2013) included quiet
acceptance concepts such as faith, inner strength, and karma. Quiet (social network
context), family and community, hounsla (hope and courage), and peer support were
other unique themes identified by South Asian women. The authors stressed the
importance of individualizing survivorship care to include cultural knowledge within the
care plan that is meaningful for that patient's quality of life.

Partridge (2013) emphasized the unique survivorship experience that the young breast cancer patient experiences. Physical and emotional changes that occur in young women include early onset of menopause resulting in vaginal dryness, night sweats, hot flashes, decreased fertility and sexual drive. Other consequences of breast cancer treatment that the young breast cancer patient may encounter include weight gain, fatigue, sleep disturbance, reduced bone mineral density with risk of osteoporosis development and increased cardiovascular disease risk (Partridge, 2013). Emotionally, depression and anxiety over diagnosis, treatment, and side effects are very common in young women. Partridge (2013) described gaps in care for this young group of survivors who also need individualized survivorship care planning.

Knobf and Coviello (2011) explored lifestyle interventions to reduce cardiovascular risk in women with breast cancer. The leading cause of death in women is cardiovascular disease and breast cancer survivors have been cited to have a higher risk of cardiovascular disease than breast cancer recurrence among breast cancer survivors. One of the nonmodifiable risk factors that breast cancer survivors may experience is cardiotoxicity associated with adjuvant chemotherapy. Modifiable risk factors include obesity, abdominal adiposity, smoking, lack of exercise, hypertension, impaired glucose tolerance and high cholesterol. Healthy eating and regular exercise are lifestyle interventions that can modify these risk factors for breast cancer survivors (Knobf & Coviello, 2011). Dietary interventions to reduce cardiovascular risk and diabetes include increased whole grains and legumes, fruits and vegetables while limiting red meat, processed meats, alcohol and sugar sweetened beverages. In this article, aerobic exercise is recommended for 30 minutes per day, five days per week, to improve blood pressure, insulin sensitivity, and cardio-respiratory fitness (Knobf & Coviello, 2011).

Shigaki, Madsen, Wanchai, Stewart, and Armer (2013) studied the long-term effects of lymphedema in breast cancer survivors, using objective limb measurements and analyses that revealed significant difficulty reported in domestic environment activities. The authors of this study reported a wide range in incidence of lymphedema among breast cancer survivors in their review of the literature. Quality of life has been reported by women as decreased due to the development of lymphedema (Shigaki et al., 2013). Participants in this study were chosen from a National Institutes of Health (NIH) funded parent study on lymphedema. The participants had preoperative limb volume measurement data available and had returned for five-year follow-up and were willing to

complete a psychosocial survey. Sixty-one participants comprised the sample size and of those participants forty percent met the criteria for lymphedema at the time of assessment. Additionally, more than half of the participants had experienced lymphedema at some point since initial treatment. The results of this study did not support the researchers' hypothesis that upper extremity lymphedema would have a negative impact on functioning across multiple environments. The findings of the psychosocial survey suggested that lymphedema is less of a barrier than the authors anticipated, except when it came to activities that involved domestic functioning (Shigaki et al., 2013).

Childhood cancer survivors have an increased risk of future health problems including impairment in cognitive function following central nervous system treatment, changes in hearing and vision, impaired growth and development, thyroid dysfunction, cardiac or respiratory dysfunction, second cancers, and impairment of fertility (Lally, 2007). This increased risk makes regular monitoring of children essential for long-term follow-up. Missed appointments can result in a missed opportunity to detect a health problem earlier rather than later. Lally (2007) provided an example of long-term follow-up care at St. Jude Children's Research Hospitals After Completion Therapy (ACT) Clinic in Memphis, TN for survivors of pediatric cancers. The clinic provides education on controlling weight, exercising, and healthy eating and lifestyle behaviors. Other services provided by the ACT clinic include helping children and teenagers determine how to balance their strength and limitations caused by cancer treatment and fatigue, creating life balance, managing stress, career counseling, taking responsibility for their own health and the importance of healthy physical and emotional lifestyles (Lally, 2007).

Comorbidities in cancer survivors are another area of concern from late effects of treatment that nurses must be cognizant of (Curcio, Lambe, Schneider, & Khan, 2012; Edgington & Morgan, 2011). As time passes from the end of active treatment from cancer the shift of survivor health focuses on common comorbidities that include diabetes mellitus, obesity, dyslipidemia, menopausal symptoms with related osteoporosis, hypothyroidism and hypertension. These comorbid conditions often develop as a result of primary treatment of cancer, which in turn cause serious health consequences that may even lead to secondary cancers, heart disease, and stroke.

Curcio et al. (2012) implemented and evaluated a cancer survivorship protocol to decrease anxiety in survivors and increase knowledge about their cancer experience. A knowledge questionnaire was used to measure baseline knowledge and the Generalized Anxiety Disorder seven-item scale was used to measure the respondents' ability to control worrying, nervousness, and the ability to relax (Curcio et al., 2012). The survivorship protocol intervention consisted of an individualized survivorship care plan developed in collaboration with a registered nurse, nurse practitioner, and medical oncologist. The nurse practitioner met with the survivor for one hour to review the care plan and answer questions. The patient received a copy of the care plan and a copy was also sent to the patient's primary care provider. Survivors filled out patient satisfaction surveys at the end of the survivorship protocol intervention, then were contacted by telephone by the nurse practitioner that delivered the protocol to reassess their anxiety level, knowledge and answer further questions. Staff and primary care providers also completed satisfaction surveys. Results of this study found that the survivorship protocol improved the participants' knowledge. Overall anxiety scores were low at baseline so

they did not change much when reassessed. Limitations included a small convenience sample of 30 participants and a low response rate on the satisfaction survey from primary care providers (Curcio et al., 2012).

Thewes et al. (2012) conducted an electronic search for instruments to measure fear of cancer recurrence in cancer survivors. Initially 187 abstracts were identified; 36 manuscripts met all inclusion criteria. Twenty relevant multi-item measures were identified for fear of cancer recurrence. Internal and external forms of validity were identified on only a few of the tools, while the psychometric properties revealed that only a few scales had comprehensive data available to the researchers. Thewes et al. (2012) concluded that existing instruments that measure fear of cancer recurrence need further refinement and validation. Instruments that are both valid and reliable are needed for research and clinical practice.

Edgington and Morgan (2011) reported that fear of cancer recurrence often takes precedence over other health care concerns in the cancer survivor. The survivor ignores often times comorbid conditions that survivors are at risk of developing due to treatment. The nurse has an important role in helping survivors manage and understand common comorbidities that result from cancer treatment which include obesity, diabetes, dyslipidemia, menopause, decreased bone mass, hypertension, and hypothyroidism.

Nursing implications in cancer survivorship care are well supported in the literature. It is clear that nurses are a vital component of the interprofessional healthcare team when providing care for this population of patients. Education of nurses should begin at the undergraduate level in order to prepare nurses to work in the range of settings that may deliver care to cancer survivors.

# **Interprofessional Care of Cancer Survivors**

Cooper, Loeb, and Smith (2010) examined continuum of primary care for longterm survivors of breast, prostate, and colorectal cancer survivors by primary care nurse practitioners (NPs). A review of the literature revealed inconsistency in follow-up care once treatment for the cancer was completed. In order to address the gaps in health care that commonly occur when cancer survivors transition from specialist (oncologist) to primary healthcare provider, Cooper et al. (2010) proposed testing two models of care delivery for this population. The first model is the "shared-care model" which includes both specialist and primary care provider when managing patient care. The primary care provider is the main communicator of care but there is significant specialist involvement. The second model is the "nurse-managed health center" which is a primary care center that provides health care services not being met within the community. These centers can have a specific focus such as a nurse-managed oncology center, which is common in countries outside of the U.S. Symptom management of disease and treatments, monitoring for recurrence, and long-term health care needs are managed by nurses to decrease potential complications.

McCorkle et al. (2011) explored self-management (SM) for modeling cancer care that includes the formation of partnerships between patients, families and providers. SM provides the ability for the survivor to partner at all phases of the survivorship experience with their provider. The survivor and family are empowered to develop and achieve their own goals of care through SM interventions. The authors used the Chronic Care Model (CCM) as a paradigm for oncology practices to use as a means of engaging survivors in SM. The CCM promoted productive interactions between patients, families and

providers, enabled and empowered patients through the provision of relevant information, skills, and confidence to engage in SM. The CCM also incorporated practice teams that utilized evidence-based practice in clinical decision-making, a "practice home" or coordinator of care, and the multi-disciplinary, collaborative CSCP. The authors identified a major limitation of SM and CCM in cancer care as a lack of a common language and the difficulty that cancer survivors have in managing their cancer care. Fragmentation of care was also cited due to the number of providers that are often involved in the care of the cancer survivor. There is a need to assess the patient and families' ability and willingness to manage not only their care, but also treatment schedules and the emotional and physical side effects as well as family dynamics (McCorkle et al., 2011).

The psychosocial impact of cancer on survivors was addressed in a study by Hodges and Winstanley (2012) through the recruitment of 102 cancer survivors via 19 online discussion groups. The cross-sectional, correlational design utilized questionnaires that measured the following factors: optimism, social support, coping, health locus of control and cancer worry, with an outcome variable of positive affect. The findings supported that optimism, social support and fighting spirit have a positive affect and significant influence on cancer survivors. Optimism contributed to a strong direct effect that was mediated by fighting spirit and social support. Since greater optimism promotes positive affect, the authors contend that optimism can prevent negative psychological consequences of cancer and maintain positive mood.

Punekar, Short, and Moran (2011) examined the use of psychotropic medications by cancer survivors in the U.S. through data obtained from two large surveys, the

Household Component of the Medical Expenditure Panel Survey (MEPS-HC) and the National Health Interview Survey (NHIS). Approximately seventeen percent of survivors younger than sixty-five years and fifteen percent of survivors sixty-five years and older had purchased at least one psychotropic medication within a year. The most frequent type of psychotropic medication used was an antidepressant, with antianxiety agents being the second most frequent drug type. Cancer survivor's use of psychotropic medications and anxiolytics in both age groups were significantly higher compared with other adults. The authors suggest that the significant higher use of psychotropic medications in cancer survivors supports that cancer has lasting psychological effects on survivors

The care of the cancer survivor is complex and requires a multidisciplinary approach. This has led to the development of a cancer survivorship care plan (CSCP), as recommended by the IOM (Morgan, 2009). The CSCP summarizes treatment and serves as a path for follow-up care and treatment related to long-term effects of cancer. The type of cancer and treatments received with potential side effects and recommendations for follow-up are included on the CSCP. Preventive practices to maintain health and well being along with psychosocial support services are also included. Morgan (2009) identified uncertainty as a major area of concern that needs to be addressed on the CSCP for all cancer survivors. Uncertainty has been closely linked to quality of life, another major area of concern that must be addressed on the CSCP.

Nutritional needs for the cancer survivor vary depending on the individual and their treatment side effects. Some patients are obese prior to treatment or gain weight during treatment due to steroids or the intake of comfort foods. Others may have an

inability to take in nutrients due to gastrointestinal obstructions, difficulty swallowing due to surgery or radiation, changes in taste due to chemotherapy or persistent fatigue (Witham, 2013). These patients may require nutritional supplements or enteral tube feeding. For long-term survivors, there is little data on advice for nutrition for cancer survivors. Witham (2013) recommended that the focus of nutrition for the cancer survivor should be on prevention of new cancers, which includes limiting energy-dense foods, sugary drinks, red meat, processed meat, alcohol, and salt while increasing plantbased nutrients. These recommendations are based on findings that cancer survivors are at a higher risk of developing second primary cancers (Witham, 2013). Studies have linked alcohol intake, body mass index and abdominal obesity to an increased risk of colorectal cancer while a diet high in fiber, fish, calcium and vitamin D has been linked with a decreased risk of colorectal cancer (Witham, 2013). Obesity has also been identified as a modifiable risk factor for the development of breast and colorectal cancers. Therefore, weight reduction is also included in the nutritional plan along with physical activity.

Campbell, Stevenson, and Crank (2012) reported that there is a growing body of research of the benefits of exercise in preventing and managing consequences of cancer treatment. Improved survival and prevention of secondary cancers from engaging in regular physical activity after a cancer diagnosis has also been suggested. Studies of breast, colorectal, and prostate cancer survivors have reported lower mortality and disease progression rates in those who indicate regular physical activity versus those who are inactive (Campbell et al., 2012). While the precise mechanism of how physical activity influences cancer recurrence and mortality is not known, there is ongoing

research on the role of metabolic and sex hormones, growth factors, adiposity, immunology and chronic inflammation.

Irwin et al. (2009) investigated the effects of a six month randomized controlled aerobic exercise intervention with the usual care on body composition in breast cancer survivors. The sample size included seventy-five physically inactive postmenopausal breast cancer survivors through the Yale-New Haven Hospital Tumor Registry. Thirtyseven women were randomly assigned to an exercise group while thirty-eight were randomly assigned to the usual care group. The exercise group participated in gym and home exercise that was of moderate aerobic intensity for 150 minutes per week. The usual care group was instructed to maintain their usual activity. Body composition was assessed at the beginning of the study and at 6 months through dual-energy x-ray absorptiometry (DXA). The participants in the exercise group increased moderate intensity aerobic exercise by 129 minutes per week over and above baseline levels compared with forty-five minutes per week among the usual care participants. Exercisers decreased percent body fat (p=0.0022) and increased in lean mass (p=0.047) (Irwin et al., 2009). The usual care group increased in body fat and decreased in lean mass. Bone mineral density was maintained among the exercise group. The usual care group had a loss of bone mineral density (p=0.043). The authors concluded that moderate intensity aerobic exercise such as brisk walking may reduce the risk of osteoporosis and fractures due to improved bone mass (Irwin et al., 2009). Further study is needed in certain subgroups such as for women taking aromatase inhibitors, which is associated with increased bone loss in breast cancer survivors.

