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# DEVELOPMENT OF A BREAST CANCER SURVIVORSHIP CARE TOOLKIT

By

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Bachelor of Science Nursing Utah Valley University 2015

A doctoral project submitted in partial fulfillment of the requirements for the

Doctor of Nursing Practice

School of Nursing Division of Health Sciences The Graduate College

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# **Doctoral Project Approval**

The Graduate College The University of Nevada, Las Vegas

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Development of a Breast Cancer Survivorship Care Toolkit

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#### Abstract

A breast cancer survivor's journey does not end with treatment. After treatment, most breast cancer survivors go on to face many life-long physical and mental challenges caused by their cancer and treatment. Once active cancer treatment is completed, patients enter the next important step in cancer care, cancer survivorship. Cancer survivorship is a comprehensive approach to post-oncology management that promotes the best outcomes for survivors as they transition from oncology care to primary care; and new breast-cancer survivorship guidelines have emerged. Research suggests that primary care NPs' lack of awareness of the current 2016 American Cancer Society/American Society of Clinical Oncology [ACS/ASCO] Breast Cancer Survivorship Care Guidelines impedes their ability to provide the best evidence-based care for breast cancer survivors. This DNP project was designed to develop a breast cancer survivorship toolkit based upon contemporary breast cancer survivorship guidelines as part of the ongoing effort to better inform primary care NPs of survivors' needs and promote best-practices implementation.

| Abstractiii   |
|---|
| Table of Contentsiv                                       |
| List of Tablesvii   |
| List of Figuresviii                                       |
| Chapter 1: Introduction1                                  |
| Phenomenon of Interest                                    |
| Problem Statement   |
| Purpose Statement   |
| Chapter 2: Review of Literature                           |
| Breast Cancer   |
| Risk factors5   |
| Screening   |
| Treatments7   |
| Survivorship9   |
| Late and Long-Term Effects9                               |
| Breast Cancer Survivors10                                 |
| Evolution of Cancer Survivorship Care10                   |
| ACS/ASCO Breast Cancer Survivorship Care Guidelines11     |
| Surveillance and Screening                                |
| Assessment and Management of Late and Long-Term Effects13 |
| Body Image Concerns13                                     |
| Lymphedema14  |
| Cardiotoxicity14  |

# Table of Contents

| Cognitive Impairment14                              | 4 |
|---|---|
| Distress, Depression, Anxiety14                     | 4 |
| Fatigue1  | 5 |
| Bone Health   | 5 |
| Musculoskeletal Health1                             | 5 |
| Pain and Neuropathy1                                | 5 |
| Sexual Health and Infertility1                      | 6 |
| Premature Menopause1                                | 6 |
| Health Promotion1                                   | 6 |
| Care Coordination1                                  | 8 |
| Survivorship Guidelines in Primary Care1            | 8 |
| Needs Assessment                                    | 9 |
| Population Identification2                          | 1 |
| Project Stakeholders                                | 1 |
| Organizational Assessment2                          | 1 |
| Scope of the Project                                | 2 |
| Mission and Goals                                   | 2 |
| Chapter 3: Theoretical Underpinnings and Framework2 | 3 |
| Nursing Intellectual Capital Theory2                | 3 |
| Chapter 4: Project Plan                             | 5 |
| Setting2  | 5 |
| Population of Interest                              | 5 |
| Measures, Instruments, and Activities2              | 5 |
| Fimeline2   | 7 |

| Project Tasks and Personnel2  | 7 |
|---|---|
| Resources and Supports2   | 7 |
| Risks and Threats23   | 8 |
| Evaluation Plan2  | 8 |
| Chapter 5: Summary of Project Results                               | 0 |
| Data Collection   | 0 |
| Data Analysis3  | 1 |
| Quantitative Data   | 1 |
| Qualitative Data  | 2 |
| Discussion of Project Results                                       | 3 |
| Future Implication  | 3 |
| Appendix A: Project Timeline  | 5 |
| Appendix B: Toolkit Deliverables                                    | 6 |
| Appendix C: Content Questionnaire and Content Validity Index Table4 | 9 |
| References  | 2 |
| Curriculum Vitae  | 6 |

| List | of | Tab | les |
|------|----|-----|-----|
|      |    |     |     |

| Table 1. Content Validity Index Table    32 |
|---|
|---|

| List of Figures                |
|--------------------------------|
| Figure 1. NICT Project Support |

#### Chapter 1

### Introduction

Though not realized by many, a breast cancer survivor's journey does not end with treatment. In fact, most breast cancer survivors go on to face many life-long physical and mental challenges caused by both their cancer and its treatment. Once active cancer treatment is completed, breast cancer patients enter the next important, but often neglected, step in cancer care, which is cancer survivorship. Cancer survivorship is a comprehensive approach to post-oncology management and aims to achieve the best outcomes for breast cancer survivors as they transition from oncology care to primary care. In this setting, nurse practitioners (NPs) share in the responsibility of providing the highest quality survivorship care for such a vulnerable population. While treatment for post-oncology care has long been a part of ongoing health care, relatively new breast cancer survivorship care guidelines are emerging. Unfortunately, most NPs in primary care remain unaware of these guidelines and implementation methodologies for the evidence-based practices to fulfill the unique needs of these patients.

Cancer survivorship care is an approach to care that addresses the specific ongoing needs of cancer survivors (American Society of Clinical Oncology [ASCO], 2013). This care includes prevention and surveillance for new or recurrent cancers, management of late and long-term disease and treatment effects, and health promotion and coordination between healthcare specialties when appropriate (ASCO, 2013). In recent years, primary care providers (PCPs) have been designated the key providers of cancer survivorship care (Sun, Olausson, Fujinami, Chong, Dunham, Tittlefitz, ... & Grant, 2015). PCPs can be physicians, physician's assistants (PAs), and NPs working within the primary care setting. This project was designed for NP primary care providers managing female breast cancer survivors.

#### **Phenomenon of Interest**

Breast cancer is the most prevalent malignancy among women (ASCO, 2017; Miller, Siegel, Lin, Mariotto, Kramer, Rowland, ... & Jemal, 2016). Research shows that a woman's lifetime risk of being diagnosed with breast cancer has increased within the last 40 years from 1 in 11 women to 1 in 8 women (American Cancer Society [ACS], 2017). According to the ACS (2017), the increased prevalence of breast cancer is a result of increased life expectancy, changes in reproductive patterns, increased obesity prevalence, use of menopausal hormones, and a rise in improved screening and early detection. Although the incidence of breast cancer has risen, the past 20 years have been characterized by a simultaneous decline in breast cancer mortality (Miller et al., 2016).

There are several factors that have contributed to the decrease in breast cancer mortality rate even in the face of its increasing prevalence. Most notably, significant advances in cancer research and effective treatment options have improved breast cancer patients' survival rate (Pandey & Nguyen, 2017). Further, advances in early detection methods and preventative measures have improved long-term life expectancy (Miller et al., 2016). As a result, the breast cancer survivor population is steadily increasing with an average five-year survival rate of 90% (ACS, 2017). This significant increase in the number of breast cancer survivors calls for a greater need for improved cancer survivorship care.

In response to the growing breast cancer survivor population, multiple cancer organizations and researchers have explored best practices for survivorship care and potential barriers to its application. Research shows that breast cancer patients experience a better quality of life when receiving cancer survivorship care; however, research has also demonstrated that the majority of primary care NPs are ill-prepared to provide such care (American Cancer Society/American Society of Clinical Oncology [ACS/ASCO], 2016; Koch, Jansen,

Herrman,...& Arndt, 2013; Pandey & Nguyen, 2017; Pandey & Barber, 2016). Pandey and Nguyen (2017) suggest that this lack of preparation stems from the NPs' minimal education and training specific to cancer survivors' follow-up needs and late and long-term cancer and treatment effects. As a result, breast cancer survivors' unique physical and emotional needs are often neglected in the transition from the oncologist to the primary care NP (Pandey & Nguyen, 2017). While breast cancer survivorship care guidelines and recommendations have been created to close the knowledge gap, there have been few study results indicating improvement in practice (ACS/ASCO, 2016; Pandey & Nguyen, 2017; Pandey & Barber, 2016; Sun et al., 2015). Luctkar-Flude et al. (2015) conducted a breast cancer guideline implementation study that showed that only 46.4% of breast cancer survivorship care guidelines were being implemented "half the time" by 82 participating PCPs. The study concluded that limited provider knowledge of the survivorship care guidelines in primary care was a leading contributor to minimal implementation (Luctkar-Flude et al., 2015). By bringing cancer survivorship care guidelines into practice and increasing primary care NPs' knowledge of these guidelines, NPs can more proficiently address breast cancer survivor needs and ultimately improve patient outcomes.

## **Problem Statement**

Primary care NPs' lack of awareness of the current 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines, impedes their ability to provide the best evidence-based care for breast cancer survivors. This lack of awareness creates inconsistencies in follow-up, screening, management of late and long-term disease and treatment effects, and health promotion for patients transitioning from oncology to primary care. Addressing the lack of awareness and resultant inconsistencies can ultimately improve the quality of life of breast cancer survivors by more fully managing cancer and treatment related side effects, minimizing inappropriate screening and subsequent allocation of resources, and reducing unnecessary oncology referrals

(Siu, 2016; Pandey & Nguyen, 2017).

# **Purpose Statement**

The purpose of this DNP project is to create a professional development project (PDP) to better inform primary care NPs of female breast cancer survivors' needs and the current breast cancer survivorship care guidelines to improve patient outcomes. The PDP includes a PowerPoint® presentation and a breast cancer survivorship Toolkit ("Toolkit") that was created based on the 2016 ASC/ASCO Breast Cancer Survivorship Care Guidelines. This project aims to help primary care NPs provide evidence-based care to breast cancer survivors throughout all stages of their post-oncology journey.

