Understanding Patient Engagement in Breast Cancer Survivorship Care: A National Web-Based Survey

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Boston College

William F. Connell School of Nursing

UNDERSTANDING PATIENT ENGAGEMENT IN BREAST CANCER SURVIVORSHIP CARE: A NATIONAL WEB-BASED SURVEY

a dissertation

by

KATHRYN E. POST

Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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ABSTRACT

UNDERSTANDING PATIENT ENGAGEMENT IN BREAST CANCER SURVIVORSHIP CARE: A NATIONAL WEB-BASED SURVEY

Kathryn E. Post

BACKGROUND: Breast cancer survivors experience a range of needs in the post-treatment phase as they transition into survivorship and beyond. The transition to survivorship requires breast cancer survivors to actively engage in self-managing their care, but little is known about patient engagement into survivorship care and what factors may contribute to this. Information is needed to further explore patient engagement into survivorship care, what factors may contribute to it and which patients are more likely to engage in their care and thus be better equipped to self-manage during survivorship.

PURPOSE: The purpose of this study was to explore how demographic/personal factors and survivorship outcomes are related to and may contribute to patient engagement in early stage breast cancer survivors.

METHODS: A cross-sectional, web-based self-report national survey was conducted using measures assessing personal/demographic factors, survivorship outcomes: health-related quality of life (HRQOL), fear of cancer recurrence (FCR), cancer health literacy (CHL) and two measures of patient engagement (patient activation (PA) and knowing participation in change (KPC). There was one open-ended question regarding additional survivorship concerns, not addressed in the previous survey items. Participants were recruited using Dr. Susan Love's Army of Women Research Foundation and Craigslist. Data were analyzed via bivariate associations and backwards linear regression modeling in SPSS.

RESULTS: The final sample included 303 participants (301 females and 2 males) with a mean age of 50.70 years. The sample was predominantly White, non-Hispanic and equally dispersed

across the United States. Patient engagement, as represented by PA and KPC, was significantly correlated with 13 predictor variables and there were 10 predictor variables that resulted in significant ANOVA relationships with PA and KPC. In both the KPC and PA regression models, HRQOL significantly predicted for patient engagement. In the KPC regression model, social support and level of education also significantly predicted for patient engagement and receipt of a survivorship care plan contributed unique variance to the model. The open-ended question response categories included: physical concerns, mental health concerns, financial toxicity, social support, body image concerns, other concerns or no concerns/none.

CONCLUSIONS: This study provides preliminary evidence that personal/demographic factors and survivorship outcomes may contribute to patient engagement in breast cancer survivors. Using assessment tools that measure factors such as HRQOL, social support, education level and patient engagement may give providers some insight as to which survivors may be ready to engage in survivorship care and those that may need more resources and/or support. Additional studies are needed to replicate and validate these results. More research is needed aimed at maximizing patient-centered care, patient engagement and ultimately improving SC. *Keywords:* breast cancer survivor, survivorship, patient engagement, health-related quality of life, social support.

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Chapter One: Statement of the Problem

An overview of the study is presented in Chapter One with sections including: (1) statement of the problem; (2) significance (3) purpose of the study; and (4) operational definitions and table of abbreviations.

Statement of the Problem

Limited work indicates that patient engagement is a critical piece in survivors' ability to benefit from and manage their survivorship care (SC) (Hibbard, Mahoney, & Sonet, 2017; Mayer et al., 2016). However, despite the growing emphasis on SC self-care management (American Society of Clinical Oncology (ASCO), 2018; Knobf, 2015), there are no studies that examine what demographic/personal factors and survivorship outcomes may contribute to patient engagement. This is a critical gap in SC especially given the need to promote patient and caregiver SC self-care.

In the decade since the seminal survivorship report from Institute of Medicine (IOM) (IOM, 2006) "*From Cancer Patient to Cancer Survivor: Lost in Transition*", SC has overwhelmingly failed to meet the needs of cancer survivors and improve patient outcomes (Admiraal et al., 2017; Brothers, Easley, Salani, & Andersen, 2013; Grunfeld et al., 2011; Hershman et al., 2013; Jefford et al., 2016; Nicolaije et al., 2015; Ruddy et al., 2016). While research supports that SC involving good patient provider communication (Kurtin, 2017) and tailored to the person (Meneses et al., 2018; Pekmezi et al., 2017) is effective, the SC delivery in most settings remains fragmented and in many cases, absent (Mayer, Nasso, & Earp, 2017). As a result of recent restraints in health care spending, patients have had a decreased ability to visit with providers for SC as often as they choose. This shift demands patients assume a greater role and are prepared to independently manage their SC (Leopold, Park, & Nekhlyudov, 2017; McCorkle et al., 2011).

Some research suggests one way to improve SC is to provide patients with the self-care SC skills needed (Hagan, Rosenzweig, Zorn, van Londen, & Donovan, 2017; Kenzik et al., 2016; Mayer et al., 2017). As such, ASCO and the Oncology Nursing Society (ONS) call for providers to partner with survivors to empower them to advocate for their healthcare needs (ASCO, 2018; Knobf et al., 2015; McCabe et al., 2013). The ONS Research Agenda (2014-2018) (Knobf et al., 2015) identifies patient self-management as one of their priority research areas. Patient self-management assumes patients are ready and able to do this. Some evidence has emerged that indicates that highly activated or empowered patients who receive SC benefit most from SC interventions (Mayer et al., 2016). However, patient engagement and/or patient empowerment are not well understood in the setting of SC.

A variety of demographic/personal factors and survivorship outcomes may contribute to a survivor's ability to actively engage in their care. However, there is limited research describing in large samples of breast cancer survivors the combinations of demographic/personal factors and key survivorship outcomes and their relationships to patient engagement measures. The ONS Research Agenda 2014-2018 (Knobf et al., 2015) and others suggest further research is needed to explore the relationships between demographic/personal factors and key survivorship outcomes to improve SC (Gast, Allen, Ruddy, & Haddad, 2017; McCabe et al., 2013). Understanding how key cancer-related outcomes and demographic variables contribute to a patient's willingness to engage in SC is an important area of SC research that lacks evidence. Patient activation (PA) and Knowing Participation in Change (KPC) are two such measures of patient engagement that may provide insight into this important aspect of SC.

Significance

In 2006 the IOM's report functioned as a call to action for the oncology community to develop and implement SC for the 15.5 million cancer survivors in the United States (American Cancer Society (ACS), 2016b). In the years since the IOM report, SC has been adopted and recommended by oncology clinicians (Halpern et al., 2014; Mayer et al., 2014; Oeffinger & McCabe, 2006), policy makers (NCCN, 2018c; IOM, 2006), advocacy organizations (National Coalition of Cancer Survivors (NCCS), 2017) and researchers (Palesh et al., 2011; Pollack, Hawkins, Peaker, Buchanan, & Risendal, 2011; Rowland et al., 2013) as a necessary component of oncology care. Many, but not all oncology clinicians and researchers answered the call with the development of SC models, programs and interventions aimed at improving the lives of cancer survivors. However, Parry, Kent, Forsythe, Alfano & Rowland noted that many models have "not adequately addressed the diverse sociocultural backgrounds that survivors bring with them to the care context" (p. 2651).

This lack of understanding of what it is the breast cancer survivor brings to the experience is evident in limited qualitative work. In these studies, participants felt they were only known by their providers for their breast cancer diagnosis and forced by others to be part of "pink ribbon" movements/events associated with breast cancer when they preferred to be viewed as the complex person they were and "more than their disease" (Flanagan, Winters, Habin, & Cashavelly, 2012). These findings also indicated that survivors often had additional demographic/personal factors such as comorbidities, which further added complexity to the survivorship experience (Flanagan, Tetler, Winters, Post, & Habin, 2016; Flanagan et al., 2012).

A review of the literature on multimorbidity in breast cancer survivors, concluded that multimorbidity was very common in breast cancer survivors and can have significant negative impacts on the survivorship experience including increased symptom burden, decreased medication adherence, decreased surveillance adherence, cognitive changes and functional decline (Meneses, Benz, Azuero, Jablonski-Jaudon, & McNees, 2015). Thus, despite advances in cancer care, the 3.5 million breast cancer survivors continue to encounter challenges in the post-treatment phase (IOM, 2006, 2008; Mayer et al., 2014; Nekhlyudov, Levit, Hurria, & Ganz, 2014; Ness et al., 2013; Rowland et al., 2013; Taplin & Rodgers, 2010).

Breast cancer survivors have well documented post-treatment needs in the survivorship phase of oncology care. These needs include treatment and disease-related side effects (Ness et al., 2013; Runowicz et al., 2015), psychosocial concerns including depression and anxiety (Mitchell, Chan, et al., 2011; Ness et al., 2013; Runowicz et al., 2015; Schumacher et al., 2013), fear of cancer recurrence (FCR) (Brennan, Butow, Spillane, & Boyle, 2016; Dunn et al., 2015; Ness et al., 2013; Runowicz et al., 2015; Simard et al., 2013), distress (Head et al., 2012; Lester et al., 2015; Ploos Van Amstel et al., 2013; Runowicz et al., 2015) and family and financial concerns (Ness et al., 2013; Runowicz et al., 2015). Breast cancer survivors can have significant post-surgical issues surrounding body image and sexuality (Davis, Meneses, & Messias, 2010; Runowicz et al., 2015; Unukovych et al., 2012), lymphedema (Kim et al., 2013; Runowicz et al., 2015), risk for infection (Runowicz et al., 2015), and myofascial pain and shoulder dysfunction (Adriaenssens et al., 2012; Runowicz et al., 2015; Torres Lacomba, Mayoral del Moral, Coperias Zazo, Gerwin, & Goñí, 2010). Similar to other cancer survivors, breast cancer patients are at risk for long-term complications related to their therapy including secondary malignancies (Kenyon, Mayer, & Owens, 2014; Runowicz et al., 2015), cardiac toxicity (Bovelli, Plataniotis, & Roila, 2010; Runowicz et al., 2015; Yu & Jones, 2016) and bone loss (Coleman, 2016; Runowicz et al., 2015).

The majority of breast cancer tumors express the estrogen receptor (ER) and as a result, "ER positive" patients are prescribed anti-estrogen therapy for 5 years, 10 years and in some cases 15 years (Goss et al., 2016; Runowicz et al., 2015). These drugs often cause significant side effects affecting health related quality of life (HRQOL) including but not limited to hot flashes, myalgias, arthralgias, vaginal discharge or dryness, increased rate of bone loss and thromboembolism (Goss et al., 2005, 2016; Higgins, Liedke, & Goss, 2013; Runowicz et al., 2015).

In addition to the substantial physical burden many breast cancer survivors endure post treatment, psychosocial issues are equally impactful. Breast cancer survivors suffer anxiety, depression and FCR especially in the first year to two years post treatment (Klemanski, Browning, & Kue, 2016; Lester et al., 2015). Many may face challenges with finances, and reentry to their roles as parents, employees and with their partners (Flanagan et al., 2016; IOM, 2004, 2006).

Purpose of the Study

The purpose of this descriptive cross-sectional, web-based self-report survey was to explore how demographic/personal factors and important survivorship outcomes might contribute to the variables that capture patient engagement in early stage breast cancer survivors. The findings from this survey may help inform which survivors may be most likely to engage in and benefit from survivorship self-care. It also provided information about those not likely to engage, which will be an important area for future research.

Specific Aims

The specific aims of this study are to:

- To describe the relationship amongst demographic/personal factors and survivorship outcomes (health related quality of life (HRQOL), FCR, cancer health literacy (CHL)) to patient engagement measures (PA and KPC) in breast cancer survivors. <u>Research Question 1a:</u> What is the relationship between demographic/personal factors, survivorship outcomes (HRQOL, FCR, CHL) and patient engagement measures (PA and KPC) in breast cancer survivors?
- To describe how demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors.

<u>Research Question 2a:</u> How do demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors?

Hypothesis 2a: Breast cancer survivors who have high levels of HRQOL, CHL and low levels of FCR will have high levels of patient engagement measures (PA and KPC).

Definitions

The following are a list of definitions to provide clarity and consistency throughout the study. All definitions have been conceptualized by the author unless otherwise noted by citation. **Breast Cancer Survivor:** For the purposes of this study, a breast cancer survivor was described similarly to the IOM's focus on survivorship as beginning following primary treatment (IOM, 2006). This study defined a breast cancer survivor as a person diagnosed with breast cancer who has completed adjuvant treatment (surgery, +/- chemotherapy, +/- radiation).

Breast Cancer Survivorship: Breast cancer survivorship is the period from the time initial breast cancer treatment is complete through the balance of the person's life.

Cancer Health Literacy: For the purposes of this study, CHL was adapted from the U.S. Department of Health and Human Services (USDHHS) Healthy People 2020 Definition of Health Literacy (USDHHS, 2010, p. iii) and referred to the degree to which cancer survivors have the capacity to obtain, process and understand basic information and services needed to make appropriate health decisions regarding their cancer and cancer treatment. In this study, CHL is measured by the Cancer Health Literacy Tool-6 (CHLT-6) (Dumenci et al., 2014)

Cancer Recurrence: Cancer recurrence was operationalized to refer to cancer found in the body in the same place as the original tumor or in a new/different place after some time has passed since completing cancer treatment. (Simard & Savard, 2014)

Distress: Distress as it relates to cancer has been defined by the NCCN as:

a multifactorial unpleasant experience of a psychological (i.e. cognitive, behavioral, emotional), social, spiritual and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (Holland et al., 2017, p. DIS-3)

Early Stage Breast Cancer: Early stage breast cancer is stage 0-3 breast cancer, both in situ and invasive disease. Metastatic disease (stage 4) is excluded from this definition. (ACS, 2018a)

Fear of Cancer Recurrence: FCR refers to the fear that cancer could "return or progress in the same place or in another part of the body" (Lebel, Simard, Harris, et al., 2016). In this study,

FCR is measured with the Fear of Cancer Recurrence Inventory short form (FCRI SF) (Lebel, Simard, Harris, et al., 2016).

Health Related Quality of Life: HRQOL for the purposes of this study was adapted from the Office of Disease Prevention and Health Promotion (ODPHP) and was defined as the impact health status has on QOL and includes domains related to physical, emotional and social functioning (ODPHP, 2019). In this study, HRQOL was measured with the Functional Assessment of Cancer Therapy General-7 (FACT-G7) (Yanez, Pearman, Lis, Beaumont, & Cella, 2013).

Patient Activation (PA): PA is the level of patient knowledge, skill and confidence in their selfmanaging their care as a collaborative partner with their provider (Hibbard, Mahoney, Stockard, & Tusler, 2005). There are four levels of PA: disengaged and overwhelmed, becoming aware but still struggling, taking action and maintaining behaviors and pushing further. (Hibbard, Stockard, Mahoney, & Tusler, 2004)

In this study, PA was measured with the Patient Activation Measure 10 (PAM 10) (Hibbard et al., 2005, 2004).

Power as Knowing Participation in Change (KPC): Power as KPC as described by Barrett (2010) is "being aware of what one is choosing to do, feeling free to do it, and doing it intentionally" (p. 49). In this study, power as KPC was measured by the KPC short form (KPC SF) (Barrett, 2010).

Table 1. Frequently Used Abbreviations – in order of ap	appearance
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Abbreviation	Definition
SC	Survivorship care
IOM	Institute of Medicine

SCP	Survivorship care plan
HRQOL	Helath-related quality of life
ACS	American Cancer Society
FCR	Fear of cancer recurrence
ER	Estrogen receptor
ASCO	American Society of Clinical Oncology
CHL	Cancer health literacy
КРС	Knowing participation in change
PA	Patient activation
CHLT-6	Cancer Health Literacy Tool -6
FACT G-7	Functional Assessment of Cancer Therapy General -7
FCRI SF	Fear of Cancer Recurrence Inventory Short Form
KPC SF	Knowing Participation in Change Short Form
PAM 10	Patient Activation Measure 10

Chapter Two: Theoretical Framework and Literature Review

A description of the conceptual frameworks used in the study are presented in Chapter Two. This will be followed by a review of the literature as it relates to the most critical outcomes of SC. This includes the natural history, incidence and prevalence of breast cancer, defining SC and personal factors that may impact the breast cancer survivorship experience such as demographics and comorbidity. Other concepts that have been reported to influence the survivorship experience such HRQOL, CHL and FCR will be reviewed. The outcome variables within this study, PA and KPC that are related to patient engagement will also be discussed.

Theoretical Framework

Rogers' Science of Unitary Human Beings is the guiding conceptual framework for the study. More specifically, Barrett's Theory of Knowing Participation in Change (KPC), derived from Rogerian Science informs this work. The next section will outline first Rogers Science followed by a discussion of Barrett's KPC.

Rogers' Science of Unitary Human Beings. Conceptually, Rogers' Science of Unitary Human Beings (1992), postulates that people are greater than the sum of their parts. They are open, dynamic energy fields. This suggests that breast cancer is an experience, but the experience does not define the person; rather, the person is an open, dynamic, increasingly complex being who is free to define the experience. It is well accepted that breast cancer is a disruptive experience in a person's life. The literature on survivorship indicates that persons' responses are individual and varied, which challenges the "one size fits all" linear approach to survivorship programming that currently exists. Unitary Science not only allows for the unpredictable and varied responses of breast cancer survivors, but also for patient individuation in SC treatment plans. Key concepts include energy field, pattern, pandimensional and unitary human being. According to Unitary Science, an energy field is continuously in flux and includes the environmental and human fields. An energy field could also be used to describe a group such a family, a group or a community such as breast cancer survivors. The energy fields or the human being/group and the environmental field are constantly interacting and evolving. Thus, change is considered "continuously innovative and creative" and that "association does not mean causality" (Rogers, 1992, p. 30). A pattern is a single wave of an energy field which is unobservable but which may manifest in observable events in the world. Each pattern (i.e. chaotic, calm or measured) is unique to that human being or group and the environmental field around them. Pandimensional describes both human beings and their environment as non-linear domains. They cannot be measured by space or time and are irreducible.

Unitary Science utilizes three principles of homeodynamics to describe the changing nature of energy fields. The principle of resonancy is defined by a continuous change that is nonlinear and unpredictable in the interacting human and environment wave patterns. It is through this interaction humans become increasingly complex. For example, the experiences we have in life (such as a breast cancer diagnosis) make us more multifaceted as we obtain new information as a result, and we cannot return to the person we were before any given experience. The principle of helicy describes the innovative and unpredictable nature of change reflecting diversity. For example, each person may react differently and unpredictably to a diagnosis of breast cancer; one person may react with extreme anxiety and grief whereas another may react with hope and positivity. The principle of integrality describes the constant interaction between human beings and their environmental field and the irreducible nature of the two (Rogers, 1992). As human beings, we cannot be broken down into the parts of an experience such as breast cancer or breast cancer survivorship; the experience is much bigger than simply the sum of our parts. These principles are relevant to this study in that people who have breast cancer are interacting in new ways within their environment. The literature supports that individual responses to the experience can be variable, unpredictable and that patients faced with breast cancer have many complexities that will impact their survivorship experience.

Barrett's Knowing Participation in Change. Conceptually, KPC is a non-linear process model that is used to partner with the patient to facilitate awareness, choice, freedom and intention to engage in change. KPC acknowledges an individual person's complexity and his/her unique response to an experience, in the study, breast cancer survivorship.

Power as KPC has four inseparable dimensions: awareness, choices, freedom to act intentionally and involvement in creating change. Together, these dimensions make up a person's "Power Profile"; a nonlinear and constantly evolving power within an individual or group. Barrett (2010) suggests that people or groups with power are able to accept change in their life, even when that change is not what they would desire, given a choice. Barrett (2010) encourages nurses and researchers to utilize the KPC theory to assist persons in their journey towards increased power in their lives.

KPC Theory. Barrett's (2010) theory describes power as KPC as "being aware of what one is choosing to do, feeling free to do it, and doing it intentionally" (p. 49). In this way, persons with power are able to knowingly participate in change. According to Barrett (2010), there are two types of power: power as control and power as freedom. Power as freedom, is conceptualized as acausal. Power conceptualized in this way is unattached to outcome, but rather recognizes the mutual processes between the individual (or group) and their environment, or world (Barrett, 2010). In this study, this theory is relevant because the breast cancer survivorship

experience although not causal, may serve as an impetus for increased awareness, freedom, choice and ultimately power for breast cancer survivors.

Power as KPC has four inseparable dimensions: awareness, choices, freedom to act intentionally and involvement in creating change. Together, these dimensions make up a person's "Power Profile"; a nonlinear and constantly evolving power within an individual or group. Barrett (2010) suggests that people or groups with power are able to accept change in their life, even when that change is not what they would desire, given a choice. Barrett (2010) encourages nurses and researchers to utilize the KPC theory to assist persons in their journey towards increased power in their lives.

Barrett (2010) advocates for developing a "Power Prescription" which is an "individually designed application of health patterning modality for a specific person or group" (Barrett, 2010, pg. 49). As such, the person may choose to actively participate in their care and wellness, freely make decisions and lifestyle choices to promote health. In this study it will be important to understand if survivors are able to identify with Barret's perception of power as this may have implications for how they address their survivorship care (Barrett, Farren, Kim, Larkin, & Mahoney, 2001). Please see Figure 1 for illustration of the KPC theory.



Literature Review

This literature review begins with background knowledge on the natural history of breast cancer natural history, incidence and prevalence. It then proceeds by summarizing and synthesizing the literature on the variables in the study as they relate to breast cancer survivors and are organized under the following subheadings: (1) selected demographic and personal factors in breast cancer survivors, (2) survivorship outcomes and (3) patient engagement in survivorship self-care and (4) summary.

Breast Cancer Natural History, Incidence and Prevalence

The ACS estimates that there will be approximately 268,670 new cases of breast cancer diagnosed and that 41,400 people will die from the disease in 2018 (ACS, 2018). This translates into about 1 out of every 8 women being diagnosed with breast cancer in her lifetime, and some men (ACS, 2018). Breast cancer is most common in White women and Black women from the ages of 60-84 but Black women are much more likely to have breast cancer under the age of 40 (ACS, 2018). Additionally, mortality with breast cancer is much higher at any age for Black women as compared to their non-Hispanic White counterparts (ACS, 2018).

Breast cancer is truly an umbrella term for a variety of malignant breast tumors. Breast cancer can be treated with surgery, +/- radiation, +/- medical therapy (such as chemotherapy or endocrine therapy). (ACS, 2015; ACS, 2018). As screening and treatments improve, survival rates have increased accordingly. For localized breast cancer (Stage 0-1 with no lymph node involvement) five year survival rates approach 99% (National Cancer Institute (NCI), 2017). For regional breast cancer (Stage 2-3), five year survival rates are 85.2% (NCI, 2017). For advanced breast cancer (Stage 4), five year survival rates are 26.3% (NCI, 2017).