Cancer rehabilitation is a component of the CSCP involving physical therapists as vital members of the multidisciplinary team approach to treating physical impairments and improves function as well as quality of life for cancer survivors (Donofrio Angelucci, 2013). Survivorship models of care have been developed for cancer survivors to help survivors navigate through their rehabilitation process. A popular model of care includes a physical therapy baseline evaluation at diagnosis with follow-up visits at intervals to identify and treat impairments that arise. This is a departure from a more traditional approach where a problem, such as the development of lymphedema, occurs and then the physical therapist is brought in to evaluate and treat the patient. The goal in prospective surveillance is early identification and management of problems in their less severe state (Donofrio Angelucci, 2013).

A review of the interprofessional literature reveals a wealth of information that supports the importance of the involvement of multiple disciplines in the care of cancer survivors. Nurses are uniquely prepared to coordinate and manage a team approach to the care of cancer survivors. Clinical experiences in undergraduate programs that are geared toward survivorship centers would greatly benefit the ability of student nurses to witness first hand how all disciplines are involved in the coordination of care for the survivor.

# **Implications for Nursing Faculty**

## **Cancer Survivorship Education: Descriptive Research**

It is widely accepted that oncology nurses are vital to the care of patients with cancer. What is less clear and sparse in the literature is the education of oncology nurses on the aspects of care that are specific to cancer patients in all stages of survivorship,

including long-term survivorship. Survivorship care from the perspective of the oncology nurse has been studied through a descriptive, cross-sectional study conducted through an online anonymous survey (Irwin, Klemp, Glennon, & Frazier, 2011; Klemp, Frazier, Glennon, Trunecek, & Irwin, 2011). The purpose of the study was to gain understanding of the continuing education needs of oncology nurses about specific survivorship issues and the scope of survivorship care that nurses provide. Approximately 10,000 nurses were selected as a target sample size to provide a sampling error of no greater than 5%, assuming a response rate of approximately 4%. The authors identified a subset of the approximate 37,000 Oncology Nursing Society (ONS) members who had valid email addresses and had indicated part-time or full-time employment for inclusion in the sample. Random selection of 9,664 members were chosen from this group, then 381 members of the ONS's Survivorship Quality of Life & Rehabilitation Special Interest Group were added. Duplicate members were removed which totaled 10,045 members who received an email invitation with the survey purpose and link, along with a statement assuring them that responses would not be individually identifiable (Klemp et al. 2011).

Key characteristics of the sample described included average years of work experience in oncology, age, and that one-third of the sample earned at least a master's degree. Most respondents worked in settings that provided care to cancer patients in extended survival (Klemp et al., 2011). An online questionnaire for reporting self-assessment of 32 knowledge items developed from documents that highlighted essential components of care of the cancer survivor was utilized. Each item was self-rated on a 0 to 5 scale (0=not at all knowledgeable to 5=very knowledgeable). To ensure accuracy of

Armstrong Foundation as well as other cancer survivorship publications were utilized (Klemp et al., 2011). Self-report measures in addition to knowledge of essential components of care included survey items that asked participants to rank their educational needs for a list of 12 survivorship topics. In addition, continuing education preferences and access were assessed along with age, education, work setting characteristics, and survivorship care provided in the work settings of the respondents (Klemp et al., 2011).

Gaps in current oncology nursing practice related to the care of cancer survivors were revealed by the findings of this survey (Irwin et al., 2011; Klemp et al., 2011). The findings support the need for the inclusion of care of the cancer survivor in nursing education. Cancer survivors are not only admitted to oncology units but often have comorbid conditions that are managed in many other health care settings. This requires that nursing care and the role of all nurses evolve to address the special comprehensive needs of cancer survivors (Irwin et al., 2011).

A more recent descriptive, cross-sectional survey of 223 nurses and APRNs in a Midwestern U.S. cancer center reported gaps in knowledge of survivorship care consistent with previous studies (Lester, Wessels, & Jung, 2014). A questionnaire was developed based on concepts from the IOM recommendations to address cancer survivorship care planning and definitions of survivorship concepts. Survey results revealed that while more than 50% of nurses were knowledgeable about acute treatments such as surgery, chemotherapy, and radiation along with side effects of treatments; less than 50% of nurses were knowledgeable about long term effects of treatment such as

lymphedema, vaccinations and the impact on family members. Less than 40% of nurses were knowledgeable about survivor and co-survivor relationships, sexuality, employment issues, and osteoporosis prevention and care. Less than 25% of nurses reported having knowledge of financial and insurance issues, or fertility and genetic risks (Lester, Wessels, & Jung, 2014).

Lester, Wessels, and Jung (2014) suggest that improving both undergraduate and graduate nursing curricula by expanding components of chronic illness to include cancer survivorship will facilitate the education of survivorship care in future oncology nurses. Faculty direction on curriculum development and how much time should be spent on specific disease processes is not provided by the National Council Licensure Examination for RNs test plan (NCLEX-RN) (Lester, Wells & Jung, 2014). This study supports the need for inclusion of cancer survivorship content in nursing curricula as well as the education of current nurses and health care providers.

A study addressing undergraduate oncology content in nursing curricula to determine the depth of nursing content taught, perceived importance of oncology nursing content, barriers to teaching oncology content, and utilization of resources for teaching oncology content was conducted by Such Lockhart et al. (2013). A comprehensive list of accredited nursing programs in the U.S. was obtained from the National League for Nursing (NLNAC) and Commission on Collegiate Nursing Education (CCNE) for contact information with each school's dean or director for survey distribution to program faculty. The authors developed a 43-item survey titled the "Cancer Nursing Curriculum Survey (CNCS)" which underwent content validity and pilot testing utilizing a national sample of nurse faculty who were prepared at the master's and doctoral levels (Such

Lockhart et al., 2013). The CNCS contained demographic questions and Likert-type questions related to the depth of cancer concepts currently taught in their curriculum as well as the importance of the cancer content, along with additional information. Four major categories for concept organization were used including pathophysiology, cancer treatment and management, management of cancer symptoms and problems, and professional standards. Open-ended questions were included at the end of the survey, which addressed barriers as well as the use of guest lecturers, clinical resources, and electives (Such Lockhart et al., 2013).

Response rates by program type revealed 37.7% of diploma programs, 18.6% of ADN programs, and 22.2% of BSN programs. Response rates by survey method revealed 74.9% completed the Web-based survey while 25.1% completed the telephone interview (Such Lockhart et al., 2013). Ranking of the five highest and five lowest cancer concepts was presented in chart format. While concepts such as cancer prevention and detection were rated by faculty as highest, cancer survivorship is rated amongst the lowest in relation to depth and importance of oncology content. Lack of time was identified as the greatest barrier to teaching oncology content by all programs (Such Lockhart et. al., 2013).

Uijtdehaage et al. (2009a) identified the lack of a comprehensive curriculum for cancer survivorship in medical schools that is potentially resulting in physicians who are not prepared for caring for cancer survivors. Lessons on long-term consequences resulting from the treatment of cancer are only beginning to be incorporated into medical education curricula (Uijtdehaage et al., 2009a). In this study, 211 students and 22 oncology fellows from the University of California, Los Angeles (UCLA), the University

of California, San Francisco (UCSF), and Drew University of Medicine and Science completed a questionnaire that assessed knowledge and experience in survivorship care. A panel of faculty experts developed this questionnaire, which included a comprehensive list of objectives based on IOM recommendations for cancer survivorship care on attitude, knowledge and skill domains. Concurrently, the three schools are developing and implementing problem-based learning self-study modules on breast and prostate cancer survivorship for online use. A knowledge test was developed to assess outcome measures of the efficacy of the self-study modules. A needs assessment was performed prior to the implementation of the new curriculum which addressed what senior medical students and fellows in oncology training programs knew about cancer survivorship and how much exposure and training medical students received and how competent they felt in caring for cancer survivors. Reliability and discriminant validity of the knowledge test was explored (Uijtdehaage et al., 2009a).

The results of the knowledge test revealed on average 56% of senior medical students answered the questions correctly compared to a mean score of 67% of fellows who answered the questions correctly (Uijtdehaage et al., 2009a). The most significant area of weakness was related to the competency that addressed long-term treatment consequences. The authors also noted that 42% of students and 31% of fellows demonstrated incorrect knowledge or lack of knowledge of basic survivorship terminology (Uijtdehaage et al., 2009a).

The experience survey revealed that most students had seen survivors of breast, colorectal, prostate, and gynecologic cancers. Less than half (48%) had exposure to a childhood cancer survivor (Uijtdehaage et al., 2009a). Most students reported having

observed others caring for survivors but 53% had never received instruction on helping survivors deal with treatment consequences, 46% had never practiced these skills except by taking a cancer history. The opportunity to take a cancer history was reported by 79% (Uijtdehaage et al., 2009a). The authors concluded that there is a surprising lack of knowledge of cancer survivorship care in current medical school curriculum. Further study is recommended on results of exposure to modifications to medical school curricula that include cancer survivorship content.

An additional study to describe a framework for cancer survivorship curriculum for medical students was done by Uijtdehaage, et al. (2009b). This article described the cancer survivorship program that was integrated into the David Geffen School of Medicine at UCLA, the University of California, San Francisco School of Medicine, and the Charles Drew University (CDU) School of Medicine and Science over a five-year period. The focus of the curriculum was on breast, colorectal, prostate, gynecological cancers and childhood cancers such as leukemia. Curriculum objectives were identified by faculty based on IOM recommendations. These included problem based learning (PBL) modules, panel presentations, and clinical experiences that included history taking of cancer-related problems (Uijtdehaage et al., 2009b).

The control group consisted of 211 members of the Class of 2006 (fourth-year medical students) from the three participating programs. The intervention group consisted of 195 students in the Class of 2007. This group was exposed to a different combination of modules at each institution (Uijtdehaage et al., 2009b). An instrument to assess the effect of the curriculum on knowledge of and experience with cancer survivorship issues was administered to both groups. The survey instrument also self-

rated comfort levels in survivorship care on a five-point Likert scale. The historical control group showed significantly serious shortcomings in knowledge of survivorship issues and long-term consequences of cancer treatments. They had less direct instruction and/or opportunity to practice critical components of survivorship care. The educational outcomes showed gradual improvement for the intervention groups as the survivorship modules were introduced into the curriculum. Students reported more comfort in care activities including working in a specialty team and identifying patients with a high risk for cancer recurrence. The intervention group also reported more encounters with cancer survivors than the control group. The authors found that this modular approach to curriculum design provided flexibility in implementing and integrating cancer survivorship into the curriculum. The modules are also suggested for students in other health professions (Uijtdehaage et al., 2009b).

# **Cancer Survivorship Education: Intervention Research**

In order to educate nurses on the needs of cancer survivors, an innovative program was designed to provide nurse educators with cancer knowledge to enhance their ability to teach cancer content, including care of the cancer survivor (Hermann, Conner, & Mundt, 2008). The *Cancer Nursing Faculty Fellows Program* intervention was developed at the University of Louisville School of Nursing to improve nurse faculty cancer knowledge. Comprehensive curriculum reviews, conferences with national consultants, cancer-specific faculty seminars, and funded instructional projects were included in this intervention (Hermann et al., 2008). This month long program provided nurse educators with access to mentors and resources to expand their knowledge base on cancer survivorship and improve cancer care.

The University of Louisville School of Nursing partnered with six area schools of nursing, five cancer practice institutions, and five cancer community groups. A Center for Cancer Nursing Education and Research was developed based on these partnerships to establish close working relationships among the various groups involved. Each school of nursing nominated a fellow who would share all information from the Faculty Fellows Program content and learning experiences with their school's faculty and students. One school chose not to participate due to administrative and faculty issues, so five participating schools resulted. The Faculty Fellows Program was a four week program with classroom and clinical experiences that covered scope of care for cancer survivors that included prevention of new cancers to end of life care.

Evaluation of the Faculty Fellows program were overwhelmingly positive for self-report of the depth, breadth and amount of knowledge and content gained, expertise of presenters, program organization, and the opportunity to network with faculty members from other schools of nursing (Hermann et al., 2008). The authors concluded that the incorporation of content related to the care of patients with cancer is imperative in all schools of nursing, as most nurses will encounter patients with cancer regardless of the practice setting that they work in. The specialized care the cancer survivors require must be communicated to nursing faculty in educational programs so that they in turn can educate their students on the appropriate needs of cancer survivors. The Faculty Fellows Program is one model program that assists faculty in acquiring the knowledge needed to integrate cancer survivorship into nursing curricula (Hermann et al., 2008).

