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Celestine G. Gochett *University of Kentucky,* cgmg3@yahoo.com

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PSYCHOLOGICAL WELL-BEING AMONG BREAST CANCER SURVIVORS: FACTORS THAT INFLUENCE TRANSITION FROM PRIMARY TREATMENT TO EARLY SURVIVORSHIP

DISSERTATION

A dissertation submitted in partial fulfillment of the Requirements for the degree of Doctor of Philosophy in the College of Nursing at the University of Kentucky

By

Celestine G. Gochett Lexington, Kentucky Director: Dr. Dorothy A. Brockopp, Professor of Nursing Lexington, Kentucky 2015

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ABSTRACT OF DISSERTATION

PSYCHOLOGICAL WELL-BEING AMONG BREAST CANCER SURVIVORS: FACTORS THAT INFLUENCE TRANSITION FROM PRIMARY TREATMENT TO EARLY SURVIVORSHIP

Eudaimonic psychological well-being (PWB) refers to a lifelong process of purposeful engagement in goal-driven tasks or activities resulting in positive psychological functioning. These activities reflect autonomy, purpose in life, self-acceptance, personal growth, positive relations with others, and environmental mastery. While more women are surviving breast cancer, they face a multitude of late and long term physiopsychosocial challenges that result from being diagnosed and treated. Protective health effects associated with the experience of PWB can potentially mitigate ill-being and benefit overall health of breast cancer survivors (BCS). Adequate preparation by healthcare teams to transition them from primary treatment to early survivorship is critical for the immediate and long term PWB of BCS.

The purpose of this dissertation was to: 1) summarize current literature addressing PWB among BCS; 2) describe the helpfulness of information BCS satisfied and dissatisfied receive from their healthcare team to prepare to transition into life immediately after treatment; and 3) examine relationships between PWB and factors that negatively influence BCS' ability to successfully transition to early survivorship

Three manuscripts describe results of data analysis. From a literature review, factors that correlate with PWB among BCS were identified: coping, social support, self-esteem, post-traumatic growth, religious struggles and the impact of physical symptoms. Based on qualitative responses, BCS who are satisfied and dissatisfied with information received to prepare for transition into early survivorship emphasized the importance of receiving comprehensive information on: (1) what to expect physically and emotionally post-treatment, and (2) how their lives moving forward will be unlike their lives prior to being diagnosed. Among a convenience sample of 56 BCS, significant negative relationships between PWB and a) cancer problems frequently experienced by early survivors of breast cancer, b) psychological distress, and c) satisfaction with information received to transition from primary treatment into early survivorship was noted from a prospective, cross-sectional research design study. PWB is becoming increasingly important given that BCS live longer. Information learned from this dissertation can be



used by healthcare teams to promote or maintain positive psychological functioning among these survivors, focusing initially on preparing them for life immediately after treatment.

KEYWORDS: Breast cancer survivors, Cancer survivorship, Eudaimonic well-being, Ryff's scales of psychological well-being, Positive psychological functioning

> Celestine G. Gochett Student's Signature

<u>May 8, 2015</u> Date



PSYCHOLOGICAL WELL-BEING AMONG BREAST CANCER SURVIVORS: FACTORS THAT INFLUENCE TRANSITION FROM PRIMARY TREATMENT TO EARLY SURVIVORSHIP

By

Celestine G. Gochett

Dr. Dorothy A. Brockopp Director of Dissertation

Dr. Terry Lennie Director of Graduate Studies

May 8, 2015



"You beat cancer by how you live, why you live and in the manner in which you live". Stuart Scott ESPY Speech, 2014

This dissertation is dedicated to those individuals most affected by cancer, their loved ones, and the cancer care clinicians who are passionate about serving this unique group of people. All of you have helped me learn what it really means to be humble. To my father, Bishop James K. Mitchell, Jr. who dedicated his life to serving Christ and subsequently touched a countless number of lives. I want to say to you that cancer may have taken your body away but it did not take your legacy; that will live on forever.



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Chapter One

Introduction

Psychological well-being (PWB), in general, refers to psychological functioning. It provides a broader platform, than traditional approaches, to determine the health of individuals living with chronic diseases, such as breast cancer. This is not to say that the ladder approach is not useful. Monitoring the health of breast cancer survivors (BCS) from a perspective that measures extremes of illness or degrees of impairment has provided clinicians with valuable information. However, such traditional approaches have failed to capture a comprehensive assessment of their lives surviving the impact of untoward disease and treatment-related outcomes.

More BCS are living longer while experiencing negative effects. BCS currently make up 41% of the 41.5 million cancer survivors alive today and experts estimate that this group will continue to make up a significant proportion of the overall cancer survivor population in the future (ACS, 2013). Unfortunately, most of these women will have to live with one or multiple deleterious physiopsychosocial effects that result from the tumor, its treatment or a combination of both for the balance of their lives. Hot flashes, fear of recurrence, fatigue, uncertainty, peripheral neuropathy, existential distress, cognitive dysfunction, sleep disturbance, weakness, lymphedema, sexual dysfunction, financial concerns, debt and weight changes are just some of the cancer-related problems more than half of BCS report experiencing as far out as 20 years or so after treatment (Brem & Kumar, 2011; Kenyon, Mayer & Owens, 2014; Ness et al., 2013; Schmitz et al., 2012). In addition, BCS associate most of these problems with their inability to complete



home and work related tasks. Subsequently, sub-optimal work performance and loss of income affects them and their families (Banning, 2011; Chirikos, 2001; Yu et al., 2012).

In 2006, the Institute of Medicine (IOM) released a seminal report addressing cancer survivorship. It emphasized the lack of attention cancer care clinicians had given to monitoring the "toll taken by both cancer and its treatment – on …the functioning and well-being" of survivors (IOM, p.1). Further, it identified the time immediately after treatment (early survivorship) as critical to begin monitoring their health, assisting with the facilitation of a successful transition into living with cancer (IOM).