Selected Demographic and Personal Factors in Breast Cancer Survivors

This study measured several different demographic and personal factors. A description of the demographic and personal factors and their relevance to the study is included below.

Age. The experience of breast cancer survivorship can differ between older and younger breast cancer patients in terms of tumor biology (more or less aggressive), treatment type, psychological response and long-term treatment toxicities and considerations (Partridge, 2013). From a treatment perspective, issues for young breast cancer survivors include fertility, sexuality and reproductive concerns (Meneses, McNees, Azuero, & Jukkala, 2010; Partridge, 2008; Partridge et al., 2004; Rosenberg et al., 2014), increased treatment toxicity concerns (Partridge, 2013; Rosenberg & Partridge, 2015) and the potential for increased psychosocial concerns (Accortt, Bower, Stanton, & Ganz, 2015; Arès, Lebel, & Bielajew, 2014; Dietze, Sistrunk, Miranda-Carboni, O'Regan, & Seewaldt, 2015; IOM, 2004; Kornblith et al., 2007; Thewes et al., 2004).

Thewes et al. (2004) reported that younger women reported more needs as compared to older women and that they expressed unique needs surrounding reproduction, fertility and early menopause as consequences of cancer treatment. Younger women in this study also reported limitations to their lifestyle and careers as a result of cancer and cancer treatment, a concern not shared by their older counterparts. The younger women in this sample reported needs for support based services regarding achieving a healthy lifestyle, diet and stress management. Lastly, the authors reported that the younger women described unmet needs for age-appropriate information and services as they discovered that much of what was available to them was focused on an older breast cancer survivor population. The older women in this study did not report many unique needs but some noted that they did not want to receive all of the available information on breast cancer survivorship.

If young breast cancer survivors are also mothers, this can negatively impact on their survivorship experience through higher levels of FCR. Arès et al. (2014) found that the young mothers with breast cancer had significantly higher levels of FCR and illness intrusiveness in both early survivorship (0-5 years post treatment) and late survivorship (5-15 years post treatment).

Dietz, Partridge, Gemignani, Javid and Kuerer (2015) echoed many of the considerations listed above regarding young breast cancer survivors, but found that in older breast cancer survivors, there is limited data to rely on, especially for those older than age 70. From optimal screening recommendations to the individual experience of the older survivor, little is documented. Bellury et al. (2013) found that high comorbidity and high symptom bother were significantly related to reduced physical functioning. Age alone, however, was not predictive of physical functioning in this sample. The authors recommend providers of older patients be alert for symptom bother, marital status and comorbidities as potential contributors to patients' physical functioning.

Nguyen et al. (2013) found that breast cancer survivors aged 65 and older scored lower than peers in general cognitive function, working memory, psychomotor speed and executive function. These results persisted even after partitioning on age, education and comorbidity status. The authors called for providers to consider longitudinal cognitive testing in older breast cancer patients with the potential to intervene and possibly prevent cognitive decline.

Gender. The vast majority of literature surrounding breast cancer and breast cancer survivorship pertains to female breast cancer patients and survivors, yet some men are also

affected by this disease. The ACS (2018b) estimates that about 2,550 men would be diagnosed with breast cancer in 2018 and that 480 men would die from the disease. Thus, it is important to consider the breast cancer survivorship from the male perspective in addition to the female perspective.

Andrykowski (2012) found that the male breast cancer survivors were significantly more likely to have comorbidities than their cancer-free comparisons such as diabetes (p = .03), heart attack (p = .03), asthma (p = .03), stroke (p = .07) and arthritis (p = .002). The male breast cancer survivors also reported poorer life satisfaction, poorer general health and more days of decreased physical and mental health, greater obesity rates and less physical activity than their cancer-free comparisons. The author also found that the male breast cancer survivors reported less leisure time than their cancer-free comparisons (p < .05). Ruddy et al. (2013) found that 40% of the male breast cancer survivors surveyed reported very poor sexual performance over the preceding four weeks and had similar FACT-B scores (and thus HRQOL) to female breast cancer survivors including increased symptom bother, anxiety and depression.

Lesbian, gay, bisexual, transgender and queer (LGBTQ) health and survivorship. There are between 420,000 and one million LGBTQ cancer survivors in the US (Kamen, 2017; Livestrong Foundation, 2010) but are underrepresented in cancer clinical trials (Kamen, 2017; Margolies & Brown, 2017), thus the ambiguity on the exact population numbers. From the little that is known about this subpopulation of cancer survivors, LGBTQ survivors have demonstrated worse QOL, increased symptoms such as depression, and decreased satisfaction with care when compared to their heterosexual cancer survivor peers (Jabson & Kamen, 2016; Kamen, Mustian, Dozier, Bowen, & Li, 2015; Kamen, 2017). This may be due to the fact that they are layering the stress of the cancer survivorship experience on top of the already present minority stress they experience in being a LGBTQ person and in navigating the cancer survivorship experience as a LGBTQ person in a heteronormative world that may not be friendly, welcoming, understanding or even accepting of LGBTQ persons (Kamen, 2017; Margolies & Brown, 2017). Further, LGBTQ survivors endorse that targeted, person-centered care is lacking specific to LGBTQ issues is currently lacking in SC, especially with regard to issues surrounding LGBTQ sexuality, sexual health, psychosocial support and SC free of discrimination and stigma (Carr, 2017).

Margolies and Brown (2017) reported on the current state of knowledge surrounding cancer in LGBTQ people and described how LGBTQ face many obstacles to receive quality care such as facing healthcare providers who are not accepting of LGBTQ people and/or not culturally competent and resultant negative experiences, low rates of health insurances among LGBTQ people. These can result in low cancer screening rates and cancer diagnoses at later stages than their heterosexual peers as well as poorer health outcomes in the cancer survivorship phase. The authors identified the following issues in the literature where nurses and other healthcare providers could intervene to provide a better healthcare experience for LGBTQ persons with cancer: the lack of data collection on sexual orientation and gender identity, the need for a culturally competent workforce, the need for a culturally competent health care system, the need to create LGBTQ tailored patient information and education. The authors suggest that nurses and healthcare providers can act to intervene and create change on each of these current challenges and create a more positive experience for LGBTQ persons with cancer. (Margolies & Brown, 2017)

Race/Ethnicity and social determinants of health. Race and/or ethnicity and social determinants of health can impact breast cancer patients from diagnosis, to treatment and through to survivorship and are deeply intertwined so are considered here together for the purposes of

this study. African American and Hispanic women are more likely to be diagnosed at a later stage than their White counterparts, resulting in decreased survival and increased morbidity (ACS, 2015, 2016a). This is likely due in part to lack of access to care and/or lack of health insurance as well as biological factors of the tumor itself (ACS, 2016a). Further, there exists limited inclusion of minority populations in oncology clinical trials for the reasons stated above and also due to the medical mistrust seen in minority populations (Barsevick et al., 2016). Additionally, social determinants of health such as neighborhood and environment, economic stability, access to health care and health insurance, education and social and community context (USDHHS, 2019) have impacts on health and thus the breast cancer survivorship experience and are also integral to this study.

Race/Ethnicity. In a sample of African American breast cancer survivors, Barsevick et al. (2016) found that being younger, having more medical mistrust, being unemployed and having more comorbidities were predictive for more severe emotional problems. Similarly, being younger, unemployed, having three or more comorbidities, more treatment types and high medical mistrust contributed to having more severe *physical* problems. This study documented the potential challenges African American breast cancer survivors can face post treatment and also helped to identify potential subgroups (i.e. being younger, unemployed) who may be at risk and therefore, could be targeted for survivorship interventions.

Much of the literature on minority breast cancer patients focuses on detection and diagnosis, but there are also considerations of late effects and long term toxicities in terms of race and/or ethnicity. In a review by Blinder and Griggs (2013), the authors reported that Black breast cancer patients have a higher risk for cardiotoxicity following anthracycline-based chemotherapy as compared to Whites. Substantial evidence points to disparities in pain

management with Black patients reporting more pain and more disability due to pain than Whites. The authors noted that there is limited evidence regarding disparities in long term toxicities such as infertility, sexual health, osteoporosis and secondary malignancies. However, several studies in this review documented inequities in terms of health care access, insurance and cancer screening for minority breast cancer patients.

Keegan et al. (2015) in comparing, Hispanic and White neighborhoods as a proxy for SES, reported that non-Hispanic White women living in a low-SES neighborhood and African American women in both neighborhood types had lower survival than that of non-Hispanic White women living in a high-SES neighborhood. These results persisted after accounting for tumor stage, biology, comorbidities and type of treatment.

Similarly, Pruitt et al. (2015) reported that areas of high Black and Hispanic segregation were adversely associated with cancer mortality, aligning with the literature on the adverse health effects of segregation in the U.S. (Corral et al., 2012; Do, Frank, Zheng, & Iceland, 2017). Further, Black women were more than twice as likely as White women to die from breast cancer. However, when all other covariates were accounted for, racial/ethnic segregation was not able to independently account for the differences in cancer specific mortality, speaking to the likely complex and multi-factorial influences on cancer-specific mortality.

Racial and/or ethnic disparities also exist in the male breast cancer survivor population. Sineshaw, Freedman, Ward, Flanders and Jemal (2015) examined differences in receipt of treatment and risk of death between Black and White men with early stage breast cancer using National Cancer Data Base data. Consistent with the literature on health disparities and access to care, the authors report that Black men in this sample were more often uninsured or Medicaid insured and lived in low income areas. Black men and older White men were less likely to receive chemotherapy as compared to younger patients. When adjusting for clinical factors such as tumor biology and stage, younger Black men had a 76% higher risk of death as compared to younger White men, but this was significantly reduced after adjusting for insurance and income level. This study also reported low rates of hormonal therapy in all men, consistent with the literature base potentially reflecting adverse side effect profiles or patient/provider preferences.

Wang et al. (2013) found that in Chinese breast cancer survivors', socioeconomic wellbeing was a dominant survivorship concern and that both the high and low acculturated Chinese immigrants had lower social wellbeing than the White group. There were also significant differences between the Chinese immigrants and the White breast cancer survivors in terms of educational level, income and insurance coverage and receipt of chemotherapy. In the final regression analysis, the high acculturation immigrant group had significantly higher social wellbeing scores than the low acculturation immigrant group (p < .05).

Concerning Latina breast cancer survivors, there is evidence of depression, uncertainty and low levels of social support and consequently, should be considered as a potential high needs survivor subgroup (Ashing-Giwa & Lim, 2009; Holden, Ramirez, & Gallion, 2014; Sammarco & Konecny, 2008, 2010). Sammarco and Konecny reported negative correlations between uncertainty and QOL (Sammarco & Konecny, 2008) and that Latina breast cancer survivors had significantly higher levels of uncertainty as compared to their White counterparts (Sammarco & Konecny, 2010). Latina breast cancer survivors are also reported to have higher levels of depression than the general population ranging from 31.6% in a study by Holden et al. (2014), to 53% in a study by Ashing-Giwa, Rosales, Lai and Weitzel (2013). Holden et al. (2014) also reported low cancer screening rates (for cancers other than breast) for those Latina survivors who had depressive symptoms and posited that depressive symptoms could be a barrier to screening for other cancers.

Latina breast cancer survivors also struggle with practical concerns such as returning to work and language barriers (Blinder et al., 2012; Rosales, Ashing, & Napoles, 2014; Yanez, Maggard Gibbons, Moreno, Jorge, & Stanton, 2016). Blinder et al. (2012) reported that Latina breast cancer survivors were significantly less likely to return to work at 6 months and 18 months post diagnosis as compared to their White counterparts and that their employment in manual labor positions may have contributed to this difference. In two studies evaluating the impact of language barriers in cancer survivors, Spanish-speaking only Latinas reported lower quality of care than English-speaking Latinas (Rosales et al., 2014) and had more cancer specific distress (Yanez et al., 2016).

Socioeconomic status (SES). Ashing-Giwa and Lim (2009) report that for every ethnic group studied (European, Latina, Asian and African American) HRQOL scores rose as income increased so that higher income resulted in higher HRQOL scores. The final regression analysis results demonstrated that higher income and education and lower life burden strongly correlate with improved HRQOL. Of all the variables, income had the most significant impact on HRQOL (p < .001). The authors stress that these findings highlight the need to identify high-needs survivor groups who may be at increased risk for low HRQOL due to factors such as SES.

In order to determine the impact a breast cancer diagnosis may have on future SES from the perspective of employment and marital status, Eaker et al. (2011) found that a greater proportion of breast cancer survivors used sickness benefits at both the three and five year marks. Treatment characteristics that were associated with using these benefits included having had a mastectomy and/or axillary dissection and/or adjuvant chemotherapy. The authors argue for improved breast cancer SC and rehabilitation programs for these patients as they transition back to work and their lives. Owusu et al. (2016) found an association between SES and functional decline and death in older breast cancer patients post diagnosis. The authors reported that participants with a high school education or less had a 2.5 times higher odds of functional decline or death as compared to those with more than a high school education, thus again linking low SES with decreased survival or reduced HRQOL.

Comorbid conditions/Multimorbidity. Comorbid conditions and multimorbidity can be pre-existing or exacerbated by treatment, for example, worsening hyperglycemia in a cancer patient with concurrent diabetes mellitus (DM), and can also impact the survivorship experience in combination with treatment related toxicities (Meneses et al., 2015). Further, as the population ages and cancer treatments improve, breast cancer survivors will live long enough to develop chronic conditions which can contribute to morbidity, including DM, obesity, hypertension, hypercholesterolemia, among others and are more likely to have a comorbidity at the time of their cancer diagnosis (Ritchie, Kvale, & Fisch, 2011). In order provide excellent SC, considering the full picture of the patient, including non-cancer significant health conditions as well as their cancer diagnoses, is necessary.

The World Health Organization (WHO) (WHO, 2016) states that multimorbidity, or at least two chronic health conditions in one person, can impact safety in that these patients have more frequent interactions with the healthcare system and more complex treatment plans, leading to a greater chance for successes or failures in providing safe, effective, care. Further, multimorbidity is more commonly found in minority populations, thus further perpetuating inequities in the healthcare system. The WHO recommended that providers take an individualized, person-centered approach to caring for persons with multimorbidity in order to achieve the best patient outcomes.

Cancer survivors follow the current U.S. trend of multimorbidity in that many cancer survivors have at least one other significant medical condition in addition to their cancer diagnosis. Leach et al. (2015) found that the average number of medical conditions reported was five and that 1.9 conditions were documented after their cancer diagnosis. The breast cancer survivors in this sample reported the highest number of comorbidities. Other factors that were associated with higher comorbidity burden included older age, being divorced, widowed or separated, being non-Hispanic White, being overweight or obese and not receiving chemotherapy. The authors posited that attaining a healthy weight and lifestyle could potentially attenuate comorbidity burden and that providers should consider this in SC planning.

Despite the fact that many breast cancer survivors have multimorbidity, it does not appear that they acquire comorbidities at a greater rate than that of their peers (Cohen, Lan, Archer, & Kornblith, 2012; Gold, Makarem, Nicholson, & Parekh, 2014; Jordan et al., 2014). Older breast cancer survivors (> 65 years old) gained comorbidities post-cancer diagnosis at the same rate as their matched cancer-free peers, but breast cancer continued to be a mortality hazard at 15 years post diagnosis (Jordan et al., 2014). Further, those breast cancer survivors with higher comorbidities had a higher risk of mortality as compared to the cancer-free peers. Young et al. (2014) also reported that similar to their cancer-free peers, breast cancer survivors who experienced weight gain during and after cancer treatment also experienced a higher degree of physical and functional limitations compared to those who did not gain weight.

Despite the fact that the levels of comorbidity are similar in breast cancer survivors as compared to their cancer-free peers, they are still happening at an alarming rate and are a significant health concern for breast cancer survivors. In the previously referenced qualitative study on the experience of the transition to survivorship by Flanagan et al. (2016) all of the breast cancer survivors reported comorbid conditions and 86% (n = 12/14 participants) of the participants reported three or greater comorbidities. All of the participants also reported taking concomitant medications not related to their breast cancer and 43% (n = 6/14 participants) reported taking eight or more concomitant medications.

To determine the extent that DM could impact breast cancer survivors' mortality, Gold et al. (2014) conducted two simultaneous systematic reviews of the literature on breast cancer comorbid with DM, and found that of the trials that evaluated all-cause mortality in breast cancer survivors with and without DM, 21 of 22 reported an increase in mortality for those breast cancer survivors with concurrent DM. The authors performed a meta-analysis of these trials and found a 52% increased risk for all-cause mortality in breast cancer survivors with DM.

Griffiths et al. (2014) evaluated SEER data on Medicare breast cancer patients and found that older age, later stage, higher grade and poor performance status were associated with higher numbers of comorbidities. For patients with stage one to three breast cancer, undetected comorbidity negatively impacted outcome in that it was associated with significantly lower likelihood of receiving chemotherapy (p < .00001) and with an increase in mortality (p < .00001). Thus, comorbidity and the possibility of undetected comorbidity must be considered in the evaluation of cancer survivors when providing optimal SC.

Comorbidities may vary based on demographics such as ethnicity, race, age, number of comorbidities and SES (Azuero, Benz, McNees, & Meneses, 2014; Cohen et al., 2012; Meneses et al., 2015). Ashing, Rosales, Lai and Hurria (2014) found in a racially diverse sample that 75% of the sample reported at least one comorbidity. Spanish language preferred Latina breast cancer
survivors were more likely to report DM, psychological issues and having more than three comorbidities (p<.05). Latina breast cancer survivors reported osteoporosis and headache twice as often as compared to the African American breast cancer survivors. Forty-nine percent of the African American breast cancer survivors in the sample reported hypertension and arthritis. In all groups, older age was associated with increased comorbidities.

The evidence on comorbidities in breast cancer survivors suggests that multimorbidity is a reality in U.S. breast cancer survivors, may differ based on survivor demographics and must be considered in comprehensive survivorship treatment planning in order to provide optimal SC. In order to do so, survivors must be screened for comorbidities and a comprehensive treatment plan must be designed, taking into account the individual needs and concerns.

In summary, there are a variety of demographic and personal factors that are important to and may impact the survivorship experience as described above. These factors along with other demographic/personal variables were captured by the investigator-developed demographics and health history worksheet. They were then explored in the study to determine how they interacted and related to important survivorship outcomes and engagement measures and will be discussed in the following chapters.

Survivorship Outcomes

For the purposes of the study, the survivorship outcomes identified in the literature as pertinent to patient engagement in survivorship self-care are HRQOL, FCR and CHL. As such, these variables and the relevant literature are reviewed herein.

Health Related Quality of Life. HRQOL is a multidimensional concept which includes physical, emotional and social functioning domains (Office of Disease Prevention and Health Promotion, 2019). HRQOL has become increasingly important to oncology providers and researchers as oncology treatments continue to improve and cancer survivors live for years and decades beyond diagnosis (Yanez et al., 2013). As such, HRQOL was explored as a potential contributor to patient engagement.

Physical Domain of Breast Cancer Survivorship and HRQOL. The post-treatment physical concerns for breast cancer survivors and the implications for HRQOL vary from survivor to survivor depending on diagnosis and treatment type but also by individual, behavior and lifestyle. Those issues which are pertinent to the study and were captured in the study measures will be discussed briefly, herein in the following sections.

Pain related to surgery, radiation and lymphedema. Breast cancer survivors undergo surgical treatment which often includes either a lumpectomy or mastectomy and sentinel node biopsy and/or axillary dissection. Post-surgery, breast cancer survivors can have physical concerns such as pain, tingling and numbness at the area of incision and across the chest wall, limited range of motion, and weakness in the upper extremity poor cosmetic outcome and body image concerns. After radiation is complete, the above side effects can be worsened with hyperpigmentation of the irradiated skin, pain and hypersensitivity of the irradiated skin as well as skin breakdown. Both breast surgical procedures and radiation are risk factors for lymphedema, a condition where the lymphovascular system is compromised (in this case the lymphovascular system of the affected arm and axilla) and the patient has resultant dependent fluid collection. Lymphedema is not only esthetically unappealing to many patients but also uncomfortable or painful and can limit physical activity utilizing the upper extremities. Further, lymphedema puts patients at increased risk for infections of the skin such as cellulitis, which often require hospitalization and IV antibiotics. (NCCN, 2018; Runowicz et al., 2015) *Fatigue*. Fatigue is one of the most common and distressing concerns among breast cancer survivors (NCCN, 2018b; Runowicz et al., 2015). The NCCN defines cancer-related fatigue as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (NCCN, 2018b). The NCCN (2018b) also states that fatigue is rarely a single symptom but much more commonly co-occurs with other symptoms such as pain, emotional distress, anemia and sleep disturbances. Fatigue can impact breast cancer survivors' HRQOL by preventing them from participating in activities they enjoy and by making it more challenging to carry out activities of daily living such as getting to work, exercising and caring for their families. (NCCN, 2018; Runowicz et al., 2015)

Sleep disturbances. Sleep disturbances are also common concerns, are often linked to fatigue, and are rarely seen in isolation. In breast cancer survivors, sleep disturbances may be related to nocturnal hot flashes due to tamoxifen treatment or menopausal symptoms or may also be due to emotional distress and anxiety. Disturbed sleep, like fatigue, leads to reduced HRQOL in that patients cannot function optimally when they are sleep deprived. (NCCN, 2018; Runowicz et al., 2015)

Premature menopause and hot flashes. Many breast cancer survivors face menopause and menopausal symptoms prematurely due to ovarian ablation during chemotherapy, side effects from endocrine therapy and/or prophylactic oophorectomy. Hot flashes range in both intensity and frequency with some survivors experiencing mild flashes only occasionally and other survivors experiencing severe flashes hourly. Nocturnal hot flashes are particularly bothersome to survivors as they lead to disturbed sleep, as described above and thus, negatively impact

HRQOL. Vaginal dryness and atrophy can interfere with sexual activity and can contribute to increased urinary tract infections. (NCCN, 2018; Runowicz et al., 2015)

Chemotherapy-induced peripheral neuropathy. Chemotherapy-induced peripheral neuropathy (CIPN) can be a side effect of treatment with a taxane or platinum-based chemotherapy in breast cancer chemotherapeutic regimens and is present in up to 30-40% of breast cancer patients. CIPN symptoms include sensation including pain, tingling, numbness and/or burning in the fingers, toes, hands and feet, occasionally extending up the arms and legs. When CIPN symptoms are moderate to severe, they can be managed with medication such as duloxetine or gabapentin, to lessen the associated symptoms. Typically, post-chemotherapy, CIPN symptoms improve at a rate similar to that of other chemotherapy side effects, over a matter of weeks and eventually resolve. With moderate to severe CIPN, which may last for months beyond therapy or in some cases become permanent, patients' HRQOL is significantly reduced in that they are less able to carry out activities of daily living (ADLs), less able to exercise, have difficulties at work, caring for their families and doing things they enjoy. (Hershman et al., 2014; National Comprehensive Cancer Network, 2018a; Runowicz et al., 2015)

Emotional Domain of Breast Cancer Survivorship and HRQOL. Emotional concerns common amongst breast cancer survivors include distress, depression and anxiety (Head et al., 2012; Lester et al., 2015; Mitchell, Vahabzadeh, & Magruder, 2011; Ness et al., 2013; Ploos Van Amstel et al., 2013; Schumacher et al., 2013). All have the potential to impact the overall survivorship outcomes of people with breast cancer. This next section reviews distress, depression and anxiety. *Distress*. Distress has emerged as an important construct in the field of cancer care and SC and has been considered to be the "sixth vital sign" (Bultz & Carlson, 2005). In considering the prevalence of distress in cancer patients, all likely experience distress at some level and at some point in their cancer journey. For clinically significant distress, numbers vary but are generally reported by survey to be between 20-50% of cancer patients and survivors (Carlson & Bultz, 2003; Gao, Bennett, Stark, Murray, & Higginson, 2010; Holland et al., 2017; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). In 2001, Zabora, et al. reviewed studies examining distress in 4,496 cancer patients and reported an overall distress rate of 35.6% (Zabora et al., 2001). However, distress is not finite and will wax and wane depending on many factors such as their diagnosis, where the person is in their cancer journey, what their distress level was prior to cancer diagnosis, how effective their coping mechanisms are, what supports they have at home and the outcome of their cancer therapy, among others (Holland et al., 2017; Zabora et al., 2001).