Trocky, McLeskey, McGuire, Griffith, and Plusen (2011) recognized the need for nurses, as the often first contact in the health care system for the breast cancer patient, to be able to deliver accurate information to patients on all aspects of cancer. These authors described how web-based modules were developed and implemented into baccalaureate nursing programs to incorporate cancer content into nursing curricula. The authors developed modules that were comprehensive for breast cancer health care, which included content on epidemiology, diagnosis, and all aspects of survivorship (Trocky et al., 2011). Faculty at the authors' school of nursing believed that their breast cancer content was fragmented and incomplete in their BSN program. Gaps in content were identified and addressed in the modules, which undergraduate faculty decided to require in several courses. The modules incorporated evidence-based practice and interprofessional care.

All undergraduate BSN students were required to view the modules and were tested on the content as part of their final examination. Formative student feedback through course evaluation revealed that students highly accepted the modules and integrated the content into the final examination (Trocky et al., 2011). Faculty evaluated the test statistics of the modified final examination. Item analysis of the questions related to the module content indicated high quality questions except for one question with a *p* value of 0.7, which was evaluated for clarity and reworded (Trocky et al., 2011). The authors concluded that the development of the modules did increase education of breast cancer among nursing students without increasing the burden of adding additional nursing content to an already content heavy curriculum.

There is minimal descriptive and interventional research on cancer survivorship in nursing education research. The implications for nursing faculty reveal a gap in the current nursing curricula regarding care of the cancer survivor. Integration of care of the

cancer survivor needs to begin at the undergraduate level and then continue through graduate study. Care of the cancer survivor content needs to be included in both the classroom and clinical settings as all nurses will care for cancer survivors regardless of their practice settings.

## **Summary of the Literature Review**

There is a significant amount of literature available on the unique needs of cancer survivors. The literature supports the IOM (2005) recommendations that care should be interprofessional and that nurses in all areas of practice should be educated in the care of the cancer survivor. The literature on inclusion of cancer survivorship content in nursing and health care education is sparse and therefore there is a need to study and identify the gap in this very important aspect of nursing care. Specifically, faculty beliefs and practices regarding care of the cancer survivor are critical to exploring whether essential content is delivered. The curriculum should address the four components of care including prevention, surveillance, intervention, and coordination (Hermann et al., 2008; Irwin et al., 2011; Klemp et al., 2011; Such Lockhart et al., 2013; Trocky et al., 2011).

### **CHAPTER III**

#### METHODOLOGY

# **Introduction to Methodology**

The purpose of this study was to identify and validate that there is a gap in content in the care of cancer survivors in undergraduate U.S. nursing programs. Nurses in all areas of practice will be involved in the care of cancer survivors. This study examined how nursing faculty in undergraduate nursing programs include cancer survivorship content in nursing curricula in both the classroom and clinical setting. Qualitative description of nurse faculty beliefs and their teaching practices regarding what undergraduate nursing students need to know about the nursing care of the cancer survivor were explored.

Qualitative research has key characteristics that apply to this area of study as little has been researched on the inclusion of cancer survivorship in nursing education curricula. Inductive analysis is based on the exploratory nature of qualitative research (Hays & Singh, 2012). Inductive analysis involves collecting data to provide a deeper understanding of an issue to identify themes and their patterns. In this study, faculty beliefs about the inclusion of care of the cancer survivor in nursing curricula were explored.

Context is an important characteristic of qualitative research and it values how the participants "create and give meaning to social experience" (Hays & Singh, 2012, p. 6).

Context allows the researcher to look at the research problem in a holistic and comprehensive manner. This study examined whether the concept of the care of the cancer survivor is valued by faculty as necessary in the context of undergraduate nursing education. This relates to another characteristic of qualitative study, humanness of research, where subjectivity is considered a strength and challenge. The researcher is considered "an instrument of the study" (Hays & Singh, 2012, p. 7).

### **Research Questions**

The research questions for this qualitative descriptive study were:

- 1. How do faculty describe the concept of cancer survivorship care?
- 2. How do faculty describe the inclusion of cancer survivorship care within the undergraduate nursing curriculum?
- 3. What academic or clinical literature about cancer survivorship care is included in the nursing program?
- 4. What types of clinical sites are used to provide nursing students with learning opportunities regarding cancer survivorship care?
- 5. What do faculty believe are barriers and facilitators to the inclusion of curriculum on care of the cancer survivor?

This chapter contains a description of the research design, population and sample, data collection and analysis, trustworthiness criteria, human subjects protection/IRB, and storage of data.

### Research Design

A qualitative descriptive study is the design of choice when descriptions of phenomena are desired (Sandelowski, 2000). The qualitative descriptive design was appropriate for this study as it entailed inquiring into the subject of faculty beliefs and practices regarding the inclusion of content on care of the cancer survivor in undergraduate nursing curriculum; thus answering the proposed study questions.

Qualitative researchers collect as much data as possible within the field in order to fully describe what is directly observed. The qualitative descriptive study provides a comprehensive summary of data that is directly observed in order to describe patterns and regularities in the data (Sandelowski, 2000).

Qualitative studies are characterized by thick description, where detail regarding process, content and participants is desired for insight and understanding of the phenomena (Hays & Singh, 2012). The focus of qualitative descriptive study is on description and understanding. Since little research has been done in nursing education and cancer survivorship, exploring the beliefs and practices of nursing faculty on the importance of including this content was an appropriate way to gain insight into the educational needs of student nurses in caring for cancer survivors.

Purposive and convenience sampling were utilized in this qualitative study as nurse faculty who teach in baccalaureate nursing programs were asked to volunteer to participate in the study. Sample size was less important as the goal was to select participants who could provide the appropriate amount of detail regarding the phenomenon being studied. The sample was purposive in that participants who could provide information-rich data were selected and convenient in that the geographical area

was limited to two states. Choosing faculty who were currently teaching in baccalaureate nursing programs was appropriate for this study.

## **Research Strategies and Techniques**

Gaining access and establishing rapport was an essential research strategy. First, Institutional Review Board (IRB) approval was obtained through Southern Connecticut State University (SCSU), as well as individual consent from the participants who agreed to be interviewed for this study. After obtaining IRB approval from SCSU, emails were sent out to baccalaureate nursing faculty in two northeastern states whose programs were within a two-hour driving radius for the principal investigator. The email contained the Letter of Information to Consent to Participate in Research (Appendix A) explaining the purpose of this doctoral dissertation and a request to interview individual faculty for completion of this study. This email explained that the interview would be face-to-face and audiotaped; informed consent and confidentiality would be provided.

# **Population, Sample, and Setting**

The population and sample consisted of 14 baccalaureate nursing faculty from schools of nursing in two northeastern states in order to explore faculty beliefs and practices about the inclusion of care of the cancer survivor in undergraduate nursing curricula. Faculty lists were obtained from websites of the Colleges and Universities in those two states. Baccalaureate nursing programs in the two northeastern states were identified through the use of the search engine "Google" and nursing program web pages were examined for faculty who teach primarily in undergraduate BSN programs. A list of nursing programs and faculty credentials with emails was created; those faculty who taught only in graduate programs or who were administrators were excluded from the

sample. If a faculty member who taught only graduate courses received an email invitation by error, the email informed the faculty that they did not qualify for the study and asked that they forward the email to a member of their faculty who may qualify for the study. This attempt at snowball sampling did not result in the acquisition of new subjects. Even though this study was limited to two states, an attempt to get differing viewpoints from faculty at different academic institutions was desired.

The principle of data saturation is used in qualitative research to guide decisions on sample size as it refers to the repetition and redundancy of themes and categories in the data, resulting in no further need for data collection (Morse, 1995; Polit & Beck, 2012). When determining if sample size is sufficient, the principle of data saturation is considered in qualitative research. The purpose of data saturation in qualitative research is to ensure replication in categories, which verifies and ensures comprehension and completeness of data (Bowen, 2008; Morse, 1995). As new participants are brought into the study and are interviewed, saturation is reached when the interviewer no longer obtains new information and redundancy is achieved (Bowen, 2008; Hays & Singh, 2012; Morse, 1995; Polit & Beck, 2012). A discussion of replication of categories, which has led the investigator to determine that data saturation has occurred will briefly be touched on here, and further expanded on in the Summary of the Results and Detailed Analysis sections of this chapter. Coding of categories began by examining how each interview question related to the research questions of this dissertation. Once the categories were identified, themes and their attributes were coded. As more participants were interviewed, if there was a similar theme expressed by the participant, that data was entered under that theme. Oftentimes, there were slight variations or expanded data,

particularly early on in the interview process that required multiple variations of the themes to ensure that all of the data was represented.

#### **Data Collection**

The study was guided by naturalistic inquiry to include neutral, natural settings that were convenient to the participants and the principal researcher was the instrument for data collection and interpretation (Lincoln & Guba, 1985). Most participants chose diners that were located near their homes for the interview, although four participants requested that the researcher interview them in their offices. Trustworthiness criteria, vital to naturalistic inquiry, will be discussed in further detail within this chapter.

Data collection began following SCSU IRB approval in March of 2015 and concluded in May of 2015. Data collection was achieved through face-to-face semi structured interviews that were audiotaped and then immediately transcribed by the principal investigator. The open-ended questions asked during the interview were derived from the research questions and the literature review of the study. The interview guide, attached in Appendix B, includes demographic questions as well as questions related to the research questions of this study and literature review. A content reviewer, methods reviewer, and nursing education researcher validated the interview guide. The Committee members of this dissertation agreed to validate the questions on the interview guide. Dr. Elizabeth Ercolano was chosen as the Committee Chairperson for her content expertise in cancer survivorship. Dr. Ercolano is an experienced quantitative and qualitative researcher. Dr. Mary Ellen Doherty, the second reader for this dissertation is a well-known expert qualitative researcher and chosen as a methods expert for this study.

Dr. Elaine Martin, the third reader for this dissertation is also an experienced researcher who qualifies as a nursing education researcher.

The interview time was identified as 30 to 45 minutes; interviews ranged from 20 minutes to one and one half hours in length. The location of the interview was at the convenience of the individual being interviewed. Most often the location was a diner near the participant's home, although four participants chose to be interviewed in their offices. Consent was obtained prior to turning on the audio recorder. The audio recorder was then turned on, and the interview questions in Appendix B commenced. A second audio recorder was purchased and available onsite should the first audio recorder malfunction. No audio recorder malfunction occurred.

In qualitative descriptive studies, data collection is typically directed toward discovering the who, what, and where of events or experiences (Sandelowski, 2000). Writing materials for note taking during the interview were utilized just in case there was a malfunction in the recorder. While writing materials were available for use, they were not needed as no malfunction of the recorder transpired. After the interview, the content from the audiotapes was immediately recorded verbatim by the principal investigator onto a manuscript. This manual procedure is parallel to automated software that is available to classify concepts and themes (Hays & Singh, 2012). A number identifies the manuscript and the digital audio recording for the individual who has been interviewed. Room was left in the right margin for reflective notes to identify emerging themes or differences that were identified during interviews.

#### **Informed Consent**

When recruiting faculty for this study, an email to gain informed consent for an interview and to arrange a meeting date and time was sent to undergraduate nursing faculty in two northeastern states. Included within the consent was the purpose of the study and how the data would be collected. In addition, the right of the participant to voluntarily withdraw at any time from the study, the protection of confidentiality, expected benefits, explanation of risks, strategies to minimize risk, and a signature of consent was included on the document as attached in Appendix A.

### **Data Analysis**

Qualitative content analysis was used for this descriptive qualitative study for the purpose of recognition of meaning by analysis of the content of narrative data to identify not only the prominent themes but also the patterns among the themes (Krippendorff, 2013; Polit & Beck, 2012). The data analysis began with organization through classification and indexing via category schemes, followed by data coding. Important concepts and themes that emerged from the data were identified as category schemes, and then coded to determine which category scheme the concept or theme was assigned. This is a reductionist method of converting data to smaller, more manageable units that can be retrieved and reviewed to represent the data more efficiently (Krippendorff, 2013). The units were coded and named according to the content that is represented, then grouped based on shared concepts (Polit & Beck, 2012). A second coder with experience in qualitative content analysis, Dr. Elizabeth Ercolano, reviewed all of the transcripts for validation of concepts and themes to ensure rigor of the content analysis (Polit & Beck,

2012). Descriptive statistics are provided to describe the characteristics of the participants including frequencies and means of the demographic data.

## **Limitations of Research Design-Internal and External Threats**

In order to minimize threats in this qualitative research study, the following strategies were applied: intense listening while interviewing the participant, gentle probing for data that is rich and comprehensive; and interviews that were audiotaped and then immediately transcribed by the interviewer (Polit & Beck, 2012). Data analysis that is ethically and more socially responsible occurs through data collection with a design that is loose rather than rigid in terms of questions. The "looser" the design is initially the more likely ethically and socially responsible data analysis will occur. Enough room in the data collection plan was left so that the research design was open to making changes once data collection begins (Hays & Singh, 2012). For example, originally interview question one was "How do you define cancer survivorship?" Due to a hesitancy in response from participants to define cancer survivorship, a loose design allowed for this question to evolve into "How do you define cancer survivorship; or do you have a personal definition of cancer survivorship?" Simultaneous data collection and analysis was used as a strategy because research questions, data sources and methods may change as a study is conducted. Enough room was left in the data collection plan so that it could be changed as data was collected. This allowed for revisions that needed to be made so that the participants could verify the findings. The researcher began with the qualitative analysis of the transcripts as the subjects were interviewed instead of waiting until all the data was collected. This provided for recognition of emerging research questions as patterns were identified.