#### Chapter 2

### Review of the Literature

#### **Breast Cancer**

Cancer is a significant health problem affecting homes and communities worldwide. It is the second leading cause of death in the United States (Siegel, Miller, & Jemal, 2018). Among women, breast cancer is the most prevalent malignancy. According to the ACS (2018), an estimated 266,120 new cases of female breast cancer will be diagnosed in 2018, comprising 30% of all cancers that will be diagnosed in women (Siegel, Miller, & Jemal, 2018). As such, awareness of breast cancer risk factors, screening, treatment(s), late and long-term side effects, and survivors' needs is imperative.

#### **Risk Factors**

Numerous risk factors have led to the increased prevalence of breast cancer. First, improved mammography techniques have caused an influx of breast cancer diagnoses over the last 20 years (ACS, 2017). Since the1980s, in situ and invasive breast cancer incident rates have continuously fluctuated with an overall steady increase in recent years. On average today, women are being diagnosed 1 to 3 years earlier than in the past due to improved technology (ACS, 2017). Second, changes in women's reproductive patterns have also been confirmed as a breast cancer risk factor. Such changes include women increasingly delaying childbearing, having their first child after age 35, and having fewer number of children born per woman over the past 40 years (ACS, 2017).

Third, experts have found a strong correlation between breast cancer and obesity. Obesity has been an especially significant risk factor in postmenopausal women. According to the ACS (2017), an overweight premenopausal woman's breast cancer risk is one and a half times greater for developing breast cancer than that of their lean counterpart. However, an overweight

postmenopausal woman's risk is two times greater compared to her lean counterpart. Experts believe that this increased risk is the result of increased estrogen levels in the fatty tissue and higher incidences of type 2 diabetes within this population (ACS, 2017). Fourth, women's sustained use of menopausal hormone therapy, and particularly combined estrogen and progestin menopausal hormones, contributes to about one-third of postmenopausal breast cancer. Finally, a woman's risk for breast cancer is affected by her strong personal and family history of breast cancer. A first-degree relative, such as a mother with a history of breast cancer, increases that woman's risk of being diagnosed two times more than a woman with no family history (ACS, 2017). This risk increases by four times more if two or more first-degree relatives have a history of breast cancer. In such cases, BRCA1 and BRCA2 inherited gene mutations should be considered as they increase a woman's risk of breast cancer by up to 10% (ACS, 2017).

## Screening

Women with average breast cancer risk, minimal risk factors, and no pre-existing cancer history should have annual mammograms from the age of 45 to 54 (ACS/ASCO, 2016). High risk women with multiple non-modifiable risk factors, however, can start annual mammograms as early as 40 years old. Between the ages of 55 to 74, all women should receive biennial mammograms. Those women with a history of normal mammogram results have the option of discontinuing biennial screening after age 75. High-risk patients with a personal history of breast cancer should receive annual mammograms as routine screening for recurrence of cancer. This excludes screening of reconstructed breast(s) after mastectomy (ACS/ASCO, 2016). Women with a family history of breast cancer from a first-degree relative or those who have inherited the BRCA mutation should begin screening at age 25 or about five to 10 years earlier than the earliest age that breast cancer was diagnosed in the family (Tirona, 2013). MRI screening is not recommended for these women, unless cancer is suspected based on symptoms or abnormal

mammogram results. As of 2013, experts do not recommend breast self-examinations, as temporary changes may occur in breast tissue with normal hormone level changes. However, women should be familiar with the normal feel and appearance of their breasts and should report any prolonged or worsening changes (Tirona, 2013).

### Treatments

There are several treatments for breast cancer. Treatment modalities include surgery, chemotherapy, radiation therapy, hormone or endocrine therapy and targeted therapy (ACS/ASCO, 2016). When deciding on the appropriate treatment(s), the patient and her oncologist must consider both the cancer's stage and biological characteristics. Additionally, the patient's age, preferences, menopausal state, and potential risks and benefits should be considered when deciding on a treatment plan. Most cases of early-stage breast cancer will require a combination of treatments to ensure best patient outcome of reduced risk of recurrence. Generally, some form of surgical intervention is performed following use of radiation or systemic therapies. Cases involving metastatic disease are primarily treated with systemic therapies only. With metastatic disease, surgical intervention is not indicated, and chemotherapy, hormone therapy, and targeted therapy are used to help prolong life while balancing quality of life (ACS, 2017).

Surgical interventions for breast cancer involve either breast-conserving surgery (BCS) or total mastectomy. BCS, which is a partial mastectomy or lumpectomy, is only recommended for early-stage breast cancer and is not an option for patients with a high tumor-to-breast ratio, advanced cancers, or multicentric cancers (ACS, 2017). BCS involves the removal of only the cancerous tissue and tumor margin, which is the normal tissue directly surrounding the tumor. BCS is regularly followed with radiation therapy that involves the use of high-energy beams to kill cancer cells. This treatment combination helps reduce the risk of breast cancer recurrence by

up to 50% at 10 years (ACS, 2017). A total mastectomy involves the removal of the entire breast. In more advanced cases, a modified radical mastectomy may be recommended if dissection of full axillary lymph nodes with the breast is indicated. Radiation therapy may be utilized for symptom relief in advanced cases with central nervous system or bone metastases (ACS, 2017).

Systemic therapy is the leading treatment option for metastatic breast cancer and is sometimes used with early-stage breast cancer (ACS, 2017). It includes the use of hormone therapy, chemotherapy, and targeted therapy. Each therapy has a different mechanism of action and can target different molecular subtypes that are specific to that tumor. These different subtypes help determine which systemic treatments will be most effective. For example, the presence or absence of hormone receptors on the tumor will dictate whether hormone therapy or chemotherapy is more appropriate (ACS, 2017). Hormone-sensitive tumors make up over 70% of breast cancers and grow from the stimulation of the body's natural production of estrogen and progesterone. Hormone therapy works to block or diminish these hormone levels for those tumors that are estrogen receptor positive (ER+) and progesterone receptor positive (PR+). Another subtype that accounts for 17% of breast cancers is the ""overproduction of the growthpromoting protein HER2" (ACS, 2017, p.28). This type of cancer requires the use of targeted therapy to specifically attack those molecules involved in active cancer growth. The HER2 subtype can be found in either hormone-sensitive or insensitive tumors allowing for the combination of the targeted therapy medications with hormone therapy or chemotherapy to help increase treatment effectiveness. Chemotherapy, which is the use of drugs that are designed to attack rapidly growing cells, is most effective in treating hormone-insensitive cancers. They can be as a neoadjuvant or adjuvant treatment depending on tumor stage and size. Research shows that treatment effectiveness is enhanced when the full dose and recommended number of cycles are given with minimal interruptions or delays (ACS, 2017).

#### **Survivorship**

#### Late and Long-Term Effects

Women who undergo surgery, radiation therapy, and systemic therapies frequently face the accompanying undesirable and often lifelong physical and psychological adverse effects. Up to 67% of breast cancer survivors report body image concerns following BCS, total mastectomy, and radiation therapy (ACS/ASCO, 2016). Contributing physical factors include scarring, disfigurement, skin discoloration, radiation-associated fibrosis, and skin laxity. Breast cancer survivors report that lymphedema is a significant contributor to body image issues. About 20% of patients who undergo axillary lymph node dissection and 6% of patients who receive sentinel lymph node biopsies develop lymphedema (ACS, 2017). Additionally, limited range of motion, pain, neuropathy, upper extremity weakness, diminished skin sensitivity, sexual dysfunction, lung fibrosis, and fatigue are also common potential late and long-term effects associated with surgery and radiation.

Breast cancer survivors who undergo chemotherapy commonly experience hair loss, weight gain, infertility, neuropathy, and cognitive impairment (ACS/ASCO, 2016). Late effects generally manifest as osteoporosis and cardiovascular disease. Tamoxifen and aromatase inhibitors (AIs), the two leading hormone therapies for breast cancer, have notable lasting effects among breast cancer survivors. Some of the most commonly reported effects are early menopause, joint pain, increased fractures, elevated cholesterol, chronic musculoskeletal pain, vaginal dryness, depression, and anxiety (ACS/ASCO, 2016). Furthermore, these treatments come with increased risk of stroke, endometrial cancer, blood clots, and cardiac dysfunction (ACS/ASCO, 2016). If not addressed, these effects can have negative implications on the quality of life among breast cancer survivors, especially younger survivors (ACS/ASCO, 2016).

## **Breast Cancer Survivors**

Breast cancer survivors account for 41% of all female cancer survivors in the United States (Westfall, Overholser, Zittleman, & Westfall, 2015). Breast cancer survival has increased considerably over the past two decades with a 39% decline in the mortality rate since 1989. This improvement is attributed to changes in early screening, advances in technology, and improvements in treatment options (ACS, 2017). As of 2016, more than 15.5 million people in the United States were cancer survivors. Of that number, more than 3.5 million were female breast cancer survivors. This overall number of cancer survivors is projected to increase to over 20 million by 2026, with female breast cancer survivors making up a significant percentage (Miller et al., 2016). The majority of breast cancer survivors are living cancer-free, while others are living with evidence of cancer or are currently receiving some form of treatment. This accounts for a wide range of unique care needs specific to this population (Siegel, Miller, & Jemal, 2018). As a result, greater stress has been placed on the cultivation and education of cancer survivorship care within the primary care setting.