Lester et al. (2015) reported on the difference in distress level in breast cancer survivors depending on time from diagnosis: during treatment, immediately following treatment, 3 months after treatment and 6 months after treatment. The authors reported that the overall distress score at all time points was moderate to severe and that the distress levels declined as time passed, with the lowest distress levels occurring at six months post treatment. The authors initially hypothesized that distress levels would improve most dramatically from after treatment to three months post treatment, but instead, the greatest improvement was noted to be from three months post treatment to six months post treatment, suggesting that there is sustained distress in early survivorship.

Lam, Shing, Bonanno, Mancini and Fielding (2012) surveyed 285 Chinese women with early stage breast cancer longitudinally from one week post-surgery to identify their distress levels and then followed up with them six years later to determine their psychosocial outcomes. The authors reported that those survivors with low levels of distress initially had the best psychosocial outcomes at the six year follow up point. Conversely, the survivors with greater initial distress had worse psychosocial outcomes as compared to their lower distress counterparts. Although potentially limited in generalizability, this study suggests that screening for distress early may help to predict subgroups of breast cancer survivors who may benefit more from SC interventions and more intensive follow up.

Ploos van Amstel et al. (2013) followed 258 breast cancer survivors longitudinally over 5.5 years and surveyed them on QOL and distress and reported that distress was linked to treatment type in that survivors who had surgery only reported lower levels of distress than survivors who had surgery plus radiation and or chemotherapy. In this sample, survivor reported distress was highest in the first two years post treatment and 69% of distressed survivors requested a referral to a provider for assistance in dealing with their distress (Ploos Van Amstel et al., 2013).

Sheldon, Blonquist, Hilaire, Hong and Berry (2015) performed a secondary data analysis of audio-recordings of patient-clinician clinic visits during active cancer therapy to evaluate predictors of clinician-initiated discussion regarding distress and clinician referral or treatment for distress. The authors identified demographic characteristics that were associated with higher levels of distress including female gender (p = .09), being younger (p = .06), giving more verbal cues (p = .01), lower QOL (p < .0001) and a higher symptom burden, for example, insomnia (p < .01) and fatigue (p < .0001). Distressed patients were found to give more verbal cues to providers

than the non-distressed patients; 2.77 cues vs. 1.70 cues per visit. Distressed patients were significantly more likely to give at least one cue per visit than non-distressed patients (70% vs. 39%, p = .01) and clinicians initiated discussion about distress and emotional issues more often with distressed patients than with non-distressed patients (65% vs. 52%). Distressed patients were also more likely to be offered at least one treatment or referral by their provider (p = .008).

Depression & anxiety. Depression and anxiety are common both in the general population and in cancer survivors, but rates are consistently noted to be elevated in breast cancer patients and survivors (Massie, 2004; Onitilo, Nietert, & Egede, 2006; Thewes et al., 2004). It can be challenging to define depression and anxiety given the variety of measurement and reporting tools such as the Hospital Anxiety and Depression Scale (HADs), the Brief Symptom Inventory (BSI) and the Functional Assessment of Cancer Therapy-Breast (FACT-B), among others (Massie, 2004; Thewes et al., 2004). However, breast cancer patients consistently demonstrate increased anxiety and depression in comparison to their unaffected counterparts, especially in early survivorship. Studies in the literature report rates of depression ranging from 10-25% and are two to four times that of the unaffected population (Massie, 2004; Onitilo et al., 2006; Thewes et al., 2004).

Philip, Merluzzi, Zhang and Heitzmann (2013) surveyed 124 post-treatment cancer survivors and found that 20% the sample reported clinically significant depression. The authors reported that coping self-efficacy was a significant predictor of depression and mediated the relationship between symptoms and depression. Social support was not found to be predictive of depression. Of note, the survivors in this study were an average of 9.3 years post treatment, well beyond the period documented to have highest levels of depression, anxiety and distress for breast cancer survivors (Klemanski et al., 2016; Lester et al., 2015). Thus, the data reported may underrepresent rates of depression, anxiety and distress in breast cancer survivors.

Tojal and Costa (2015) surveyed 150 breast cancer survivors and found that 56.5% had clinically significant depression and that only 18.4% of women had no symptoms of depression. Level of education and marital status were predictive for symptoms of depression (p < .001; p = .041, respectively). Women with higher levels of depression had more helplessness and hopelessness and anxious preoccupation. The authors suggest interventions targeting depression and resilience would benefit breast cancer patients and survivors.

Stafford et al. (2015) reported that anxiety, depression and distress were highest at diagnosis and were 18.1%, 33.3% and 36.2% respectively. Demographic characteristics associated with higher distress, depression and anxiety were neuroticism, past treatment of anxiety and/or depression, and younger age at diagnosis. Depression, anxiety and distress all decreased significantly over time post-treatment but did not disappear completely.

Maass et al. (2015) conducted a systematic review of 17 trials regarding long-term symptoms of depression and anxiety in breast cancer survivors and reported rates of depressive symptoms more than 1 year after treatment ranged from 9.4% to 66.1%, and anxiety symptoms from 17.9% to 33.3%. The analysis suggests that breast cancer survivors are at increased risk for depressive symptoms early into survivorship (at one year post treatment) but that this risk decreases with time. The analysis also did not reveal any increased risk for anxiety symptoms as compared to the general population.

A recent systematic ROL evaluating longitudinal studies of psychological adjustment post breast cancer by Brandao, Schulz and Matos (2016) noted that patients who had a prior history of depression and/or anxiety were more likely to have increased depression and anxiety post breast cancer diagnosis. The authors also noted that symptoms of anxiety at diagnosis predicted poorer QOL and increased depression, and that the same was noted for depression, predicting poorer QOL and increased anxiety. The authors also found that patients with symptoms of fatigue were more likely to have increased depression, anxiety and poorer QOL. Better physical functioning was related to less depressive symptoms and better QOL. The only demographic factor found to be predictive of increased depression, anxiety and worse QOL was income; less income predicted for increased depression, anxiety and worse QOL. The authors could not definitively report on psychosocial factors predicting psychological adjustment due to the variety of tools, constructs and methods used but they did noted that factors such as trait optimism, initial well-being, perceived social support, perceived control and self-efficacy were protective and predictive of better psychological adjustment. The converse was also true in that factors such as neuroticism, trait anxiety and maladaptive coping strategies were risk factors for poor psychological adjustment to cancer and cancer treatments.

In summary, depression and anxiety are common symptoms reported in breast cancer survivors and can potentially impact HRQOL and the survivorship experience. As such, they were important to capture in the study and were measured via the FACT G-7.

Social Functioning Domain of Breast Cancer Survivorship and HRQOL. ASCO

recognizes the importance of social support in their guidelines for breast cancer survivors when they recommend "the inclusion of caregivers, spouses, or partners in usual breast cancer survivorship care and support" (Runowicz et al., 2015, p.18). In the study, survivors were asked to identify if they had a person of support and if so, who that person was. The literature on social support is reviewed below.

Social Support. Social support has been documented to be an important aspect of psychological adjustment to the diagnosis of breast cancer and the subsequent impact it has on a patient's life and is thus an important concept to consider in breast cancer survivors (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Kornblith et al., 2001; Nosarti, Roberts, Crayford, McKenzie, & David, 2002). Boinon et al. (2014) reported that higher levels of depressive symptoms were reported at the completion of treatment in those survivors who reported lower quantities of support (Boinon et al., 2014). Waters, Liu, Schootman and Jeffe (2013) found that breast cancer survivors who reported low social supports at one year post diagnosis reported the low QOL (Waters et al., 2013), potentially due to the fact that this is a high distress and high needs period for breast cancer survivors (Lester et al., 2015), again highlighting the importance of social supports during the survivorship phase. Leung, Pachana and McLaughlin (2014) performed a secondary analysis of the Australian Longitudinal Study on Women's Health database examining social support and HRQOL in breast cancer survivors and reported that those survivors who reported higher social supports also reported higher HRQOL and that this difference persisted for three years post diagnosis. In this study, marital status was also predictive for HRQOL in that being partnered predicted for higher HRQOL (Leung et al., 2014).

Fear of Cancer Recurrence. FCR is cited as a frequent and significant concern of breast cancer survivors (De Vries et al., 2014; Dunn et al., 2015; Knobf, 2015; Lebel et al., 2016; Lengacher et al., 2014; NCCN, 2018c; Ness et al., 2013; Runowicz et al., 2015; Simard et al., 2013). The extent to which FCR poses a challenge will vary based on a variety of factors such as age, stage of disease, past history of distress and/or mental illness (Dunn et al., 2015; Lebel, Beattie, Arès, & Bielajew, 2013; Simard & Savard, 2014). Thus, it was an important construct to consider in the study due to its potential influence on the survivorship experience and health

outcomes (Hall, Lennes, Pirl, Friedman, & Park, 2017; Hall, Mishel, & Germino, 2014; Simard et al., 2013) and thus potentially on patient engagement in SC.

FCR Literature. FCR has been noted to be more prevalent in young breast cancer survivors and this has been well documented in the literature. In 2013, Lebel, Beattie, Arès and Bielajew found that FCR was highest within the youngest age categories (p < .001) (Lebel et al., 2013). Women less than age 34 experienced greater FCR than women in any other age category. However, all age categories experiences some level of FCR. Motherhood was also predictive for FCR, regardless of their age or how old their children were (p < .001). Illness intrustiveness and anxiety also mediated the relationship between FCR and age, but severity of cancer was not shown to mediate the relationship. This study adds to the existing literature on young breast cancer survivors and FCR and the fact that psychological distress may not align with cancer stage and risk of recurrence.

Simard et al. (2013) conducted a systematic review of quantitative studies on FCR in adult cancer survivors and also endorsed younger age as a characteristic associated with higher FCR in addition to presence and severity of physical symptoms, decreased QOL and distress. The authors reported that the majority of the studies focused on breast cancer patients (n = 42) and over 25% of the studies used a mixed sample of different cancer survivor types. The authors noted that it was challenging to compare across studies due to differing measures of FCR and the lack of consensus about clinical cutoffs for FCR. Unlike other concerns and symptoms survivors may experiences such as anxiety, the authors noted that based on the studies in this reivew, FCR does not appear to attenuate over time but instead remains relatively stable throughout survivorship. The authors found moderate evidence indicating that women experience greater FCR than men, but there were 12 studies that found no relationship, leading to mixed conclusions regarding the relationship between gender and FCR. The evidence was similarly mixed regarding FCR and education, ethnicity, race, stage of disease and income. The authors reported strong evidence regarding the relationship between symptom burden and FCR in that patients with greater reported symptoms also reported greater FCR. Moderate evidence was reported regarding comorbidities and FCR in that having a concomitant comorbidity predicted higher FCR in half of the studies that evaluated for comorbidities. Further, eight studies reported a correlation between psychological distress and FCR and that depression was significantly correlated to FCR. Ten studies reported the negative relationship between FCR and HRQOL in that those that reported higher FCR also reported lower HRQOL or wellbeing. The authors also reported a strong association between high levels of FCR and unmet needs.

Dunn et al. (2015) conducted a secondary analysis on FCR from a longitudinal study evaluating neuropathic pain and lymphedema following breast cancer surgery and found that participants who did not live alone, who had greater changes in spiritual life, who had higher anxiety and more difficulty coping at baseline and whose diagnosis caused more distress to family members, reported increased FCR at baseline. With regard to changes in FCR throughout the study, participants who reported higher FCR scores at baseline and greater overall physical health had steeper declines in FCR throughout the study.

McGinty, Small, Laronga and Jacobsen (2016) found that in one group of participants, FCR rose prior to mammogram screening and fell when they received negative results, rising again over time. The second group, about a quarter of the participants, had lower overall FCR, with more gradual slopes over time and little variability. Interestingly, neither demographic nor clinical characteristics predicted for group membership. Also, the authors noted that an important limitation to the study was that several survivors refused participation in the trial because they did not want additional reminders of their cancer, highlighting the significance of FCR in breast cancer survivors' lives and potential impact on decision making.

Hall, Lennes, Pirl, Friedman and Park (2017) surveyed 67 adult cancer survivors with a median of 2.4 years since diagnosis and 32% breast cancer survivors regarding somatic symptoms, perceived stress and FCR to determine their potential relationships. Most participants reported moderate levels of FCR and perceived stress. As expected, the level of somatic symptoms was positively correlated with increased perceived stress (r = .47, p < .001), somatic symptoms (r = .29, p = .02) and the levels of perceived stress (r = .38, p = .002). This study provides some empirical evidence to document the relationship between physical symptoms and psychosocial stress levels in cancer survivors.

As demonstrated above, FCR is a frequently reported concern of breast cancer survivors which impacts their QOL and is a key outcome in the survivorship experience. As FCR is a top concern of breast cancer survivors and could have the potential to impact patient engagement in SC, it was included in the study for consideration along with the other key survivorship outcomes.

Cancer Health Literacy. To have adequate CHL, a breast cancer survivor must have an understanding of complex medical language such as "hemoglobin" and "inoperable" and be able to interpret and apply this information to manage their SC (Dumenci et al., 2014). When the transition to survivorship begins, decisions surrounding post-treatment surveillance, screening and maintenance treatment options must be made. Survivors need to be able to understand what their diagnosis and treatments are and the resulting implications in order to be engaged in their survivorship self-care.

Multiple studies have demonstrated that poor health literacy can be associated with negative outcomes such as knowledge gaps surrounding cancer screening and follow ups (Morris et al., 2013), increased comorbidities and obesity (Husson, Mols, Fransen, van de Poll-Franse, & Ezendam, 2015) and some evidence for low health literacy and decreased cancer screening rates (Oldach & Katz, 2014). However, CHL as its own construct has not been measured, yet if a survivor does not understand their treatment options or the implications of their decisions, they cannot be fully engaged in their care. SC must then incorporate a way to measure and then maximize CHL in order for patients to be fully engaged in their SC.

Patient Engagement in Survivorship Self-Care

Demographic/personal factors and survivorship outcomes may impact a person's potential to achieve greater independence in their own self-care. In the study, that potential for increased independence is being measured by PA and KPC, two similar and yet conceptually different constructs described in the following section. The aims of this study were to identify through examining survivorship outcomes and demographic/personal factors in relation to patient engagement measures who is at risk for being not engaged or who has the most potential to benefit from SC interventions.

Patient Activation. Conceptually, PA is a four-step developmental model that assumes that once a person achieves one level, the next level follows. The four levels are: disengaged and overwhelmed, becoming aware but still struggling, taking action and maintaining behaviors and pushing further (Hibbard et al., 2004). Generally, this is a unidirectional linear model capturing the person's level of knowledge, skill and confidence as it relates to their self-care in partnership with their provider (Hibbard et al., 2005).

Patient Activation Research. Hibbard and Greene (2013) wrote a review on what the evidence shows regarding patient outcomes and PA and reported that people who are highly activated are more likely to undergo screening such as regular physical exams and receive vaccinations and are more likely to exercise and eat a healthy diet. The authors also reported that highly activated patients are more likely to ask their provider questions about their treatment and adhere to chronic treatment, such as diabetic foot exams. Conversely, the review also concluded that patients who have low levels of PA are more likely to have unmet medical needs and more likely to delay medical care. (Hibbard & Greene, 2013)

In terms of the literature of PA in oncology patients, there has been some work done (Krouse et al., 2016; Mayer et al., 2016; Mazanec, Sattar, Delaney, & Daly, 2016; Rocque et al., 2017; van Maarschalkerweerd, Rademakers, & Rijken, 2017), but it is largely a new area of exploration with the potential for much future work. In a recent online survey of cancer patients, Hibbard, Mahoney and Sonet (2017) reported that highly activated patients were 4.7 times more likely to exercise and 3.3 times more likely to eat a healthier diet post cancer diagnosis as compared to their less activated peers. In terms of advocating for themselves, higher activated patients in this study were 10% more likely to voice concerns when planning their treatment than less activated patients and were 9.5 times more likely to feel that their treatment plan reflected their values. Higher activated patients were 3.2 times more likely to report they were informed, 45% more likely to be adherent to medications and 4.5 times more likely to report effectively managing side effects. This is one of the first studies to assess how patient activation can impact the patient's cancer journey, providing insight into how PA level can inform SC and future SC interventions.

Evidence is beginning to emerge in support of SC programs when they are evaluated in terms of patient activation subgroups. Mayer et al. (2016) conducted a pilot RCT where patients were randomized to a SC visit with an SCP plus a follow up transition visit with their primary care providers (PCP) compared to SC visit/SCP alone. The authors found that both group the intervention and control groups demonstrated increased confidence in survivorship information but also reported that patients who were "highly activated" (as measured by the PAM (Hibbard et al., 2004)) had greater benefits from the intervention. The highly activated patients had significantly higher confidence in survivorship information (the study primary outcome) as compared to less activated patients (p = .05). These findings suggest that tailoring survivorship intervention by patient activation level may improve survivorship outcomes. What is not understood from this work is why some patients were highly activated, while others were not.

Knowing Participation in Change. Conceptually, KPC is a non-linear process model that is used to partner with the patient to facilitate awareness, choice, freedom and intention to engage in change. KPC acknowledges an individual person's complexity and his/her unique response to an experience, in the study, breast cancer survivorship.

KPC Literature. KPC in breast cancer survivors is a largely underdeveloped area of research with the exception of the work done by Farren (2010a, 2010b). Expanding the literature search to all cancer survivors and all recent KPC studies, there remains a paucity of literature, but the available literature is described herein.

In a randomized trial on exercise in patients with lung cancer, Wall (2000) measured whether an exercise intervention increased the participant's power and hope. Wall reported a moderate correlation between hope and power in this sample suggesting that power positively impacted hope. Farren (2010a) used a correlational, cross-sectional design to survey 104 breast cancer survivors to examine the relationships between power as KPC, uncertainty, selftranscendence and QOL and found that uncertainty was inversely related to power, selftranscendence and QOL. All of the variables with the exception of uncertainty were positively correlated with each other. In a secondary analysis of this trial, Farren (2010b) reported that this sample of breast cancer survivors' power as KPC was present at high frequencies, and that there were groups within the sample with low, moderate and high intensity power as KPC levels. These findings suggest that power as KPC could potentially impact survivorship outcomes such as QOL, but there is a need for more research to confirm these findings.

In summary, there are few studies to date on cancer survivorship outcomes and patient engagement. PA and KPC are constructs that are important to the study because they are measures of patient engagement. The patient's level of engagement may directly impact the person's ability to engage in survivorship self-care.

Summary and Conceptual Model of the Study

It is well documented that breast cancer survivors face challenges in survivorship. However, there are gaps in our understanding about how demographic/personal factors, and important survivorship outcomes (HRQOL, FCR, CHL) relate to measures of patient engagement (PA, KPC). Recognizing this process may not be linear is important. However, this study sought to better understand patient engagement in survivorship self-care through the exploration of demographic/personal factors, important survivorship outcomes (HRQOL, FCR, CHL) and their relationship to two measures of patient engagement: PA and KPC as captured in the figure below. It is hoped that the findings from this study will provide data to inform future qualitative and quantitative work and nursing-led, targeted survivorship interventions. Figure 2. Conceptual Model illustrating the potential relationships between

demographic/personal factors, survivorship outcomes and patient engagement measures in the study.



Chapter 3: Design & Methods

Chapter three will present the research design and methods used in the study under the following headings: (1) research design; (2) setting; (3) sample; (4) instruments/measures; (5) study procedures and (6) analytic plan.

Research Design

The purpose of this descriptive, cross-sectional, web-based self-report survey was to explore how demographic/personal factors and important survivorship outcomes (HRQOL, FCR, CHL) contribute to variables that capture breast cancer survivors' patient engagement (PA and KPC). A single group, cross-sectional, web-based survey design was utilized to measure breast cancer survivors' demographic characteristics, HRQOL, CHL, FCR, KPC and PA within two years of completing adjuvant treatment for breast cancer (surgery, +/- chemotherapy, +/- radiation). This timeframe was selected to align with the literature describing the transition to survivorship and early survivorship as challenging for survivors and that distress and survivorship needs are highest in this timeframe (IOM, 2004; Klemanski et al., 2016; Lester et al., 2015; Pirl et al., 2014).