Some strategies to meet the trustworthiness criteria included utilization of the use of field notes and memos to describe and analyze findings. This served to provide credibility as conclusions were drawn from the transcription of the findings. The use of these methods of description will aid in transferability for others to apply the information that was collected into their academic settings. The process of note taking allowed for comparison between what was written and what was later heard on the tapes and transcribed, which will also aid confirmability and authenticity.

Member checking, or respondent validation, where participants reviewed their own transcripts served to confirm authentic representation for authenticity, ethical validation, and creativity. The member checking for this research involved review of only the transcript by the participant, followed by discussion regarding any inaccuracies or clarification that was required. Seventy-five percent of transcripts were reviewed by participants; only one grammatical change was made in one participant's transcript after member checking.

Negative case analysis is a strategy to ensure trustworthiness that involves looking for information that goes against the findings. This would be useful as a practical way of looking at ethical validation. For example, there are those who may believe that "generalist" nurses do not need to know how to care for cancer survivors. Maintaining an open mind to this information in the literature and in the responses obtained from the participants' aides in trustworthiness. The researcher did not receive any responses from participants or find literature to support negative case analysis.

Thick description of findings, which are vivid accounts of the research process and outcome, was another strategy necessary to achieve trustworthiness in this qualitative

study. It included inferences into data including context, intentions and meanings, evolution and development, and presents the action as a text for interpretation (Lincoln & Guba, 1985).

Lastly, an audit trail as a strategy for trustworthiness for the provision of physical evidence of data collection and analysis procedures was used. All data was collected and analyzed in a methodical and organized manner as outlined in the research design to meet the criteria for coherence. The audit trail consisted of organization by an assigned number to each participant, of the following items; the interview digital audio recordings, transcripts, responses from member checking, data reduction and analysis, notes, and drafts of the final data compilation (Polit & Beck, 2012).

# **Human Subjects Protection/IRB**

The rights of human subjects were protected throughout the study. All of the subjects were informed of the purpose of the study, that their participation was voluntary, and that they were free to withdraw from the study at any time if they so desired. All participants were given the opportunity to ask this researcher questions prior to the interview session. In addition confidentiality was guaranteed and a letter of consent was signed. Data was coded by giving each subject a number so that the identity of the subjects would not be revealed during data transcription and analysis. Institutional confidentiality was also guaranteed and IRB approval was obtained through SCSU. A summary of the results of the study will be made available to all participants who request them.

# **Storage of Data**

Storage of data involved backing up digital audio recordings and transcribed interviews on hard drives. Anonymity of each participant was maintained by the assignment of a number to each individual after they were interviewed. The digital audio recordings, field notes, and transcript were labeled "subject #1" with subsequent numbers allotted as the interviews progressed. Digital audio recordings and data transcription from the recordings were saved onto a computer immediately following the interview. All digital audio recordings and transcribed interviews were backed up on an external hard drive that is stored with field notes in a locked office cabinet.

### **CHAPTER IV**

### DATA ANALYSIS AND RESULTS

#### Introduction

The purpose of Chapter IV is to report on the findings of the content analysis of transcripts representing audiotaped interviews of undergraduate nursing faculty's beliefs about cancer survivorship curriculum and their teaching practices related to cancer survivorship. The content analysis is organized by research questions and related themes derived from a systematic examination of the participants' responses to the questions. In addition, Chapter IV will report on the demographic characteristics of the sample, summarize study results, and conclude with a detailed report of the content analysis findings.

# **Description of the Sample**

Introductory emails describing the purpose of this qualitative descriptive study were sent to 243 faculty from 16 schools of nursing in two states in northeastern states in the United States. Two schools were identified as ineligible. One institution required a separate IRB approval. The other was ineligible due to the principal investigator's enrollment as a doctoral student at the institution.

The final potential sample of 209 faculty members belonging to 14 schools of nursing were approached to participate in the study. Of the 209 potential participants, 21 (10 %) of the participants were not recruited due to the following reasons: (a) five were

ineligible due to only teaching in graduate courses, (b) six declined, (c) seven were lost to follow-up, (d) two were "too busy", and (e) one was undergoing cancer treatment and in the early stages survivorship. Fourteen faculty members (7%) representing six schools (43%) agreed to participate represented the final sample.

Participants were informed about the purpose, study procedures, study risk and benefits, and steps to protect their confidentiality and anonymity. They were asked to sign an informed consent form that contained this information (Appendix A). At the start of the audiotaped interview, participants were asked to respond to questions about their teaching and educational characteristics, including: years teaching, years between curriculum revisions, areas of specialty, current teaching assignment, and cancer-related continuing education.

Table 1 outlines these characteristics of the final sample. All faculty taught in undergraduate nursing programs. The length of teaching time of the faculty ranged from ten months to 24 years, with a mean of 11.38 years of teaching. The majority (50%) of participants identified medical-surgical nursing as their area of specialty; other specialty areas that were predominant were pediatric nursing (14%) and critical care nursing (14%). Teaching assignments included medical-surgical courses (43%) with lesser percentages of participants teaching in transition courses, health assessment, fundamentals and maternal child nursing. Most participants (79%) had not performed continuing education on the care of the cancer survivor. The mean was 1.93 years for review or revision of curricula, which ranged from four months to seven years.

Table 1

Demographic Characteristics of Nursing Faculty in the Study (N=14)

Characteristic	M	SD	Range
Length of Time	11.38	8.35	.83-24
Teaching (years)			
Last Revision of	1.93	1.84	.33-7
Program (years)			
Characteristic		n	%
Area of Specialty			
Medical/surgical		7	50
Pediatrics		2	14
Critical care		2	14
Psychiatric/mental		1	7
health			
Maternal/child		1	7
Cardiology		1	7
Home care		1	7
Geriatrics		1	7
Current Teaching			
Assignment			
Medical/surgical		6	43
Transition practicum		4	29
Health assessment		3	21
Fundamentals		3	21
Maternal/pediatric		2	14
Holistic care		1	7
Community health		1	7
Critical care		1	7
Geriatric health		1	7
Nursing research		1	7
Simulation		1	7
Continuing Education			
No	1	1	79
Yes		2	14
Can't Recall		1	7

Note. Participants identified more than one area of specialty and teaching assignment.

# **Summary of the Results**

The results of this qualitative descriptive study about the beliefs and teaching practices of undergraduate nursing faculty on cancer survivorship care are summarized by the study research questions. Each research question is presented, along with the corresponding interview questions (Appendix B) and a brief summary of the major results. A more detailed presentation of the results is provided under the detailed analysis section of Chapter IV.

### **Sample Characteristics**

The final potential sample of 209 faculty members representing 14 undergraduate nursing programs in two northeastern United States were approached by email to seek their participation in this qualitative descriptive study. The email outlined the study's purpose and subject responsibilities. Fourteen faculty members (7%) representing 6 schools (43%) participated. The length of teaching time of the faculty ranged from ten months to 24 years, with a mean of 11.38 years of teaching. The majority (50%) of participants identified medical-surgical nursing as their area of specialty; other specialty areas that were predominant were pediatric nursing (14%) and critical care nursing (14%).

### **Research Question One**

How do faculty describe the concept of cancer survivorship care?

The investigator led the interview with the NCCS definition of cancer survivorship and asked the participant: "How do you define cancer survivorship?" The NCCS definition of cancer survivorship contains a broad description of the experience of a person with cancer from diagnosis, acute care, chronic management, and end-of-life

care. Management of the patient in all phases is holistic, meaning care should address physical, mental, social, and spiritual needs of patients, however, needs and related care are phase-specific. As subsequent interviews took place, the principal investigator found that in order to obtain a well-rounded and comprehensive description of cancer survivorship, the first question was changed to: "How do you define cancer survivorship; or do you have a personal definition of cancer survivorship?"

Of the 14 participants who were asked how they defined cancer survivorship care after reading the NCCS definition, six participants (42.8%) reported definitions that were consistent with the NCCS definition of cancer survivorship. In several interviews, participants were not familiar with the exact wording of the NCCS definition, but were in agreement with the description provided by the principal investigator. Of the 14 participants who were asked how they defined cancer survivorship care after reading the NCCS definition, eight participants (57.1%) had definitions that were not aligned with the NCCS definition of cancer survivorship. Some common attributes that did not support the NCCS definition included that cancer survivorship begins once acute treatment ends; participants described not having a "clear definition" of cancer survivorship; participants did not include family, friends, and caregivers in the definition; and participants believed it was necessary for the patient to have survived five years after initial diagnosis in order to be considered a survivor.

### **Research Question Two**

How do faculty describe the inclusion of cancer survivorship care within the undergraduate nursing curriculum?

Two interview questions were asked about the presence of cancer survivorship care content in undergraduate nursing curriculum. The first question addressed faculty beliefs about including cancer survivorship content; the second question about whether cancer survivorship curriculum existed, and if so, the specifics of the curriculum. The first question was: "Do you believe that content related to caring for needs of the cancer survivor belongs in undergraduate nursing education?" Thirteen of the 14 participants (92.8%) responded that they believed that cancer survivorship care belongs in undergraduate nursing programs and one participant (7.1%) did not answer the question.

The second question, "What is currently taught in your curriculum regarding physical, psychosocial or spiritual needs of the cancer survivor"? Most participants responded that they covered content that is related to the acute stage of survivorship or the time that surrounds the initial diagnosis when patients are in active treatment. Participants also reported covering end-of-life and hospice care. The extended and permanent stage of survivorship is not integrated into most curricula, or that phase when acute treatment ends and cure may be realized or recurrent disease treated.

Of the 14 faculty members interviewed, thirteen (92.8%) identified there were gaps in their curriculum as it pertained to long-term physical, psychosocial, and spiritual needs of the cancer survivor. While eight of the fourteen (57.1%) faculty members teach some aspects of cancer survivorship care, only two (14.2%) of the participants integrated the theory and nursing care of the cancer survivor in the extended or permanent stage of survivorship. The remaining six (42.8%) participants who did teach cancer survivorship content did so briefly and covered only limited content.

### **Research Question Three**

What academic or clinical literature about cancer survivorship care is included in the nursing program?

The interview question asked by the investigator was "Do you assign textbook or journal articles for students to read on care of the cancer survivor topics that may be included on tests?" Three participants (21.4%) reported that academic or clinical literature or test questions on cancer survivorship care were not included in their nursing program. Three participants (21.4%) included a limited amount of academic or clinical literature and test questions or essay/short answer questions on cancer survivorship care in their nursing program. Eight participants (57.1%) reported there might be articles in other courses on cancer survivorship, but if so, it was an extremely limited content area that was not discussed in their curriculum meetings.

## **Research Question Four**

What types of clinical sites are used to provide nursing students with learning opportunities regarding cancer survivorship care?

The interview probe asked by the investigator was "Describe the inpatient and community clinical experiences where your students provide care for cancer survivors." While only five participants (35.7%) stated that there were no clinical sites used to provide nursing students with learning opportunities regarding cancer survivorship care, only two (14.2%) participants described clinical opportunities that encompass all stages of cancer survivorship care (acute treatment, post-treatment management, palliative care and end-of-life care). The rest of the clinical experiences (50.1%) are opportunities to provide care for cancer patients, however, faculty had not set-up the experiences using the definition or theory of cancer survivorship care beforehand. Because these clinical

experiences focused on the acute or end-of-life experiences, students did not have exposure to the chronic features of cancer or its treatments, therefore, missed the relationship of these features to cancer patients' quality of life outcomes.

## **Research Question Five**

What do faculty believe are barriers and facilitators to the inclusion of curriculum on care of the cancer survivor?

The interview question asked by the investigator was: Do you perceive barriers or facilitators in integrating care of the cancer survivor content into your curriculum? Participants identified barriers or obstacles that prevented them from including cancer survivorship curriculum and facilitators that supported cancer survivorship curriculum adoption. Barriers to teaching cancer survivorship included: (a) lack of time to teach cancer survivorship in a curriculum that is overloaded with content, (b) faculty lack of knowledge and awareness of cancer survivorship needs, (c) the need to cover AACN Baccalaureate Essentials and other content considered crucial in undergraduate curriculum, (d) lack of resources and books on cancer survivorship, (e) concern over what content is tested on NCLEX-RN, (f) a pediatric population that has moved on from their cancer experience, (g) students' characteristics, (h) a disconnect between what is taught and societal needs, and (i) complexity of medical management of the cancer patient.

Facilitators or factors that promoted curriculum inclusion reported by participants were: (a) faculty who strongly believed that cancer survivorship content must be included, (b) informing the public of the needs of cancer survivors through media, (c) increasing faculty awareness on the health care needs of cancer survivors, (d) providing

holistic training of faculty, (e) including family members as co-survivors, (f) a supportive Dean and Program Chair, (g) ELNEC content incorporated into the curriculum, (h) correlation between classroom and clinical practice, (i) students who are cancer survivors, and (j) simulation of a cancer survivor scenario in the educational setting.

### **Detailed Analysis**

This section is organized by the five study questions and an explanation of their themes. For each theme a detailed description of attributes is provided. By participant ten, recurrent content was noted, however, the investigator continued with interviews to ensure that there were no new responses associated with a particular question. By participant number 14, redundancy of data was evident by the same or similar responses to the interview questions from the previous participants (Bowen, 2008; Morse, 1995; Polit & Beck, 2012).