Descriptive accounts of women surviving this disease further support why evaluations of their health stemming from a positive functioning framework better reflects their ability to live within the context of cancer. They consistently acknowledge that while physiopsychosocial effects of treatment linger beyond the end of treatment and are problematic, they continue to live and do not allow the negative experience of cancer to completely consume their lives (Allen, Savadatti & Levy, 2009; Lethborg et al., 2000; Mollica & Nemeth, 2014; Sadler-Gerhardt et al., 2010). Therefore, using an indicator of health, such as PWB, that evaluates the survivor's ability to continue to engage in life while experiencing cancer-related problems is more aligned with their accounts of surviving the disease as well as the aim of organizations committed to improving their quality of life.

Theoretical Framework

There are two perspectives of PWB (psychological functioning) predominant in the literature: hedonic and eudaimonic. These perspectives differ based on interpretations of philosophical writings according to Aristotle (Ryff & Singer, 2008). Hedonic theorist



define PWB as life satisfaction and happiness and purports that happiness results from an individuals' ability to balance positive and negative affect (Ryan & Deci, 2001). Using measures of subjective well-being, this perspective values subjective evaluations of what makes one satisfied and happy. However, this thought process has been challenged by critics; their main concern being the possibility that one may determine to seek satisfaction and happiness through activities that may not be good for the individual and/or society (Ryan & Deci, 2001).

Ryff (1989), a critic of traditional determinates of health based solely on physical ill-being as well as hedonic well-being, proposed eudaimonic well-being as an alternative. Eudaimonia, according to Ryff, represents innate abilities unique to each individual; through a lifelong process of self-realization and actualization each individual becomes capable of reaching their life's potential. Ryff also contends that engagement in purposeful, goal-driven life tasks or activities become the avenue by which the process of knowing who you are and perfecting it occurs. Full engagement in life activities associated with eudaimonic well-being result in optimal positive psychological functioning. Viewed from this perspective, both the individual and society benefits as a result of the individual experiencing PWB.

Eudaimonic PWB diverges from that of the Hedonic perspective on one other point. Ryff (1989) proposed a theoretical framework for PWB while a framework for hedonic well-being has not been made available. Using shared features of positive psychological functioning described among developmental, existential and humanistic theories, Ryff operationalized Eudaimonic PWB into six related but distinct dimensions of life activities: (1) autonomy, (2) purpose in life, (3) self-acceptance, (4) personal



growth, (5) positive relationships with others, and (6) environmental mastery (see Table 1.1 for description of each dimension). Together, these dimensions make up the Scales of Psychological Well-being (SPWB).

Focus of Dissertation

This dissertation will focus on Eudaimonic PWB among BCS and factors thought to effect their transition from primary treatment to early survivorship. To date, 5-year relative survival rates for BCS diagnosed with regional or local disease are 86% and 99%, respectively (ACS, 2013). Given the increasing length of survivorship, an interest in how women deal with the sequelae of their disease in terms of positive functioning is of considerable interest. Eudaimonic PWB, operationalized by the SPWB, provides a framework capable of reflecting the survivors' ability to continue to engage in activities of life while experiencing cancer.

It is important to not only understand the PWB of BCS but to also gain insight into factors that might affect their PWB during a critical time that can have lasting effects the balance of their lives. There is a paucity of literature addressing PWB from a Eudaimonic perspective among BCS during early survivorship. This dissertation, comprised of three manuscripts (Chapters Two, Three and Four), was designed to add to this limited body of evidence.

A prospective, cross-sectional research proposal that includes a qualitative and quantitative component was developed. Once IRB approval was obtained, potential participants, drawn from two local community hospital-based cancer centers, were mailed survey packets. Fifty-six BCS returned completed questionnaires. The sample was representative of middle-aged, Caucasian women who were well-educated and financial



viable. Just under half were employed at the time of data collection. Clinically, the majority of the sample were diagnosed at an early stage and were within 6 months of completing treatment with either radiation therapy alone, chemotherapy alone, or combined treatment modality with both radiation therapy and chemotherapy.

Overview of Chapters Two, Three, and Four

Chapter Two outlines the findings of a review conducted to summarize the current body of literature addressing PWB according to Ryff's Eudaimonic approach among BCS. A total of 12 studies are included. The research design of all 12 consisted of aspects that evaluated relationships between PWB (using the SPWB) and factors thought to be associated with it. These factors included coping mechanisms, social support, selfesteem, level of gratitude, post-traumatic growth and physical symptoms.

Satisfaction with preparatory information BCS receive to transition to early survivorship is a factor thought to correlate with PWB. Therefore, it is important for cancer care clinicians to fully understand the helpfulness of the information. Open-ended survey questions, presented in Chapter Three, were used to elicit qualitative responses from the women. BCS were asked to determine if they were satisfied with information received to transition and, responding to questions included in an investigator developed questionnaire, describe the helpfulness of the information (Appendix A includes an example of this questionnaire). Responses to the open-ended survey questions were analyzed using content manifest and summative analysis. A total of 14 categories of information emerged from the text data. Information most frequently described as helpful was common for both groups of survivors (those satisfied and those not satisfied with preparatory information).



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In order to add to the current body of research addressing Eudaimonic PWB among BCS during early survivorship, the quantitative component of the research proposal was designed to examine the relationship between PWB and factors thought to correlate with it as BCS transition from primary treatment. In Chapter Four, the correlation coefficients between PWB and a) the burden of cancer problems frequently experienced by early survivors of breast cancer, b) psychological distress, and c) satisfaction with information received by healthcare teams to transition from primary treatment into early survivorship are presented.

Dissertation Conclusion

Relevant research findings from this dissertation are summarized in Chapter Five. Suggestions for future research and how findings from this dissertation can be used by cancer care clinicians are discussed as well.