#### **Evolution of Cancer Survivorship Care**

In 2005, the Institute of Medicine (IOM) issued a seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition.* This report highlighted the need for change in cancer survivors' care and recommended specific goals and standards to improve the process (Hewitt, Greenfield, & Stovall, 2005). Since the report's release, components of cancer survivorship care and the roles of oncology and primary care have been better defined. The National Comprehensive Cancer Network (NCCN) (2017) states that individuals are considered cancer survivors from the time of diagnosis until his or her death. Survivorship care is a specific standard of care designed to address the multifaceted needs unique to cancer survivors (NCCN, 2017). Cancer survivorship is recognized as the final phase of the cancer care continuum and is considered the transition to post-treatment care (George Washington University Cancer Institute [GWCI], 2013). Fundamental components of survivorship care include prevention of new or recurrent cancers, surveillance, assessment and management of physical and psychological effects, coordination of care, and health promotion. Combined, these care components help in the management of physical, psychological, social, spiritual, and informational needs of cancer survivors (NCCN, 2017; GWCI, 2013).

Research organizations, such as the ACS, NCCN, ASCO, and Centers for Disease Control and Prevention (CDC), among others, have contributed to cancer survivorship research, survivorship care programs, and cancer-specific practice guidelines to improve the practitioners' ability to care for cancer patients (ACS/ASCO, 2016; NCCN, 2017; GWCI, 2013). This research supports the central role primary care NPs have in cancer survivorship care as well as the existing knowledge limitations (Pandey & Nguyen, 2017). To address knowledge limitations, the ACS and ASCO created current cancer survivorship care guidelines to assist providers in the comprehensive care of cancer survivors. This includes the ACS/ASCO's 2016 Breast Cancer Survivorship Care Guidelines, which are specifically designed to help NPs address the needs of the growing breast cancer survivor population.

#### **ACS/ASCO Breast Cancer Survivorship Care Guidelines**

In 2016, the ACS and ASCO released Breast Cancer Survivorship Care Guidelines aimed specifically at helping NPs provide evidence-based care to adult female breast cancer survivors. The guidelines focus on the ongoing impact that breast cancer diagnosis and treatment(s) have on female survivors. Included are specific recommendations for treating survivors after completion of their primary treatment and continuing throughout the balance of their life. These specific recommendations provide a framework for NPs to follow in addressing breast cancer survivor surveillance for recurrence, screening for second primary cancers, assessment and management

of physical and psychological late and long-term effects, health promotion, and coordination of care (ACS/ASCO, 2016). In addition to these guidelines, NPs should refer to the cancer survivor's treatment summary or survivorship care plan if made available by the referring oncologist (ACS, 2017).

## Surveillance and Screening

To increase the chances of a prolonged life, breast cancer survivors must continue surveillance and screening after treatment. The survivorship guidelines recommend that NPs perform a cancer-related history and physical examination every 3 to 6 months for the first three years, then every 6 to 12 months for the next two years after primary therapy (ACS/ASCO, 2016). After the five-year mark, an annual history and physical is recommended for survivors' continued surveillance. Women who received a unilateral mastectomy should have annual mammogram screenings of the remaining breast. Bilateral mastectomy does not require routine mammograms, but these women should be screened through a detailed annual history and physical. Breast cancer survivors with lumpectomies should receive annual mammograms of both breasts. MRI screening is not recommended for breast cancer survivors unless they are suspected of local recurrence or evidence of a new primary breast cancer. Routine laboratory tests for tumor markers and imaging studies (i.e., chest radiograph, CT scans, and bone scans) are not recommended in the primary care setting for screening purposes. Additionally, NPs should educate breast cancer survivors on relevant signs and symptoms of cancer recurrence. Such signs and symptoms include the presence of new lumps in the axillae or neck, skin changes over the chest wall or breast, changes in breast contour/size/shape, or prolonged swelling and pain in breast or arm (ACS/ASCO, 2016).

Cancer surveillance also includes the assessment of continuous adherence and symptom management of those women being treated with adjuvant antiestrogen therapy. Women with a

strong family history of breast cancer should be offered a genetic counseling referral by the NP to better assess risk factors. Additionally, the guidelines recommend that NPs perform routine screening for other cancers due to the survivor's increased risk of second primary cancers. For breast cancer survivors, this routine screening should include annual gynecological examinations. NPs should especially perform gynecological exams in the postmenopausal women receiving selective estrogen receptor modulator (SERMs) therapy (ACS/ASCO, 2016).

#### Assessment and Management of Late and Long-Term Effects

The risk for physical and psychological late and long-term effects is associated with several factors. These factors include treatment(s) type, duration and dose, age of the patient, and any existing cancer or treatment complications (ASC, 2017). As previously recommended, the oncology treatment summary or survivorship care plan can be a helpful tool for NPs when assessing and managing these effects; NPs in primary care should request these documents from the referring oncologist if not made available. In assessing and managing these effects, the ACS/ASCO (2016) offers specific guidelines for management of the most common complaints. These effects are as follows:

**Body Image Concerns.** ACS/ASCO (2016) recommends that NPs assess patients for body image concerns as a result of the breast cancer and subsequent treatments. If physical concerns are present, women should be offered adaptive devices (i.e., wigs or prosthetics breast) or if appropriate be referred for a surgical consult. Surgical consultations should be considered with women who underwent a partial or total mastectomy and opted out of breast reconstruction at the time of treatment. If body image concerns persist, NPs should refer these patients for psychological care. Such care can offer "support groups, psychotherapy, cognitive behavioral therapy, couple-based interventions, or sex therapy" depending on the individual's needs (ACS/ASCO, 2016, p.54).

**Lymphedema.** NPs should counsel breast cancer survivors in the prevention and reduction of lymphedema. Such counseling includes healthy weight maintenance, routine physical activity of slowly progressive resistance training, and avoiding venipunctures, blood pressure or injections on the affected arm. If lymphedema develops and persists, NPs are recommended to refer the patient to a physical therapist, occupational therapist, or lymphedema specialist for symptom management (ACS/ASCO, 2016).

**Cardiotoxicity**. Breast cancer survivors are at increased risk for cardiotoxicity. As such, the guidelines recommend NPs routinely monitor cholesterol levels and screen for cardiovascular disease. Survivors should be educated about their increased cardiovascular disease risk and be instructed in maintaining a heart-healthy lifestyle to help minimize potential effects. Likewise, breast cancer survivors should be made aware of pertinent symptoms (i.e., chest pain, shortness of breath, or fatigue) that if experienced should be reported to the NP immediately (ACS/ASCO, 2016).

**Cognitive Impairment.** It is recommended that NPs assess for cognitive impairment of breast cancer survivors with specific questions to the patient and family member(s). These questions should address whether or not the patient subjectively perceives cognitive difficulties. Such difficulties can include problems with concentration, memory, and executive function. If difficulties exist, guidelines recommend NPs refer the patient for a consultation with a neuropsychologist for potential neurocognitive rehabilitation (ACS/ASCO, 2016).

**Distress, Depression, Anxiety.** All breast cancer survivors should be assessed for symptoms of distress, depression and or anxiety by the NP. Those survivors at high risk for depression (i.e., younger women, history of psychiatric disorders, or women with lower socioeconomic status) should have a more extensive assessment performed by the NP to determine if intervention is necessary. In-office counseling, pharmacotherapy, and mental health

referrals should be offered by the NP to survivors experiencing distress, depression, and anxiety (ACS/ASCO, 2016).

**Fatigue.** Up to 91% of breast cancer survivors experience prolonged fatigue (ACS/ASCO, 2016). It is therefore recommended that NPs assess breast cancer survivors for fatigue. As is routine, causative factors should be assessed and treated appropriately. If the underlining cause of fatigue is unidentifiable, NPs should encourage routine physical activity and other healthy lifestyle modifications (ACS/ASCO, 2016).

**Bone Health.** Guidelines recommend a NP obtain a baseline dual-energy X-ray absorptiometry (DEXA) for postmenopausal breast cancer survivors. Repeat DEXA scans are recommended every two years for women actively taking aromatase inhibitors, and premenopausal patients taking tamoxifen or GnRH agonist. Likewise, NPs should refer women with chemotherapy-induced premature menopause for repeat DEXA scans every two years (ACS/ASCO, 2016).

**Musculoskeletal Health.** NPs are encouraged to assess breast cancer survivors for musculoskeletal symptoms at each encounter. This patient assessment should include pain, weakness, and decreased ROM. Guidelines recommend patient education regarding physical activity and appropriate referrals to physical therapy, acupuncture, or rehabilitation (ACS/ASCO, 2016).

**Pain and Neuropathy.** When NPs are assessing pain and its contributing factors, ACS/ASCO (2016) recommends the use of the pain scale and comprehensive subjective history. Survivors experiencing pain should first be offered NSAIDs, acetaminophen, acupuncture and physical activity as interventions for pain relief. If the pain is uncontrolled, NPs should refer the patient to the appropriate specialist depending on the determined underlying etiology. Such specialists may include physical therapist, occupational therapist, lymphedema specialist, and

pain management specialist. Similarly, guidelines dictate that breast cancer survivors should be assessed for peripheral neuropathy symptoms through a detailed history and physical. Those with neuropathic symptoms (i.e., pain, numbness, and tingling in hands and feet) should be instructed by the NP to manage symptoms with physical activity and offer duloxetine as an option (ACS/ASCO, 2016).

**Sexual Health and Infertility.** The guidelines recommend that NPs assess survivors for signs and symptoms of sexual dysfunction or issues with intimacy. The assessment should determine contributing factors to the sexual dysfunction. If contributing factors are reversible, they should be addressed by the NP when appropriate. These factors may include vaginal dryness, decreased libido, or body image concerns. NPs should offer water-based lubricants, vaginal moisturizers, support groups, sexual or marital counseling or intensive psychotherapy, when appropriate. If the breast cancer survivor is of childbearing years and experiencing infertility, the NP should refer the patient to a reproductive endocrinology specialist as soon as possible (ACS/ASCO, 2016).