Setting

The study included a convenience sample of women and men with a history of stage 0-3 breast cancer who have enrolled on to the Dr. Susan Love's Army of Women (AOW) website as a potential participant for a research study. The AOW currently has over 110,000 subscribers of this site are of every ethnicity, with and without a breast cancer diagnosis and those at high risk of breast cancer with the goal of connecting researchers with women and men who are willing to participate in breast cancer research studies. The subscribers' age ranges are 18-39 years old (18%), 40-59 years old (45%), 60+ (37%). Ethnicities are reported as White (86%), African

American (3.4%), Hispanic (3%), Native American (1.6%), Asian (1%) and self-identified as Other (5%). (AOW, 2018)

In an effort to reach targeted enrollment and potentially recruit a more diverse sample, the investigator also recruited participants from internet sites such as Craigslist in metropolitan areas across the United States such as Boston, New York, San Francisco, Miami, Detroit and Atlanta. There is some literature to suggest that Internet sites such as Craigslist can be effective recruitment strategies for research studies (Mohebati et al., 2012; Norr, Gibby, Fuller, Portero, & Schmidt, 2017) and although the demographics of Craigslist cannot be definitively predicted, researchers are increasingly utilizing these sites as ways to reach diverse populations (Alto, McCullough, & Levant, 2016).

Sample

The sample for the study included a convenience sample of approximately 300 breast cancer survivors. The target population was stage 0-3, English reading and aged greater than age 18. Stage IV breast cancer patients were excluded from the study because of the well documented different needs and different survivorship experience in this population (Frick et al., 2017; Mayer et al., 2015). This target population from both the AOW and Craigslist was selfselected and their experience may not be representative of all breast cancer survivors; this is an acknowledged limitation of the study.

Inclusion Criteria. All persons eligible for this study met the self-reported inclusion criteria as listed below.

- 1. A breast cancer survivor with stage 0-3 breast cancer (DCIS included)
- 2. Aged greater than or equal to 18 years old
- 3. Able to read English.

- 4. Completed adjuvant breast cancer treatment which includes breast cancer surgery, +/- chemotherapy, +/- radiation within approximately the past two years.
- 5. Access to an internet-enabled computer, laptop, tablet or smartphone.
- 6. Willing and able to give written consent to participate in the study.

Sample Size Estimation. Power analysis was conducted via G*power analysis system (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007) and indicates that a sample of 246 participants will provide 85% power, a small to medium effect size of .06 and an alpha of .05. A potential participant pool of at least 1200 email addresses was chosen to account for oversampling for the purposes of missing data. Previous researchers reported a 15-38% response rates in web-based surveys (Partridge et al., 2004; Sutherland, Fantasia, & Hutchinson, 2015). Thus, a potential participant pool of at least 1200 should result in the desired sample size of approximately 300 breast cancer survivors, assuming a response rate which falls in the middle at approximately 25%. This would be adequate to detect a small to medium effect size of categorical and continuous variables with regression models with 5-10 predictor variables. The American Cancer Society estimates that male breast cancer accounts for only 1% of the breast cancer population (ACS, 2018). Given this, a sample of 300 women was targeted and to capture men an additional 3 participants (1%) were included for a total of 303 participants.

However, given the online recruitment methods, this study was unable to assess a response rate for this study. The AOW website cites 110,000 people registered to their research foundation as potential participants to their research studies. However, not all of these potential participants are breast cancer survivors; some are people only at risk for breast cancer, so it is not possible to know the denominator of breast cancer survivors who received the survey in the email blast. Second, using the Craigslist online recruitment method, it is also not possible to determine the denominator of breast cancer survivors who saw the online posting for this study. This will be addressed in the limitations of this study.

Participant Recruitment. The AOW sent a convenience sample of breast cancer survivors greater than age 18 a link to the study survey. The contact email explained the study and invited the breast cancer survivor to participate by clicking on a link to the Research Electronic Data Capture (REDCapTM) survey site. The same link and information was posted to Craigslist in major metropolitan areas as described above. Once the respondents clicked on the study link, they were directed to the study informed consent and were asked to click "yes" to the inclusion criteria and agreed to participate, before they were directed to the survey questions. Upon completion of the survey, participants were provided with a \$10 Amazon gift card.

Instruments & Measures

The survey was estimated to take about 20 minutes to complete, but participants could start the survey and come back to complete it at a later time, prior to submitting. The survey was pretested with a convenience sample of 6 colleagues, some who were breast cancer survivors, prior to administration for functionality, ease of reading, validity and timing. A pilot of the survey was also sent to five content experts (oncology nurses, physicians and researchers) for functionality, ease of use and validity. The survey was created via REDCapTM and tested with a range of popular web browsers, devices, connection speeds and if Java Script was disabled. The key variables and related measures in this study are listed in Table 2.

TABLE 2

Key Variables and Related Measures

Variable	Measure	Scoring	Time to Complete
Health related quality of life (HRQOL)	FACT-G7	0-28, higher score indicating higher	3 minutes
Cancer Health Literacy (CHL)	CHLT-6	0-6, higher score indicating higher CHL	2 minutes
Fear of Cancer Recurrence (FCR)	FCRI SF	0-36, higher score indicating higher FCR	3 mins
Knowing Participation in Change (KPC)	KPC SF	12	5 mins
Patient Activation (PA)	PAM 10	1-4, higher score indicating higher PA	3 mins
Demographics and Health History	Demographics Worksheet	Demographic Statistics	5 minutes
Open-Ended Question	Open-Ended Question	Free Text	1-2 minutes

Functional Assessment of Cancer Therapy General-7 (FACT-G7). The FACT-G7 is a

7-item, self-report HRQOL measure developed specifically for cancer patients by Yanez, Pearman, Lis, Beaumont & Cella (2013) from their general measure of HRQOL, the Functional Assessment of Cancer Therapy – General (FACT-G). However, at 44-items, this scale can be cumbersome to administer and so the authors sought to develop an abbreviated version that would still capture the most relevant concerns of oncology patients in a rapid and facile manner. Thus, a sample of 533 oncology patients and 2000 patients from the general population were sampled to attempt to streamline the FACT-G.

FACT-G7 development. The 533 oncology patients were asked to select their top five concerns from the list of the previous list of FACT HRQOL questionnaires and were also given the opportunity to write in any concerns not listed. They were also asked to complete the original FACT-G with the four intact subscales, performance status measurements and EuroQol's five item health status measure (EQ-5D), a widely-used measure of health status (Euro-Qol Foundation, 2017). Items that were within one point of being selected by patients more frequently than by chance were kept as potential candidates for final cancer-specific symptom indexes. Across cancer sites, an item was kept in for final consideration if it was endorsed by patients in at least six out of the eleven cancer specific sites.

(Yanez et al., 2013)

Results. In total, seven items met the criteria for inclusion into the final FACT-G7. Three items remained from the physical wellbeing (fatigue, pain and nausea), one item from emotional wellbeing (worry), and three from functional wellbeing (enjoyment of life, contentment with QOL, sleep). Fatigue was the most frequently endorsed of all symptoms by patients across disease sites and pain had the lowest frequency endorsement. (Yanez et al., 2013)

FACT-G7 Reliability and Validity. The FACT-G7 demonstrated good internal consistency with group comparisons for the cancer sample and the general population sample with Cronbach's alphas of .74 and .80, respectively. The FACT-G7 items were highly correlated with the FACT-G, the physical wellbeing, and the emotional wellbeing subscales in the cancer sample. The FACT-G7 items were moderately correlated with the emotional wellbeing subscales and the EQ-5d index and weakly correlated with the social wellbeing subscale in the cancer

sample. The FACT-G7 was able to successfully differentiate between performance status groups in both the cancer sample (p<.001) and the general population groups (p < .001). (Yanez et al., 2013)

FACT-G7 Scoring and Interpretation. The 7 items on the FACT-B are each given a range of item options which participants can select related to breast cancer symptoms or concerns which may impact HRQOL: 0 - "not at all", 1 –"a little bit", 2 –"somewhat", 3 –"quite a bit", 4 –"very much". With regards to interpretation, the higher the participant FACT-G7 score, the higher the HRQOL. The participants should be encouraged to answer all items on the FACT-G7 measure, selecting "not at all" if they feel an item does not apply to them. If there is missing data for an item, that subscale can be prorated as long as at least 50% of the items in that subscale have been answered. The FACT-G7 score can be considered an acceptable indicator of HRQOL as long as there is an overall item response rate of at least 80% and all of the subscales have valid scores. (Yanez et al., 2013)

FACT-G7 Summary. In summary, the FACT-G7 is a rigorously developed, psychometrically sound measure specifically developed for the oncology patient population to measure HRQOL, an important construct for cancer survivorship and the study. It demonstrates good internal consistency, convergence and known groups' validity and highly correlates to the established FACT-G score with the exception of social wellbeing. This tool has the advantage of brevity and ease of administration making it an ideal tool for the web-based survey study.

Cancer Health Literacy Tool-6 (CHLT-6). The CHLT-6 is a six item, self-report measure developed by Dumenci et al. (2014) which measures the construct of CHL, or the degree to which cancer survivors have the capacity to obtain, process and understand basic information and services needed to make appropriate health decisions regarding their cancer and cancer

treatment. This measure was developed by the authors due to the lack of available tools to measure this important construct in the oncology population, a population who often face complex treatments and treatment decisions.

CHLT-6 Development. The authors recruited 1306 oncology patients and used a mixed methods design to first qualitatively identify CHL as a construct and then quantitatively create the measurement tools. The authors conducted qualitative focus groups with patients and clinicians and oncology experts and used content analysis to elicit their understanding of CHL to determine test items representative of CHL. This resulted in 112 initial items which were piloted with 25 oncology patients and reduced to a list of 76 items which were then moved on to the quantitative testing phase of the study. First, interim analyses were conducted to reduce the item number and assess the scale dimensionality with the 1,306 participants and this resulted in a set of 30 test items. A subset of the 30 test items was then determined as the six most informative items and were used to define those participants with limited CHL. (Dumenci et al., 2014)

Results. The results of the study revealed that 30 test items data fit well with the statistical model created by the authors, indicating that it was a good representation of CHL as a latent variable. There were significant relationships (all p < .01) between the item responses and the continuous CHL latent variable and high scale precision, high percent correct item responses, high Cronbach's alpha of .88, 2-week test-retest reliability of .90, and a 6 month test-retest of .92, all indicating a highly reliable measure. The authors used structural equation modeling to externally validate the CHLT-30 scores and found that the scores significantly predicted for outcomes related to engaging in health related decisions (all p < .01). The authors then used a two-class solution from the latent class analysis to classify participants who were tested on the CHLT-6 test items as either "adequate CHL" in which the probability of correct responses was

very high or "limited CHL" in which the probability of correct responses was similar to chance. The results of this analysis revealed that the CHLT-6 accuracy is extremely high, that the prevalence estimates are free from gender and racial/ethnic bias. It also revealed that people belonging to the "limited CHL" group are more likely to be "Black, undereducated, low income, insured by state/federal government...and tend not to engage in health decisions" (Dumenci, et al., 2014, p.216).

CHLT-6 Scoring and Interpretation. The CHLT-6 consists of 6 test items which relate to cancer health decisions and information which the participant must answer. Each participant receives a score from 0-6, depending on the number of correct answers for each test item. The participant must answer 5 or more answers correctly to be considered to have adequate CHL. (Dumenci et al., 2014)

CHLT-6 Summary. In summary, the CHLT-6 is a psychometrically strong tool which rapidly and efficiently identifies patients with limited CHL. It is quick with minimal burden to the participant and can be administered and scored in approximately two minutes.

Fear of Cancer Recurrence Inventory Short Form (FCRI SF). The FCRI SF, developed by Simard and Savard (2014) and then translated and validated into English in 2016 (Lebel, Simard, Harris, et al., 2016) is a 9-item, self-report measure to evaluate FCR, or the fear that cancer could "return or progress in the same place or in another part of the body" (Lebel, Simard, Harris, et al., 2016). The measure was developed by the authors to abbreviate their existing tool and to establish the prevalence of comorbidity in patients with clinically significant FCR. The authors recruited 60 breast, prostate, lung and colorectal cancer survivors who were administered the following measures: semi-structured interview on FCR, the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, the Hospital Anxiety and Depression Scale (HADs), the European Organization for Research and Treatment of Cancer (EORTC) Quality of life Questionnaire (QLQ-C30) and the FCR Inventory. Participants were then categorized according to their semi-structured interview on FCR scores as either having clinical levels of FCR or having nonclinical levels of FCR. Inter-rater agreement on the level and presence or absence of FCR was 90.5% between interviewers (weighted kappa = .71, 95% CI = .56 to .86). While a FCR score of 13 was able to detect the presence of clinically significant FCR in the study sample, the authors determined that a score of 16 or higher appeared to increase the specificity of the instrument and to decrease the number of participants incorrectly identified as having clinically significant FCR. Thus, the authors suggest that 16 is the ideal cut-off point for investigators using the FCRI SF to evaluate participants for clinical versus nonclinical levels of FCR. At this level, the specificity of the FCRI SF is 97% and the sensitivity is 67%, while the positive predictive value is 94% and the negative predictive value is 81%.

FCRI SF and Comorbidity. In the development of the FCRI SF, the authors also looked at comorbidities and found that 42% of their sample met the DSM-IV criteria for a current psychiatric disorder and 65% met criteria for a past psychiatric disorder. The most common disorders were anxiety (68%, followed by mood disorders (36%), adjustment disorders (16%) and alcohol dependence (4%).

FCRI SF Scoring and Interpretation. The FCRI SF consists of 9 test items relating to FCR which the participant must answer. The test items each have responses the participant can choose from on a scale from 0-4 with responses on a Likert scale ranging from "not at all", "a little", "somewhat", "a lot" to "a great deal". Each participant receives a total score of 0-36, with a higher score indicating a higher level of FCR. As stated above, a score of 16 or greater

indicates clinically significant FCR. A score of 15 or less indicates non-clinically significant FCR.

FCRI SF Summary. In summary, the FCRI SF is a measure which can rapidly and costeffectively identify FCR in cancer survivors. It has been rigorously developed and has strong psychometric properties including high specificity, validity and reliability and thus was an appropriate tool for this exploratory study in breast cancer survivors.

The Knowing Participation in Change Short Form (KPC SF). Originally developed as a patient assessment tool for practice, Barrett developed the KPC tool to measure power as she conceptualized it within her theory. Her goal was to better assist her clients to enhance their awareness of their intentions and choices, and to feel more able to be involved in those choices by "creating the changes they intend without having an attachment to the outcomes" (Barrett, 2010, p.49). The KPC is a 52 item self-report measure developed by Barret and later used in research (Barrett, Farren, Kim, Larkin, & Mahoney, 2001). KPC measures the construct of power or the person's sense of "being aware of what one is choosing to do, feeling free to do it, and doing it intentionally" (Barrett, 2010, p.49). Since its development, the KPC tool has been used in various studies and has demonstrated strong psychometric properties. A review was published by Kim (2009) of literature using Barrett's KPC and reported that reliability data was available from 28 studies and internal consistency reliability by Cronbach's alphas ranged from .93-.99 with the exception of one study, with a Cronbach's alpha of .72. Strong validity was also noted in the review by Kim (2009) across studies. Content and construct validity were also established in earlier studies reported by Barrett and Caroselli (Barrett & Caroselli, 1998; Caroselli & Barrett, 1998). In a survey study of breast cancer survivors using the KPC tool, Farren (2010) reported Cronbach's alpha reliability for the tool of .96. However, a common

challenge reported with the tool was the length of the form (Barrett & Caroselli, 1998). As a result, a short form was developed, the KPC SF, and will be pilot tested in the study. The KPC SF is appropriate because it is a brief, nursing focused measure that aligns theoretically with the study and had the potential to contribute to nursing's understanding of this concept and how it impacts breast cancer survivorship.

The Patient Activation Measure 10 (PAM 10). The PAM 10 is a 10 item, self-report measure originally developed by Hibbard, Mahoney, Stockard and Tusler (2005) which measures the construct of PA and now abbreviated to 10 items. This measure was developed out of a desire to clarify the concept of PA in chronic illness, a concept thought to be imperative to patient-centered care delivery models and to ultimately develop interventions to address low levels of PA and engage patients with chronic illness as members of their own care team.

The first phase in the development of the PAM was to review the literature using a consensus method and focus groups to define PA. Their review of the literature demonstrated that the patients who are more likely to have better health outcomes share certain characteristics including: they self-manage problems, they engage in activities that maintain function and reduce decline, they are involved in treatment choices, they collaborate with providers, they select providers based on performance or quality and they navigate the health care system. These six characteristics were considered as domains from which to launch an expert consensus and patient focus groups to examine PA as a construct. The expert panel and focus groups agreed on most of the domains with the exception that the patient focus groups put more emphasis on social support as important for successful management of chronic illness. The conceptual definition of patient activation was derived from these two groups and became the basis for developing the PAM and is as follows:

Those who are activated *believe* patients have important roles to play in selfmanaging care, collaborating with providers, and maintaining their health. They *know* how to manage their condition and maintain functioning and prevent health declines; and they have the *skills and behavioral repertoire* to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care (Hibbard et al., 2004, p.1010).

The second phase of development involved preliminary scale development and testing a large number of preliminary items using the Rasch model. A set of 80 items was tested with three rounds of cognitive testing with 20 participants who had chronic illness and 75 items were maintained after this process. A pilot study with 100 participants with chronic illness was then conducted to evaluate the 75 items using the Rasch model to determine the item difficulty and how well the item fit according the expected fit of the model. From this analysis, a preliminary 21 item PAM was created. The Cronbach's alpha for the 21-item PAM was .87. The test-retest reliability was also demonstrated using 30 participants from the initial sample who were contacted two weeks later and again took the PAM and 28 of the 30 participants had a score within the 95% confidence interval (CI) of their initial score. Criterion validity was assessed via interviews with 10 participants from the pilot study, five from the "low" activation level and five from the "high" activation level. They were then blinded and reviewed by judges who independently categorized their level of activation. The judges agreed with the participants characterization of activation 83% of the time and Cohen's kappa for each judge was .80, .90 and .90 (p < .001 for all judges).

Stage three included refining the response categories and testing the PAM on patients without chronic illness. From this analysis, the authors constructed the four stages of PA: 1) beliefs about the importance of the patient role 2) confidence and knowledge needed to act, including surrounding lifestyle and medication and confidence in interacting with providers 3)

taking action, maintaining lifestyle changes, handling symptoms independently, 4) continuing to take these actions even when challenges occur. All of the items from this stage of development had infit values between .76 and 1.32 and the Cronbach's alpha was .91. The Rasch person reliability at this stage was between .85 (real) and .88 (model).

The final stage of development utilized a national probability sample to assess the PAM across different samples and to assess reliability and validity. The Rasch analysis of this sample replicated the results from the pilot study again demonstrating the developmental nature of PA and that the items maintained the same level of difficulty and acceptable infit, outfit, reliability and validity. The infit values ranged from .71 to 1.44 and all of the outfit values except one were between .80 and 1.34. The Rasch person reliability for the national sample was between .87 (real) and .91 (model), again demonstrating high reliability.

To assess validity, the authors compared PA against other patient reported outcomes such as visits to the doctor's office, exercise, fruit and vegetable consumption and found that high levels of activation strongly correlated with positive patient outcomes. They also found that self-management behaviors associated with certain chronic illnesses are also associated with activation levels. For example, diabetic patients with high activation levels were more likely to closely monitor glucose levels. The authors state that these findings support strong construct and criterion validity. (Hibbard et al., 2004)

PAM 13. In 2005, Hibbard et al. conducted a reduction item analysis on the initial PAM 22-item measure, resulting in the PAM-13 (Hibbard et al., 2005). The psychometric properties are similar with infit and outfit statistics which are almost identical to the 22-item measure and are within the acceptable range of 0.5-1.5. The 13-item measure does have slightly lower reliability for certain subgroups such as those without chronic illness, those 85 years and older,

those with poor self-rated health and lower income and education, but are still within the acceptable range. The authors regressed the 13-item PAM score on the 22-item PAM score and the model accounted for 92% of the variation, demonstrating that little information was lost in the item reduction procedures. Finally, the reduction in burden to participants makes the 13-item PAM a more attractive option for survey studies looking to reduce the time participants must spend responding. Since that time, the PAM has been further reduced to 10 items by the authors through additional statistical modeling further streamlining the tool.

PAM 10 Scoring and Interpretation. Participants who take the PAM 10 measure will be scored and grouped into one of four levels. In Level One, participants are described as "disengaged and overwhelmed" (Insignia Health, 2018) and their perspective is that the physician is in charge of their health. In Level Two, participants are described as "becoming aware, but still struggling" (Insignia Health, 2018) and their perspective is that they believe they know they could be participating more in their care. In Level Three, they are described as "taking action" (Insignia Health, 2018) and their perspective is that they are part of the health care team. In Level Four, they are described as "maintaining behaviors and pushing further" (Insignia Health, 2018) and their perspective is that they are capable of advocating for themselves. As this tool is under psychometric testing, the developers will score and psychometrically evaluate de-identified data.

PAM 10 Summary. In summary, the PAM 10 is a rigorously developed, psychometrically strong tool that is valid, reliable and was appropriate for use in this exploratory study in breast cancer survivors.

Demographics and Health History Worksheet. The investigator developed a demographics and past medical history worksheet based on the literature and expert opinion of oncology

providers and researchers comprised of basic demographic and past medical history questions. The demographic section includes questions such as date of birth, ethnicity, gender, height, weight, income, highest education level, employment status, caregiver status and marital status. The medical history questions include questions such as date of breast cancer diagnosis, stage of breast cancer, treatment completion date, hormonal treatment (y/n), comorbidities, menopausal status, concomitant medications, alcohol intake, smoking status and physical activity/exercise frequency.

Open-Ended Question. At the end of the survey, one open-ended question was asked of the participants: Are there any needs related to your breast cancer, that you have not been asked about, that you would like to share? This was intended to allow the participants to share any aspect of their survivorship experience that was not elicited from the survey questions, but that they would like to share with the study investigator. It was estimated that this question would take one to two minutes for the participants to complete and like the rest of the survey questions, is optional.

Study Procedures

Recruitment and Informed Consent. Participants were recruited from the Dr. Susan Love's AOW Research Foundation email list and Craigslist after IRB approval was obtained. As described by Dillman, Smyth and Christian (2014), participants received a pre-survey email introducing the study on Day 1 inviting them to participate. If the participant wanted to participate, they were asked to click on a link to the survey. They were then directed to the survey and consent information and then typed "YES" to indicate consent and that they had read, understood and agreed to the informed consent information and met the inclusion criteria. Each individual was assigned a unique ID number and an access code. The access code allowed

participants to work on the survey in parts and return to it later. However, once the survey is submitted, their access code was no longer valid. As referenced above, REDCapTM online platform was used to create and distribute the surveys via the AOW email list and Craigslist. The REDCapTM platform was configured to anonymize the participant's information and did not record any identifying information such as location, IP addresses or email addresses. Thus, the data received was not linked to any individual study participant.