# **Research Question One**

How do faculty describe the concept of cancer survivorship care?

Theme one: Descriptions of cancer survivorship. Six (42.8%) faculty members described the concept of cancer survivorship and their descriptions were consistent and aligned with the NCCS definition of cancer survivorship. Consistency with the NCCS definition meant that the respondents concurred with the survivorship organization's explanation of cancer survivorship that, survivorship of cancer was the experience from diagnosis to death and that living with the effects of cancer and its treatments represented a permanent, chronic stage. Various modifications, however, were presented by those respondents who concurred with the NCCS definition. They explained that the definition, although substantive, be expanded as follows, to: (a) acknowledge significant

others, but keep the focus on the patient; (b) expand the definition to include coworkers, friends, and social networks; (c) focus on the developmental needs of the pediatric survivor as they age; (d) include a multidisciplinary perspective; and (e) integrate the role of society in contributing to the environmental hazards significant to cancer development. One participant with a specialty in psychiatric nursing stated:

I think we need to look at cancer survivorship from a multidisciplinary perspective that focuses on stress, adaptation, and a healing perspective. Cancer is a huge stress not only on the person, the survivor, but also on the family so we need to look at stress management for the patient and family. I believe strongly that we must look at the role of the family and empowerment of the family as caregivers to help them with the care of there loved one.

Eight (57.1%) faculty members reported definitions that were different than the NCCS definition of cancer survivorship. These differences included: (a) cancer survivorship begins from the time treatment ends and the patient is cured, (b) participants did not have a "clear" definition of cancer survivorship, (c), "someone who has been treated for cancer and is still alive and able to do ADL's", (d) a lack of inclusion of the family in the definition of cancer survivorship, and (e) a cancer survivor is someone who has survived cancer for five years after their diagnosis. One participant stated:

If I were to develop a definition it would be someone that was diagnosed with a type of cancer and they went through all types of treatment, whether it was simple treatment or extensive treatment and the end result is that they survived. And the survival might be the time when they say, when the cancer doesn't come back and

within five years you are a survivor. So after that five years I would say that's the start of your survivorship.

#### **Research Question Two**

How do faculty describe the inclusion of cancer survivorship care within the undergraduate nursing curriculum?

Theme two: Beliefs on inclusion of cancer survivorship care within undergraduate nursing curriculum. Thirteen of the 14 (92.8%) participants stated that content related to caring for the needs of the cancer survivor belonged in undergraduate nursing education and that cancer in general is neglected in undergraduate nursing curricula. One participant did not answer the question, but instead focused on the courses that she taught which did not include care of the cancer survivor.

The belief that cancer survivorship belongs in undergraduate nursing curriculum is due to most participants' perceptions that the numbers of cancer survivors are "staggering" across all age groups. "Cancer survivorship is something that just transcends all age groups, all specialties," reported a participant. A pediatric faculty member reported that surveillance of the pediatric population is necessary by nurses as this population of cancer survivor ages (later on in life they are at higher risk for "issues"). Participants also reported that there is an increase in patients that students are caring for with medical histories of cancers and thus, it is important for students to recognize what the differences in care are for the patient who has had cancer versus the patient who has not. Their recognition of the psychological and emotional effects associated with cancer (for example, physical losses such as mastectomy) were also reported to influence their belief that it was necessary to incorporate cancer survivorship

curriculum which is different nursing curriculum than care of the patient who is not a cancer survivor.

As one participant described these unique needs:

Care needs depend on where the survivor is in their journey. There are special needs of younger cancer survivors as disease progression occurs. An increased need for family involvement and the role of the nurse in teaching for both the patient and family should be included in the curriculum. Inclusion of end-of-life care in cancer survivorship curricula as undergraduate content is also essential.

A participant with experience in home care described how important it is to educate nurses on the needs of patients and families who are survivors living at home and being cared for in the home, including hospice services. She felt that she addressed the needs of survivors in her clinical practice with students in hospice home care, but is not as cognizant of survivorship issues in other settings, although she will be after considering the NCCS definition.

Theme three: Established content on cancer survivorship care: Teaching practices. The second interview question probed further about what content was specifically taught in the participant's curriculum on cancer survivorship care. Of the eight participants who included some aspects of cancer survivorship care, only two (7.1%) participants included care that extended beyond the acute stage of cancer survivorship to the extended and permanent stage of survivorship; meaning the majority of faculty focused curriculum on acute cancer management of patients at the time of diagnosis.

Participants who believed that cancer survivorship was a lifelong experience found creative ways to integrate content into their nursing programs. A participant who "absolutely believes" that cancer survivorship belongs in undergraduate nursing curriculum as a whole unit of study, developed a one credit elective course in her curriculum. She stated, "There was no other place in the curriculum to put cancer survivorship care." Another participant stated that cancer survivorship should be taught from the beginning of nursing education, since it is such a predominant clinical problem and that environmental issues play a large role in cancer development and destruction of the ecosystem, so students should be taught this early on in their education. This participant stated that she is "a strong believer in prevention and a holistic perspective to health care."

Faculty who addressed the many stages of survivorship in their curriculum did so by either addressing the holistic needs of the pediatric cancer survivor or the adult cancer survivor. For example, content on pediatric cancer survivorship focused on physical needs and common responses to their illness and treatments, with two units of study (classes) on survivorship, one unit of study on family-centered care, and one unit of study on palliative care. End-of-Life Nursing Education Consortium (ELNEC) curriculum is also presented throughout this undergraduate program. This curriculum addresses the psychosocial needs of cancer survivors inter-professionally. The psychosocial needs include developmental considerations and loss of milestones related to the treatment plan or a psychological response to the treatment plan (such as regression). There is also a focus on adolescent needs, including evolving sexual identity, loss of hair, use of a book that illustrates two teenagers in hospice care "stripped down to their raw emotions and

feelings." The students attend a book reading by the author on two adolescents in hospice who are not far in age from her own students. Student reflections have also described student's psychosocial response to the book. This university has a religious affiliation, so students must complete a spiritual assessment on all care plans. Cancer survivorship is also threaded throughout the curriculum in other nursing courses. This faculty participant stated:

And just to close on the psychosocial piece, I feel that the students go to the hospital for their clinical experience and it's all about them right and "my learning experience"...and the psychosocial piece, my students aren't very different in age from the characters in the book. They are between 19 and 21, not too far away from their own adolescence that they faced but then seeing it now from the perspective of the survivor who's now hospitalized and has all these issues that they care about.

Another participant who taught educational content on acute and chronic management of physiological and psychological issues of the adult cancer survivor adjusted their medical-surgical courses to accommodate this information. In addition, during these courses there is also a discussion of psychological distress as well as the whole needs of the patient during and after acute treatment and "life after treatment." There is a curriculum emphasis on the time between treatment ending and end-of-life when people live very well for many years, but may have psychological distress, physical effects, and unique care needs. The faculty participant focuses students on the patient's "journey" throughout these phases. She stated:

We talk about the physiological needs of oncology patients and then I bring in a whole piece about the psychological distress and the whole needs of this patient that they're going through and the process of being treated and then life after. You know, after, this gap between the patient who is being treated. We do that very well and we do end-of-life very well but it's the people living with this thing for 5 years, 10 years, 20 years, that we don't do so well. And that's what I try to focus on, at least personally in my class. That is my goal, to get these people to understand the journey of these patients.

Six (42.8%) faculty members described including some features of cancer survivorship care in their courses or curriculum. Participants taught disease process, acute treatment, and immediate needs of the family. This content was reported as "briefly touched on." Specifically, participants reported that surgical interventions, treatments such as chemotherapy and radiation and their side effects would be topics covered on NCLEX-RN so these participants included these topics in their courses.

Theme four: Gaps in content on cancer survivorship care. Thirteen of the fourteen (92.8%) participants reported a gap in their curriculum on the care of the cancer survivor. Participant descriptions of the missing cancer survivorship content in their curriculum were reported for the following reasons. One participant reported that there is a lack of integration of cancer survivorship as a concept into the curriculum and stated that, "It is not a conversation that the faculty has had". Other participants were unsure how much cancer survivorship is included in medical-surgical courses, and believed it may be "buried" in courses they did not teach. Several faculty described cancer survivorship as a "loose thread" or "loosely threaded throughout the curriculum" since

the focus if their curriculum is on acute care. Another reason cited by faculty for the gap in including cancer survivorship content is the emphasis on including "what will probably be on NCLEX-RN such as surgery, chemotherapeutic drugs and short-term side effects along with oncological emergencies, hospice and end-of-life care." One participant, acknowledging the gap in survivorship content, stated "nurses need to advise patients on prevention, surveillance, and screening as well as restoration and maintenance of health." Another participant reported that, "there is a class on spirituality and care plans where students need to address a spiritual nursing diagnosis, but not specific to survivorship".

### **Research Question Three**

What academic or clinical literature about cancer survivorship care is included in the nursing program?

Theme five: Lack of supportive literature on cancer survivorship care. Participants described that limited to no academic and clinical literature on cancer survivorship care exists in their current undergraduate nursing programs. Three participants (21.4%) responded that no textbook, journal articles, or test questions about cancer survivorship care were represented in their nursing courses or program. Eleven participants (78.5%) replied that there were no assigned readings except what might be included in the textbook, "if anything". This theme was further described by those participants reporting that assigned readings were extremely limited (no more than two pages) textbook content on survivorship, survivorship content that may be in the holistic textbook that is used in the curriculum, and inconsistent limited assignment of journal articles and testing on cancer survivorship.

For those faculty who do include test questions on cancer survivorship, the questions were not inclusive of the entire cancer survivorship experience, but limited in number and the content areas focus on infertility as a consequence of cancer treatment, grief and loss, and general questions on cancer content. The concern over NCLEX-RN preparation and the belief that cancer survivorship content is not included on the NCLEX-RN was described as one of the reasons for the lack of inclusion on tests, along with the curricular gap.

This participant expressed concern over the focus on NCLEX-RN and illustrates how cancer survivorship literature and testing can be integrated into undergraduate curricula. She stated:

Because it's an undergraduate course where so much is focused on the NCLEX, the opportunities to have standardized test questions sometimes don't capture, in my opinion as a nurse, first as a nurse and then as an educator. I don't think that multiple choice or multiple multiple choice questions adequately capture that. But I've stepped outside the box related to family-centered care of kids who have special needs and have offered essay type/short answer questions in addition to NCLEX multiple choice.

#### **Research Ouestion Four**

What types of clinical sites are used to provide nursing students with learning opportunities regarding cancer survivorship care?

Theme six: Clinical sites providing opportunities for cancer survivorship care: planned versus unplanned. Faculty (50.1%) reported that the majority of assigned clinical experiences were experiences where students had an opportunity to provide care

for cancer patients; however, they were not planned cancer survivorship experiences grounded in cancer survivorship concepts and interventions. This participant stated:

The inpatient experiences that my students have in my course are medical surgical and the medical surgical units that they are on are not oncology so the only opportunities that they have to care for cancer survivors is if the patient has a previous history of cancer, which definitely happens, but that's really the luck of the draw.

Although participants reported that students encountered cancer patients in their clinical experiences, they were focused on acute management of the disease or in the community setting without a purposeful focus on patients' chronic needs: (a) inpatient acute care experiences on oncology units where patients are admitted for active treatment or acute exacerbation of symptoms; (b) outpatient infusion center clinical experiences where students may have interactions with cancer survivors; (c) participants state these clinical experiences were not identified or planned as a "cancer survivor" clinical experiences; (d) participants reported that whether students are on pediatric-oncology, medical/surgical, or specialty units they care for patients with cancer all the time; (e) participants stated that "cancer is everywhere" and that all clinical units have cancer survivors to care for; (f) participants were unsure if students have community clinical experiences with cancer survivors but they do have experiences with visiting nursing services so "they most likely would"; (g) no clinical sites are planned for the provision of care for cancer survivors for students; and (h) students participate in health fairs for screenings but not in relation to the cancer survivor or for surveillance for the development of a

secondary cancer.

Participants revealed that 14.2% of participants described clinical experiences where students had the opportunity to provide care for patients not only in the acute stage of survivorship, but also in the extended or permanent stages of survivorship. Planned clinical experiences that addressed cancer survivorship included students caring for cancer survivors in the obstetric setting where patients have infertility issues as a result of cancer treatment. Another planned survivorship experience was a pediatric rotation where students may interact with cancer survivors in several areas: a pediatric oncology floor in a major medical center, an outpatient infusion area, and meeting with the director of a family-centered department for families of pediatric oncology patients.

Five (35.7%) participants reported no clinical experiences in which students have an opportunity to provide care for cancer survivors. Although these participants identified no inpatient or community clinical experiences for their students to care for cancer survivors, some reference was made to caring for medical-surgical patients with histories of cancer. However, no mention was made of the potential specific learning opportunities on caring for cancer survivors for student engagement with those patients. Participants whose students were placed in geriatric community settings or who were involved in community health screenings did not identify these opportunities as potential survivorship experiences. One participant, when probed by the investigator, did acknowledge that there could be a possibility for a student to do something preventive if a patient identified himself or herself as a survivor. She stated:

We might not know that they are cancer survivors. They're not identified as cancer survivors. We are in the community doing a lot of health fairs and

screenings. I'm trying to think of what we would think of for cancer, maybe malignant melanoma or something like that. We could do something preventative or some health promotion on something like that, you know sun block and stuff like that but not for the survivor. I mean, if someone said that they have malignant melanoma we would know that their risk for getting another one is really high, they should really stay out of the sun, but nothing for survivorship.