**Premature Menopause.** The guidelines recommend that NPs utilize pharmacotherapy and encourage lifestyle modifications in the management of premature menopausal symptoms with breast cancer survivors. Recommended pharmacotherapy for vasomotor symptom management includes SSRIs, SNRIs, and gabapentin. Lifestyle and environmental modifications that may help with symptom management involve rhythmic breathing, exercise, vitamins, cool rooms, and avoidance of caffeine, alcohol and spicy foods (ACS/ASCO, 2016).

#### **Health Promotion**

In addition to cancer surveillance and management of late and long-term side effects, the ACS/ASCO Breast Cancer Survivorship Care Guidelines (2016) also provides evidence-based health promotion recommendations for breast cancer survivors. Health promotion is key to

enhancing the quality and length of life for breast cancer survivors. It consists of healthy behaviors that can help reduce secondary cancers, possible recurrence, comorbidities, and presences or severity of late or long-term effects. The ACS/ASCO (2016) recognizes that health promotion is essential to survivors and provides recommendations to address five health promotion domains for NPs and patients to utilize in pursuing best health outcomes. These domains include information, obesity, physical activity, nutrition, and smoking cessation (ACS/ASCO, 2016).

Under the "information" recommendation, NPs are advised to assess the patient for knowledge gaps related to diagnosis, treatment, side effects, or available resources. NPs should provide relevant information to the patient or refer them to appropriate resources to meet their informational needs. The "obesity" and "nutrition" recommendations advise that NPs counsel breast cancer survivors to help them achieve and maintain a healthy weight. Overweight or obese breast cancer survivors should be instructed to consume a low-calorie and balanced diet. The "physical activity" recommendation advises that breast cancer survivors engage in regular physical activity (i.e., 75 minutes of vigorous aerobic exercise per week). NPs should encourage physical activity to include strength training at least two days per week. Strength training should be emphasized in women treated with hormone therapy or chemotherapy. This is emphasized in these cases to help improve posture, upper body mobility, energy, and muscle endurance, all of which may be significantly diminished as a result of systemic treatment (Stefani, Galanti, & Klika, 2017). Finally, the "smoking cessation" recommendation strongly advises that breast cancer survivors avoid smoking or seek counseling concerning smoking cessation. NPs should educate survivors about the increased risk of mortality among those survivors who smoke versus those who don't (ACS/ASCO, 2016).

### **Care Coordination**

To promote care coordination, NP's are encouraged to establish communication with the patient's oncology team and consult with them to create the survivorship care plan (ACS/ASCO, 2016). Survivorship care plans provide information to create a smoother transition from oncology to primary care for the breast cancer survivor. Survivorship care plans include oncology-specific recommendations and pertinent patient and treatment information to help guide the NP's decisions with survivorship care. Additionally, NPs are encouraged to include and coordinate with caregivers and other pertinent family members in survivorship care (ACS/ASCO, 2016).

#### **Survivorship Guidelines in Primary Care**

The ACS/ASCO Breast Cancer Survivorship Guidelines were created in response to the strong consensus in the literature that NPs have inadequate knowledge of survivorship care (Hewitt et al., 2005; Pandey & Barber, 2016; ACS/ASCO, 2016; GWCI, 2013). These guidelines are intended to help clinicians efficiently navigate post-cancer care needs of female breast cancer survivors. As the breast cancer survivor population continues to rise, so does the need for breast cancer survivorship care implementation. As such, NPs must increase their understanding of the updated Breast Cancer Survivorship Care Guidelines (Pandey & Barber, 2016; ACS/ASCO, 2016).

Although NPs play a significant role in caring for breast cancer survivors, they frequently lack necessary training and understanding to care for them properly. As the emerging backbone of primary care, NPs have a significant role in assessing, diagnosing, and treating breast cancer survivors. This role includes determining if patient complaints are sequelae from previous treatment(s) or a result of the diagnosed cancer (Weaver, Jessup, & Mayer, 2013). However, in primary care, most NPs have minimal post-cancer care experience or training and need guidance

in properly incorporating survivorship care into their practice (Pandey & Barber, 2016).

Currently, NP education typically includes "one to two didactic hours that cover cancer prevention and screening" (Pandey & Barber, 2016, p. 335). This limited overview excludes oncology-specific training regarding post-treatment care, provider expectations, and survivorship guidelines (ASCO, 2018). Consequently, NPs who are unfamiliar with survivorship care are likely to inconsistently screen for primary or secondary cancers, manage late and long-term disease, and treat the effects of breast cancer survivors (Pandey & Nguyen, 2017).

Similarly, inadequately informed NPs are likely to misdiagnose, underdiagnose or overdiagnosis primary cancer recurrence or development of secondary malignancies (Siu, 2016; Pandey & Nguyen, 2017). For example, the U.S. Preventative Services Task Force (USPSTF) found that early breast cancer screening (before age 45) in average-risk women results in more false-positives than number of deaths averted (Siu, 2016). Inappropriate screening can result in unnecessary physical and physiological trauma (i.e., biopsies, distress or anxiety), overuse of costly procedures (i.e., PET, CT or bone scans), and unnecessary oncology referrals (Schnipper, Smith, Raghavan, Blayney, Ganz, Mulvey, & Wollins, 2012; Siu, 2016). Additionally, inappropriate management of late and long-term complications of breast cancer treatment(s) can adversely affect the quality of life and long-term health outcomes of breast cancer survivors (ACS, 2017; Pandey & Nguyen, 2017).

## **Needs Assessment**

Literature brings to light an existing need in primary care for training in cancer survivorship care and has suggested continuing education as a potential outlet for enhancing survivorship knowledge (Hewitt et al., 2005; Pandey & Barber, 2016; ACS/ASCO, 2016; GWCI, 2013). However, within the last two years, annual family medicine conferences, such as the American Academy of Family Physician's (AAFP) conference, have not addressed topics

concerning cancer survivorship (AAFP, 2017; AAFP, 2018).

Further, prominent national nurse practitioner conferences during 2017 and 2018 conference season did not address any topics about cancer survivorship (American Association of Nurse Practitioners [AANP], 2017; AANP, 2018). Conversely, oncology-specific conferences (i.e., ASCO Annual Conference, NCCN Annual Conference, Annual Survivorship Conference, etc.) have offered multiple topics addressing general survivorship care and breast cancer survivors for the past two years. This disparity in cancer survivorship content is also seen in peer-reviewed journals. For example, the *Journal of Clinical Oncology* published 227 articles about "cancer survivorship" between the years 2006 through 2018. In contrast, the *American Family Physician* generated 11 publications while the *Journal of Nurse Practitioners* only generated two publications addressing cancer survivorship.

In conjunction with the consistent anecdotal evidence provided in the literature, these results further illustrate that cancer survivorship care information is not being adequately disseminated to NPs in primary care (Pandey & Barber, 2016). NPs and their patients would benefit from an increased understanding of the needs of breast cancer survivors and relevant clinical practice guidelines. Thus, it is essential that an intervention be employed to increase NPs' knowledge of the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines. This DNP project therefore created a professional development project (PDP) based on the current ACS/ASCO Breast Cancer Survivorship Care Guidelines in primary care.

This project created an informative breast cancer survivorship care PowerPoint® presentation covering the importance of cancer survivorship, key components of the current guidelines, and an explanation of the breast cancer survivorship Toolkit ("Toolkit"). The Toolkit includes a Quick Care Guide document and a list of available resources that the provider can

access for further information and patient resources. Combined, these project components increase the NP's knowledge of current guidelines and assist them in providing evidence-based care.

## **Population Identification**

The project deliverables, PowerPoint® and associated Toolkit, were developed with the eventual goal of distribution and use in a specific NP population. That population includes primary care NPs working in a metropolitan region with over 2.2 million residents (U.S. Department of Commerce, 2017). This urban region offers adequate oncology referrals from over 20 different oncology-specific clinics and organizations practicing locally. The PowerPoint® and Toolkit may be used by primary care NPs in other regions of the U.S. as desired.

#### **Project Stakeholders**

Those NPs who work in designated primary care clinics were key stakeholders for this DNP project. Additional stakeholders included the organization's leaders and the providers' patients who were female breast cancer survivors.

#### **Organizational Assessment**

The PowerPoint® presentation and Toolkit as project deliverables were developed within the curriculum of the Doctor of Nursing Practice (DNP) at a metropolitan state university. The curriculum and faculty offered appropriate resources and guidance for development, completion, and presentation of the deliverables. In the future, the ultimate goal is to implement the Toolkit at the chosen sites in a large medical practice group in a southwestern U.S. state. This healthcare organization provides primary care services from approximately 36 primary care offices to the surrounding patient population.

# **Scope of the Project**

The scope of this project includes the development of an informative evidence-based PowerPoint® presentation and Toolkit designed to promote guideline retention and implementation with the intention of increasing the NP's awareness of breast cancer survivorship needs and current guidelines.

## **Mission and Goals**

The mission of this DNP project was to develop a PowerPoint® presentation and Toolkit to improve the understanding and resources of primary care NPs who manage female breast cancer survivors. At some future point, these tools will be implemented and enhance the breast cancer survivors' health outcomes as a result of the NPs' improved understanding and implementation of the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines in primary care. The goal of this project was to develop tools to improve awareness of these guidelines among primary care NPs.