Upon study completion, the participants were directed to a link for a \$10 Amazon gift card as remuneration for participation in the study. Once they submitted the survey, they were directed to a Qualtrics link that is not associated with any of the other study data. At this Qualtrics link, they entered their email address to claim their \$10 Amazon gift card. The study staff received this email address which was not linked in any way to the original responses and used this to send out the gift cards by email. Once the gift card was sent out, the study staff immediately deleted the participant's email address. Additionally, participants were given the option to click on a separate Qualtrics link that is not associated with any of the other study information to provide contact information to be contacted for future research. However, this contact information was not linked to their original study responses and will be used for future studies only. The contact information will be stored by the Principal Investigator on a password protected and encrypted computer to which only the PI has access. The contact information will be stored only if a participant in the survey agreed to be contacted for a future study. If a person agreed to their contact information being stored so that they can be contacted in the future, they were notified that if at any time they choose to no longer have their name stored, they can request this and the PI will permanently delete their contact information.

IRB and Protection of Human Subjects. The study was reviewed by the Boston College (BC) Institutional Review Board (IRB). All study materials were provided to the Boston College IRB with the online application materials: study consent form (Appendix A), study emails (Appendix B), study survey and measures, link to raffle for Amazon gift card and email contact (Appendix C), and letter of support from the Dr. Susan Love Army of Women Research Foundation.

Only research team members and members of the dissertation committee have access to the data forms. Participants were informed during the consent process that their responses were anonymous and will remain confidential throughout the research process, including publication. The survey data will be archived for a maximum of 5 years.

The data is stored on REDCapTM, a secure, encrypted and HIPAA compliant web-based application. Firewalls protect the REDCapTM systems. Networks and systems are monitored for intrusion detections with an outside manage security service providing its own IDS with its own rules for a third perspective as well. The data center is protected from the Internet by two layers of Intrusion Prevention. Multiple failed login attempts are blocked. All network devices and data center services are monitored day and night, every day of the week.

Risks to Subjects. This study involved minimal risk to study participants. The web-based survey did not involve any change to the participant's standard treatment and was not experimental in nature. Participants may have experienced some inconvenience related to the time they may spend filling out the web-based survey (approximately 20 minutes). Study measures were purposefully chosen for their brevity in recognition of this issue. Participants may also have experienced emotional distress when answering questions related to their breast cancer treatment and experience. There was no monetary cost to the participants and a web-based
methods allowed participants to complete the survey at their convenience and in their chosen location.

Analytic Plan

Study data were collected and managed using REDCapTM electronic data capture tools hosted at BC. REDCapTM is a secure, encrypted and HIPAA compliant web-based application designed to support data capture for research studies, providing audit trails for tracking and validating data entry and export, allowing for seamless automated export of data to statistical packages such as SPSS for analysis and procedures for importing data from external resources.

Preliminary Analyses. A codebook was created prior to data analysis. The data analysis plan to export study data without identifiers from REDCap[™] into SPSS (IBM Corporation, 2017) for analysis was completed. Descriptive statistics were used to examine the characteristics of the study sample and were analyzed for trends and correlations with study variables as will be discussed in Chapter Four. Nominal or categorical demographic variables such as sex and race were reported as frequencies and continuous demographic variables such as age were reported using measures of central tendencies.

Each variable was examined for normality, descriptive statistics, outliers and missing values. Where missing data was discovered, this was approached by utilizing the list-wise deletion function in SPSS as the data was identified as missing at random (MAR) and did not result in substantial loss of power to the study. Cronbach's alphas were calculated for all multi-item scales (FACT-G7, CHLT-6, FCRI, KPC SF, PAM 10).

Main Analyses.

Specific Aim 1: To describe the relationship amongst demographic/personal factors and survivorship outcomes (HRQOL, CHL, FCR) to patient engagement measures (PA and KPC) in breast cancer survivors.

<u>Research Question 1a:</u> What is the relationship between demographic/personal factors, survivorship outcomes (HRQOL, FCR, CHL) and patient engagement measures (PA and KPC)

in breast cancer survivors?

Frequencies for each research aim and research question were calculated and reported. Bivariate analyses were calculated using Pearson's r if both variables are interval/continuous measures/otherwise, one way ANOVA or chi square were calculated. Please see Table 2 for the statistical tests for each demographic variable.

Variable	Variable Level	Research Question	Statistical Procedure
Age vs. PA/KPC	Continuous vs. continuous	Is there an association between age and patient engagement outcomes?	Bivariate Correlation – Pearson's
Race vs. PA/KPC	Categorical vs. continuous	Is there an association between race and patient engagement outcomes?	One Way ANOVA
Ethnicity vs. PA/KPC	Categorical vs. continuous	Is there an association between ethnicity and patient engagement outcomes?	One Way ANOVA
Sex vs. PA/KPC	Continuous vs. continuous	Is there an association between sex and patient engagement outcomes?	Dummy (Male = 0, Female = 1), Bivariate Correlation – Pearson's
Sexual identity vs. PA/KPC	Categorical vs. continuous	Is there an association between sexual identity and patient engagement outcomes?	One Way ANOVA
Weight (normal, overweight, etc.) vs. PA/KPC	Categorical vs. continuous	Is there an association between weight and patient engagement outcomes?	One Way ANOVA

Table 2. Statistical Tests Table

Variable	Variable Level	Research Question	Statistical Procedure
Employment vs. PA/KPC	Categorical vs. continuous	Is there an association between employment and patient engagement outcomes?	One Way ANOVA
Income vs. PA/KPC	Categorical vs. continuous	Is there an association between income and patient engagement outcomes?	One Way ANOVA
Educational Level vs. PA/KPC	Categorical vs. continuous	Is there an association between educational level and patient engagement outcomes?	One Way ANOVA
Health Insurance (Y/N) vs. PA/KPC	Continuous vs. continuous	Is there an association between health insurance status and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation, Pearson's
Zip Code vs. PA/KPC	Categorical vs. continuous	Is there an association between geographic region/location and patient engagement outcomes?	One Way ANOVA
Length of survivorship vs. PA/KPC	Categorical vs. continuous	Is there an association between length of survivorship and patient engagement outcomes?	One Way ANOVA
Stage of disease vs. PA/KPC	Categorical vs. continuous	Is there an association between stage of disease and patient engagement outcomes?	One Way ANOVA
Hormonal therapy vs. PA/KPC	Continuous vs. continuous	Is there an association between hormonal therapy and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
Chemotherapy Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between chemotherapy receipt and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation, Pearson's
Comorbidities (#) vs. PA/KPC	Continuous vs. continuous	Is there an association between comorbidities and patient engagement outcomes?	Pearson's
Concomitant meds (#) vs. PA/KPC	Continuous vs. continuous	Is there an association between concomitant meds and patient engagement outcomes?	Pearson's
Hot flashes Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between hot flashes and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
Exercise 150 mins Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between exercise and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's

Variable	Variable Level	Research Question	Statistical Procedure
Caregiver status Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between caregiver status and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
Social Support vs. PA/KPC	Categorical vs. continuous	Is there an association between social support and patient engagement outcomes?	One Way ANOVA
Smoking Status Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between smoking status and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
Alcohol Y/N vs. PA/KPC	Continuous vs. continuous	Is there an association between alcohol and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
Survivorship Care Plan Y/N vs. PA/KPC	Continuous vs. Continuous	Is there an association between SCP receipt and patient engagement outcomes?	Dummy (No = 0, Yes = 1), Bivariate Correlation – Pearson's
HRQOL vs. PA/KPC	Continuous vs. Continuous	Is there an association between HRQOL and patient engagement outcomes?	Pearson's
FCR vs. PA/KPC	Continuous vs. Continuous	Is there an association between FCR and patient engagement outcomes?	Pearson's
CHL vs. PA/KPC	Continuous vs. Continuous	Is there an association between CHL and patient engagement outcomes?	Pearson's

Specific Aim 2: To describe how demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors.

Research Question 2a: How do demographic/personal factors and survivorship outcomes

(HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer

survivors?

Hypothesis 2a: Breast cancer survivors who have high levels of HRQOL, CHL and low

levels of FCR will have high levels of patient engagement measures of PA and KPC.

To address Research Question 2a, general linear regression modeling was conducted to assess the multivariate associations between demographic/personal factors and HRQOL, CHL, FCR, KPC and PA in breast cancer survivors. Predictor variables were analyzed using general linear regression modeling strategies such as backward elimination (Pedhazur, 1997).

Summary

This chapter described the methods for the study aimed at evaluating the relationships between demographic/personal factors, HRQOL, CHL, FCR, KPC and PA in breast cancer survivors and the implications for breast cancer SC. Information on the setting, sample, study measures, study procedures, analytic plan, and protection of human subjects has been presented. The study methodology has been presented as it will attempt to answer the research questions presented in Chapter 1.

Chapter Four: Results

This cross-sectional descriptive study was designed to explore how demographic/personal factors and survivorship outcomes might contribute to variables that capture patient engagement in breast cancer survivors. Chapter Four presents the results with sections including: (1) description of the sample; (2) preliminary analyses with descriptions of the predictor and outcome variables and bivariate associations; (3) main analyses related to the specific aims and (4) qualitative results of the single open ended question in the survey.

Description of the Sample

Surveys were distributed to a national sample of participants via two distribution sites: Dr. Susan Love's AOW website and Craigslist. The AOW is a website aimed at connecting people with or at risk for breast cancer with breast cancer researchers. The contact person at AOW who served as a recruiter for this study sent an initial email blast in June of 2018 to their email distribution list. Following this initial email, a reminder e-blast was sent two days later. Two hundred and three AOW participants completed enrollment over a three-week period. The second site was Craigslist and this researcher invited potential participants through a posting on this website. The posting was listed in a section focused on the recruitment of potential subjects for research studies and more specifically, it was targeted to people who identified as having breast cancer. Within a 24-hour period 100 participants responded. This process allowed for the targeted number of participants (303) to be recruited within a 3-week period. The power analysis for this study indicated that 246 participants would yield 85% power, a small to medium effect size of .06 and an alpha of .05. The sample in the current study contained 303 participants, thus surpassing the goals for power and recruitment. For the recruitment flyer used on both sites, please refer to Appendix B.

Response rate could not be assessed for this study due to the online recruitment methods as discussed in Chapter 3. Not all the registered users of the AOW website are survivors, as some are only at risk for breast cancer due to family history, so it would not be possible to determine the denominator of survivors who saw the e-blast. Similarly, it is not possible to determine the denominator of survivors who saw the Craigslist posting.

Although 303 people responded and opened the combined surveys, in five instances the surveys were left blank. Excluding these five from the final total, there were 298 completed surveys from breast cancer survivors.

Preliminary Analyses

This section describes the results for the preliminary analyses which includes descriptive statistics and bivariate analyses for the demographic/personal factors, survivorship outcomes and patient engagement variables.

Demographic Characteristics and Personal Factors. The following describes the demographic characteristics and personal factors as reported by the participants in text and table format. Please see Table 1A located in Appendix D which summarizes the participants' demographic characteristics.

Age. Participants' mean age was 50.70 with a standard deviation of 14.01 years. All participants were between 25 to 78 years old. The sample was very evenly distributed with a mode of 38 and a median of 49.

Race and Ethnicity. The majority of the participants (87.5%) self-identified as White, while 5.6% self-identified as Black or African American. One percent of this sample self-identified as unknown or selected prefer not to answer. The majority of the participants (86.4%)

self-identified as non-Hispanic or non-Latino with 11.9% of the participants self-identified as Hispanic or Latino.

Sex, current sex identity and sexual orientation. Participants' self-reported sex was overwhelmingly female (99.3%) but the sample did include 2 males (0.7%). When asked how they currently identified their sex, 99% of the sample reported their current sex identity as female, 0.3% reported their current sex identity as transgender and 0.7% reported their current sex identity as male. Self-reported sexual orientation was 94.8% straight, 2.1% self-reported gay or lesbian, 2.1% bisexual, transgender or gender non-conforming or queer and 1.0% prefer not to answer.

Education and income. The majority of the participants (70.6%) reported their highest level of education to be a Bachelor's Degree or higher. The majority of participants (68%) reported an annual income of greater than \$75,000 per year. An equal percent of participants (16%) self-reported an annual income of less than \$50,000 per year and between \$50,000 and \$75,000 annual income per year.

Employment and health insurance status. The majority of the participants (54.3%) reported that they were employed full time, 22% reported being retired and 5.3% of the sample reported being unemployed. When asked whether or not they had health insurance, 98.9% (n = 281) of the sample self-reported health insurance coverage.

Perceived Weight. Participants were also asked to self-report their weight. Almost half (49.3%) of the participants self-reported their weight as normal, and 38.7% self-reported their weight as overweight, obese or morbidly obese.

Region. The participants self-reported their residence by zip code. The sample was equally dispersed across the US. Participants from the Northeast comprised 23.3% of the sample, 24.9% self-reported a zip code within the South region of the US, 22.4% self-reported a zip code in the Midwest region of the US and 29.4% reported a zip code in the Western region of the US.

Health History. Table 2A, located in Appendix D summarizes results related to participants' self-reported health history including stage at diagnosis and treatment related factors, concomitant medications and comorbidities, social support, health promotion activities and cancer survivorship plan receipt.

Stage at Diagnosis. The majority of the participants (51.6%) self-reported being diagnosed with Stage 1 breast cancer. 9.1% of the participants reported being diagnosed with Stage 0 or "in-situ" breast cancer. The remaining 39.3% of the participants reported either Stage 2 or 3 breast cancer.

Hormonal therapy and chemotherapy receipt. A large majority of the participants (70.5%) reported that at the time of participation in the study, they were currently being treated with hormonal therapy such as tamoxifen or an aromatase inhibitor. The majority of participants (52.3%) in this study responded "yes" that they had been treated with chemotherapy as part of their treatment regimen for breast cancer.

First degree relatives with breast cancer. Participants were asked if any of their first degree relatives (parents or siblings) had been diagnosed with breast cancer. The majority of participants (58.4%) did not have any first degree relatives that were diagnosed with breast cancer and 36.2% of participants reported that they had one first degree relative diagnosed with breast cancer.

Comorbidities. Participants were asked to report any comorbidities they may have in addition to their breast cancer diagnosis. About one third of the participants (30.9%) reported no comorbidities. Almost another third (29.2%) reported only one comorbidity. Of note, 11.3% of patients noted four or more comorbidities. Comorbidities reported included: hypertension, hyperlipidemia, history of myocardial infarction, diabetes, asthma, thyroid disease, osteoporosis, arthritis, cancer other than breast, depression, anxiety and substance use disorder.

Concomitant Medications. Participants were asked to self-report their non-breast cancer related medications using a free text box in the survey. A sum variable was then created to report the number of concomitant medications the participants were taking in addition to any medications prescribed for their breast cancer treatment regimen. The majority of participants (63.6%) were on at least one concomitant medication. 10.3% reported being on three concomitant medications and 8.6% of the sample reported five or more concomitant medications.

Hot flashes and hot flash frequency. The majority of participants (55.7%) reported currently experiencing hot flashes, while 44.3% did not. For those participants that did report experiencing hot flashes, 63.4% experienced them 1-5 times per day and 11.5% of participants reported severe hot flashes occurring 11 or more times per day.

Physical Activity. Participants were asked to report if they met the American Heart Association's (AHA) recommended guideline of 150 minutes of physical activity each week (AHA, 2018). The vast majority of the participants (72.1%) reported that they did exercise 150 minutes each week and 27.9% reported that they did not.

Caregiver status and social support. Participants were asked if they were a caregiver for anyone such as a child or adult relative. The majority (64.1%) were not caregivers, however,

35.9% of the participants reported that they were caregivers. In terms of social support, the participants were asked if there was someone in their lives they could rely on for support during their time in survivorship. Overwhelmingly, the participants reported that they did identify someone as a source of social support with 76.5% participants responding "yes".

Smoking status and alcohol use. Participants were asked to self-report on both their smoking status and daily and weekly alcohol use. A large majority of the participants (88%) reported that they were currently non-smokers. The majority (74.8%) also reported no daily drinking and 22% reporting 1-2 drinks per day. In terms of weekly alcohol use, 47.7% of participants reporting no drinking and 37.2% reporting 1-4 drinks per week.

SCP receipt. Participants were asked whether or not they received a SCP and were given the option of answering "yes", "no" or "don't know". The responses to this item were closely split with 44.6% of participants reporting that they did receive a SCP and 41.1% of participants reporting that they did not receive a SCP. Of note is that 14.3% of the participants reported that they did not know if they received a SCP.

Descriptive Statistics for Survivorship Outcomes. The following section describes the three survivorship outcome scales' (FACTG7, FCRI and CHLT) descriptive statistics in this sample of breast cancer survivors.

Functional Assessment of Cancer Therapy- General 7 (*FACTG7*). FACT-G7 questions were completed by most of the participants (n = 294). The Cronbach's alpha for the FACTG7 was .770. Higher scores on the FACT-G7 correspond to higher HRQOL and the score range is from 0-28. A sum variable was created according to the scoring guidelines provided by the

authors of the tool. The mean for this sample of breast cancer survivors was 17.66. Table 3A, located in Appendix D displays responses to the FACT-G7.

Fear of Cancer Recurrence Inventory Short Form (FCRI SF). The majority of participants (*n* = 291) completed most of the items on the FCRI SF. The Cronbach's Alpha for the FCRI SF was .784. The scale contains nine items and scores range from 0-32 with a higher score denoting a greater fear of cancer recurrence. The mean for this sample of participants was 11.79. A score of 16 is the cut-off point to determine clinically significant FCR (Lebel, Simard, Feldstain, et al., 2016) and 25.8% of the sample met this criteria. Table 4A, located in Appendix D displays responses to the FCRI SF.

Cancer Health Literacy Tool - 6 (CHLT-6). A majority of participants completed most of the items of the CHLT-6 (n = 289). The mean CHLT-6 for the entire sample was 1.78 and the standard deviation was 0.416. For this tool, participants had to answer 4 out of 6 items correctly to be considered to have "adequate" cancer health literacy. Otherwise, their cancer health literacy was considered to be "limited". In this sample of breast cancer survivors, 199 (68.6%) participants had adequate CHL and 91(31.4%) had limited CHL. Table 5A, located in Appendix D summarizes the results.

Cronbach's Alpha for the CHLT-6 was .279 and was excluded from the final regression analysis. Although the longer version the CHLT-30 reported excellent Cronbach's Alphas in the tool validation studies (Dumenci et al., 2014), no other studies have been done using the CHLT-6 for which to compare the Cronbach's Alpha values. Figure 2 illustrates the histograms for the survivorship outcomes. FACT-G7 and FCRI SF met the assumption of normality but the CHLT-6 did not, as illustrated below and was excluded from data analysis.











Descriptive Statistics for Outcome Variables. The following section describes the descriptive statistics in this sample of breast cancer survivors for the following outcome variables: Patient Activation Measure and Knowing Participation in Change Short Form.

Patient Activation Measure 10 (PAM10). The majority of participants (n = 287) completed most of the items on the PAM 10. The PAM assigns each participant an activation level ranging from 1-4, with 4 being more activated than 1. This is calculated by Insignia Health as per their requirements and then was sent back to the principal investigator to be included in the final analysis. The mean activation level of this sample of breast cancer survivors was 3.03 with a standard deviation of 0.815. The Cronbach's Alpha for the PAM 10 was .718. Table 6A, located in Appendix D, summarizes the results.

Knowing Participation in Change Short Form (KPCSF). The majority of participants (n = 282) participants completed most of the items on the KPC SF. A KPC Sum variable was created according to the scoring guidelines provided by the tool authors. The KPC SF is a visual analog scale and scores range from 12 to 84 with a higher score indicating a higher participation in change. The mean KPC score in this sample of breast cancer survivors was 62.47 and the standard deviation was 11.00. The Cronbach's Alpha for the KPC SF was 0.866. Table 7A, located in Appendix D, summarizes the results.

Figure 3 illustrates the histograms for the outcome variables, KPC SG and PAM 10. Both scales met the assumption of normality.







Specific Aim 1: To describe the relationship amongst demographic/personal factors and survivorship outcomes (HRQOL, CHL, FCR) to patient engagement measures (PA and KPC) in breast cancer survivors.

Bivariate Analyses. The first research question asked, "What is the relationship between demographic/personal factors, survivorship outcomes (HRQOL, FCR, CHL) and patient engagement measures (PA and KPC) in breast cancer survivors?" Bivariate associations among the predictor variables and between predictors and the outcome variables (KPC and PAM) were assessed. All bivariate correlations were two-tailed. Bivariate correlations between the predictor and outcome and/or included in the final model that were significant at the $p \leq .05$ level are displayed in Table 3. ANOVA analyses were performed on categorical predictor variables and the outcome variables and 10 variables resulted in significant relationships and are summarized in Table 4.

TABLE 3

Bivariate Analysis

Significant associations betw	een predictor a	and outcome variables.
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	Coefficient	р	п
KPC and CHLT	.631	.001	278
SCP receipt and CHLT	.459	.001	280
PAM and KPC sum	.439	.001	274
FACTG sum and KPC sum	.426	.001	278
KPC Sum and Social Support Sum	.413	.001	278
PAM and FACTG	.314	.001	291
PAM and Social Support Sum	.310	.001	294
PAM and CHLT	.270	.001	286
KPC sum and smoking status	.269	.001	274
KPC sum and SCP receipt	.259	.001	272
KPC Sum and Comorbidity Sum	.256	.001	278
PAM and FCRI Sum	181	.002	289
PAM and smoking status	.142	.017	279
KPC and FCRI Sum	106	.018	277

Table 4 summarizes the significant findings from the ANOVAs analyses on the predictor variables and outcome variables.

TABLE 4

Significant ANOVA relationship between predictor and outcome variables.

	Sum of Squares	df	Mean Square Between	Mean Square Within	F statistic	р	n
KPC and education*	33211.74	4, 73.71	1627.95	98.52	26.43	.001	275
PAM and education	155.22	7, 274	1.38	0.53	2.61	.013	281
KPC and perceived weight*	31973.17	2, 85.43	830.42	112.69	8.91	.001	271
PAM and perceived weight*	152.38	2, 83.77	2.93	0.53	5.28	.007	277
KPC and employment status*	32889.28	5, 31.52	824.43	108.15	9.90	.001	271
PAM and employment status	149.54	8, 269	1.12	0.52	2.14	.033	277
KPC and race	33184.90	3, 273	1141.68	109.01	10.473	.001	276
KPC and income	30172.11	4, 237	576.02	117.59	4.90	.001	241
PAM and income	137.21	4, 241	1.67	0.54	3.08	.017	245
KPC and alcohol per day*	33254.21	2, 21.29	408.13	120.14	3.63	.044	272

*denotes Welch's ANOVA

Main Analyses

Specific Aim 2: To describe how demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors.