Table 1.1

Description of Ryff's Six Psychological Well-being Dimensions

Dimension	Description of Positive Psychological Functioning Activity
Autonomy	Individual is independent and able to resist social pressures; regulates their own behavior; and evaluates self by personal values and standards.
Purpose in Life	Individual self-selects to pursue their life goals; believes that life has meaning and that there is a purpose for their life.
Self-Acceptance	Individual thinks positive about their self and their life; accepts both of their good and bad qualities.
Personal Growth	Individual engages in life long process of growth and development to realize their potential in life; is open to new opportunities.
Positive Relationships with Others	Individual is able to negotiate and participate in warm and trusting relationships with others; displays empathy and affection toward others.
Environmental Mastery	Individual feels they are competent and have mastered their surroundings; is in control of external environment.



Chapter Two

Psychological Well-being among Breast Cancer Survivors:

A Literature Review

There are two predominant views on psychological well-being (PWB); the Hedonic and the Eudaimonic. The Hedonic view defines well-being as life satisfaction and happiness that represents a balance between the experience of positive and negative emotions (Ryan & Deci, 2001). Eudaimonic well-being refers to psychological functioning as a result of engagement in life to one's highest potential. Eudaimonia is a guiding life principle that places ownership on each individual to live life being the best they can be; continuously realizing and perfecting innate unique abilities (Ryff & Singer, 2008). Thus the premise of eudaimonic PWB, constructed from developmental, existential and humanistic theories, is that positive psychological functioning is much less about absence of illness and much more about purposeful engagement in multiple lifelong activities that can help one live a full productive life (Ryff & Singer, 1998). When the individual perceives that the life they live is a mirror image of their greatest potential, optimal PWB results (Ryan & Deci; Ryff & Singer).

Ryff contends that it makes more sense to evaluate health from eudaimonic PWB because as long as an individual is alive, life and activities of living are constants while biological and even social stressors are not (Ryff & Singer, 1998). She further emphasizes that when stressors do occur they can positively or negatively impact how well one functions psychologically. This position originated from an intricate, physiopsychosocial interaction previously proposed as a plausible approach to understand and treat disease over 40 years ago (Engel, 1977; Parkes, 1971; Ryff & Singer). Given



this philosophical approach to health and well-being, measuring health as simply an extreme of physical illness or degree of impairment points to the fact that there is more to health than the absence of illness. Ryff's approach to well-being, termed PWB therefore, serves as a more accurate indicator of health because it takes into account the subjective perception of an individual's ability to continue to engage in life while facing unavoidable life stressors such as physical disease/illness. This review is focused on research conducted from Ryff's eudaimonic perspective.

Using PWB as an indicator of health is particularly appropriate for most breast cancer survivors (BCS). Breast cancer is a complex, multifaceted, unpredictable and lifethreatening disease that survivors identify as a significant life stressor from the moment of diagnosis to survivorship (Kangas, Henry & Bryant, 2002; Kenyon, Mayer & Owens, 2014; Vin-Raviv et al., 2013). Research on breast cancer has led to life preserving screening strategies as well as individualized treatments that enable the majority of survivors who are diagnosed at early stages to live five or more years following diagnosis (ACS, 2013). Given the increasing length of survivorship, an interest in how women deal with the sequelae of their disease in terms of their well-being is of considerable interest.

While survivorship continues to increase (DeAngelis et al., 2009), healthcare providers' abilities to adequately address the physiopsychosocial complications resulting from the diagnosis, disease, its treatment or a combination of these factors post-treatment is limited. Women report experiencing late and long-term side effects and symptoms such as fatigue, weakness, lymphedema, pain, cognitive dysfunction, fear of recurrence, anxiety and depression to name a few (Banning, 2011; Kenyon et al., 2014; Ness et al., 2013). In addition, these complications contribute to their difficulties associated with



completing home and work related tasks. Possible loss of income as a result of suboptimal work performance further compounds post-treatment challenges these women and their families face (Banning; Chirikos, 2001; Yu et al., 2012). These factors may or may not impact the PWB of these women.

Ryff (1989) operationalized PWB as six dimensions of distinct but related life activities that are reflective of a positive, psychological functioning life. These dimensions make up the Scales of Psychological Well-being (SPWB) and include activities associated with being independent, having a purpose in life, self-acceptance, personal growth and development, having positive relations with others, and mastering one's environment (Ryff & Singer, 1998). According to Ryff and Singer (2008), "progress toward understanding positive human health follows from first assessing human flourishing...formulated within the eudaimonic tradition" (2008, p.31). Thus the purpose of this review is to summarize current literature addressing PWB among BCS according to Ryff's eudaimonic approach.

Methods

A literature search was conducted using CINAHLwith full text, PsycINFO, PubMed Cancer literature, Psychology and Behavioral Sciences Collection and ProQuest databases for English articles and dissertations evaluating eudaimonic PWB in the BCS population. No geographic limitations were placed on the search. The following terms were entered into the title or text search fields either alone or in combination: psychological, well-being, eudaimoni*, mental, health, positive, adjustment, adaptation, post-traumatic, growth, scale*, breast, cancer, neoplasm* and Ryff. From the literature search, a total of 21 articles were identified. Twelve of these articles met the criteria. Figure 2.1 is a flow chart outlining the article selection process.