### Chapter 3

Theoretical Underpinnings and Framework

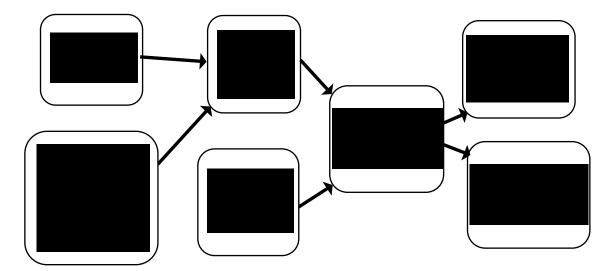
#### **Nursing Intellectual Capital Theory**

The nursing intellectual capital theory (NICT) is a middle-range nursing theory that supports increasing and developing healthcare personnel's knowledge as a way to improve patient and system outcomes. The NICT was originally derived from the intellectual capital theory grounded in economics and business (Covell & Sidani, 2013). The intellectual capital theory suggests that an increase in organizational stock knowledge at individual and group levels leads to an increase in business performance. Similar studies have shown that this theory in practice increased healthcare provider and patient knowledge of guidelines, resources, and policies, which thereby enhanced the quality of care, decreased organizational costs, and improved work environments (Covell & Sidani, 2013; Aiken, Cimiotti, Sloane,...& Neff, 2011; Duffield, Diers, O'Brien-Pallas,...& Aisbett, 2011).

NICT is comprised of two codependent concepts: the nursing human capital concept and the nursing structural capital concept. The nursing human capital concept is defined as "the theoretical and practical knowledge nurses obtain from academic education, participation in continuing professional development activities and specialty training and work experience" (Covell & Sidani, 2013, p.70). Nursing structural capital is the structural or organizational resources that contain the necessary information to support nursing knowledge and its application in the delivery of patient care. These resources include evidence-based practice guidelines, care plans, information technology, and other informational resources aimed at professional development. As these resources become more available to providers and caretakers, so does the opportunity for improved practice and healthcare outcomes (Covell & Sidani, 2013).

The NICT supports this DNP project because it promotes enhanced patient care by focusing on improving provider knowledge (See Figure 1). Structurally, the NICT supports knowledge acquisition through the use of organized resources that facilitate increased nursing knowledge and clinical application. Covell and Sidani (2013) recommend the use of evidence-based guidelines as a relevant resource to promote professional development. In accordance with this concept, this project uses an informative PowerPoint and Toolkit adapted from the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines to help advance the primary care NP's knowledge on survivorship. The Toolkit includes a Quick Care Guide that details key information regarding the survivor's needs and the NPs' role during care. Combined, these components work towards improving the NPs' knowledge of breast cancer survivor's needs and current clinical guidelines through the development of informative resources (Covell & Sidani, 2013).





#### Chapter 4

### Project Plan

#### Setting

The development of the PowerPoint® Presentation and Toolkit occurred within the DNP curriculum structure of a metropolitan state university school of nursing under the guidance of a project chair and committee. Ultimately the goal is that these deliverables will be, at some future point, implemented in three primary care clinics owned by a large for-profit organization in an urban community of Southern Nevada.

Two of the clinics operate seven days per week while the other operates five days per week. Each provider at these clinics treats 20 to 30 patients daily. Two of the clinics serve adult patients only while one serves both pediatric and adult patients. While no data is available for the number of patients seen at these clinics that are female breast cancer survivors, these clinics serve the same patient population as a large local oncology group with two clinics located within proximity of the clinics of interest.

## **Population of Interest**

The project deliverables were developed for a population of primary care NPs as previously described. This population includes six NPs currently working in primary care who provide care for local female breast cancer survivors. These NPs have varying educational levels with five having masters degrees and one having a doctoral degree in family nursing practice. The NPs' years of experience in primary care range from 1 to 18 years of practice.

## Measures, Instruments, and Activities

Deliverables of this DNP project included an informative PowerPoint® presentation and a Toolkit adapted from the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines. Both parts were designed to help advance the primary care NP's knowledge of survivorship care by promoting guideline retention and implementation. The project presentation was designed to be given over a pre-arranged 40-minute meeting with participating NPs, with 20 minutes allotted to the PowerPoint® presentation and Toolkit presentation and 20 minutes allotted to group discussion and evaluation. This presentation was designed to be presented to the providers during the scheduled one-hour lunch break at each clinic individually with lunch provided. The PowerPoint® presentation covers pertinent information concerning the importance of breast cancer survivorship care, why its implementation is necessary for the primary care setting, the primary care NP's role in survivorship care, current evidence-based guidelines, and the presentation of the Toolkit, as further described in Appendix A.

The Toolkit incorporated content overview as well as implementation instructions. The Toolkit consists of a provider Quick Care guide for breast cancer survivorship. The Quick Care guide provided a summary of care to aid the provider in appropriately managing surveillance, screening, late and long-term effects, health promotion, and coordination of care for the breast cancer survivor.

Content validity of the developed Toolkit with the PowerPoint® presentation was established by six content expert reviewers. The expert reviewers were comprised of three primary care NPs and three oncology NPs. The three oncology NPs work in outpatient oncology centers in suburban areas in Nevada, Utah, and Tennessee. Their experience ranges from 6 to 20 years with two NPs holding master's degrees and one NP holding a doctorate degree. Similarly, the three primary care NPs currently work in primary care outpatient clinics in suburban areas in Utah and Nevada. Their experience in this setting ranges from 3 to 20 years with two NPs holding masters degrees and one NP holding a doctorate degree. As expert reviewers, the varying years of experience provided important perspectives and unique feedback on the Toolkit deliverables and its usability in the primary care setting.

Content validity for the project deliverables was obtained with the use of an 8-item questionnaire (See Appendix C). Each expert reviewer was asked to review the Toolkit containing both the PowerPoint® presentation and the Quick Care Guide with the use of the questionnaire to report feedback via a grading scale and comment section over a 15-day period (See Appendix B). Content validity for this scale was ascertained using a 5-point Likert scale. Mean expert ratings and content validity ratios (CVR) for each item was calculated to determine content validity for the Toolkit and is further detailed in Chapter 5 and in Appendix C.

## Timeline

Activities for this DNP project commenced at the beginning of 2018 with the completion of chapters 1-4. The DNP project proposal was defended at the University of Nevada, Las Vegas (UNLV) during the Summer of 2018. The complete PowerPoint® presentation, Toolkit, project evaluation, and write-up was completed by the end of Fall of 2018. All DNP project chapters, final submission to DNP advisory committee, and final DNP project defense occurred during Spring of 2019. The complete project timeline is outlined in Appendix A.

## **Project Tasks and Personnel**

The personnel for this project was the DNP student. No other personnel was required for the creation of this project. The student was responsible for creating the PowerPoint® presentation and the Toolkit adapted from the evidence-based guidelines. The tasks for this DNP project included developing an introductory PowerPoint® presentation, the Toolkit, and project evaluation.

## **Resources and Supports**

Resources needed for the creation and completion of this DNP project included access to the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines and a computer with an updated version of Microsoft Word. Additionally, access to a printer, copier, and paper were

needed for assembling hardcopies of the Toolkit and PowerPoint®.

### **Risks and Threats**

Risks and threats to this DNP project centered around potential issues during the development process of the presentation and Toolkit. One such risk was potentially not including all essential guideline information in the provider's Toolkit. For the Toolkit to be most effective and promote provider utilization, it should include all relevant information while being concise and easy for the NP to use. In developing the PowerPoint presentation, the risk of not adequately conveying the need for change in breast cancer survivorship care could have adversely affected the project outcomes. The PowerPoint® presentation needed to have accurately demonstrated the present need for change in breast cancer survivorship care to ensure provider buy-in. Lastly, the final Toolkit design could have threatened the project outcomes if components were no longer user-friendly, clear, and comparable in size to other commonly used primary care tools.

### **Evaluation Plan**

The evaluation plan focused on the development of the project's Toolkit and PowerPoint® presentation. This process consisted of self-reflection questions of the project deliverables and any potential barriers to their use in the primary care setting. First, an evaluation of how the evidence-based guidelines translated into the Toolkit and PowerPoint® was vital. This evaluation helped determine if the materials were clearly representing and explaining the information from the guidelines.

Second, the Toolkit evaluation determined whether all the necessary information was included to successfully assist providers with breast cancer survivorship care. The 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines contain 26 pages of information and recommendations in addressing specific needs of the survivor. While all of this information was

28

relevant, it was essential to determine what information was most important to include in the Toolkit and PowerPoint®.

Third, the project's theoretical framework and its underpinnings demonstrated support upon evaluation of the completed Toolkit and PowerPoint®. Finally, the Toolkit was assessed for whether it is concise and realistic enough for utilization in primary care. These tools must stay meaningful, be easily updated, and remain practical for use during busy clinic hours.

### Chapter 5

### Summary of Project Results

Research and literature have expressed a growing need for improved breast cancer survivorship care in the primary care setting (Hewitt et al., 2005; Pandey & Barber, 2016; ACS/ASCO, 2016; GWCI, 2013). With an average five-year survival rate of 90%, knowledge and utilization of current breast cancer survivorship care guidelines is becoming increasingly more relevant as this growing patient population is cared for by more NPs in the primary care setting each year. However, primary care NPs' lack of awareness of the current 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines may hinder their ability to provide the best evidence-based care for breast cancer survivors (Pandey & Barber, 2016; ACS/ASCO, 2016; Pandey & Nguyen, 2017). The development and expert review of this informative Toolkit containing the PowerPoint® presentation and the Quick Care Guide was in response to this identified need for further information and resources of female breast cancer survivorship care for NPs in the primary care setting.