The second research question asked, "How do demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors?"

From the preliminary analyses, variables were selected for the linear regression modeling in addition to the survivorship outcomes. From the correlations, variables that were both significant at the $p \le .05$ level *and* correlated with a *r* or *rho* > .4 and most representative of the study aims were included in the linear regression models. ANOVA relationships that were both significant with both outcome variables and most representative of the study aims were included in the linear regression models. The final demographic/personal factors included in the regression models meeting the above criteria were education, income, social support and survivorship care plan receipt. These variables were then entered into SPSS using linear regression modeling with a backward elimination strategy.

Backward regression resulted in two final models; one for KPC and one for PA. Assumptions for both models were checked including independence of observations, linearity of the relationship between the predictor and outcome variables, homoscedasticity of residuals and multicollinearity and will be reported below. Both models described patient engagement scores (KPC or PA) that were significantly predicted by demographic/personal factors and survivorship outcomes as described in the following section.

PAM Final Regression Model. Assumptions were checked and met as follows. There was independence of residuals as demonstrated by a Durbin Watson statistic of 2.000. There was no evidence of collinearity as evidenced by VIF values of 1.188-1.710. The scatterplot demonstrating homoscedasticity of residuals is illustrated in Figure 4. The P-P plot demonstrating normality of residuals is demonstrated in Figure 5. Outliers were examined for

data entry error, for which none was found. Cook's Distance was examined and no values were found greater than 1, evidencing no data points with high leverage.

Figure 4. Scatterplot of PAM residuals



Figure 5. P-P Plot of PAM residuals



Normal P-P Plot of Regression Standardized Residual

The final regression model statistically significantly predicted patient activation level and explained 13.6% of the variance. Only FACT-G7 added statistically significantly to the prediction ($p \le .001$). Social support contributed unique variance but did not meet statistical significance. Education, income, SCP receipt and FCR were all excluded and thus did not contribute any unique variance. In the final model, in general, as HRQOL and social support increased so did the participants' activation level. The regression model equation is - Predicted PAM level (y) = $2.228 + (0.44 \text{ x}_{FACTG7}) + (.057 \text{ x}_{SocialSupport})$.

This standardized coefficient equation indicates that for every one unit increase in the PAM level, FACT-G7 scores would increase by 0.44 standardized units and social support would increase by .057 standardized units. The part correlations, which determine the unique contribution of each variable to the model, are 0.275 for FACT-G7 and 0.105 for social support.

The model summary is listed in Table 12.

TABLE 12

PAM Backward	Regression	Model	Summary	1
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Variables	В	β	SE (B)	t	95% Confidence Interval	<i>p</i> value
FACT-G7	0.044	0.304	0.010	4.505	0.03, 0.06	.001
Social Support	0.057	0.117	0.033	1.730	-0.01, 0.12	.085

 $R^2 = .136$; adjusted $R^2 = .129$; Standard error of estimate = .69783; SS = 131.958 N = 237

KPC Final Regression Model. Assumptions were checked and met as follows. There was independence of residuals as demonstrated by a Durbin Watson statistic of 1.756. There was no evidence of collinearity as evidenced by VIF values of 1.175-1.812. The scatterplot demonstrating homoscedasticity of residuals is illustrated in Figure 6. The P-P plot demonstrating normality of residuals is demonstrated in Figure 7. Outliers were examined for

data entry error, for which none was found. Cook's Distance was examined and no values were found greater than 1, evidencing no data points with high leverage.



Figure 6. Scatterplot of KPC residuals.

Figure 7. P-P Plot of KPC residuals.



Normal P-P Plot of Regression Standardized Residual

The final regression model statistically significantly predicted KPC and explained 32% of the variance in this sample of breast cancer survivors. FACT-G7, education, social support added statistically significantly to the prediction, p < .05. SCP receipt contributed unique variance but did not meet statistical significance. FCR and income were excluded from the model and thus did not contribute any unique variance. In the final model, in general, as FACT-G7, education and social support increased, so did KPC. In the final model, if patients received a SCP, KPC increased. The regression model equation is – Predicted KPC scores (y) = 33.302 + (.500 x_{FACT-G7}) + (2.445 x_{Education}) + (1.556 x_{SocialSupport}) + (1.547 x_{SCPReceipt}).

This standardized coefficient equation indicates that for every one unit in KPC scores, the FACT-G7 score would increase by .500 standardized units, education would increase by 2.445 standardized units, social support would increase by 1.556 standardized units and SCP receipt would increase by 1.547 standardized units. The part correlations, which determine the unique contribution of each variable to the model are .194 for FACT-G7, .230 for education, .181 for social support and .091 for SCP receipt.

The model summary is listed in Table 13.

TABLE 13

Variables	В	β	SE (B)	t	95% Confidence Interval	<i>p</i> value
FACT-G7	0.500	.227	.140	3.566	0.22, 0.78	.001
Education	2.445	.250	.579	4.219	1.30, 3.59	.001
Social Support	1.556	.215	.468	3.325	0.63, 2.48	.001
SCP Receipt	1.547	.098	.930	1.664	-0.29, 3.38	.098

KPC Backward Regression Model Summary

 $R^2 = .320$; adjusted $R^2 = .308$; Standard error of estimate = 9.20113; SS = 28521.162 N = 234

Open Ended Survey Question Results

At the end of the survey, one open-ended question was asked of the participants. Of the 298 participants included in the final sample, 130 participants responded to this question. The responses were placed into the following seven categories: physical concerns (such as pain, fatigue, lymphedema), mental health concerns (such as anxiety, depression), financial toxicity (such as trouble paying for medications, health insurance coverage issues), social support (such as need for resources such as individual or group support/therapy), other concerns (such as describing their own treatment histories or personal situations) body image concerns and reports of no concerns or "none". Table 14 summarizes the results. The total number of responses is greater than 130, as some participants gave responses that fell into more than one category.

TABLE 14

Open-Ended Question Responses		
Open-Ended Question Response Categories	n	%
Total number of responses	146	
No Concerns/None	48	32.87
Physical Concerns	34	23.29
Social Support	20	13.70
Mental Health Concerns	17	11.64
Other	15	10.27
Financial Toxicity	6	4.11
Body Image Concerns	6	4.11

Summary

The results of this study sought to answer two research questions, (1) What is the relationship between demographic/personal factors, survivorship outcomes (HRQOL, FCR,

CHL) and patient engagement measures (PA and KPC) in breast cancer survivors? and (2) How do demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors? For question one, there were 13 variables that resulted in significant bivariate correlations with the outcome variables and 10 variables that resulted in significant ANOVA relationships with the outcome variables as described above. For question two, linear regression models were created for the two outcome variables representing patient engagement, PA and KPC. For PA, HRQOL (as represented by the FACT-G7 measure) and social support predicted 13.6% of the variance in patient activation levels among this sample of breast cancer survivors. For KPC, HRQOL, education, social support and SCP receipt explained 32% of the variance in KPC scores among this sample of breast cancer survivors.

Chapter Five: Discussion of Results, Strengths Limitations and Implications

The purpose of this study was to 1) describe the relationship among demographic/personal factors and survivorship outcomes (FCR, HRQOL, CHL) and patient engagement variables (KPC and PA) and 2) explore how demographic/personal factors and survivorship outcomes (FCR, HRQOL and CHL) contributed to patient engagement variables (KPC and PA). Using a convenience sample obtained via a national, web-based survey, this study aimed to answer the following research questions: 1) what is the relationship between demographic/personal factors, survivorship outcomes (HRQOL, FCR, CHL) and patient engagement measures (PA and KPC) in breast cancer survivors and 2) how demographic/personal factors and survivorship outcomes (HRQOL, FCR, CHL) contribute to patient engagement measures (PA and KPC) in breast cancer survivors. This chapter describes how the results answer the research questions. This chapter also reviews the study strengths, limitations and implications for practice, research, education and policy.

Description of the Sample

The following section will discuss the results in terms of the demographics and health history as reported by the participants in this study.

Age, race & sex. The sample in this study is younger than the national median age of breast cancer patients at diagnosis of 62 years (NCI SEERs, 2018) with a mean age of 50.70 years. This may be due to the study mode of web-based survey, since in 2018, only 66% of people aged 65 or older are estimated to use the Internet (Pew Research Center: Internet and Technology, 2018). The sample was fairly homogenous with 87.5% self-reported White, roughly ten percent more than the US Census estimate (US Census Bureau, 2018). 5.6% self-reported as Black or African American as compared to a reported 13.6% in the US Census data (US Census

Bureau, 2018). 11.9% self-identified as Hispanic or Latino as compared to 18.1% reported by the US Census data (US Census Bureau, 2018). The sample was largely female, as would be expected in a sample of breast cancer survivors but did contain two males, which is representative of the less than 1% male breast cancer accounts for each year (ACS, 2018).

Education, employment & income. This sample of breast cancer survivors was highly educated, with 70.6% reporting a Bachelor's degree or higher. This reflects a higher educational attainment in the current sample of breast cancer survivors than the US Census Bureau's data which reports only 30% of the US population reporting a Bachelor's degree or higher (US Census Bureau, 2018). Consistent with higher educational achievement, 68% of the participants reported an annual income greater than \$75,000 per year which is greater than the US Census Bureau, 2018). Although income was higher in this sample, unemployment was higher than the national average with 5.3% reporting being unemployed compared to the current annual rate of 3.9% (U.S. Department of Labor, 2018). Higher unemployment among cancer survivors is consistent with previous findings reporting that survivors may be at higher risk for unemployment after treatment (Jagsi et al., 2014; Rottenberg et al., 2016).

Weight & physical activity. When asked about their perceived weight category, 38.7% of the sample self-reported their weight as overweight, obese or morbidly obese approximating the obesity rate for US adults (CDC National Center for Health Statistics, 2017). Obesity is a significant issue for breast cancer survivors whether obese at diagnosis or if weight is gained during therapy, or into survivorship, as it can impact disease outcomes and potentially decrease HRQOL (Sheng, Sharma, Jerome, & Santa-Maria, 2018; Yung & Ligibel, 2016). When asked about their physical activity levels and whether or not they met the AHA recommended 150

minutes of physical activity per week, 72.1% reported that they did. This is higher than what the AHA reports, which is that only about half of American adults currently meet the recommended guidelines for exercise (AHA, 2018). This sample also self-reported more weekly physical activity as compared to recent studies on breast cancer survivors with self-reported physical activity (Liu et al., 2016; Schmidt, Wiskemann, Ulrich, Schneeweiss, & Steindorf, 2017).

Hormonal therapy & chemotherapy receipt. In terms of treatment history, 70.5% of this sample reported taking hormonal therapy. This is consistent with the fact that the majority of breast cancers are estrogen receptor positive at diagnosis and thus, these survivors would be prescribed hormonal therapy as part of their treatment plan for years into survivorship (ACS, 2018). Regarding chemotherapy receipt, 52.3% of the participants reported having received it as part of their treatment regimen. Although gene expression panels such as Oncotype DXTM have allowed providers to begin to differentiate between early stage breast cancer patients who will benefit from chemotherapy and those that will not, chemotherapy remains a mainstay of treatment for breast cancer and may have long-lasting impacts into survivorship (NCCN, 2018).

Multimorbidity & polypharmacy. Multimorbidity, as defined by the WHO, is at least two chronic illnesses occurring in one person (WHO, 2016). In this sample, 39.9% of the participants met the WHO criteria for multimorbidity and 11.3% self-reported 4 or more comorbidities. Further, these comorbidities were in addition to their cancer diagnosis. This is consistent with literature citing cancer survivors as having multimorbidity at similar rates to their peers (Cohen et al., 2012; Gold et al., 2014; Jordan et al., 2014). Another issue to consider with multimorbidity is polypharmacy, which can be defined as an individual taking five or more medications concurrently (Masnoon, Shakib, Kalisch-Ellett, & Caughey, 2017) and there is some evidence that polypharmacy is associated with poorer outcomes such as falls, adverse drug events or mortality, especially in older adults (Fried et al., 2014; Salvi, Rossi, Lattanzio, & Cherubini, 2017). Using this definition and including breast cancer medications, between 8.6-12.4% of this sample meets the criteria for polypharmacy. Although multimorbidity and polypharmacy did not contribute significantly to patient engagement in this study, both can add to the complexity of the survivorship experience in breast cancer survivors (Meneses et al., 2015).

Caregiver status. A substantial proportion of the sample (35.9%) reported being caregivers themselves. The survey options included caring for a child or an adult parent or relative. The caregiver literature clearly documents the added stressors caregiving can bring to everyday life (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014), so it is likely that adding the responsibility of caring for others to the survivorship experience could have an impact on a person's ability for self-care. Caregiving is not well documented or understood in the context of cancer survivors, except in the context of motherhood where previous findings suggest it is an added strain for survivors and is associated with increased FCR (Arès et al., 2014; Lebel et al., 2013).

Social support. In terms of social support, the vast majority of participants reported (76.5%) they did have someone in their lives they could count on for support during their survivorship journey. From the breast cancer survivorship literature, social support has been documented to be an important predictor of wellbeing and HRQOL (Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2017; Leung et al., 2014; Lim, Shon, Paek, & Daly, 2014) and a mediator capable of enhancing intervention outcomes (Schellekens et al., 2017). Consistent with other work indicating that social support positively impacts outcomes such as QOL, social support was positively correlated with patient engagement in the current study.

Risk factors for breast cancer. Smoking and alcohol intake are both risk factors for breast cancer diagnosis (ACS, 2018; Liu, Nguyen, & Colditz, 2015; Reynolds, 2013) and rates were assessed in this survey. In terms of alcohol and breast cancer recurrence and disease-related survival, the literature is still mixed. There are some studies which suggest that there is an increased risk of recurrence or decrease in survival for those who drink more often (Kwan et al., 2013; Susan G. Komen, 2018), but others suggest no effect from drinking alcohol (Newcomb et al., 2013; Zeinomar et al., 2017). Some have suggested that a reason for the conflicted findings may be that drinking alcohol in moderation can actually have some health benefits (Forman, Stampfer, & Curhan, 2009; Fuchs et al., 1995). In terms of smoking, there is increasing support in the literature that smoking will decrease survival for women with breast cancer (Susan G. Komen, 2019).

The percentage of current smokers in this study was small (12%), less than the reported 15.5% national average of current smokers as reported by the CDC (CDC, 2018). The majority of the participants (74.8%) reported no daily drinking and close to half of the participants reported (47.7%) reported no weekly drinking. This is less than the recommendation for "moderate" alcohol intake as defined by the CDC, which is up to one drink per day for women (CDC, 2018a).

SCP receipt. In this sample, 44.6% of the participants reported receiving a SCP which are recommended by the IOM (2006) and mandated by the American College of Surgeons (ACoS) (ACoS, 2016), despite mixed evidence in the literature supporting their efficacy and problematic implementation (Birken, Mayer, & Weiner, 2013; Mayer, Birken, & Chen, 2015; Powel & Seibert, 2017). The 14.3% of the participants in the current study who reported that

they did not know if they received a SCP could reflect this problematic implementation or and/or less than optimal efficacy.

Survivorship Outcomes

The survivorship outcomes examined in this study included HRQOL as measured by the FACT-G7, FCR as measured by the FCRI-SF and CHL as measured by the CHLT-6. The findings from each of these tools are discussed in the following section.

FACT-G7. HRQOL in this study was measured by FACT-G7 (B. Yanez et al., 2013). Scores range from 0-28 and the mean in this sample of breast cancer survivors was 17.57. This tool is relatively new and it was challenging to find studies in the literature that reported FACT-G7 scores by which to compare this sample. However, Pearman et al. (2014) reported a study evaluating both adults diagnosed with cancer and a non-cancer sample of US adults where the mean FACT-G7 scores were 19.1 and 20.1, respectively. The same study also separated out breast cancer patients by disease status and their mean FACT-G7 scores were as follows: no evidence of disease (22), local disease (20.3), regional spread (19.1), metastatic disease (19.4) (Pearman et al., 2014). It is notable that for this study's participants, the mean HRQOL FACT-G7 score was lower than the all of the breast cancer patients and the sample of adult US control patients in Pearmen et al's (2014) trial.

FCRI SF. Clinically significant FCR as determined by the FCRI SF is cited as a score of 16 (Lebel, Simard, Feldstain, et al., 2016) and 25.8% of this sample of breast cancer survivors met this criteria. The mean FCRI SF score in this sample, however, did not represent clinically significant FCR, at 11.77. In a study examining FCR in colorectal cancer survivors, Custers, Gielissen, Janssen, de Wilt & Prins (2016) reported 38% of their sample as having "high" FCR. However, in this study, a lower cutoff score of 14 was used to determine clinically significant

FCR than the author suggested score of 16. Fardell et al. (2018) recently explored the screening capacity of the FCRI SF and suggested a higher cutoff range of greater than or equal to a score of 22 in a sample of cancer survivors (made up largely of breast cancer survivors). In this study, the rate of clinically significant FCR using the higher cutoff range, was 25% (Fardell et al., 2018). Although there is not consensus about the FCRI SF's optimal cutoff range, the current study's findings align with findings in the cancer survivor literature that a significant proportion of breast cancer survivors report clinically meaningful FCR.

CHLT-6. The CHLT-6 tool categorizes participants as having "adequate" or "limited" cancer health literacy. This tool is a shortened version of the longer version of the tool, the CHLT-30 (Dumenci et al., 2014). This is the first time this tool has been tested, outside of the validation study. In this study, 68.6% of the participants were rated as having adequate CHL and 31.4% had limited CHL.

Patient Engagement Measures

The patient engagement measures in this study were PAM-10, measuring patient activation (PA) and KPC SF, measuring knowing participation in change (KPC). The findings will be discussed in the following section.

PAM 10. Patient activation, one of the two outcome variables in the present study, was measured by the PAM 10 tool (Hibbard et al., 2005, 2004). Patient activation is categorized into four levels ranging from disengaged and overwhelmed at level one to fully participating in one's care at level four. In this study, the sample of breast cancer survivors mean PAM level was 3.03. This aligns with other studies on cancer survivors such as a study by Mazanec, Sattar, Delaney & Daly (2016) which examined PAM level in colorectal cancer survivors and their caregivers from the time of surgery through early survivorship. This study reported 62.5% of their sample as

having PAM level 3 at 4 months into survivorship. O'Malley et al. (2018) reported on a sample of breast and prostate cancer survivors' levels of PA further into survivorship (1-10 years after diagnosis) and also reported that the breast cancer survivors were at PAM level 3 (M = 3.34) and that they were significantly higher than the prostate cancer survivors (p = 0.39). This evidence aligns with the current study findings placing the majority of the sample (51%) in PAM level 3.

KPC SF. The Knowing Participation in Change Short Form measures the construct of KPC and a person's sense of power or "being aware of what one is choosing to do, feeling free to do it, and doing it intentionally" (Barrett, 2010, p.49). The KPC SF scores range from 12-84 with higher scores indicating higher power, and in this sample of breast cancer survivors the mean score was 62.47. To this researcher's knowledge, there have not been any other studies in breast cancer survivors using the KPC SF for which to compare these scores. However, Farren's work (Farren, 2010a) on KPC and breast cancer survivor outcomes can be compared to the findings of this study and will be discussed in the following section on the research aims.

Relationship among Demographic/Personal Factors, Survivorship Outcomes and Patient Engagement Variables

The first aim of this study was to describe the relationship between the predictor and outcome variables. The data indicated that for both patient engagement outcome variables there was a positive correlation with cancer health literacy, health related quality of life, social support and surprisingly, smoking status. Thus, the data suggests that as these variables increase, so will patient engagement. Although limited, there is some research to support the positive correlation between the outcome variables and HRQOL in that KPC has been shown to be positively associated with QOL (Farren, 2010a) as has PAM (Zimbudzi et al., 2017).

In terms of smoking status, as patient engagement increased, there was a change in category from non-smoker to smoker. This was a surprising finding in the data. The correlation between smoking status and KPC was weak (r = .269, $p \le .001$) and between smoking status and PAM was very weak (r = .142, p = .017), yet both were significant so the findings were interesting and noteworthy, nonetheless. There is some data to suggest that with increasing female empowerment, there can be an associated increase in female smoking rates which approach the same rate as male smoking rates (Hitchman & Fong, 2011). Hitchman & Fong (2011) describe a pattern where in countries where women are less empowered, female smoking rates tend to be lower, but as they gain power and freedoms, historically their smoking rates tend to rise. The finding in this study may reflect a similar pattern that with increased patient engagement, participants (largely female) were more likely to be smokers.

Another somewhat counterintuitive finding was that there was a weak positive correlation between KPC and the comorbidity sum variable so that as the number of comorbidities increased, so did KPC. However, as Barrett (2010) envisioned power as KPC as having four dimensions (awareness, choices, freedom to act intentionally and involvement in creating change), this could be translated to the participant with multimorbidity, in that with many chronic health conditions comes the need for increased self-management and thus increased patient engagement in order to manage the many conditions and decisions that come with multimorbidity. This phenomenon may be what the data in this study are demonstrating. Previous work with KPC has not examined an association with comorbidity.

Conversely, for both patient engagement outcome variables, there was an inverse relationship with FCR, as expected. In this case, the data suggest that as FCR increases, patient engagement will decrease. Significant ANOVA relationships as illustrated in Table 11 in Chapter 4 were identified for both patient engagement variables with regards to education, employment status, income and perceived weight suggesting that demographic/personal factors and survivorship outcomes contribute to patient engagement.

KPC and PAM were significantly moderately positively correlated with each other ($r = .439, p \le .001$). A positive correlation is expected as they are both measures of patient engagement. The strength of the correlation suggests that they are linked, but perhaps capture different dimensions of the construct. This supports the study plan to build two separate linear regression models.

KPC and CHL had the strongest bivariate correlation in the preliminary analysis (r = .631 $p \le .001$). CHL also had a weak positive correlation with PAM (r = .270 p =000). Due to CHLT-6's poor Cronbach Alpha, it was not included in the final regression analysis. However, these bivariate associations lend support to the idea that CHL is an important survivorship outcome to consider when trying to optimize patient engagement. There is some evidence in the literature that poor health literacy may be associated with poor health outcomes (Husson et al., 2015; Morris et al., 2013), but CHL as its own construct has yet to be fully explored. This study is the first to use the CHLT-6, providing some findings from which to build further research. These findings do support the study hypothesis that breast cancer survivors who have high levels of HRQOL and CHL and low levels of FCR will have high levels of patient engagement measures (KPC/PA).