Results

Study Characteristics

A complete description of the study characteristics are outlined in Table 2.1. In summary, a descriptive, cross-sectional design was used in each of the studies reviewed. Sample sizes ranged from 18 to 192. The mean age of study participants was reported in 11 of the 12 studies and ranged from 48 (Holland & Holahan, 2003) to 74 years old (Heidrich, Egan, Hengudomsub & Randolph, 2006). In all studies survivors with both non-invasive and invasive neoplasms were enrolled after completing treatment consisting of surgery, radiation, and chemotherapy either alone or in combination. One study enrolled just under half (46%) of their subjects while undergoing active treatment (Holland& Holahan) and 10 studies reported the use of long-term hormonal therapy in their sample (Carpenter, 1997; Carpenter, Brockopp & Andrykowski, 1999; Cordova, Cunningham, Carlson & Andrykowski, 2001; Egert, 1999; Heidrich, 1996; Heidrich et al., 2006; Roiland & Heidrich, 2011; Ruini & Vescovelli, 2012; Ruini & Vescovelli, 2013; Schreiber, 2011). In all studies researchers used a version of Ryff's measurement of PWB, the SPWB (14, 9 or 7 item version).

As previously described, the purpose of this literature review is to understand the PWB of BCS according to a eudaimonic perspective. Articles included in this review focus on the psychological state of women with a diagnosis of breast cancer. Although research in this area is limited, factors supporting PWB are emerging. This literature review describes those factors thought to affect PWB among BCS.



Factors that Correlate With or Influence PWB among BCS

Research to date strongly suggests that women diagnosed with breast cancer may experience anxiety, depression, and distress (Brem & Kumar, 2011; Fiszer, Dolbeault, Sultan & Bredart, 2014; Krebber et al., 2014). Given this response to the disease, it is important to understand what factors may impact the difficulties encountered during survivorship. Factors evaluated in this review that have the potential to correlate with or influence PWB among BCS include: coping mechanisms, social support, self-esteem, level of gratitude toward others who have helped them, post-traumatic growth, and physical symptoms.

The coping strategies of social comparisons and engagement with one's social network were found to influence PWB. Social comparisons are coping strategies from which positive thoughts about oneself are generated by comparing self to someone who is perceived to have more or fewer problems. An essential component of this coping mechanism is the frequency with which the positive thoughts occur. Combined upward and downward social comparisons emerged as the strongest significant predictor of higher levels of positive relations with others ($\beta = .24$, p < .05), personal growth ($\beta = .19$, p < .05) subscales followed by the extent to which individuals interact with their social network ($\beta = .3$ positive relations with others; .4 personal growth; .4 purpose in life, p < .05) (Heidrich, 1996). An additional benefit was that the frequent use of social comparisons mediated the effects of poor physical health on PWB among this older sample of BCS (Heidrich).

Egert (1999) studied social support (satisfaction and size of network) and coping (use of social support, focus on the positive, behavior avoidance, and cognitive



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avoidance) that included approach and avoidance strategies. Together, perceived satisfaction with social support ($\beta = .10$ for autonomy; .14 for self-acceptance; .15 for purpose in life, personal growth and environmental mastery; and .22 for positive relations with others, p < .001) and use of social support as a coping strategy ($\beta = .026$ for personal growth, .035 environmental mastery, .060 self-acceptance, .079 positive relations with others, and .089 for purpose in life, p < .05) significantly accounted for the most variance in PWB of all variables evaluated. In an attempt to demonstrate PWB as a distinct measure of adjustment as opposed to ill-being, perceived satisfaction with social support was found to be a stronger predictor of PWB while behavior and cognitive avoidance was associated more strongly with measures of distress and physical impairment (Egert).

Using another approach to social support, Holland and Holahan (2003) studied the quality of social relationships. A quality social support relationship was deemed as providing guidance, reliable alliance, reassurance of worth, an opportunity for nurturance, attachment, and social integration. When social support was correlated with PWB a strong positive relationship was found; r = .65, p < .05 (Holland & Holahan). Coping was associated with PWB as well in this study. Approach coping strategies (positive appraisal, planful problem-solving, confrontive coping and seeking social support) were effective in promoting higher levels of PWB; r = .44, p < .05 (Holland & Holahan). Avoidance coping strategies that deployed negative cognitive processes such as distancing, engaging in self-control, escape avoidance and accepting responsibility were significantly associated with lower levels of PWB; r = .32, p < .05 (Holland & Holahan).



Coping from a religious perspective was studied by Price-Abdelrazzaq (2006) and Schreiber (2011). Price-Abdelrazzaq examined 10 variables that could potentially influence PWB among 70 BCS between the ages of 35 and 80. Having a sense of how God works was found to be a major positive predictor of higher levels of PWB (β = .48, p < .05). Two variables, problem solving independent of a church community (β = .42) and anxiety attachment (β = -.32, p < .05) were negative predictors of PWB. Results reported by Schreiber, suggests that lower levels of PWB are associated with negative religious coping strategies (r = -.42, p = .05). PWB, however, was unrelated to coping through positive religious strategies.

Two studies have identified a relationship between self-esteem and PWB in this population. Both studies used three different measures of self-esteem: (1) the Self-esteem Self-Anchoring Scale that rates current, present and future self-esteem, (2) a global measure of self-esteem and (3) Ryff's self-acceptance subscale. PWB levels varied in BCS and healthy controls according to changes in perceived self-esteem ratings. Decreases and increases in current to past self-esteem ratings resulted in decreases in environment mastery and increases in personal growth, positive relationships with others and purpose in life, respectively. In a similar fashion, increases in current to future ratings of self-esteem resulted in higher levels of autonomy and environmental mastery compared to not having a change in one's current to future ratings (Carpenter, 1997). Another important finding from this study is that significantly stronger Cronbach alpha correlations between Ryff's subscale of positive relationships with others and all three measures of self-esteem were found among BCS' when compared with a healthy control group; r = .58 to .68 versus r = .21 to .35, respectively, p < .05 (Carpenter).



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A similar study later published by Carpenter et al. (1999) evaluated differences in PWB and self-esteem once a sample of BCS (n = 60) was categorized into three distinct levels of transformation. BCS who perceived they were "stuck" in the process of transformation experienced significantly lower levels of PWB and ratings of self-esteem than those who perceived having a "minimal" or "positive" transformation process. Mean scores of PWB for those reporting feeling stuck versus those reporting aminimal autonomy, *XX* 55.9 versus 71.7 and 70.1 for environmental mastery, *XX* 64.4 versus 75.7

and 79.2 for positive relations with others; and XX 62.0 versus 73.1 and 72.5 for purpose in life (p < .01), respectively.