## **Data Collection**

The development of the Toolkit and content questionnaire was completed in early November of 2018. All six expert reviewers were sent an email mid-November with a letter detailing further information and instruction for the review process as well as the project deliverables of the Quick Care Guide document and PowerPoint® presentation that comprised the Toolkit (See Appendix B). Additionally, the email contained a content questionnaire that was used by the expert reviewers to report feedback via a 5-point Likert scale and comment section (See Appendix C). Expert reviewers were asked to complete and return the content questionnaire via email after a 15-day period to review the Toolkit. The content questionnaire was an 8-item document used to aid the expert reviewers in critiquing and reporting feedback for both the PowerPoint® presentation and Quick Care Guide. Each reviewer was initially asked basic demographic information on years of experience and practice specialty. Instructions on the use of the questionnaire's 5-point Likert scale and comment section were provided to clarify proper use. Questionnaire items focused on content presence, accuracy, and usability of the Toolkit deliverables. All completed questionnaires were returned to the DNP student by each expert reviewer in early December 2018 via email.

### **Data Analysis**

### **Quantitative Data**

Content validity was determined using the reported data from the 5-point Likert scale, with 5 indicating "strongly agree" and 1 indicating "strongly disagree," for each item of the content questionnaire. First, all items were reviewed to determine if they were essential or non-essential. Items that were deemed non-essential contained ratings of 3 or below from the expert reviewers. Second, the mean and content validity ratio (CVR) was calculated for each item using the formula [(E-(N/2)) / (N/2)] with "E" representing the number of experts who rated the item as essential and "N" being the total number of expert reviewers (See Appendix C). A CVR of 1 indicates that all expert reviewers strongly agreed that the item was essential. Data showed that all expert reviewers rated items 1, 2, and 4 as essential with a CVR of 1. A CVR of 0.67 was calculated for items 3, 5, 6, 7, and 8 indicating that 5 out of 6 expert reviewers found the items essential (See Table 1).

| Item | Expert 1 | Expert 2 | Expert 3 | Expert 4 | Expert 5 | Experts | Mean | CVR  |
|------|----------|----------|----------|----------|----------|---------|------|------|
|      |          |          |          |          |          | 6       |      |      |
| 1    | 5        | 5        | 5        | 5        | 5        | 5       | 5    | 1    |
| 2    | 5        | 5        | 4        | 5        | 5        | 5       | 4.83 | 1    |
| 3    | 5        | 2        | 4        | 5        | 4        | 5       | 4.17 | 0.67 |
| 4    | 5        | 4        | 4        | 4        | 5        | 5       | 4.5  | 1    |
| 5    | 5        | 5        | 3        | 5        | 5        | 5       | 4.7  | 0.67 |
| 6    | 5        | 4        | 4        | 5        | 2        | 5       | 4.17 | 0.67 |
| 7    | 5        | 3        | 5        | 5        | 4        | 5       | 4.5  | 0.67 |
| 8    | 5        | 5        | 3        | 5        | 5        | 5       | 4.7  | 0.67 |

Table 1Content Validity Index Table

### **Qualitative Data**

In addition to content validity, comments from each item was reviewed to determine rating rational and Toolkit observations, concerns, or critiques. Items 1, 2, and 4 asked if the Toolkit was complete, accurately identified all elements of care, and if all the information was in accordance with current guidelines. All expert reviewers' feedback agreed that the Toolkit was a comprehensive review of breast cancer survivorship care and reflected the current 2016 ASC/ASCO Breast Cancer Survivorship Care Guidelines. Items 3, 6, and 7 asked if all the information presented in the Toolkit was necessary and if the Quick Care Guide was userfriendly and appropriate for the primary care setting. Based on feedback, all expert reviewers agreed that the information in the PowerPoint® presentation was necessary and helpful for primary care. However, the majority of feedback for the Quick Care Guide centered around minimizing the amount of information provided and possibly cutting it down to a 1-sided document. Lastly, items 5 and 8 asked the expert reviewers if the Toolkit could be readily incorporated into the primary care setting and if it would improve the management of breast cancer survivors. All expert reviewers' feedback agreed that the Toolkit would be an educational and useful resource for NPs in the primary care setting.

### **Discussion of Project Results**

Based on the provided feedback from the expert reviewers, the Toolkit provided complete, accurate, and current information based on the 2016 ASC/ASCO Breast Cancer Survivorship Care Guidelines. As such, these results show that the content of the Toolkit deliverables would address this project's goal of helping to increase the primary care NP's knowledge of current guidelines and assist them in providing evidence-based care for female breast cancer survivors. However, the results of the feedback also revealed that the usability and size of the Quick Care Guide was not ideal for the primary care setting. While it was reported that the PowerPoint® presentation supplied sufficient information for the primary care NP, 4 out of the 6 experts agreed that the Quick Care Guide provided too much information as a reference document and needed to be edited down. Based on this information, additional adjustments to the Quick Care Guide will be to simplify the document to a more concise outline format to help improve usability within the primary care setting.

### **Future Implication**

The mission of this DNP project was to develop a Toolkit to improve the understanding and educational resources of primary care NPs who manage the care of female breast cancer survivors. Results from the content questionnaire have demonstrated content validity for the PowerPoint® presentation and Quick Care Guide. Furthermore, they revealed the need for additional editing of information and formatting changes for the Quick Care Guide. This feedback will be used to improve the Toolkit by making it more succinct and appropriate for future use in primary care. Additionally, future implications for this project include a pilot implementation in three primary care clinics owned by a large for-profit organization in an urban community of Southern Nevada. This pilot implementation will include the presentation of the revised Toolkit base on the expert feedback. The presentation will be followed by group discussion and evaluation over a pre-arranged 40-minute lunch meeting with participating NPs from the primary care clinics. The future implementation of this Toolkit will help in working towards enhanced female breast cancer survivors' health outcomes as a result of the primary care NPs' improved understanding and implementation of the 2016 ACS/ASCO Breast Cancer Survivorship Care Guidelines.

# Appendix A

# Project Timeline

| January 2018          | Begin DNP project proposal  |
|-----------------------|---|
| February-April 2018   | Completion of chapters 1-3  |
| May 2018              | Completion of chapter 4   |
| June 2018             | Defend DNP project proposal at UNLV   |
| July-September 2018   | Begin development of project PowerPoint® presentation and Toolkit content         |
| October-December 2018 | Complete PowerPoint® presentation and<br>Toolkit, project evaluation and write-up |
| January-March 2019    | Complete DNP project chapters and submitted to DNP Advisory Committee             |
| March 2019            | Defend DNP project at UNLV  |

## Appendix B

### **Toolkit Deliverables**



University of Nevada, Las Vegas

November 15, 2018

Dear Content Expert:

Thank you so much for taking the time to review my materials and offer me your expertise. I know that your time is valuable and I appreciate you sharing it with me in my effort to improve the primary care of breast cancer survivors.

I have attached three documents: (1) a PowerPoint presentation, (2) a Quick Care Guide, and (3) a content expert questionnaire.

This project is designed to be presented to nurse practitioners in the primary care setting. During a one-hour lunch presentation, the PowerPoint presentation will be presented to them and the Quick Care Guide will be distributed. My hope is that following the presentation, primary care nurse practitioners will be interested in and able to utilize the Quick Care Guide to support improved breast cancer survivor care.

Please review the toolkit, consisting of the PowerPoint presentation and Quick Care Guide, and answer the content expert questionnaire attached. Please be honest and thorough, as your critical evaluation will be most helpful to me.

If you would please return the questionnaire to me by November 30<sup>th</sup>, I would very much appreciate it. If you have any problems or questions, please feel free to email me.

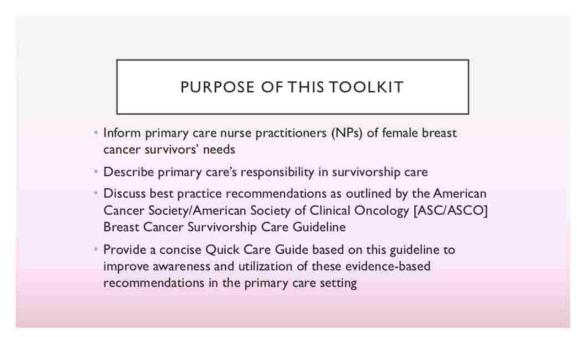
With much appreciation,

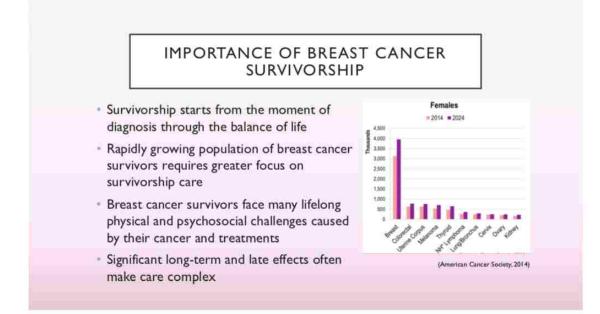
Lauren Scott, RN, BSN, DNP candidate UNLV School of Nursing

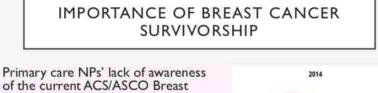
Box 453018 • 4505 S. Maryland Parkway • Las Vegas, NV 89154-3018 • Tel: 702-895-3360 • Fax 702-895-4807 http://nursing.unlv.edu/

# BREAST CANCER SURVIVORSHIP CLINICAL PRACTICE TOOLKIT

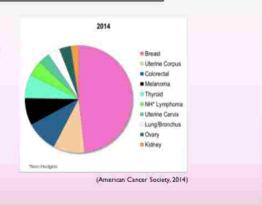
Lauren Scott BSN-DNP Student University of Nevada, Las Vegas