## **Research Question Five**

What do faculty believe are barriers and facilitators to the inclusion of curriculum on care of the cancer survivor?

Theme seven: Barriers and facilitators to the inclusion of cancer survivorship.

Multiple reasons were reported as barriers and facilitators to including cancer survivorship curriculum. Barriers represent perceived obstacles to including cancer survivorship content. On the other hand, facilitators enhance the inclusion of cancer survivorship content.

"Content overload" or curriculum that is packed with content with no capacity to teach cancer survivorship clinical issues and management, was described by the participants (42.8%) as a barrier. "Basically I touch on that particular aspect (cancer survivorship) and that's just because there's so very many things that we have to squeeze into a curriculum in a short amount of time". There is not enough time to cover cancer survivorship along with all of the other content that is considered essential.

Faculty expressed concern (36%) about teaching content that did not prepare students for the NCLEX-RN exam along with the American Association of Colleges of Nursing (AACN) mandate to include "content essentials" that were more important than

cancer survivorship content. There is an uncertainty over whether cancer survivorship content is included on the NCLEX-RN exam. In most cases, there is a belief by faculty that cancer survivorship content is not included on the NCLEX-RN exam and that the focus is on the management of the acutely ill cancer patient so that is what is covered. There is more important content to cover that is considered essential, as it will be included on NCLEX-RN. A lack of agreement exists amongst faculty regarding what is "essential" content to teach. Faculty reported holding onto "sacred cows" and old content without updating it. One participant stated:

I think the biggest barrier is that we are so focused on what's going to be on NCLEX, you know, disease process, management of the acutely ill cancer patient is what you will typically see on NCLEX and so you know we focus so much on preparing them for the NCLEX.

Lack of faculty knowledge (36%) and awareness of cancer survivors' needs and their management inhibits the inclusion of cancer survivorship content. There is a lack of professional development opportunities for faculty in this area. It was also reported that unless faculty have a background in oncology or have a "value system of this patient post diagnosis and really understand the special needs of these patients, they are not necessarily going to teach that." Academic freedom was cited as a factor that allows faculty to teach whatever they want. A study participant stated, "you can write a curriculum and assign a topic in the syllabus but cannot force someone to teach it."

Faculty (28.5%) identified student characteristics as a potential barrier. Possible student characteristics as obstacles are: (a) an inability for students to administer chemotherapeutic drugs in the clinical area due to the need for chemotherapy

certification, (b) student age is younger and right out of high school, (c) students have less life experiences and are less likely to have experienced loss, (d) students are more sheltered culturally, (e) students do not like to talk about death and dying or the possibility of a life threatening illness, and (f) students have difficulty transferring knowledge of prevention of side effects from the classroom to the clinical setting.

Participants recognized the need to include survivorship content, but also recognized that there was a disconnect (7%) between what is taught and what society needs. This was expressed by a participant who stated:

I think we need to revise or write our books to reflect contemporary illnesses or diseases or whatever we need to look at what we have in society right now not what we had 100 years ago because we are spending a lot of money. Let's look at Medicaid and Medicare and our economic issues and where we are spending money on health care. There is very much a disconnect from what we are teaching in our nursing programs and what society needs.

One participant (7%) identified the complexity of the medical management of the cancer patient as a barrier. There is a need to utilize evidence-based practice to guide curriculum development. The complexity of the medical management of the cancer patient involves multiple nursing care needs for these patients. There is an inability of the students to focus on these complex needs. In addition, there is a need for awareness of customer service and holistically addressing all care needs, including finances and resources that are available to cancer survivors.

The lack of nursing textbooks and resources that focus on cancer survivorship were identified by faculty (7%) as an obstacle. There is a need for more current resources and textbooks that are focused on nursing care of the cancer survivor.

Lastly, one faculty member (7%), expressed the sentiments of many when she related the "pediatric population has moved on from their cancer experience" which serves as a barrier. Many pediatric patients do not remember their cancer experiences and so there is a particular need for follow-up with this population.

The following facilitators were identified for including care of the cancer survivor content in undergraduate nursing curriculum. Faculty (35.7%) reported the large presence of cancer survivors in our society. Seven percent of participants suggested that emphasizing a personal connection or experience that all faculty have with cancer somewhere in their family would help to encourage survivorship content. It was frequently reported that everyone knows someone who is a cancer survivor. A study participant stated, "Everybody's touched by cancer." Thus, presenting the importance of the prevalence of cancer survivors and their needs would be well received by faculty.

Providing professional development programs for faculty (35.7%) on the cancer survivorship needs of patients was viewed by participants as a facilitator. Increasing faculty awareness of cancer survivors was identified (28.5%) as a method to support curriculum changes to include survivorship content. Supplying faculty with more evidence-based information on cancer survivors in a professional development forum will increase inclusion of this content in the curriculum. It was suggested that cancer survivorship needs to become the new "buzzword" in nursing education.

One way to promote curriculum changes would be to inform the public on the needs of cancer survivors through the use of multiple media sources (28.5%). Media awareness would also provide insight on genetic predispositions to cancers. If the public was informed about the experience of cancer survivorship and the care that is needed, the public would demand an educated nursing workforce to meet these challenges.

Participants (21.4%) identified other faculty who feel strongly that cancer survivorship must be included in curricula as a catalyst. New, young faculty with contemporary views are seen as more likely to incorporate survivorship content into the curriculum. Curricula that are holistically endorsed tend to include cancer survivorship concepts in their curricula. One study participant stated:

The faculty that are holistically trained definitely include cancer survivorship into our program since we are holistically endorsed. I think if we didn't have it, you might get a mention of care for the cancer survivor but not as in depth as certain people would be teaching it. Because we have accreditation standards we have to meet to so we have to make sure that the content, a certain amount of the content, is included, testing, all that stuff. I think without having to meet the standards for holistic endorsement, cancer survivorship probably would be minimal, if talked about at all.

Several study participants suggested that any nursing content on "the family" could include reference to the family as co-survivors (14.2%). Recognition of the unique issues of the family such as role strain, reversal of roles, grieving, and denial.

Faculty (14.2%) identified the support from their Dean and undergraduate Program Director as a facilitator in integrating survivorship into their curricula. In

addition to a supportive Dean and undergraduate Program Director the following factors need to be considered: (a) encouragement by course coordinators, department chairs, and researchers to include content along with curriculum reviews; (b) flexibility in the utilization of lecture time to bring students to listen to speakers on cancer survivorship; (c) supportive co-faculty; and (d) an ELNEC threaded curriculum.

The presence of students in nursing courses who are cancer survivors was identified as a catalyst for change (14.2%). Students who are cancer survivors as discussion facilitators in courses may lead to student panels where other students could learn a great deal from the cancer survivors. Faculty expressed the need to be cognizant of what their students, who self-identify as cancer survivors, want to share with their classmates and the importance of being aware of the "reactions and responses when assigning them to their clinical placements."

One impetus to improve the gap in cancer survivorship curriculum was to correlate clinical and classroom experiences on cancer survivorship content (14.2%). The use of simulation in the educational setting was suggested (14.2%). Reflective journaling and sharing of clinical experiences in the classroom and on Blackboard Learn that emphasize the importance of dialogue in the classroom regarding the assessment of patients and interactions with families. It was suggested that a simulation scenario on cancer survivorship and how to deal with family members through role-playing with the family and support systems would be a helpful way to incorporate clinical concepts of cancer survivorship. The fact that there is "an awareness that this population lives with a fear that you never know when the cancer will come back" (7%) should be an important reason to educate future nurses on this clinical information.

Fear of recurrence is best illustrated by the following words shared by this participant:

They don't ever know when it's going to come back. So they live in fear, even if they don't state that they may be feeling that, they're living with the fear of the cancer coming back. That's always there; the specter is always there. ...waiting for the other shoe to drop. Or Damocles sword, ...always having a sword over your neck, waiting. So these are the kinds of things that I think students need to learn about what it's like to live with the specter of this diagnosis.

## Summary

Answers to the five research questions were accomplished by an open-interview process with questions designed to examine undergraduate nursing faculty's beliefs and practices about cancer survivorship curriculum. From the participants' responses, content was derived and organized by questions and analyzed for recurrent themes and attributes. From the data analysis the following themes were identified: (a) descriptions of cancer survivorship; (b) beliefs on inclusion of cancer survivorship care within undergraduate nursing curriculum; (c) established content on cancer survivorship care: teaching practices; (d) gaps in content on cancer survivorship care; (e) lack of supportive literature on cancer survivorship care; (f) clinical sites providing opportunities for cancer survivorship care: planned versus unplanned; and (g) barriers and facilitators to the inclusion of cancer survivorship in undergraduate nursing curriculum.

Most participants did not conceptualize cancer survivorship consistent with the NCCS definition; a definition that represents a holistic view of cancer as a chronic illness with phases requiring distinct and overlapping management. While nearly all faculty

believed that care of the cancer survivor belonged in undergraduate nursing education, the data analysis found that of the fourteen participants, thirteen (92.8%) believed there is a gap in their educational programs specific to cancer survivorship curriculum. On the other hand, eight participants (57.1%) integrated care of the cancer survivor into their courses during the acute stage of survivorship or during end-of-life and hospice stages. However, only two (14.2%) of the fourteen participants integrated care of the cancer survivor in the extended or permanent stage of survivorship in their teaching practices on cancer survivorship. Only two (14.2%) of the fourteen participants integrated planned clinical opportunities that are consistent with the concept of nursing care of the cancer survivor. In addition, readings and test questions were not focused on cancer survivorship care.

Barriers to including cancer survivorship in undergraduate nursing curriculum were reported, including "content overload", NCLEX requirements, lack of faculty knowledge or development opportunities and student behavioral and academic barriers. However, many opportunities to facilitate cancer survivorship in undergraduate nursing curriculum were also discussed. Cancer survivorship curriculum changes may be facilitated by increased faculty development on the topic, support from Deans or Program Directors, increasing the correlation between clinical and classroom learning, and integrating student and faculty personal experiences with cancer more routinely.

## **CHAPTER V**

#### CONCLUSIONS AND DISCUSSION

#### Introduction

The purpose of this qualitative descriptive study was to gain an understanding of faculty beliefs about including cancer survivorship curriculum in undergraduate nursing education and the specific teaching practices of faculty on cancer survivorship care. In addition, Mezirow's transformational learning theory will be discussed in view of the study findings and literature on cancer survivorship care.

A qualitative descriptive design guided the study, which consisted of open-ended interviews with 14 undergraduate nursing faculty. Five research questions served as the foundation for the interviews. Interview transcripts were examined and analyzed. Similar content was grouped as shared concepts and coded based on its relationship to the study research question, after data saturation was achieved (Krippendorff, 2013; Polit & Beck, 2012). Themes and their attributes were identified and named from these groupings. The content groupings and themes were validated by a second reviewer with training in content analysis and a clinical background in cancer survivorship.

This chapter will provide a brief summary of the results, a discussion of the results as they relate to the cancer survivorship and educational literature, limitations of the study, implications of the results to practice, and suggestions for further research.

# **Summary of the Results**

Content analysis of the interviews resulted in seven themes. The themes were: (a) descriptions of cancer survivorship; (b) beliefs on inclusion of cancer survivorship care within undergraduate nursing curriculum; (c) established content on cancer survivorship care: teaching practices; (d) gaps in content on cancer survivorship care; (e) lack of supportive literature on cancer survivorship care; (f) clinical sites providing opportunities for cancer survivorship care: planned versus unplanned; and (g) barriers and facilitators to the inclusion of cancer survivorship in undergraduate nursing curricula.

Theme one: Descriptions of cancer survivorship. Less than half of those interviewed (42%) defined cancer survivorship care that was consistent with the NCCS definition, or a holistic description about the patient experience that addresses needs and care from diagnosis to end-of-life. Those participants with definitions that were inconsistent (57%) with the NCCS definition of cancer survivorship care viewed cancer survivorship as an experience that begins once acute treatment ends; participants did not have a "clear definition" of cancer survivorship; participants did not include family, friends, and caregivers in the definition; and it was necessary for the patient to have survived five years after their initial diagnosis in order to be considered a survivor.

Theme two: Beliefs on inclusion of cancer survivorship care within undergraduate nursing curriculum. While nearly all faculty (92%) agreed that cancer survivorship care belongs in undergraduate nursing programs, the same number of faculty (92%) identified a gap in their curriculum regarding the physical, psychosocial, and spiritual needs of the cancer survivor.

Theme three: Established content on cancer survivorship care: teaching practices. Participants reported covering content related to the acute stage of survivorship that surrounds the initial time of diagnosis when patients are in the acute stage of treatment (42%), along with end-of-life and hospice care. Survivorship content was, for the most part, reported as being taught briefly and covering "limited aspects of care." The extended and permanent stage of survivorship was integrated into only 14 percent of curricula.

Theme four: Gaps in content on cancer survivorship care. Forty-three percent of the participants did not teach cancer survivorship at all.