In addition to coping mechanisms, social support, and self-esteem, BCS' level of gratitude has been addressed. Ryff's subscale of positive relations with others and the personality disposition of gratitude was noted to have a positive significant relationship among 67 BCS; r = .26, p < .05 (Ruini & Vescovelli, 2013). When the survivors were grouped according to those having higher and lower levels of gratitude, after controlling for age, those with higher levels of gratitude reported significantly higher levels of personal growth (XX = 30.59) and purpose in life (XX = 28.07) than those with lower levels

of gratitude (XX = 29.75 personal growth and XX = 27.95 purpose in life, $p \le .01$) (Ruini & Vescovelli). Although the difference between high and low levels of gratitude was statistically significant, it was not clinically meaningful.

Two studies were found that investigated the relationship between post-traumatic growth and PWB (Cordova et al., 2001; Ruini & Vescovelli, 2012). Post-traumatic growth was not significantly related to personal growth, purpose in life, and self-



acceptance among a sample of 70 BCS (Cordova et al). However, Ruini and Vescovelli did find a significant relationship between post-traumatic growth and purpose in life among a sample of 60 survivors. Compared to those experiencing lower levels of posttraumatic growth, those experiencing higher levels were reported as having higher levels

of purpose in life; XX 26.03 versus 29.67, respectively, $y^2 = .104$, $p \le .05$ (Ruini & Vescovelli).

The impact of symptoms on PWB has also been investigated (Heidrich et al., 2006; Roiland & Heidrich, 2011). After controlling for the number of health problems experienced by older BCS, a significant negative relationship (r = -.42, p < 0.1) was noted between Ryff's purpose in life subscale and a survivor being unable to determine if their symptom experience is a result of aging, chronic illness or their disease (Heidrich et al.). Symptom clusters pose a greater threat in that multiple clusters (musculoskeletal, neuroendocrine, dryness, urinary, circulatory, and hormonal symptoms) were negatively related to the subscales of purpose in life (r = -.19 to -.54) and positive relationships with others (r = -.03 to -.45), p < .01(Roiland & Heidrich).

Discussion

There is evidence to suggest that both coping mechanisms and social support may influence PWB among BCS. BCS' use a variety of coping strategies and resources (such as social support) to manage cancer-related stress (Franks & Roesch, 2006). Five of the 12 studies reviewed report similar findings of the relationship between these two variables. Approach coping and positive religious coping strategies enhance a survivor's PWB (Egert, 1999; Heidrich, 1996; Holland & Holahan, 2003; Price-Abdelrazzaq, 2006) while some strategies used to distract from stress (avoidance) as well as negative



religious coping strategies are associated with lower PWB levels (Egert; Holland & Holahan; Schreiber, 2011). In addition, BCS who perceive having adequate social support report higher levels of PWB (Egert; Holland & Holahan).

Findings from the 5 studies reviewed are consistent with the reported mental health benefit resulting from the use of positive non-religious and religious coping strategies documented in prior research (Franks & Roesch, 2006; Lavery & O'Hea, 2010; Taylor & Stanton, 2007). The effect of avoidance coping strategies is less clear. There is empirical evidence to suggest that BCS who use avoidance coping strategies can experience both positive and negative mental health outcomes (Taylor & Stanton). Descriptions of the use of negative religious coping strategies in this review are consistent with prior research that suggest these types of strategies are reflective of an inward "struggle stemming from a negative view of life" (Lavery & O'Hea, p. 58). Therefore, this negative view of life may lead to feelings of ill-being and/or maladjustment to the cancer diagnosis (Lavery & O'Hea).

Self-esteem, which taps into affective evaluations, is reported to be a correlating factor with PWB. Changes in self-esteem (despite the direction) are positively associated with corresponding changes in PWB among BCS (Carpenter, 1997; Carpenter et al., 1999). Self-esteem is one of the initial correlates of PWB reported by Ryff (1989) from a sample of healthy adults. Findings from the 2 articles included in this review are reflective of those reported in her seminal article describing eudaimonic well-being (Ryff, 1989).

Three remaining factors discussed in this review include post-traumatic growth, symptom clusters, and the personality dispositional trait of gratitude. In the Cordova et



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al. (2001) and Ruini and Vescovelli (2012) articles, post-traumatic growth is defined as a subjective positive psychological change that occurs after an individual experiences a stressful event. Ruini and Vescovelli reported simultaneous increases in post-traumatic growth and PWB levels among their sample, yet a significant increase in levels of Ryff's purpose in life subscale (with a large effect size) were noted as those of post-traumatic growth increased. Symptoms, whether experienced alone or in a cluster, are reported to result in lower levels of Ryff's purpose in life and positive relations with others dimensions of PWB. Finally, while gratitude was the focus of one article, no clinically meaningful relationship was noted between it and PWB.

Conclusion

Eudaimonic PWB is positive psychological functioning characterized by engagement in six distinct life activities: autonomy, purpose in life, self-acceptance, personal growth, positive relations with others, and environment mastery (Ryff & Singer, 1998). BCS are living longer and are therefore having to face a multitude of physiopsychosocial challenges, all of which can potentially thwart their ability to fully engage in life activities. Without full engagement, these survivors will lose out on the mental and physical health benefit that results from the mind-body interaction. Factors reported from a review of the literature that positively influence PWB among BCS include coping, social support, self-esteem, and post-traumatic growth. Negative influencing factors include coping with cancer by using religious struggles and the impact of physical symptoms.



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The health of this group of survivors is especially important as the number of BCS is expected to rise over the next decade. Co-morbidities as well as the normal process of aging will compound their post treatment challenges. Having a clear understanding of factors that can influence their PWB will assist clinicians and researchers to develop interventions to either promote or maintain well-being among these survivors.