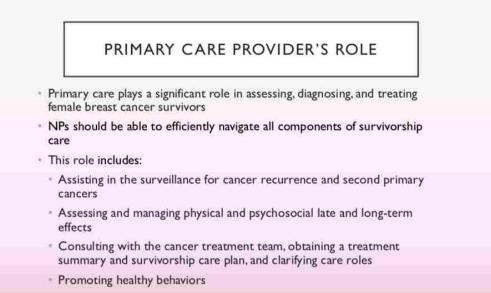


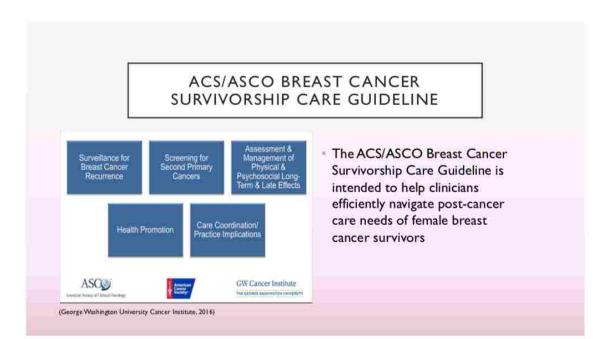




- of the current ACS/ASCO Breast Cancer Survivorship Care Guidelines impedes their ability to provide the best evidence-based care for breast cancer survivors
- This can create inconsistencies in follow-up, screening, management of late and long-term disease and treatment effects, and health promotion for patients transitioning from oncology to primary care







## ACS/ASCO BREAST CANCER SURVIVORSHIP CARE GUIDELINE

- Included are specific recommendations for treating survivors after completion of their primary treatment and continuing throughout the balance of their life
- These specific recommendations provide a framework for NPs to follow in addressing surveillance for recurrence, screening for second primary cancers, assessment and management of physical and psychological late and long-term effects, health promotion, and coordination of care

## SURVEILLANCE

- Detailed Cancer-Related History & Physical:
  - Years 1-3—Every 3-6 months
  - Years 4-5—Every 6-12 months
  - Every year after—Annually
- Routine laboratory tests or imaging, except mammography, should ONLY be considered when disease recurrence is suspected and NOT for detection of disease recurrence in the absences of symptoms
- Annual Mammograms on both breasts with lumpectomies and remaining breast with unilateral mastectomy

### SURVEILLANCE

- Only survivors meeting HIGH-RISK criteria should receive an annual mammogram and a breast MRI as part of routine screening
  - HIGH-RISK criteria: Women with lifetime risk of a second primary breast cancer >20% (e.g., woman with a BRCA1/BRCA2 mutation, very strong history of breast cancer)
- AVERAGE-RISK survivors should NOT receive an MRI or other advanced body imaging unless disease recurrence is suspected
- Adherence to adjuvant endocrine (antiestrogen) therapy should be discussed to help with symptom management

# SURVEILLANCE

- \* Signs and symptoms of local and regional recurrence should be discussed
- Risk evaluation should be performed and genetic counseling offered if hereditary risk factors suspected. This includes:
  - At least one grandparent of Ashkenazi Jewish heritage, younger than age 50 at diagnosis, history of ovarian cancer at any age or in any first-degree or second-degree relative, first-degree relative who had breast cancer before age 50, 2+ first- or second-degree relatives diagnosed with breast cancer at any age, diagnosis of bilateral breast cancer, history of breast cancer in a male relative, and/or any survivor diagnosed at age 60 or younger with triple-negative breast cancer

## SCREENING

- Screening for cervical, colorectal, endometrial, and lung cancers should be performed annually, as you would in the general population
- Postmenopausal women on selective estrogen receptor modulator therapies should receive an annual gynecologic assessment

# HEALTH PROMOTION

- Assess information needs regarding breast cancer, treatment(s), side effects, and available resources
- Provide or refer appropriate resources, as needed
- Strongly encourage achievement and maintenance of healthy weight with regular physical activity (e.g., aerobic exercise at least 150 minutes per week, strength training exercise at least 2 days per week) and balanced diet
- Assess for tobacco and alcohol use
- Offer resources/counseling for smoking cessation if indicated and counsel survivors to limit alcohol consumption to no more than 1 drink per day

## CARE COORDINATION

- Consult with oncology team and request a treatment summary and survivorship care plan
- Maintain communication with oncology to promote wellcoordinated and evidence-based care
- Encourage the inclusion of caregivers, spouses, or partners in usual breast cancer survivorship care and support

## ASSESSMENT & MANAGEMENT: LATE & LONG-TERM EFFECTS

- Long-term effects:
  - Medical problems that develop during active treatment and persist after the completion of treatment
- Late effects:
  - Medical problems that develop or become apparent months or years after treatment is completed

## ASSESSMENT & MANAGEMENT: LATE & LONG-TERM EFFECTS

### It's recommended that female breast cancer survivors be assessed for:

- Distress, depression, anxiety
- Body image issues
- Cognitive impairment
- Fatigue
- Lymphedema
- Musculoskeletal health

- Cardiotoxicity
- Bone health
- Pain and neuropathy
- Sexual health and infertility
- Premature menopause and
- hot flashes

# EXPLANATION OF QUICK CARE GUIDE

- The Toolkit includes a 2-page guideline reference document called the Quick Care Guide that can be used as a convenient provider resource during clinic
- This guide is intended as a concise summary of care to aid the provider in appropriately assessing and managing:
  - Surveillance

Coordination of care

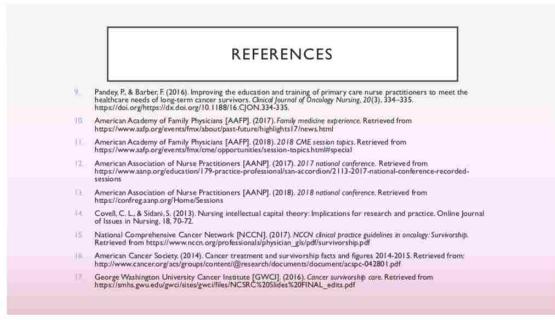
Screening

- Assessment and management of late and long-term effects
- Health promotion

## BREAST CANCER SURVOVIRSHIP RESOURCES

- American Cancer Society/American Society of Clinical Oncology [ASC/ASCO] Breast Cancer Survivorship Care Guideline
  - https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21319
- National Cancer Survivorship Resource Center
  - https://www.cancer.org/health-care-professionals/national-cancersurvivorship-resource-center.html?src=NCSRCToolkitSlides
- Cancer Survivorship E-Learning Series for Primary Care Providers
  - http://gwcehp.learnercommunity.com/elearningseries?src=NCSRCToolkitSlides

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# FEMALE BREAST CANCER SURVIVORSHIP: QUICK CARE GUIDE

# SURVEILLANCE

- Detailed Cancer-Related History & Physical
  - Years 1- 3—Every 3-6 months
  - Years 4-5—Every 6-12 months
  - Every year after—Annually
- · Annual Mammograms on both breasts with lumpectomies and remaining breast with unilateral mastectomy
- Only survivors meeting HIGH-RISK criteria (e.g. woman with a BRCA1/BRCA2 mutation or very strong history
  of breast cancer) should receive an annual mammogram and a breast MRI as part of routine screening
- AVERAGE-RISK survivors should NOT receive an MRI or other advanced body imaging unless disease recurrence is suspected
- Routine laboratory tests or imaging, except mammography, should ONLY be considered when disease
  recurrence is suspected and NOT for detection of disease recurrence in the absences of symptoms
- Adherence to adjuvant endocrine (antiestrogen) therapy should be discussed to help with symptom management
- · Signs and symptoms of local and regional recurrence should be discussed
- · Risk evaluation should be performed and genetic counseling offered if hereditary risk factors suspected

# SCREENING

- Screening for cervical, colorectal, endometrial, and lung cancers should be performed annually, as you would in the general population
- Postmenopausal women on selective estrogen receptor modulator therapies should receive an annual gynecologic assessment

# **HEALTH PROMOTION RECOMMENDATIONS**

- · Assess information needs regarding breast cancer, treatment(s), side effects, and available resources
- Provide or refer appropriate resources, as needed
- Strongly encourage achievement and maintenance of healthy weight with regular physical activity (e.g., aerobic exercise at least 150 minutes per week, strength training exercise at least 2 days per week) and balanced diet
- Assess for tobacco and alcohol use
- Offer resources and counseling for smoking cessation if indicated and counsel survivors to limit alcohol consumption to no more than 1 drink per day

# CARE COORDINATION

- · Consult with oncology team and request a treatment summary and survivorship care plan
- · Maintain communication with oncology to promote well-coordinated and evidence-based care
- Encourage the inclusion of caregivers, spouses or partners in usual breast cancer survivorship care and support

American Cancer Society/American Society of Clinical Oncology [ACS/ASCO]. (2016). American cancer society/American society of clinical oncology breast cancer survivorship care guidelines. CA: A Cancer Journal For Clinicians, 66(1), 43-73.