Multivariate Analysis of Patient Engagement

The second aim of this study was to examine the contribution of the demographic/personal factors and survivorship outcomes to the patient engagement variables (KPC and PA). The two final regression models resulted in statistically significant predictions
regarding patient engagement. The PAM regression model explained 13.6% of the variance and significantly predicted PAM level ($p \le .001$) with FACT-G7 (representing HRQOL) adding significantly to the model. The KPC regression model explained 32% of the variance and significantly predicted KPC ($p \le .001$) with FACT-G7, education and social support all adding significantly to the model.

Thus, the data indicated that HRQOL significantly predicted patient engagement as represented by both outcome variables, PA and KPC. This is an important findings as cancer survivors often rate their HRQOL lower than their cancer free peers, as a result of the physical and psychosocial impact of their cancer diagnosis and treatment (Arndt et al., 2017; LeMasters, Madhavan, Sambamoorthi, & Kurian, 2013; Rodriguez, Hawkins, Berkowitz, & Li, 2015; Schoormans, Czene, Hall, & Brandberg, 2015) suggesting that if HRQOL is not optimized, this could have significant implications for patient engagement into SC.

In the KPC regression model, education level and social support also significantly predicted patient engagement as represented by KPC. The finding on education suggests a lower education level may prevent some patients from rising to their full expression of power as KPC, and thus, patient engagement. The evidence in the literature is mixed with regards to how education level impacts survivorship outcomes such as survival (Aarts et al., 2013; Hussain, Lenner, Sundquist, & Hemminki, 2008), physical functioning and pain (Hussain et al., 2008) and health behaviors such as smoking and physical activity (Naik et al., 2014).

Social support also significantly predicted for KPC in the final regression model. This is not a surprising finding given that social support has been documented to be a key component of the survivorship experience (Fong et al., 2017; Leung et al., 2014; Lim et al., 2014) and that social support may become increasingly important as provider contact becomes less frequent during the survivorship transition. Of note, SCP receipt was included in the final regression models but did not significantly predict for patient engagement, but did contribute unique variance (9.1%) to the KPC model.

Open-Ended Survey Question

One open-ended question was asked at the end of the survey, "Are there any needs related to your breast cancer, that you have not been asked about, that you would like to share?" The responses were placed into seven categories: physical concerns, mental health concerns, financial toxicity, social support, body image concerns, other concerns or no concerns/none. The most frequently reported concerns were physical concerns, with 23.29% of the sample reporting concerns such as pain, fatigue and lymphedema. The second most frequently reported category was social support (13.7%) followed by mental health concerns (11.7%). These findings align with the findings from both research question 1 and 2 in that HRQOL and social support are key survivorship outcomes for this sample of breast cancer survivors. Two categories that were not asked about in the survey but were brought up by the participants were financial toxicity (4.8%) and body image (4.8%).

Financial toxicity, or the "adverse impacts of out-of-pocket health care costs as a form of treatment-related toxicity" (p.381) (Zafar et al., 2013) is a significant concern for many cancer survivors during treatment and through survivorship as they may struggle returning to work or paying for expensive medications they may require for years after therapy (NCCN, 2018c; Runowicz et al., 2015). Further, financial toxicity can predispose survivors to decreases in outcomes such as HRQOL (Kale & Carroll, 2016) or increase medication non-adherence (Bestvina et al., 2014). The participants in this survey were clearly expressing a need for more support regarding this issue and it is a subject worth further exploration.

Body image is a commonly reported concern of breast cancer survivors (Davis et al., 2010; Runowicz et al., 2015), so it was not surprising that it came up repeatedly in responses to the open-ended question. However, the fact that 4.8% of the participants chose to discuss this when given an opportunity, speaks to its continued importance in the lives of breast cancer survivors as they transition from treatment into survivorship.

Of note, 32.87% of the respondents reported "no concerns" or "none", which may represent the variation in needs among breast cancer survivors with some having high needs during the transition to survivorship and others faring quite well. This finding also aligns with the assertion that SC should be targeted to the individual and their needs, as opposed to a "one sized fits all" approach. As this study demonstrates, many breast cancer survivors have high levels of needs in the survivorship period, but there are some survivors who may not require intensive survivorship care. This is an important distinction as future survivorship interventions and research studies are developed and optimized for real-world applications.

Also, in the "other" category, many participants (10.27%), wanted to share their own personal journey with breast cancer, demonstrating the continued need for connection throughout the survivorship journey. This could reflect the disconnect many feel at the transition into survivorship when they move from many visits with their providers to abruptly having very few medical appointments, or the need to share their story as a way to process through a tumultuous, and in some cases, traumatic experience. This has been reflected in previous qualitative work (Flanagan et al., 2016) with breast cancer survivors transitioning to survivorship, and aligns with the findings from the current study. The need for breast cancer survivors to share their story is also supported by limited research on expressive writing/journaling and its impact on improved physical and psychological outcomes (Craft, Davis, & Paulson, 2013).

Summary of the Findings

In summary, a number of personal/demographic and survivorship outcomes were found to have statistically significant relationships with the outcome variables during bivariate correlations and ANOVA analyses. However, only HRQOL significantly predicted for both patient engagement variables as represented by PAM and KPC when adjusting for other factors. Education level and social support significantly predicted for patient engagement as represented by KPC when adjusting for other factors. Further investigation is needed to validate these findings and further explore the relationship of these factors and the patient engagement experience as it relates to breast cancer survivors.

Limitations

The study findings should be viewed in light of several study limitations. First, the crosssectional design of this study is a limitation in that it lacks temporal precedence and cannot assert any causation (Shadish, Cook, & Campbell, 2002). Additionally, it is not possible to control for all of the potential contributing factors to patient engagement and the breast cancer survivorship experience. Therefore, relationships among the predictor variables were taken into consideration, acknowledging the potential exclusion of other influencing factors not controlled for.

Caregiver status did not significantly contribute to patient engagement in this study, however, the questions asked in this survey may not have adequately explored this phenomenon. The question asked about smoking status did not delineate between tobacco versus cannabis smoking, which could have contributed to the findings on smoking status and patient engagement. Consistent with many research studies on breast cancer survivors, there was low minority representation in this study sample and the participants reported high income and high levels of educational preparation as compared to the average US population (United States Census Bureau, 2018).

This convenience sample of breast cancer survivors recruited from the Army of Women website and on Craigslist represents a self-selected sample of survivors who are active on the Internet and willing to participate in a web-based survey and may not be representative of all breast cancer survivors' experiences. This sample and the findings from this study may not be generalizable to all breast cancer survivors, for example, that of metastatic breast cancer survivors whose experiences may be different than those without metastatic disease.

Additionally, due to this study's online recruitment methods and the inability to document the denominator of survivors who viewed the study invitation, this study could not report a response rate. This is a challenge with online recruiting and for web-based surveys. Despite this challenge, the study was able to meet its goals for power and recruitment. In addition, participants self-reported all of the measures and may have over or under-reported on certain measures.

Discussion

To the best of this researcher's knowledge, this is the first study to examine which factors contribute to patient engagement as represented by PA and KPC in a sample of breast cancer survivors. This study was novel because it adds to the previously poorly understood construct of patient engagement and what factors may contribute to its makeup. This study looked at the unique differences between breast cancer survivors which may account for differences in patient engagement levels, which may ultimately have impacts on their survivorship care outcomes. Additionally, the study design using multiple linear regression modeling allowed for adjustment of multiple factors to determine which may be of particular interest going forward to further understand patient engagement of survivorship care.

This study provided preliminary insight into selected demographic/personal factors, survivorship outcomes and patient engagement in a sample of breast cancer survivors. Findings from this initial study provide the groundwork for future research and have implications for practice, education and policy which will be discussed in the following sections. This study was framed by two guiding theoretical models: Rogers Science of Unitary Human Beings and Barrett's Knowing Participation in Change which postulate that people are irreducible, greater than the sum of their parts and cannot be defined by any one experience. This belief that each individual will respond to breast cancer in different and varied ways guided the premise of this study.

Rogers Science of Unitary Human Beings (1992) described the diversity in response among individuals to any given experience and argued for an "individualization of nursing services" (p. 31) which aligns with the current study's findings that there are different survivor groups who may be more, or less, ready to engage in SC, depending on their engagement level. What was not previously understood, is what factors may contribute to patient engagement. This study sought to begin to answer that question. If we can better understand who is ready to engage in survivorship care (and who is not), this information can be used in practice, research and policy to move the science forward and ultimately, better serve cancer survivors. Rogers (1992) also postulated that individuals are continuously undergoing change and interacting with their environment, so in the case of breast cancer survivors, their engagement will flux as they travel through survivorship. Providers need to be able to assess breast cancer survivors' engagement using factors such as those highlighted in this study to determine where their level of

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engagement is throughout the survivorship journey, and respond accordingly. As Rogers (1992) states, "the purpose of nursing is to promote human betterment, wherever people are" (p. 33), in terms of their survivorship journey, or other health concern. Barrett's Theory of KPC (Barrett, 2010) is also a guiding theory for this study. The idea that breast cancer survivors, while unable to fully control all outcomes, may participate knowingly in changing their health, their survivorship experience and their lives can be a helpful lens through which to view patient engagement in SC.

Implications for nursing practice. According to the NCI (2019), the current 15.5 million cancer survivors will increase to approximately 20.3 million by 2026. Thus, cancer survivorship is likely to touch all areas of nursing practice, whether oncology focused, or not. This highlights the need for all nurses to understand the needs of their patients who may not present as, but are also cancer survivors, and the need to work together with them to optimize their cancer survivorship journey. While increased self-management and patient engagement have been recommended (ASCO, 2018; Knobf, 2015), there is little evidence to guide nurses as to how to maximize patient engagement.

The data from this study suggest attention should be given to factors such as HRQOL, social support, education and the SCP when considering patient engagement. Given that one-size fits all SC has not been effective, using assessment tools that measure factors such as HRQOL, social support, education level and patient engagement in clinical practice would allow providers some insight as to which patients may potentially be "ready to engage" and able to benefit from SC interventions. Additionally, using these tools may help to illuminate those survivors who are at risk for decreased levels of patient engagement and may need more supports and resources. This assessment will also provide the necessary evidence to tailor interventions to meet

individual's breast cancer survivor's needs. This aligns with a patient-centered nursing approach to survivorship care; considering not only the patient's symptomology, but also the demographic variations and social supports that may contribute to their ability to engage in their SC.

Implications for research. There are a number of implications for research given the findings from this study. Given the findings from this study, patient-centered interventions should be developed seeking to optimize HRQOL and social support as a method to maximize patient engagement. Secondly, interventions should also be education-level sensitive, and this may too, reflect CHL. More than a third of this sample reported being caregivers themselves, an area of research that is currently understudied and could be a potential target for future research. Further, the moderate positive, correlation between KPC and PA suggests two related, yet distinct, patient engagement variables. This relationship requires further evaluation. Comorbidity was positively associated with KPC in this study, and 39.9% of the participants in this study met the WHO criteria for multimorbidity (WHO, 2016). As multimorbidity can increase the complexity of the survivorship experience (Meneses et al., 2015) and the findings from this study suggest a relationship between multimorbidity and KPC, it is important to further explore this relationship, and elucidate what role if any, multimorbidity has on patient engagement.

Educational level was not examined as a covariate in previous work with KPC, thus further research is needed to validate these findings and explore how and why education impacts KPC. Additionally, the CHLT-6, a concise measure examining cancer health literacy which could potentially have significant implications for patient engagement into survivorship care is a novel outcome measure which has never been used before in a sample of cancer survivors. Although the CHLT-6 did not meet the standard for being included in the final regression analysis, the findings around a lower education level correlating with a lower level KPC suggests that both these factors – education level and CHL require further exploration in order to develop and engage breast cancer survivors in patient-centered SC.

Moreover, as described above, social support was positively correlated with both outcome variables and significantly predicted for KPC. Thus, it is important to consider for further research patient engagement in SC where the patient is expected to increasingly selfmanage (ASCO, 2018; Knobf, 2015). If social support can enhance a survivor's ability to do this, then facilitating optimal social support should be considered in the care of the breast cancer survivor. Future work is needed to explore with breast cancer survivors their experiences of social support currently and what they would ideally seek in social support during survivorship. KPC is a measure for a person having an increased awareness and ability to make change over time, it would be important to consider longitudinal study designs in future work with KPC and patient engagement in breast cancer survivors.

To validate the findings from this initial study, a web-based study could be repeated with a larger sample size. Ultimately, rigorous, experimental studies should be conducted, testing interventions to optimize patient engagement. These findings could also be translated in work with other cancer survivors such as those with gynecological malignancies or colorectal cancer survivors to search for potential similarities or differences and determine if the findings are generalizable across cancer survivor populations.

These results are encouraging in that they suggest that these survivorship outcomes and demographic/personal factors are areas important to breast cancer survivors that should be used as part of patient's assessment. Further work is needed to understand if those that seem to be able to benefit most actually receive SC, do engage in and benefit from it. These findings also begin

to indicate areas where more patient-tailored SC is needed. Overall, more research is needed aimed at maximizing patient-centered care, patient engagement and ultimately improving SC.

Implications for nursing education. The findings from this study yield the following implications for nursing education. Since higher levels of HRQOL were predictive for higher levels of PA and KPC, these findings should be disseminated to persons working with cancer survivors, such as oncology providers and primary care providers. From a broader perspective, the findings from this study suggest that breast cancer survivors enter the survivorship experience at varying levels of patient engagement and there are personal/demographic factors and/or survivorship outcomes which may contribute to this. Understanding these contributing factors is key to providing optimal SC. Thus, nursing education needs a framework where nurses can view patients as more than the sum of their parts or solely by their diagnosis and symptoms, but instead as irreducible human beings capable of a variety of responses to any given condition or experience.

Further, nursing education tends to focus on nursing care around single diseases. This study suggests multimorbidity was an important factor in cancer survivorship. The belief that people are greater than their disease and do not want to be labeled by their disease is consistent with the ideas in Rogers' (1992) Science of Unitary Human Beings and the work of Flanagan et al., (2016). This suggests nursing education should focus on the whole person and the entirety of their experiences rather than by parts that are not functioning.

Implications for policy. The policy implications from this dissertation include informing key stakeholders such as the oncology community, policy groups, health insurance providers and funding bodies regarding the concept of patient engagement, its contributing factors and its potential link to improved self-management. Given the link between personal/demographic and

survivorship outcomes to patient engagement, policy should focus on supporting research and programs aimed at understanding and increasing patient engagement in an effort to improve the effectiveness and efficiency of SC. Highly engaged survivors may be ready to move forward with SC interventions and programs, while less engaged survivors may require more resources and support to increase their level of engagement, and improve their survivorship outcomes. SC policy must reflect this patient-centered approach and abandon the one-size fits all SC models of the past. As this research is further developed and interventions are created to support patient engagement, it will be imperative to educate policy makers and insurers on the need to support patient engagement in cancer survivors.

Further, self-management policy and funding opportunities should be considered in light of this work. The National Institute of Nursing Research (NINR) is seeking to fund research related to self-management programs that "allow an individual and their provider to adapt treatments to individual circumstances by accounting for social, cultural, economic, and emotional factors that can influence their health and quality of life" (p.22) (NINR, 2016). Similarly, the ONS Research Agenda 2014-2018 (Knobf et al., 2015) suggested researchers focus on self-management intervention work and also "developing guidelines to promote and improve self-management outcomes in patients with cancer" (p. 24). Since the data from this study links HRQOL to patient engagement which could support survivor self-management, NINR and/or ONS funding could be used to further explore this relationship and interventions supporting patient engagement for improved self-management of SC.

Summary

In summary, this study provides an important first step in understanding the contributing factors to patient engagement in survivorship care. To this researcher's knowledge, it is the first

study to explore personal/demographic factors and survivorship outcomes and their contribution to patient engagement as measured by PAM and KPC. The findings from this study suggest that HRQOL predicted for both outcome variables and that education level and social support predicted for KPC. In addition, a number of demographic/personal factors and survivorship outcomes were found to be associated with PA and KPC. If engaged patients benefit more from SC (Mayer et al., 2016), identifying contributing factors to patient engagement is an important first step in determining which survivors are "ready" to engage in survivorship care interventions and which survivors may need a different level of support. This study provides a strong base from which to build upon to move the science forward with the ultimate goal of improving the lives of cancer survivors and their families.

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Appendix A

Consent Form



Boston College William F. Connell School of Nursing Informed Consent to be in the Many Voices, Many Needs: Understanding Life After Breast Cancer Study Researcher: Kathryn E. Post, PhD(c), RN, ANP-BC Adult Consent Form

Introduction:

You are being asked to be in a research study titled "Many Voices, Many Needs: Understanding Life After Breast Cancer". You were selected to be in the study because you are 18 years or older, have a history of Stage 0-III breast cancer and completed treatment within the last two years. People in this study are from all over the United States and were contacted through the Dr. Susan Love Army of Women Research Foundation or Craigslist.

Please read this form. Ask any questions that you may have before you agree to be in the study.

Purpose of the Study:

The purpose of this research is to gather information that will help researchers at Boston College understand the experiences of persons with breast cancer once treatment is complete.

What will happen in this study:

It is expected that about 303 people will participate in this study. This study will be conducted through this online survey with 63 questions. The survey should take you approximately 20 minutes to complete.

Risks and discomforts in the study:

There are no expected risks of participating in this survey. There are no costs to you associated with your participation and no known risks to you if you participate.

Benefits of being in the study:

Participation is not expected to directly benefit you, but you may feel gratified knowing that you helped further the scholarly work in this research area.

Payments:

If you choose to complete the survey, you will be compensated with a \$10 Amazon gift card.

Costs:

There is no cost to you to be in this research study.

Confidentiality:

This survey is anonymous. The Principal Investigator and study staff will not be able to connect you with the answers you provide. The survey responses will not have any identifying information (such as name or date of birth) attached when they arrive to the study team and will remain confidential if the research is later published in an academic journal. The data will be stored on a website which is encrypted and password protected. Please note that regulatory agencies, the Boston College Institutional Review Board, and Boston College internal auditors may review research records.

You will need to provide your email address to receive the Amazon gift card once you complete the survey. However, this will be done through a separate link not connected to your survey responses and your email address will be deleted from our records as soon as the gift card is sent to you. If you choose to provide us your contact information for future studies, this will also be done through a separate link not connected to your survey responses. You may contact us at any time in the future if you change your mind and we will delete your contact information immediately.

Choosing to be in the study and choosing to quit the study:

Your participation is voluntary. If you choose not to participate it will not affect your relations with Boston College. You are free to withdraw or skip questions for any reason. There are no penalties for withdrawing or skipping questions.

Getting dismissed from the study:

The researcher may dismiss you from the study at any time for the following reasons: (1) it is in your best interests (e.g. distress has resulted), (2) you have failed to comply with the study rules, or (3) the study sponsor decides to end the study.

Contacts and Questions:

If you have questions or concerns concerning this research you may contact the Principal Investigator Kathryn E. Post at 617-216-1744 or <u>postk@bc.edu</u>. This research is being supervised by Dr. Jane Flanagan, PhD, ANP-BC. She can be reached by email at <u>jane.flanagan@bc.edu</u> or by phone at 617-552-8949. If you have questions about your rights as a research participant, you may contact the Office for Research Protections, Boston College, at 617-552-4778 or <u>irb@bc.edu</u>.

This study was reviewed by the Boston College Institutional Review Board and its approval was granted on 05/02/2018.

If you agree to the statements above and agree to participate in this study, please press the "Consent Given" button below.

Statement of Consent:

• I have read (or have had read to me) the contents of this consent form. I have been encouraged to ask questions. I have received answers to my questions. I give my consent to be in this study. I have received (or will receive) a copy of this form.

Appendix B

Study Emails

Text for First Email Blast

Dear Army of Women Member,

You are receiving this email because you are a member of the Army of Women Research Foundation and a potential participant in the "Many Voices, Many Needs: Understanding Life After Breast Cancer" survey study. The study is looking to learn more about the experience of breast cancer survivorship from breast cancer survivors themselves. Your opinions are important and we want to hear from you! It usually takes about 15-20 minutes to complete the survey. **Participation is completely voluntary. Information will be collected without names, email addresses or any other individual identifiers, and therefore your responses cannot be linked to you. Participants must be 18 years of age or older to participate.**

We hope that you will participate. The findings will be used to inform future breast cancer survivorship care.

As a small "Thank You" for your time, at the end of the survey you can click on a separate link to **claim a \$10 Amazon gift card**. You will need to enter your first name and email address to claim the gift card. This site is completely separate from the survey website. The researchers will have email addresses for those who sign up for the gift cards, but they will not be able to link email addresses to survey responses.

We hope that you will consider participating in this survey. It's only with your help that our research can be successful. Thank you.

<LINK TO STUDY CONSENT AND SURVEY>

Very best wishes,

Kathryn E. Post, PhD(c), RN, ANP-BC

Doctoral Candidate

Boston College William F. Connell School of Nursing

Text for Second Email Blast

Dear Army of Women Member,

The "Many Voices, Many Needs: Understanding Life After Breast Cancer" is just a click away....

Your opinions and experiences are very important to us.

By participating, you can provide information that will help us design interventions and guide person-centered survivorship care for breast cancer survivors like you.

Again...participation is voluntary. Information will be collected without names, email addresses or any other individual identifiers, and therefore your responses cannot be linked to you. The survey should take about 15-20 minutes to complete.

As a small "thank you" for your time, at the end of the survey you can click on a separate link to **claim a \$10 Amazon gift card.** You will need to enter your name and email address to claim the gift card. This site is completely separate from the survey website. The researchers will have email addresses for those who claim the gift card, but they will not be able to link email addresses to survey responses.

The study is being conducted by Kathryn Post at the Boston College Connell School of Nursing. To participate, or for more information, please click on the link below.

<LINK TO CONSENT AND SURVEY>

Thank you for your time and consideration. It's only with your participation that our research can be successful.

Best,

Kathryn Post, PhD(c), RN, ANP-BC

Text for Craigslist Posting

Posting Title: "Life After Breast Cancer" - national survey volunteers needed!

The "Many Voices, Many Needs: Understanding Life After Breast Cancer" national survey study is looking to learn more about the experience of breast cancer survivorship from breast cancer survivors themselves. Your opinions are important and we want to hear from you! It usually takes about 15-20 minutes to complete the survey. **Participation is completely voluntary. Information will be collected without names, email addresses or any other individual identifiers, and therefore your responses cannot be linked to you. Participants must be 18 years of age or older to participate.**

We hope that you will participate. The findings will be used to inform future breast cancer survivorship care.