1996interpretive mechanisms used as coping strategies to maintain PWBBCS Arth	s-sectional DescriptiveFor both groups, coping strategies $n = 86$ demonstrated ability to maintainritic groupPWB by mediating the effects of 102 physical health. ≥ 60 years
1996interpretive mechanisms used as coping strategies to maintain PWBBCS Arth	n = 86demonstrated ability to maintainritic groupPWB by mediating the effects of02physical health.
coping strategies to maintain PWB Arth	ritic groupPWB by mediating the effects of physical health.
	02 physical health.
n — 1	r Januaria and Andrea
	≥ 60 years
6	ent treatment with H allowed.
	s-sectional Self-esteem is reported to be similar
	across both groups.
	n = 64 PWB is influenced by perceived
HC r	n = 64 changes in past, present and future
BCS	μ age 53.5(10.5) self-esteem.
Stag	e IA-IIIB enrolled 2-54 months
post	treatment with OR, CT, RT, H
Carpenter et al. Explore self- transformation and its Cros	s-sectional Self-esteem and PWB are impacted
▲	when a BCS experiences a positive
	n = 60 or negative transformation post
	n = 60 diagnosis.
	μ age
	(15.3)
	e 0-IIIB enrolled 2-54 months
	treatment with OR, CT, RT, H
∂	s-sectional Inverse relationship between PWB,
	criptive distress and physical impairment.
psychosocial adjustment N =	
	e 56.0(12.2) from traditional measures of
	e I-II enrolled 9-15 months post adjustment.
diag	
Trea	ted with OR, CT, RT, H

Table 2.1 Summary of Articles Based on Ryff's Approach to PWB in BCS Population

المناركة للاستشارات

Study	Purpose	Design	Results
Cordova et al. 2001	Examine differences in PTG, PWB and distress between BCS and age / education matched HC	Cross-sectional Descriptive BCS $n = 70$ HC $n = 70$ BCS μ age 54.7(12.1) Stage 0-IIIB enrolled 2-58 months post treatment with OR, CT, RT, H	BCS experience greater levels of PTG but similar levels of distress and PWB to HC.
Holland& Holahan 2003	Determine relationship between social support, coping and positive adaptation (PWB & positive health behaviors)	Cross-sectional Descriptive N = 56 μ age 48(4.67) stage I-II Enrolled 1-26 months post diagnosis Treated with OR, CT, RT	PWB positively related to positive health behaviors, social support and positive coping strategies; inverse relationship with negative coping strategies. Social support has direct and indirect relationship with PWB (mediated by positive coping strategies)
Heidrich et al. 2006	Compare symptom experience and existential QOL of older BCS and HC	Cross-sectional Descriptive BCS n = 18 HC n = 24 Enrolled 1-25 years post diagnosis; $\mu = 10.6$ years BCS μ age 74.16(7.12) Only reported treatment with H	Symptom experience of both groups comparable. PL subscale influenced by belief of symptom source.
Price-Abdelrazzaq 2006	Determine relationship between coping by use of spiritual and religious strategies and PWB	Cross-sectional Descriptive N = 70 μ age 55(10.5)	Use of awareness of God and decision making independent of church community impacts PWB



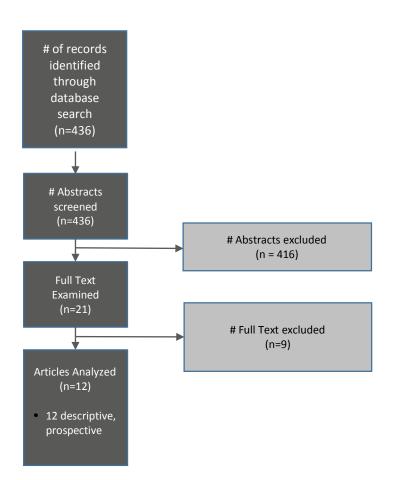
Study	Purpose	Design	Results
Schreiber	Eventing difference in religious coning	Cross-sectional	DWD stress and face of requiremence
2011	Examine difference in religious coping style, PWB, distress, and fear of	Descriptive	PWB, stress and fear of recurrence are influenced by one's image of
2011	recurrence based on ones image of	N = 129	God. Negative religious coping
	God		strategies are related to PWB
	000	μ age 55 BCS enrolled 6-30 months post	strategies are related to F w B
		diagnosis	
		Current treatment with H allowed	
Roiland & Heidrich	Examine symptom cluster experience	Cross sectional	7 symptom clusters negatively
2011	and existential QOL	Descriptive	impact PWB
2011		N = 192	impact () D
		μ age 70(5.3)	
		μ 34.8 months post treatment	
		with OR, CT, RT, H	
Ruini & Vescovelli	Examine relationship between positive	Cross-sectional	BCS experience poorer health and
2012	functioning (PTG and PWB),	Descriptive	PWB than HC however high levels
	symptomatology and distress using	BCS $n = 60$	of PTG influenced PWB and
	BCS and HC group experiencing	HC n = 60	distress in BCS.
	stressful life event	BCS µ age 56.31(11.78)	
		Noninvasive and invasive	
		neoplasms enrolled 1-15 years post	
		diagnosis	
		Treated with OR, RT, CT, H	
Ruini & Vescovelli	Determine difference in PTG, PWB	Cross-sectional	Higher levels of gratitude
2013	and distress based on level of gratitude	Descriptive	associated with higher levels of
	experience	N = 67	PWB
		μ age 56.6(11.7)	
		Noninvasive and invasive	
		neoplasms	
		enrolled 1-15 years post diagnosis	
and DWD Drevel 1	al well-being; BCS = Breast Cancer Survivors; HC = heal	Treated with OR, CT, RT,H	