Theme five: Lack of supportive literature on cancer survivorship care. Twentyone percent of participants included no literature or testing on cancer survivorship care in
their program. Twenty-one percent of faculty included a limited amount of literature and
testing on cancer survivorship care in their program. Fifty-seven percent of participants
reported that extremely limited literature may be included in their curriculum but they
were unsure.

Theme six: Clinical sites providing opportunities for cancer survivorship care: planned versus unplanned. Fourteen percent of participants described clinical opportunities that were planned experiences for patients in all stages of survivorship. Thirty-six percent of faculty stated that there were no clinical learning opportunities for cancer survivorship care. Fifty percent of the faculty interviewed described clinical experiences where students provide care for cancer patients but the experiences focused on acute, end-of-life, or hospice stages of care only.

Theme seven: Barriers and facilitators to the inclusion of cancer survivorship in undergraduate nursing curricula. Participants reported barriers such as lack of faculty knowledge and awareness of cancer survivorship needs; lack of resources and books on cancer survivorship; the need to cover AACN essentials and other content considered crucial in undergraduate curriculum; lack of time to teach cancer survivorship due to content overload in curriculum; concern over what content is tested on NCLEX-RN; a pediatric population that has moved on from their cancer experience; characteristics of students; a disconnect between what is taught and societal needs; the complexity of medical management for the cancer patient; and a focus on holistic care with an awareness of customer service

Facilitators included faculty whose beliefs were strong that cancer survivorship must be included in the curriculum; use of media to inform the public about the needs of cancer survivors; increasing faculty awareness on the health care needs of cancer survivors; holistic training of faculty; inclusion of the family as co-survivors; a supportive Dean and Program Chair; ELNEC threaded curriculum; correlation of classroom and clinical practice; students who are cancer survivors; and use of simulation in the educational setting with a scenario on cancer survivorship.

#### Discussion of the Results in Relation to the Literature

A review of the literature identified three content areas important to cancer survivorship care. These areas are: (a) nursing implications in cancer survivorship care, (b) interprofessional care of cancer survivors, and (c) implications for nursing faculty. It is important to examine the findings of this study in relation to theory and research on cancer survivorship in order to either validate previous research or to identify future

opportunities for additional research or change in nursing educational practice. The findings of this study will also be discussed in relation to the theoretical framework, Mezirow's transformational learning theory.

# **Nursing Implications in Cancer Survivorship Care**

In the U.S. there is currently an estimated 14.5 million cancer survivors with unique health care needs that must be addressed in the education of nurses (DeSantis et al., 2014; IOM, 2005). Record numbers of individuals are now surviving cancer, which is the second leading cause of death in the U.S. (DeSantis et al., 2014). Cancer survivors require that nurses in current practice are aware of their unique needs as survivors of a chronic disease, recognize survivorship as a distinct stage of cancer care, and are able to coordinate a survivorship care plan utilizing evidence-based clinical practice guidelines (IOM, 2005).

The four components of cancer survivorship care that nurses must address to ensure that the health care needs of cancer survivors are met include: (a) prevention and detection of new and recurrent cancers; (b) surveillance for cancer spread, recurrence, or second cancers; (c) intervention for consequences of cancer and its treatment; and (d) coordination between specialists and primary care providers (Chubak et al., 2012; IOM, 2005).

The findings of this study reveal that these four components are not routinely addressed in undergraduate nursing curricula. Of the fourteen participants, only two (14.2%) reported including these content areas in their teaching practices.

Themes identified in this study that are pertinent to this area of the literature include: established content on cancer survivorship care: teaching practices; gaps in

content on cancer survivorship care; lack of supportive literature on cancer survivorship care; and clinical sites providing opportunities for cancer survivorship care; planned versus unplanned. While 92 percent of participants stated that content related to caring for the needs of cancer survivors belonged in undergraduate nursing education; the same percentage of respondents believe that it is neglected and reported cancer survivorship as a gap in their curricula. This was demonstrated in the study's sample as only 14% of participants included care of the patient that expanded upon the acute stage of cancer survivorship, to include the extended and permanent stages of survivorship. Participants also assigned limited or no academic and clinical literature on cancer survivorship care in their current undergraduate nursing programs. Students have ample opportunity to provide care for cancer patients during clinical experiences; however, 50 percent of faculty reported that the clinical experiences were not planned cancer survivorship experiences grounded in cancer survivorship concepts and interventions. The IOM (2005) recommendations released by From Cancer Patient to Cancer Survivor: Lost in Transition calls for the establishment and provision of appropriate care to cancer survivors by all healthcare providers as a distinct stage of cancer care. Furthermore, this report recommends that all healthcare providers must increase awareness of the needs of cancer survivors in order to improve the quality of care to cancer survivors (IOM, 2005).

# **Interprofessional Care of Cancer Survivors**

Interprofessional care of the cancer survivor through the use of multiple disciplines and care models is discussed in the literature to address health care gaps for survivors (Cooper et al., 2010; McCorckle et al., 2011). The IOM (2005) identified the importance of educating nurses, physicians, rehabilitation specialists, and psychosocial

and mental health providers on content that is related to the care of the cancer survivor. The development of the CSCP as a tool for multiple disciplines to coordinate care needs of the cancer survivor in multiple settings was discussed in the literature review (Donofrio Angelucci, 2013; Morgan, 2009). In this study, no participants mentioned the use of the CSCP in their teaching practices. Thus, the findings of this study did not align with the literature review. Only one participant (7%) in this study reported the importance of interprofessional care for cancer survivors. This participant viewed cancer survivorship from a multidisciplinary perspective and stated she "believes it takes multiple disciplines to empower families to care for their loved ones who are cancer survivors."

Themes identified in this study that pertain to this area of the literature include: established content on cancer survivorship care: teaching practices; gaps in content on cancer survivorship care; lack of supportive literature on cancer survivorship care; clinical sites providing opportunities for cancer survivorship care: planned versus unplanned; and barriers and facilitators to the inclusion of cancer survivorship. The findings of this study did not support the literature review on interprofessional care and collaboration with other disciplines in the care of the cancer survivor. Interprofessional care was not found to be evident in established content on cancer survivorship care, thus it would be included as a gap in content on cancer survivorship care. In addition, the study participants reported no supportive literature or planned clinical experiences that would include interprofessional care or collaboration with other disciplines in clinical practice or on a CSCP.

# **Implications for Nursing Faculty**

The inclusion of cancer survivorship content in nursing and health care education is critical to meet the IOM (2005) recommendations to educate nurses and other health professionals in the care of the cancer survivor. Nursing education research literature that includes cancer survivorship care integration in undergraduate curricula is scant.

Such Lockhart et al. (2013) conducted the most recent and comprehensive study that addressed undergraduate oncology content in nursing curricula. A national sample of nurse faculty were surveyed to explore the depth of oncology nursing content taught in prelicensure nursing curricula, the perceived importance of this content, barriers to providing this content, and the use of resources that were oncology-related (Such Lockhart et al., 2013). Cancer survivorship content was rated amongst the lowest in relation to depth and importance of oncology content in this study due to a lack of time to include survivorship in the curriculum (Such Lockhart et al., 2013). This study supported Such Lockhart et al.'s (2013) finding of lack of time as a barrier to inclusion of cancer survivorship content in undergraduate nursing curriculum. However, this study is different from Such Lockhart et al.'s in that 92 percent of participants believed that cancer survivorship care should be included in undergraduate nursing education.

Barriers and facilitators to the inclusion of cancer survivorship were identified as a theme in this study. Other barriers included "content overload"; the need to cover content to prepare the students for the NCLEX-RN exam; lack of faculty knowledge on cancer survivorship; "there is more important content to cover"; "a disconnect between what is taught and what society needs"; the complexity of medical management of the patient with cancer involving multiple nursing care needs; lack of nursing textbooks and

resources that focus on cancer survivorship; a pediatric population that has moved on; and student characteristics. While there is no nursing education research to relate the findings of many of the barriers, they are significant to add to the literature on nursing education and for further study.

Faculty identified many facilitators to integrate cancer survivorship content into undergraduate nursing curricula. Facilitators include: the large presence of cancer survivors in society; a professional development presentation for faculty on cancer survivorship; faculty awareness; use of the media to inform the public on the needs of cancer survivors; faculty who feel strongly that cancer survivorship should be included in undergraduate nursing curricula; support from the Dean and undergraduate Program Director; the presence of students who are cancer survivors in nursing courses; correlation of clinical and classroom experiences on cancer survivorship content; the use of simulation; and fear of recurrence. While there is no current nursing education literature on facilitators to increase the inclusion of care of the cancer survivor in undergraduate nursing curricula, it is important to add these to the literature and to disseminate these facilitators to other educators.

Similarly, Uijtdehaage et al. (2009a) identified a significant gap in a comprehensive curriculum for medical schools resulting in physicians who are not prepared for caring for cancer survivors. This study supported these findings with the identification of the theme: gaps in content on cancer survivorship care. Uijtdehaage et al. (2009a) conducted an additional study in which a cancer survivorship curriculum was implemented for an intervention group. The intervention group demonstrated

improvement in the educational outcomes for the critical components of survivorship care (Uijtdehaage et al., 2009b).

There is a paucity of research on integrating cancer survivorship education in undergraduate nursing programs. Hermann et al. (2008) designed a month long intervention to improve nurse faculty cancer knowledge on cancer survivorship and improve cancer care. This study correlates to the recommendation of faculty development programs as a facilitator to the inclusion of cancer survivorship that was identified in the theme: barriers and facilitators to the inclusion of cancer survivorship. The lack of faculty knowledge on the unique needs of cancer survivors was found to be a recurring barrier in this study. Improving faculty knowledge on cancer survivorship will increase the inclusion of content of care of the cancer survivor in undergraduate nursing curriculum. Trocky et al. (2011) developed web-based modules for breast cancer health care, which included content on epidemiology, diagnosis, and all aspects of survivorship that students were required to view in the BSN program. The importance of educating students on all aspects of survivorship was revealed in this study as only 14 percent of participants were found to cover all stages of survivorship in their teaching of cancer survivorship care.

#### Theoretical Framework

Mezirow's transformational learning theory is an adult learning theory in which adults draw on prior experiences to transform one's frame of reference through critical reflection and self-reflection (Mezirow & Taylor, 2009). This theory was supported during data collection when one participant described why she did not teach cancer survivorship in her course because she "has not had any experience with cancer survivors

personally and does not address it specifically in the classroom." This was the one participant who did not answer the interview question: "Do you believe that content related to caring for needs of the cancer survivor belongs in undergraduate nursing education?" Another participant reported that he "believes survivorship has a place in the curriculum, probably because it is 'close to my heart' as my mother is a survivor." As one faculty participant described "cancer survivorship was not directly covered as a thread, but covered 'loosely' depending on how faculty draw from prior experiences." Most participants supported the integration of cancer survivorship care into undergraduate nursing curriculum, even though it is not currently being taught.

"Everyone knows a cancer survivor" was expressed repeatedly during data collection and this would serve as the core element for individual experience in transformative learning to begin discourse with both faculty and students (Mezirow & Taylor, 2009). One participant reported the use of reflections providing "rich" feedback regarding the student's psychosocial response to a book on an assignment about two teenage cancer survivors. This educator promoted critical reflection of a story of two young cancer survivors, one of which was dying, that were similar in age to her own students. This provoked a "disorienting dilemma" which activated critical reflection and transformative learning (Mezirow & Taylor, 2009).

The facilitators to the inclusion of cancer survivorship that were suggested by participants can be considered transformational as they have the potential to change one's frame of reference and meaning perspectives in relation to including cancer survivorship care in undergraduate nursing curricula. These facilitators that may promote transformation include: (a) emphasizing the large presence of cancer survivors in our

society and the personal connection many faculty may have with survivors; (b) increasing faculty awareness of the needs of cancer survivors through professional development programs; (c) increase media awareness to allow for a more informed public on the needs of cancer survivors; (d) faculty who feel strongly about the inclusion of survivorship content can serve as the catalyst for presenting the "disorienting dilemma", stimulating reflection and dialogue with colleagues; (e) recognition of the importance of the family as co-survivors subject to unique role issues; (f) support from program administrators and co-faculty; (g) students who are cancer survivors; (h) correlation of clinical experiences and classroom cancer survivorship content; (i) using simulation in the educational setting involving a cancer survivorship scenario; and (j) the realization that survivors live with a fear of recurrence.

#### Limitations

In a qualitative descriptive study sample size is based on quality and data saturation, but some may consider the number of participants to be small and therefore a limitation. The topic of the dissertation may be considered a limitation, as it has been previously found by a few studies that nursing curricula do not routinely address cancer survivorship care, however, this study was designed to provide an in-depth description of the reasons that have contributed to this lack of cancer survivorship curriculum (IOM, 2005; Such Lockhart et al., 2013). When faculty received the introductory email, they may not have had interest in participating in the study if they do not teach it. The study was limited geographically to two states for convenience sampling. Every attempt was made to minimize threats to the research design as outlined in the methodology chapter of this dissertation. These strategies included: (a) intense listening during the interview; (b)

gentle probing for rich data collection; (c) audiotaping of interviews and immediate transcription by the interviewer; (d) a loose research design with open-ended questions; (e) member checking; (f) thick description of findings; and (g) an audit trail of digital recordings, transcripts, responses from member checking, data reduction and analysis, notes and drafts of the data compilation.