As a small "Thank You" for your time, at the end of the survey you can click on a separate link to **claim a \$10 Amazon gift card**. You will need to enter your first name and email address to claim the gift card. This site is completely separate from the survey website. The researchers will have email addresses for those who sign up for the gift cards, but they will not be able to link email addresses to survey responses.

We hope that you will consider participating in this survey. It's only with your help that our research can be successful. Thank you.

<LINK TO STUDY CONSENT AND SURVEY>

Very best wishes,

Kathryn E. Post, PhD(c), RN, ANP-BC

Doctoral Candidate

Boston College William F. Connell School of Nursing

Appendix C

Link for Amazon Gift Card

Thank you for participating in the "Many Voices, Many Needs: Understanding Life After Breast Cancer" survey study! We truly value your input and your time.

Please enter your email address below to receive your \$10 Amazon gift card via email. Once your gift card is sent, your email address will be deleted from our records. As a reminder, your email address cannot be connected to any of the information you provided in the survey. Thank you again for participating!!

Email Address:

FUTURE CONTACT

	No ▼	Yes ▼
 May we contact you within the next five years to participate in another similar study? 	D 0	
2. May we invite you to participate in a future research study with a group of fellow breast cancer survivors?	۵	
Today's date:		
Name:		
Street address:		
City, State, Zip		
Phone:		
E-mail address:		

***Please note that if at <u>any time now or in the future</u> you decide that you do not want to have your contact information stored or you do not want to be contacted for future studies, you can contact the Principal Investigator Kathryn Post, PhD(c) at <u>postk@bc.edu</u>, or 617-216-1744 to have your information removed from the database immediately.

Appendix D.

Results Tables

TABLE 1A.

Demographic Characteristics

Variable	п	%	Mean	SD	Confidence Interval
Age (in years)	265		50.70	14.01	49.01, 52.39
Race	287				
White	251	87.50			
Black/African American	16	5.60			
Asian	12	4.20			
Native American/Alaskan Native	1	0.30			
More than one race	4	1.40			
Unknown	2	0.70			
Prefer not to answer	1	0.30			
Ethnicity	286				
Hispanic or Latino	34	11.90			
Not Hispanic or Latino	247	86.40			
Unknown	1	0.30			
Prefer not to answer	4	1.40			
Sex	287				
Male	2	0.70			
Female	285	99.30			
Sex Orientation					
Straight	272	94.80			
Gay or Lesbian	6	2.10			
Bisexual/ Transgender/Gender Non-	6	2 10			
conforming/Queer	0	2.10			
Prefer not to answer	3	1.00			
Weight	281				
Underweight	31	10.90			
Normal weight	140	49.30			
Overweight	93	32.70			
Obese	16	5.60			
Morbidly Obese	1	0.40			
Prefer not to answer	3	1.10			
Employment status	282				
Employed Full Time	153	54.30			
Employed Part Time	28	9.90			
Retired	62	22.00			
Unemployed/seeking	4	1.40			
Unemployed/disabled	11	3.90			
Homemaker	17	6.00			
Student	1	0.40			
Other	5	1.80			
Prefer not to answer	1	0.40			

TABLE 1A. (cont.)

Demographic Characteristics

Variable	п	%	Mean	SD	Confidence Interval
Education	286				
9-11 th grade	1	0.30			
High School graduate/GED	7	2.40			
Vocation/Technical school graduate	20	7.00			
AD or Some College	46	16.10			
Bachelor's Degree	115	40.20			
Master's Degree	78	27.30			
Terminal Degree (JD, MD, PhD, etc.)	18	6.30			
Other	1	0.30			
Income					
0-\$50,000	40	16.00			
\$50,001-\$75,000	40	16.00			
\$75,001-\$100,000	68	27.20			
\$100,001-\$150,000	59	23.60			
More than \$150,001	43	17.20			
Health Insurance	284				
Insured	281	98.90			
Uninsured	3	1.10			
US Region	245				
Northeast	57	23.30			
South	61	24.90			
Midwest	55	22.40			
West	72	29.40			

TABLE 2A.

Health History					
Variable	п	%	Mean	SD	Confidence Interval
Stage at Diagnosis	285				
Stage 0	26	9.10			
Stage 1	147	51.60			
Stage 2	89	31.20			
Stage 3	23	8.10			
Hormonal Therapy	285				
Yes	201	70.50			
No	84	29.50			
Chemotherapy	298				
Yes	156	52.30			
No	142	47.70			
1st Degree Relative with Breast Cancer	298				
None	174	58.40			
1	108	36.20			
2	14	4.70			
3	1	0.30			
4	1	0.30			
Comorbidities	298				
0	92	30.90			
1	87	29.20			
2	47	15.80			
3	38	12.80			
4 or more	14	11.30			
Concomitant Medications	185				
0	66	35.70			
1	45	24.30			
2	30	16.20			
3	21	11.40			
4	8	4.30			
5	5	2.70			
6	4	2.20			
9	2	1.10			
10	3	1.60			
12	1	0.50			
Hot Flashes	298				
Yes	166	55.70			
No	132	44.30			
Hot Flash Frequency	131				
1-5/day	83	63.40			
6-10/day	33	25.20			
11-15/day	12	9.20			
>15/day	3	2.30			
Exercise minimum 150 mins/week	283				
Yes	204	72.10			
No	79	27.90			

 TABLE 2A. (cont.)

 Health History

Treatin Thistory					
Variable	n	%	Mean	SD	Confidence Interval
Caregiver Status	281				
Yes	101	35.90			
No	180	64.10			
Social Support	298				
Yes	218	76.50			
No	67	23.50			
Smoking Status	283				
Current Smoker	34	12.00			
Current Non-smoker	249	88.00			
Alcohol consumption per day	282				
0 drinks/day	211	74.80			
1-2 drinks/day	62	22.00			
3-4 drinks/day	9	3.20			
Alcohol consumption per week	285				
0 drinks/week	136	47.70			
1-4 drinks/week	106	37.20			
5-10 drinks/week	35	12.30			
11 or more drinks/week	8	2.80			
Survivorship Care Plan receipt	280				
Yes	125	44.60			
No	115	41.10			
Don't Know	40	14.30			

TABLE 3A.

FACT-G7					
Item	п	%	Mean	SD	Confidence Interval
FACTG Sum	295		17.57	4.96	17.01, 18.14
I have a lack of energy.	294		1.66	1.02	
0 - Not at all	42	14.30			
1 - A little bit	86	29.30			
2 – Somewhat	106	36.10			
3 – Quite a bit	51	17.30			
4 – Very much	9	3.10			
I have pain.	293				
$\hat{0}$ – Not at all	64	21.80			
1 – A little bit	102	34.80			
2 – Somewhat	58	19.80			
3 – Quite a bit	51	17.40			
4 – Very much	18	6.10			
I have nausea.	292				
0 - Not at all	161	55.10			
1 – A little bit	40	13.70			
2 – Somewhat	51	17.50			
3 – Quite a bit	27	9.20			
4 – Very much	13	4.50			
I worry that my condition will get worse.	295				
0 - Not at all	47	15.90			
1 - A little bit	85	28.80			
2 – Somewhat	85	28.80			
3 – Quite a bit	53	18.00			
4 – Very much	25	8.50			
I am sleeping.	293				
0 - Not at all	11	3.80			
1 - A little bit	38	13.00			
2 – Somewhat	117	39.90			
3 – Quite a bit	89	30.40			
4 – Very much	38	13.00			
I am able to enjoy life.	293				
0 - Not at all	9	3.10			
1 – A little bit	26	8.90			
2 – Somewhat	88	30.00			
3 – Quite a bit	93	31.70			
4 – Very much	77	26.30			
I am content with the quality of my life right now.	294				
0 - Not at all	12	4.10			
1 - A little bit	32	10.90			
2 – Somewhat	98	33.30			
3 – Quite a bit	101	34.40			
4 – Very much	51	17.30			

TABLE 4A.

FCRI SF.					
Item	n	%	Mean	SD	Confidence Interval
FCRI Sum	293		11.77	5.59	11.13, 12.41
I am worried or anxious about the possibility of	204				
cancer recurrence.	294				
0 - Not at all	76	25.90			
1 - A little	89	30.30			
2 – Somewhat	75	25.50			
3 - A lot	52	17.70			
4 – A great deal	2	0.70			
I am afraid of cancer recurrence.	291				
0 - Not at all	75	25.80			
1 – A little	79	27.10			
2 – Somewhat	76	26.10			
3 - A lot	55	18.90			
4 – A great deal	6	2.10			
I believe it is normal to be worried or anxious about	202				
the possibility of cancer recurrence.	293				
0 - Not at all	18	6.10			
1 - A little	47	16.00			
2 – Somewhat	140	47.80			
3 - A lot	79	27.00			
4 – A great deal	9	3.10			
When I think about the possibility of cancer					
recurrence, this triggers other unpleasant thoughts or	292				
images.		2 0.10			
0 - Not at all	82	28.10			
1 - A little	56	19.20			
2 – Somewhat	85	29.10			
3 - A lot	61	20.90			
4 – A great deal	8	2.70			
I believe that I am cured and that the cancer will not	291				
come back.	80	20.00			
0 - Not at all	89 01	30.00			
1 - A induce	81 72	27.80			
2 - Somewhat	12	24.70			
3 - A lot	40	15.80			
4 - very mucn	3	1.00			
recurrence?	291				
0 - Not at all	12	4.10			
1 – A little	92	31.60			
2 – Somewhat	129	44.30			
3 - A lot	50	17.20			
4 – A great deal	8	2.70			

TABLE 4A. (cont.)

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FCRIS	SF

Item	n	%	Mean	SD	Confidence Interval
How often do you think about the possibility of a	201				
cancer recurrence?	291				
0 - Never	28	9.60			
1 - A few times a month	119	40.90			
2 - A few times a week	103	35.40			
3 - A few times a day	34	11.70			
4 – Several times a day	7	2.40			
How much time per day do you spend thinking about the possibility of cancer recurrence?	293				
0 - I don't think about it	55	18.80			
1 - A few seconds	90	30.70			
2 - A few minutes	122	41.60			
3 - A few hours	20	6.80			
4 – Several hours	6	2.00			
How long have you been thinking about the possibility of cancer recurrence?	293				
0 - I don't think about it	40	13.70			
1 - A few weeks	53	18.10			
2 - A few months	116	39.60			
3 - A few years	68	23.20			
4 – Several years	16	5.50			
5					

TABLE 5A.

CHLT-6.			
Item	п	%	
CHLT Adequate or Limited	290		
CHL Adequate	199	31.40	
CHL Limited	91	68.60	
The normal range for hemoglobin for a male is 13.3-			
17.2g/dl. Joe's hemoglobin is 9.7g/dl. Is Joe within	289		
the normal range?			
1 - Yes	64	22.10	
2 - No	225	77.90	
A biopsy of a tumor is done to	290		
1 – Remove it	39	13.40	
2 – Diagnose it	227	78.30	
3 – Treat it	24	8.30	
If a patient has a stage 1 cancer, it means the cancer	•		
is	289		
1 – Localized	240	83.00	
2 – In nearby organs	40	13.80	
3 – In distant sites	9	3.10	
The role of the physical therapist is to talk to a	200		
patient about emotional needs.	289		
1 – True	82	28.40	
2 – False	207	71.60	
A tumor is considered "inoperable" when it cannot	200		
be treated with	289		
1 – Radiation	57	19.70	
2 – Surgery	224	77.50	
3 – Chemotherapy	8	2.80	
Sally will get radiation therapy once a day, Monday			
through Friday. If Sally has therapy for 4 weeks,	290		
how many times will she get radiation therapy?			
1 - 5	37	12.80	
2 - 15	27	9.30	
3 - 20	226	77.90	

TABLE 6A.

Itemn%MeanSDConfidence IntervalPAM Level2943.030.822.94, 3.12PAM Level2892892.94, 3.12 $0 - NA$ 00.000.011 - Disagree Strongly10.302 - Disagree93.103 - Agree9633.204 - Agree Strongly18363.301 - Disagree Strongly10.302 - Disagree Strongly10.301 - Disagree Strongly10.302 - Disagree206.903 - Agree9633.304 - Agree Strongly10.302 - Disagree Strongly10.301 - Disagree Strongly10.302 - Disagree206.903 - Agree9633.304 - Agree Strongly1059.001 know what each of my prescribed medications do.2880 - N/A124.201 - Disagree Strongly00 - N/A124 - Agree Strongly101 - Disagree Strongly21 - Disagree Strongly21 - Disagree Strongly21 - Disagree Strongly102 - Disagree371 - Disagree Strongly21 - Disagree Strongly21 - Disagree Strongly21 - Disagree Strongly21 - Disagree Strongly1083 - Agree384 - Agree Strongly1083 - Agree <td< th=""><th>PAM 10</th><th></th><th></th><th></th><th></th><th></th></td<>	PAM 10					
PAM Level 294 3.03 0.82 $2.94, 3.12$ When all is said and done, I am the person who is responsible for taking care of my health. 0 0.00 $0 - N/A$ 0 0.00 $1 - \text{Disagree Strongly}$ 1 0.30 $2 - \text{Disagree}$ 96 33.20 $4 - \text{Agree Strongly}$ 183 63.30 Taking an active role in my own health care is the most important thing that affects my health. 0 0.00 $0 - N/A$ 1 0.30 $ 2 - \text{Disagree Strongly}$ 1 0.30 $ 2 - \text{Disagree Strongly}$ 1 0.30 $ 2 - \text{Disagree Strongly}$ 10 0.00 $ 4 - \text{Agree Strongly}$ 12 4.20 $ 1 - \text{Disagree Strongly}$ 0 0.00 $ 2 - \text{Disagree}$ 16 5.60 3.4 $3 - \text{Agree Strongly}$ 155 53.80 $ 1 = \text{Disagree Strongly}$ 2 0.70 2 $0 - N/A$ 2 0.70 2 <tr< th=""><th>Item</th><th>n</th><th>%</th><th>Mean</th><th>SD</th><th>Confidence Interval</th></tr<>	Item	n	%	Mean	SD	Confidence Interval
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responsible for taking care of my health. 209 0 - N/A 0 0.00 1 - Disagree Strongly 1 0.30 2 - Disagree 9 3.10 3 - Agree 96 33.20 4 - Agree Strongly 183 63.30 Taking an active role in my own health care is the most important thing that affects my health. 288 0 - N/A 1 0.30 2 - Disagree Strongly 1 0.30 2 - Disagree Strongly 1 0.30 2 - Disagree Strongly 10 0.30 2 - Disagree Strongly 170 59.00 1 know what each of my prescribed medications do. 288 0 - N/A 12 4.20 1 - Disagree Strongly 10 0.00 2 - Disagree 16 5.60 3 - Agree 105 36.50 4 - Agree Strongly 155 53.80 1 am confident that I can tell whether I need to go to the doctor or whether I can take care of a health 287 0 - N/A 2 0.70 1 - Disagree Strongly 1083 7.60 1 am co	When all is said and done, I am the person who is	280				
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	responsible for taking care of my health.	289				
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I am confident that I can tell a doctor concerns I have even when he or she does not ask. 286 $0 - N/A$ 3 $1 - Disagree Strongly$ 1 $2 - Disagree$ 33 $3 - Agree$ 83 $4 - Agree Strongly$ 166 58.00 I am confident that I can follow through on medical 289	4 – Agree Strongly	108	37.60			
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$\begin{array}{ccccccc} 0 - N/A & 3 & 1.00 \\ 1 - Disagree Strongly & 1 & 0.30 \\ 2 - Disagree & 33 & 11.50 \\ 3 - Agree & 83 & 29.00 \\ 4 - Agree Strongly & 166 & 58.00 \\ 1 \text{ am confident that I can follow through on medical} \\ 289 \end{array}$	even when he or she does not ask.	200				
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2 - Disagree3311.503 - Agree8329.004 - Agree Strongly16658.00I am confident that I can follow through on medical289	1 – Disagree Strongly	1	0.30			
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4 – Agree Strongly 166 58.00 I am confident that I can follow through on medical 289	3 – Agree	83	29.00			
I am confident that I can follow through on medical 289	4 – Agree Strongly	166	58.00			
4 + 4 + 1 = 14 + 1 + 1 = 207	I am confident that I can follow through on medical	289				
treatments 1 may need to do at home.	treatments I may need to do at home.	207				
0 - N/A 6 2.10	0 - N/A	6	2.10			
1 – Disagree Strongly 3 1.00	1 – Disagree Strongly	3	1.00			
2 – Disagree 11 3.80	2 – Disagree	11	3.80			
3 – Agree 90 31.10	3 – Agree	90	31.10			
4 – Agree Strongly 179 61.90	4 – Agree Strongly	179	61.90			

TABLE 6A. (cont.)

Item	п	%	Mean	SD	Confidence Interval
I have been able to maintain (keep up with) lifestyle	289				
changes, like eating right or exercising.	207				
0 - N/A	5	1.70			
1 – Disagree Strongly	9	3.10			
2 – Disagree	47	16.30			
3 – Agree	107	37.00			
4 – Agree Strongly	121	41.90			
I know how to prevent problems with my health.	288				
0 - N/A	3	1.00			
1 – Disagree Strongly	5	1.70			
2 – Disagree	26	9.00			
3 – Agree	169	58.70			
4 – Agree Strongly	85	29.50			
I am confident I can figure out solutions when new	285				
problems arise with my health.	205				
0 - N/A	1	0.40			
1 – Disagree Strongly	4	1.40			
2 – Disagree	41	14.40			
3 – Agree	149	52.30			
4 – Agree Strongly	90	31.60			
I am confident that I can maintain lifestyle changes,					
like eating right and exercising, even during times of	288				
stress.					
0 - N/A	3	1.00			
1 – Disagree Strongly	7	2.40			
2 – Disagree	55	19.10			
3 – Agree	114	39.60			
4 – Agree Strongly	109	37.80			

TABLE 7A.

KPC SF					
Item	n	%	Mean	SD	Confidence Interval
KPC Sum Score	278		62.47	11.00	61.18, 63.77
In relation to breast cancer, my AWARENESS is	283				
1 – Unpleasant	39	13.80			
2 -	65	23.00			
3 –	33	11.70			
4 –	104	36.70			
5 -	42	14.80			
6 -	0	0.00			
7 – Pleasant	0	0.00			
In relation to breast cancer, my AWARENESS is	285				
1 – Unimportant	3	1.10			
2 -	4	1.40			
3 –	29	10.20			
4 –	27	9.50			
5 –	33	11.60			
6 -	60	21.10			
7 – Important	129	45.30			
In relation to breast cancer, my AWARENESS is	279				
1 – Avoiding	5	1.80			
2 -	14	5.00			
3 –	29	10.40			
4 –	58	20.80			
5 -	52	18.60			
6 -	57	20.40			
7 – Seeking	64	22.90			
In relation to breast cancer, my CHOICES are	281				
1 – Shrinking	9	3.20			
2 -	10	3.60			
3 –	30	10.70			
4 –	74	26.30			
5 –	62	22.10			
6 –	49	17.40			
7 – Expanding	47	16.70			
In relation to breast cancer, my CHOICES are	287				
1 – Informed	0	0.00			
2 –	0	0.00			
3 –	27	9.40			
4 –	42	14.60			
5 –	31	10.80			
6 -	80	27.90			
7 – Uninformed	107	37.30			

 TABLE 7A. (cont.)

 KPC SE

N'U SI					
Item	n	%	Mean	SD	Confidence Interval
In relation to breast cancer, my CHOICES are	282				
1 – Intentional	0	0.00			
2 –	0	0.00			
3 –	35	12.40			
4 –	40	14.20			
5 –	36	12.80			
6 -	70	24.80			
7 – Unintentional	101	35.80			
In relation to breast cancer, my FREEDOM TO ACT INTENTIONALLY is	283				
1 - free	0	0.00			
2 –	0	0.00			
3 -	45	15.90			
4 –	58	20.50			
5 -	29	10.20			
6 -	69	24.40			
7 - constrained	82	29.00			
In relation to breast cancer, my FREEDOM TO ACT INTENTIONALLY is	283	_,			
1 – valuable	0	0.00			
2 –	0	0.00			
3 –	40	14.10			
4 –	46	16.30			
5 –	23	8.10			
6 -	52	18.40			
7 - worthless	122	43.10			
In relation to breast cancer, my FREEDOM TO ACT INTENTIONALLY is	279				
1 – profound	0	0.00			
2 –	0	0.00			
3 –	47	16.80			
4 –	48	17.20			
5 –	30	10.80			
6 -	72	25.80			
7 – superficial	82	29.40			
In relation to breast cancer, my INVOLVEMENT IN CREATING CHANGE is	283				
1 – timid	4	1.40			
2 –	12	4.20			
3 –	23	8.10			
4 –	55	19.40			
5 -	78	27.60			
6 -	67	23.70			
7 – assertive	44	15.50			

TABLE 7A. (cont.)

 KPC SF

KI C SI					
Item	n	%	Mean	SD	Confidence Interval
In relation to breast cancer, my INVOLVEMENT IN CREATING CHANGE is	285				
1 - leading	0	0.00			
2 -	0	0.00			
3 -	44	15.40			
4-	71	24.90			
5 –	53	18.60			
6 –	65	22.80			
7 – following	52	18.20			
In relation to breast cancer, my INVOLVEMENT IN CREATING CHANGE is	282				
1 – chaotic	3	1.10			
2 -	13	4.60			
3 –	20	7.10			
4 –	72	25.50			
5 –	74	26.20			
6 -	68	24.10			
7 – orderly	32	11.30			

Appendix E

Knowing Participation in Change Copyright Email

From: Violet Malinski <vmalinski@optimum.net>

Date: Wed, Mar 14, 2018 at 1:44 PM

Subject: Re: KPC Theory Image

To: Kathryn Post <postk@bc.edu>

Cc: Violet Malinski </ vmalinski@optimum.net>

Hello Ms. Post,

Yes, you may use the diagram with appropriate citation. Regards,

Violet Malinski, RN;PhD

On Mar 13, 2018, at 5:24 PM, Kathryn Post cpostk@bc.edu> wrote:

Hello Dr. Malinski,

I am a doctoral student working with Dr. Jane Flanagan at Boston College and I am writing to ask for permission to use the PKPC Theory copyrighted image in my dissertation. I am a nurse practitioner caring for breast oncology patients and my area of research will be in cancer survivorship. My dissertation study is going to be an exploratory web-based survey study looking to understand more about the experience of breast cancer survivorship. I would now like to use the image of Dr. Barrett's theory in the dissertation itself. I wrote to Dr. Barrett who directed me to you. Could you let me know if I could be granted permission to use this image? Thank you for considering this and please let me know if you have further questions.

Best,

Kathryn Post, PhD(c), RN, ANP-BC