Legend – PWB = Psychological well-being; BCS = Breast Cancer Survivors; HC = healthy controls; OR = surgery; RT = radiation therapy; CT = chemotherapy; H = hormonal therapy; PTG = post-traumatic growth; PL = Ryff's purpose in life subscale



Figure 2.1

Article Selection Process





Chapter Three

Satisfaction with Preparation to Transition from Primary Treatment

Psychological well-being (PWB) is a construct that generally refers to psychological functioning. Hedonic PWB is one perspective of well-being. According to this perspective, well-being results from life-satisfaction and happiness. This manuscript focuses on Eudaimonic well-being, a lifelong process of purposeful engagement in goaldriven tasks or activities that enables an individual to discover and perfect their innate life potential; subsequently, optimal psychological functioning results (Ryff, 1989). Ryff operationalized these life activities into six dimensions: autonomy, purpose in life, selfacceptance, personal growth, positive relationships with others and environmental mastery.

Breast cancer survivors (BCS) can potentially miss out on some or even all of the positive health benefits that come with experiencing PWB because of their disease or its treatment. Results of studies evaluating the physical and psychological health of individuals as well as Eudaimonic PWB show that PWB can be influential in preventing illness and promoting wellness (Kimiecik, 2011; Rafanelli & Ruini, 2012; Ruini & Fava, 2012; Wood & Joseph, 2010). Compared to their healthy peers, BCS are especially vulnerable to experiencing more mood disturbances and physical ailments while engaging in routine life activities and the unavoidable stressors that come with it over the balance of their lives (Costanzo et al., 2012). This finding may be explained by the impact of disease and treatment-related physical and psychological impairments on BCS; all of which interfere with their ability to be fully functioning individuals. Since PWB has



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the potential to mitigate ill-being in these women, it is important to not only understand PWB among BCS but to identify factors related to optimal psychological functioning.

Satisfaction with information BCS receive to prepare for the transition from primary treatment into survivorship has been shown to be a correlate of positive mental health (Griggs et al., 2007; Mallinger, Griggs & Shields, 2005). Literature to date suggests that this concept may also be associated with PWB. Clinicians and BCS view information as vital to a successful transition process into life after treatment. For instance, transitional theorists Schumacher and Meleis (2010) suggest that preparatory information and education is essential for producing optimal post-transition outcomes, such as role mastery, growth, high self-esteem and enhanced, close interpersonal relationships. During their initial follow-up clinic visit, BCS reported that information provided by their healthcare clinician covering symptom management positively influenced their transition from treatment to survivorship (Wilmoth, 2001).

Survivorship guidelines developed for clinicians include suggestions on what information should be given to BCS as they transition from treatment (IOM, 2006). It would be of more benefit for clinicians to first gain an understanding of what information BCS deem to be most helpful.

Aim/Research Question

As a component of a study addressing factors that influence PWB among BCS, this manuscript details results of a specific aim to identify and describe how helpful BCS consider the information given to them by healthcare teams to effectively transition from treatment to survivorship. The purpose of this component of the study was to better understand to what extent preparatory information was helpful to participants in



transitioning to survivorship. A single occasion qualitative descriptive design using open-ended survey questions was used (Kondracki, Wellman & Amundson, 2002).

Methods

Participants

A convenience sample of 52 BCS who were (1) at least 18 years old, (2) able to read and write English, (3) within 6 months of completing primary treatment, and (4) without cognitive impairment responded to open ended survey questions. Women receiving hormonal therapy and Herceptin as part of their treatment plan were allowed to participate. Approval from an Institutional Review Board (IRB) was received prior to participant enrollment.

The sample consisted primarily of Caucasian women who were on average 59 years old, married and living with a partner or spouse, college educated, and worked either full-time or were retired with an annual household income \geq 40,000.00. Seventy-seven percent of the sample reported being stage I or II at initial diagnosis. Finally, the median time since completing treatment was 2 months with BCS receiving radiation and chemotherapy either alone or in combination.

Procedures

Hematology/Oncology and Radiation Oncology Physicians affiliated with two local community-based cancer programs in Kentucky were asked to identify BCS eligible to participate in study. Research packets were mailed to potential participants by a hospital staff member. Each packet included an IRB approved consent cover letter, study surveys and a self-addressed, stamped return envelope. Informed consent was implied



upon return of the completed surveys. The study investigator received grant funds to compensate participants for their time completing the research packets.

An investigator developed survey assessing BCS' satisfaction with information received from their healthcare team, including education on what to expect and how to manage ongoing side effects and symptoms was used (Appendix A). Responses to the question, "Now that you have recently completed treatment, do you feel that you have been given the information you needed to transition into life after treatment?" included (1) Yes: I feel that I have been given <u>all</u> of the information I needed to transition into life after treatment; (2) Yes: I feel that I have been given <u>most</u> of the information I needed to transition into life after treatment; (3) No: I feel that I did not receive <u>some</u> of the information I needed to transition into life after treatment; or (4) No: I feel that I received very <u>little to no information that I needed to transition into life after treatment</u>.

Four open-ended survey questions followed; two questions specific to BCS who felt they received all or most of the information needed to transition and two questions specific to BCS who felt they did not receive some of the information needed or received little to none of any information needed to transition into life post treatment. The former group (satisfied group) was asked "What information was most helpful to you?" and "What information was least helpful to you?" while the latter group (group not satisfied with information) was asked "What information were you provided?" and "What additional information would have been helpful to you?".

Data Analysis

Data was analyzed using content analysis, a process commonly used in qualitative research to systematically interpret text data using codes to allow for the emergence of



themes and patterns (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Sandelowski, 2010). Since the aim of this component was to identify and describe the helpfulness of information BCS' received in preparation to transition into survivorship, two analyses were conducted, content manifest and summative. Content of the responses was analyzed as follows: after reviewing the unit of analysis several times, text data was divided into meaning units, condensed, and then assigned a code. Condensed meaning units, according to Graneheim and Lundman, are abbreviated text data with similar content (meaning) abstracted from the unit of analysis. See Table 3.1 for an example of this analysis. Descriptive statistics were then calculated to determine the frequency of condensed units assigned to each code (Table 3.2).