### **Distress, Depression, Anxiety**

- Assess for distress, depression and anxiety
- Probe higher risk survivors (e.g., younger patients, history of psychiatric disease) with further assessments
- If indicated, offer in-office counseling, pharmacotherapy and/or refer to appropriate psycho-oncology and mental health resources

#### **Body Image**

- Assess for body image concerns including:
   Breast asymmetry and atrophy, hair loss, sexual dysfunction/chemotherapy- related early menopause, loss of breast, poor cosmetic outcome, scarring and/or lymphedema after surgery, skin changes from radiation, skin discoloration, telangiectasia
- Offer adaptive devices (e.g., breast prostheses, wigs, etc.) and/or surgery when appropriate
- Survivors with radiation-associated breast/softtissue fibrosis should be considered for therapy with oral pentoxifylline (Trental) and vitamin E
- Refer for psychosocial care as indicated

# Premature Menopause & Hot

### Flashes

- Assess for premature menopause, including hot flashes, changes in menstruation, and chemotherapy-related early menopause
- Help mitigate vasomotor symptoms of premature menopausal symptoms by offering:
- Serotonin-norepinephrine reuptake inhibitors (SNRIs), selective serotonin reuptake inhibitors (SSRIs), gabapentin (anticonvulsant), clonidine (antihypertensive medication), acupuncture, lifestyle modifications (e.g., rhythmic breathing, vitamins, exercise, avoiding spicy foods, caffeine and alcohol) and/or environmental modifications (e.g., cool rooms, dressing in layers)

# **ASSESSMENT & MANAGEMENT: LATE & LONG-TERM EFFECTS**

#### Lymphedema

- Weight loss for those who are overweight or obese should be recommended to help prevent/reduce risk of lymphedema
- Refer survivors with clinical or suggestive symptoms of lymphedema to physical therapist,
- occupational therapist, or lymphedema specialist

#### Musculoskeletal Health

- Assess for musculoskeletal symptoms at each encounter including:
- Numbness and weakness of upper extremity/limb, musculoskeletal pain, difficulties with ipsilateral upper extremity: decreased/limited range of motion (e.g., adhesive capsulitis and rotator cuff injury), axillary web syndrome
- Offer acupuncture, physical activity, or referral for physical therapy or rehabilitation based on clinical indication

### **Sexual Health & Infertility**

- Assess for sexual dysfunction or problems with sexual intimacy including:
- Sexual desire disorder, arousal or lubrication concerns, dyspareunia, orgasm concerns, loss of sexual function, loss of sexual sensitivity of the skin, and vaginal dryness
- Treat any reversible contributing factors when appropriate
- Offer nonhormonal, water-based lubricants, and moisturizers for vaginal dryness
- Refer for psychoeducational support, group therapy, sexual counseling, marital counseling, or intensive psychotherapy when appropriate
- Survivors of childbearing age who experience infertility should be referred to a specialist in reproductive endocrinology and infertility as soon as possible

#### **Cognitive Impairment & Fatigue**

- Assess for cognitive difficulties (e.g., problems with concentration, executive function and memory during and after treatment)
- Determine if any contributing factors are reversible and refer for a neurocognitive assessment and rehabilitation, if available
- Address any causative factors for fatigue (e.g., anemia, sleep disturbance, pain), counsel for regular physical activity, and refer for cognitive behavioral therapy, if needed

#### **Cardiovascular & Bone Health**

- Survivors are at higher risk for cardiotoxicity. Monitor lipid levels and provide cardiovascular monitoring as indicated
- Postmenopausal survivors should receive baseline DEXA scan and repeat every 2 years for women younger than 65 years who are taking an aromatase inhibitor
- Premenopausal women taking tamoxifen and/or a gonadotropin-releasing hormone (GnRH) agonist and women who have chemotherapy-induced premature menopause should repeat DEXA scans every 2 years
- Bisphosphonates or denosumab can prevent bone loss and/or treat established osteoporosis, but must weigh benefits and risks
- SERMs should NOT be used in the prevention of osteoporosis in women who are taking an aromatase inhibitor

#### Pain & Neuropathy

- Ask about symptoms for pain and peripheral neuropathy and assess for contributing factors
- Offer interventions (e.g., acetaminophen, NSAIDS, physical activity, acupuncture) for pain or refer to an appropriate specialist if indicated during assessment
- Encourage physical activity for peripheral neuropathy and offer duloxetine for survivors with neuropathic pain, numbness, and tingling

American Cancer Society/American Society of Clinical Oncology [ACS/ASCO]. (2016). American cancer society/American society of clinical oncology breast cancer survivorship care guidelines. CA: A Cancer Journal For Clinicians, 66(1), 43-73.

## Appendix C

## Content Questionnaire

### **Expert Rating Form**

Provider Name:

Practice Specialty: ONC or PC

Years of Experience: \_\_\_\_\_

### Instructions

For each item, please indicate the following:

1. Rate each item using the following grading scale by placing a number in the column entitled "Content Rating 1-5" in the table below.

1=Strongly disagree

2=Disagree

3=Neither agree nor disagree

4=Agree

5=Strongly agree

 Please provide your comments in the column entitled "Comments" for each item. Your honest feedback is appreciated and will be used to enhance the quality of this project. If you believe content is missing or have any other subjective input, please include in the "Additional Comments" section at the end.

| Item  | Content<br>Rating 1-5 | Comments |
|---|-----------------------|----------|
| This toolkit<br>(PowerPoint®<br>presentation and Quick<br>Care Guide) accurately<br>identifies elements of<br>post-breast cancer<br>oncology care that<br>should be addressed in<br>the primary care setting. |                       |          |

| All information in this<br>toolkit is current and<br>accurate in accordance<br>with current standards<br>of care.                             |  |  |
|---|--|--|
| All information presented is necessary.   |  |  |
| The toolkit is complete;<br>all topics that should be<br>addressed are included.  |  |  |
| This toolkit will<br>improve the primary<br>care management of<br>breast cancer survivors.  |  |  |
| The Quick Care Guide is user-friendly.  |  |  |
| The size of the Quick<br>Care Guide is<br>appropriate for use in<br>the primary care setting.   |  |  |
| Primary care providers<br>can readily<br>incorporate this toolkit<br>and its information into<br>patient care in the<br>primary care setting. |  |  |

Additional Comments:

# **Content Validity Index Table**

| Item | Expert 1 | Expert 2 | Expert 3 | Expert 4 | Expert 5 | Experts 6 | Mean | CVR  |
|------|----------|----------|----------|----------|----------|-----------|------|------|
|      |          |          |          |          |          |           |      |      |
| 1    | 5        | 5        | 5        | 5        | 5        | 5         | 5    | 1    |
| 2    | 5        | 5        | 4        | 5        | 5        | 5         | 4.83 | 1    |
| 3    | 5        | 2        | 4        | 5        | 4        | 5         | 4.17 | 0.67 |
| 4    | 5        | 4        | 4        | 4        | 5        | 5         | 4.5  | 1    |
| 5    | 5        | 5        | 3        | 5        | 5        | 5         | 4.7  | 0.67 |
| 6    | 5        | 4        | 4        | 5        | 2        | 5         | 4.17 | 0.67 |
| 7    | 5        | 3        | 5        | 5        | 4        | 5         | 4.5  | 0.67 |
| 8    | 5        | 5        | 3        | 5        | 5        | 5         | 4.7  | 0.67 |

The content validity index is calculated using the following formula:

CVR = [(E-(N/2)) / (N/2)] with E representing the number of experts who rated the item as essential and N being the total number of experts.

The mean total of all of the means was 4.56 indicating that all of the questions were essential.

The calculation is as follows:

CVR = [(6-(6/2)) / (6/2)] CVR = [(6-3) / 3] CVR=[3/3]

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# Curriculum Vitae

# Lauren Scott, RN, BSN

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# PROFESSIONAL OBJECTIVE

To continue to develop and grow within the nursing education field.

# **EDUCATION**

| University of Nevada, Las Vegas<br>Doctor of Nursing Practice, FNP   | Las Vegas, NV | May 2019      |  |  |  |  |
|--|---------------|---------------|--|--|--|--|
| Utah Valley University   | Orem, UT      | Aug 2015      |  |  |  |  |
| Bachelor of Science in Nursing<br>Provo College  | Provo, UT     | Aug 2012      |  |  |  |  |
| Associate Degree in Nursing  |               |               |  |  |  |  |
| LICENSURE/CERTIFICATION  |               |               |  |  |  |  |
| Registered Nurse   |               | Sept 2020     |  |  |  |  |
| Basic Life Support   |               | April 2020    |  |  |  |  |
| EXPERIENCE   |               |               |  |  |  |  |
| Huntsman Cancer Hospital, GU Med/Onc, Salt Lake City, UTJune 2015-July 2016Registered Nurse• Placing PIVs and accessing Ports• Caring for CVAD lines and administrating medicine• Treating patients through infusion therapy• Educating patients about treatments, signs/symptoms, etc.Intermountain Healthcare North Orem InstaCare, Orem, UTJune 2014-May 2016Registered Nurse• Content of the section of the sect |               |               |  |  |  |  |
| • Collaborated with physician on p   | batient care  |               |  |  |  |  |
| <ul><li>Triaged high risk patients</li><li>Provided wound care</li></ul>   |               |               |  |  |  |  |
|  | modiantian    |               |  |  |  |  |
| • Started PIVs and administrating a<br><b>Phoumatic Personal Utab Valley Univ</b>  |               | May 2015 2017 |  |  |  |  |
| Rheumatic Rescue/Utah Valley University, Western SamoaMay 2015-2017Registered NurseMay 2015-2017   |               |               |  |  |  |  |
| <ul> <li><i>Registered Nurse</i></li> <li>Traveled to and lived in Samoa for a 4-week duration to work with children affected with rheumatic heart disease</li> <li>Screened hearts for murmurs using stethoscope and echocardiograms</li> <li>Collected DNA of high-risk children through saliva sample</li> <li>Educated Samoan communities about signs/symptoms, prevention, and treatment of rheumatic heart disease</li> </ul>  |               |               |  |  |  |  |
| The Church of Jesus Christ of Latter-day Saints, Managua, Nicaragua Oct 2012-Apr 2014  |               |               |  |  |  |  |

# Mission Nurse Specialist

- Provided full-time healthcare to 226 full-time missionaries, both in person and over the phone
- Worked with local and church assigned healthcare provider to ensure the delivery of proper care
- Taught monthly health seminars, including illness prevention and treatment instructions