# **Implications of the Results for Practice**

Education of nursing faculty on the current definition of cancer survivorship is critical to the inclusion of this content in undergraduate nursing curricula. This not only includes the NCCS definition of the cancer survivor, but the recognition of the acute, extended, and permanent stages of cancer survivorship along with the nursing care that is needed for survivors during these stages (Morgan, 2009). While the IOM report (2005) *From Cancer Patient to Cancer Survivor: Lost in Transition* identified cancer survivorship as content that required research in provision of care and inclusion in nursing education, there remains a significant gap in this area regarding nursing education ten years after the report has been published.

In addition to the stages of cancer survivorship, faculty must be educated on the four components of cancer survivorship care that all nurses must provide to cancer survivors. These four components of care include: prevention and detection of new and recurrent cancers; surveillance for cancer spread, recurrence, or second cancers; intervention for consequences of cancer and its treatment; and coordination between specialists and primary care providers to ensure that the health needs of the survivor are met (IOM, 2005; Chubak et al., 2012).

A review of current undergraduate curriculum and what is necessary for prelicensure BSN students to know upon entering into practice regarding cancer survivorship is a dialogue that must occur amongst faculty. Cancer is the second leading cause of death in the United States with record numbers of individuals surviving with this disease (DeSantis et al., 2014). It is second only to heart disease in incidence in the United States and yet would faculty consider not covering nursing care of the patient with congestive heart failure in their curriculum?

Another interesting finding of this study is the concern expressed by faculty over whether cancer survivorship content is included on the NCLEX-RN exam. Faculty reported that there is an emphasis on NCLEX-RN scores and on teaching care of the acutely ill cancer patient as that is what they perceive is being tested on the NCLEX-RN exam. Curriculum mapping of undergraduate nursing programs by faculty to determine the appropriate placement of content is necessary as it relates to current nursing practice as well as the NCLEX-RN test plan. Discussion of the results of this study in relation to the development of nursing licensure examinations that include content on care of the cancer survivor would be appropriate with the National Council of State Boards of Nursing (NCSBN). Policy implications may also include discussion with the American Association of Colleges of Nursing (AACN) to include care of the cancer survivor in The Essentials of Baccalaureate Education for Professional Nursing Practice.

Based on the results of this study, the following recommendations for implementation of educational practice changes include: (a) professional development and education of faculty on the needs of cancer survivors and the importance of integrating this content into undergraduate curricula; (b) utilization of Mezirow's

theoretical framework by faculty to integrate cancer survivorship content as a "disorienting dilemma", critical reflection and discourse will allow for transformative learning by faculty; (c) designate a faculty "lead" for the integration of cancer survivorship content into the nursing program; (d) integrate cancer survivorship into every nursing course, cover survivorship in depth with oncology content and thread it through with pediatrics, women's health, fertility and all aspects of nursing care; (e) provide community clinical experiences for students that are planned for the cancer survivor such as the Connecticut Challenge which provides services for those in stages of survivorship in addition to the acute stage; (f) recognize the value of interprofessional experiences that can be found in settings such as cancer centers where students may interact with radiation technologists, oncologists, social workers, nurse navigators, integrative and alternative therapy professionals, as well as the role of the nurse in outpatient infusion centers; (g) utilize evolving case studies and simulation that follow patients over time and in multiple courses as their complexity of care increases; (h) include simulation of care of the cancer survivor and co-survivor scenarios in nursing courses throughout the curriculum; and (i) introduce students to the online resources available for developing CSCPs and have them complete a CSCP for an assigned patient.

# **Suggestions for Further Research**

Future research is needed on the incorporation of cancer survivorship content into graduate nursing programs. Does a gap in care of the cancer survivor content exist in graduate programs also? It is vital to explore if nurse practitioners that will serve as primary care providers are prepared to care for individuals who are cancer survivors. This can be achieved through a replication of this study or through a quantitative

descriptive survey of graduate faculty to include questions on specific content that may be covered on cancer survivorship care in graduate nursing programs.

In regards to undergraduate nursing education, it is time to re-examine what is included in our prelicensure programs and why faculty are still reporting "sacred cows" and content overload. How is current prelicensure nursing curricula viewed through our conceptual frameworks? Is it defined based on the NCLEX-RN blueprint? More qualitative studies are needed to examine undergraduate curriculum mapping and the content that is needed for the contemporary generalist baccalaureate nurse.

The practice of holding on to "sacred cows" and adding content to existing curricula can be studied in an experimental design by comparing a traditional curriculum with a curriculum that has been developed utilizing Mezirow's transformational learning theory. With Mezirow's transformational learning theory, the curricular design would require faculty to critically reflect upon prior experiences and problem solve to transform beliefs about including "sacred cows" versus the inclusion of content that is pertinent to the current needs of society. Faculty use of critical reflection of assumptions related to the evolving and emerging problems in society, including the large population of cancer survivors and their unique needs, could be integrated with the NCLEX-RN blueprint to allay concerns over whether content that is included on NCLEX-RN is being taught. Evaluation of student knowledge and NCLEX-RN performance could be measured in this experimental design of a change in curriculum based on Mezirow's theory.

Another intervention study would involve the development of modules on cancer survivorship for undergraduate students which would be available through the National League for Nursing (NLN) website. Schools of nursing would be asked to participate in

enrolling an experimental group of students to view the modules while a control group received their usual curriculum. Effectiveness of this educational intervention on care of cancer survivors would be tested and compared to the control group.

An additional qualitative study utilizing the data from this research would include another level of analysis with research questions that would examine the seven themes of this study and the relationships between the themes. For example, how might the barriers described by the study participants relate to gaps in content on cancer survivorship care?

Development of a survey for national distribution based on the research questions of this study for faculty on beliefs and teaching practices on care of the cancer survivor may be used for both undergraduate and graduate nursing faculty. It is apparent that more research needs to be done on this topic.

# APPENDIX

# APPENDIX A: LETTER OF INFORMATION TO CONSENT TO PARTICIPATE IN RESEARCH

Dear Undergraduate Nursing Faculty Member,

My name is Mary Dietmann and I am pursuing an Ed.D. in Nursing Education at Southern Connecticut State University (SCSU) in New Haven, CT. As part of the requirement for the Ed.D. in Nursing Education at SCSU, I am carrying out a research study on The Inclusion of the Care of the Cancer Survivor in Undergraduate Nursing Curricula. This study will focus specifically on faculty beliefs and practices about the inclusion of care of the cancer survivor content in undergraduate nursing curricula.

The study will involve a 30 to 45 minute tape-recorded interview at a location of your convenience, outside of your workplace. Suggestions for meeting locations are a local restaurant or coffee shop, your home or my home.

You have been chosen as a potential participant as my sample has been identified as undergraduate nursing faculty in BSN programs. If you teach in graduate courses only, you will not qualify for this study but I would be very grateful if you could forward this email to any undergraduate nursing faculty in CT or NY that you believe may be interested in participating. Participation is voluntary and informed consent is attached. A copy of the informed consent will be signed at our meeting and I will provide you with a copy of the signed informed consent. Participants have the option to withdraw from the study at any time. If you choose to withdraw after data has been collected, all potentially identifiable data, including audiotapes, will be destroyed. If you have questions regarding your rights as a research subject, contact: Institutional Review Board at Southern Connecticut State University (203) 392-5243 or hauseltw1@southernct.edu.

Your participation in the study will be kept confidential. I will ensure that there are no clues to your identity in the dissertation. Any quotes used in the dissertation will be anonymous.

The data will be kept confidential for the duration of the study. On completion of the dissertation, they will be retained for a further three years and then destroyed. The results

will be presented in my dissertation and submitted to my dissertation committee. The dissertation will be published in ProQuest.

I do not envision any negative consequences of participation in this study. SCSU's IRB and my dissertation committee, of which Dr. Elizabeth Ercolano serves as primary advisor, have approved it.

If you agree to this study, please respond by email or call me directly at (203) 332-3261.

Sincerely,

Mary Dietmann, MSN, APRN, ACNS-BC, CNE

## **Consent Document**

## Introduction

The title of this study is "The Inclusion of the Care of the Cancer Survivor in Undergraduate Nursing Curricula". The principal investigator is Mary E. Dietmann, a doctoral student at Southern Connecticut State University who is pursuing a degree of Doctor of Nursing Education. In order to decide whether or not you wish to be a part of this research, you should be aware of all aspects of the study, its purpose, the procedures to be used and any risks or benefits. This consent form provides you with detailed information about the research study. I will discuss any aspects of the study with you that you do not understand. Once you understand the study, you will be asked if you wish to participate, if you do, you will be asked to sign this form.

## **Purpose**

The purpose of this study is to explore faculty beliefs and teaching practices regarding the inclusion of cancer survivorship care in nursing curricula. This study will identify and validate if there is a gap in content in the care of cancer survivors in undergraduate U.S. nursing programs. The exploration of faculty beliefs regarding the importance of teaching students about the unique needs of cancer survivors will give insight into the curricular gap on cancer survivorship content in nursing education.

## **Procedures**

If you decide to volunteer we will meet for 30 to 45 minutes at a location of your convenience for an audiotaped interview in which you will be asked some demographic questions regarding your teaching experience as well as your beliefs and teaching practices regarding cancer survivorship care.

Participant's	<b>Initials</b>	}
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#### Risks and Inconveniences

I do not envision any negative consequences but am asking for 30 to 45 minutes of your time, which may be considered an inconvenience.

#### **Benefits**

This study was not designed to benefit you directly, however there is the possibility that through your participation greater insight into nursing curricula on cancer survivorship care will be obtained.

## **Costs/Compensations**

There are no costs or compensation to participate in this research.

## **Voluntary Participation**

Your participation in this research is entirely voluntary. You may refuse to participate in this research without any negative consequences for you. If you begin to participate in this research, you may at any time and for any reason, discontinue your participation without any negative consequences. Simply let the researcher know.

## **Confidentiality**

Any and all information obtained from you will be confidential. Your privacy will be protected at all times. You will not be identified individually in any way as a result of your participation in this research. The data collected however, may be used as part of publications and papers related to nursing education curriculum and cancer survivorship care.

#### **Signature Section**

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to decide if you wish to participate. If you have further questions, you may contact Mary Dietmann (203) 332-3261. If you have questions regarding your rights as a research participant you may contact the SCSU Institutional Review Board at (203) 392-5243.

Partic	Participant's Initials	
Investigator Signature: I have explained to		
of this research, the procedures required, and the possible my ability. To the best of my knowledge, the information is true and accurate.	contained in this consent form	
Date:		
Participant Signature: I confirm that me the purpose of this research, the study procedures that I risks and discomforts as well as benefits that I may experie read to me this consent form and I understand it. Thereforengaged as a participant in this research project.	I will undergo and the possible ence. I have read or have had	
Date:		

## APPENDIX B: INTERVIEW GUIDE

"My name is Mary Dietmann and I am a doctoral student in nursing education at Southern Connecticut State University. My dissertation topic is on including care of the cancer survivor in undergraduate nursing curricula. I am interviewing you today to explore what you currently teach about care of the cancer survivor and your beliefs about including care of the cancer survivor in undergraduate nursing curricula.

The first four questions are general questions about your academic experience and specialty area(s). The following six questions relate specifically to the dissertation topic on including care of the cancer survivor content in undergraduate nursing curriculum. As I indicated in the consent letter, I will turn the tape recorder on now."

## Part 1: Demographic

- 1. How long have you been teaching?
- 2. What is your area of specialty?
- 3. What do you currently teach?
- 4. Have you done any continuing education on care of cancer survivors?
- 5. When was the last time the courses and curriculum in your program were reviewed/revised?

## Part 2: Beliefs and Practices about Cancer Survivorship Care

**Provide definition of cancer survivorship here.** "For my study, I am using the definition of cancer survivorship provided by the National Coalition for Cancer Survivorship (NCCS) which states that survivorship encompasses the time of diagnosis through the balance of life, and includes family, friends, and caregivers".

5. How do you define cancer survivorship care? (**Probe**: do you include family and caregivers?)

- 6. Do you believe that content related to caring for needs of the cancer survivor belongs in undergraduate nursing education? (**Probe**: can you explain more about that?)
- 7. What is currently taught in your curriculum regarding physical, psychosocial or spiritual needs of the cancer survivor? (**Probe**: if it is not taught, was it ever discussed as a content area that should be included in the curriculum? **Probe**: are the 4 components per Morgan included—prevention and detection of new or recurrent cancers; surveillance for cancer spread, recurrence, or second cancers; intervention for consequences of cancer and its treatment; coordination between professionals to ensure the survivors health care needs are met **Probe**: Is care of the cancer survivor content taught in one course or is it taught throughout the curriculum? **Probe**: How was the placement of the content determined?
- 8. Do you assign textbook or journal articles for students to read on care of the cancer survivor topics that may be included on tests? (**Probe**: are students tested on this content?)
- 9. Describe the inpatient and community clinical experiences where your students provide care for cancer survivors. (**Probe**: CT Challenge, Cancer Centers)
- 10. Do you perceive barriers or facilitators in integrating care of the cancer survivor content into your curriculum? (**Probe:** if so, what are they? **Probe:** barriers such as lack of time and lack of faculty knowledge on cancer survivorship content. **Probe:** facilitators such as critical reflection on cancer experiences and lifelong effects; changes in meaning perspectives due to previous clinical experiences with cancer patients)

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