Findings

The aim of this study component was to identify and describe helpfulness of information BCS received from their healthcare teams to transition into survivorship after treatment. A total of 14 data-driven codes were assigned to condensed units of meaning for both groups of BCS, those satisfied and those not satisfied with information received (Table 3.2).

Helpfulness of Information Reported by Satisfied BCS

Breast cancer survivors satisfied with the information received to transition were asked to provide insight into which information they found to be most helpful and which was considered to be least helpful. Information reported to be <u>most helpful</u> included expectations covering physical, psychological and social effects that would linger post treatment. This was supported by responses from the survivors as follows:



"What to expect after my treatment is completed, such as body changes,
emotional issues...Also, knowing it is okay to be tired, moody..."
"Physical limitation, mental status changes, decreased strength and endurance."
"Information on what to expect, i.e. fatigue, pain, burn, rash."
"Skin care after radiation; that fatigue is a normal result of/reaction to radiation..."

"That I could continue my daily schedules. That I would be very tired"

"I should be able to continue with my family life..."

While the following comments that were returned were not specific to a physical, psychological or social effect of treatment, still, it was apparent that these survivors considered information preparing them on what to expect after their treatments ended as valuable.

"Doctors explained in detail what to expect"

"What symptoms I might have during the months after my treatment ended."

"Conversation with nurses and doctors; detailing treatment effects and recovery"

"That I could experience the effects of the chemo for up to a year after finishing the treatment."

"The doctor gave me a packet that explained how I should feel and what would be going on."

In addition to information regarding what to expect post treatment, these survivors found information that would teach them how to manage life during early survivorship to be helpful. For example, information covering nutrition, skin care, and exercise were



provided. The types of information they reported as most helpful included resources for support and how ongoing, follow-up treatment would occur.

BCS who were satisfied with the information they received found it <u>least helpful</u> when they did not receive enough information addressing post-treatment expectations, side effects of medication(s), and follow-up appointments. For example, 5 survivors wrote:

"I would have liked more information on radiation therapy and the effects that it has on my body long term and the changes that can occur after treatments ended." "There was very little information regarding lasting effects of chemo; how long do side effects last after the last treatment"

"I lacked basic information on the side effects of letrozole. Never having experienced a "rough" menopause, I was not prepared for the inferno; was not prepared for the lingering effects of radiation."

"I need more information about the letrozole drug", and

"I would like to have upfront information on when my checkups (etc.) will be..."

Helpfulness of Information Reported by BCS Not Satisfied

The group of BCS who were not satisfied with the information they received to transition into survivorship were asked to detail what information they were provided and to also comment on what additional information would have been helpful to them. While the number of condensed meaning units were fewer for the unsatisfied group of survivors versus those satisfied (Table 3.2), it was evident from responses that information on what to expect physically and psychologically during the post treatment phase was lacking.



BCS felt that they needed additional information as described by the following comments:

"I was not prepared for the long term effects of chemotherapy as far as "chemo brain". I didn't know what was wrong with me until I read an article in Cure magazine. All chemo patients should be counseled",

"All the feelings I felt, weak; inadequate for daily life"

"That the fatigue would/could be worse after completion of radiation for several months" and

"I would have like more information about the chemotherapy drugs, side effects, and suggestions to minimize the side effects".

Shared Responses Regarding Helpfulness of Information

One other similarity between both groups were noted. BCS who were satisfied as well as those not satisfied with information they received from the clinician to transition into survivorship felt unprepared for the self-change they underwent as a result of being diagnosed and treated. For instance, BCS commented:

"Making sure there was an effort made to make sure women understand that they will never be their old self, and to work on ways to learn to accept the new normal they have become, even when they didn't want to..."

"Not telling me what life will be like after; just going from visit to visit" "How long it takes to feel "normal" again or when I would expect to have my energy back to be able to fully function at work, home and exercise" and



"The team was always helpful with any questions I had, but truly deep down I always felt alone, even in a room full of people. With the best intentions in mind, they needed to help me accept that I was not going to be myself again".

Discussion

BCS who are satisfied and those not satisfied with information received to prepare them to transition into survivorship emphasized the importance of receiving comprehensive information on: (1) what to expect physically and psychologically post treatment and (2) how their lives moving forward will be different from their lives prior to their cancer diagnosis. The majority of the survivors participating in this study reported receiving information regarding what to expect physically, psychologically and socially, post treatment. Even so, they felt that they were not adequately prepared to return to their former lives given the changes they had experienced. The survivors also shared insight into the helpfulness of information they received addressing: risk of recurrence, disease specific information, reconstructive surgery, hormonal therapy, financial counseling, prognosis/diagnosis, return to work and drugs received for treatment (Table 3.2). The literature supports providing this kind of information in order to assist the transition from treatment to survivorship (Raupach & Hiller, 2002; Salz et al., 2012)

Findings from this study support prior research. When 18 BCS were asked their perception of how well they were prepared to transition to life after treatment, 45% lacked information on what to expect regarding physical and psychological distress (Cappello, Cunningham & Knobf, 2007). As a result of physical and psychological treatment-related effects that continued into early survivorship, BCS requested the need for post treatment psychological support, education and information (Mollica & Nemeth,



2014). As early as 6 months post primary treatment, large disparities between informational needs BCS reported as important and the actual receipt of this information was noted among a sample of 270 women (Raupach & Hiller, 2002). Finally, the IOM (2006), in an attempt to coordinate care for cancer survivors, published recommendations to implement survivorship care plans. Part of their recommendation included information that should be made available to cancer survivors post treatment. In a study conducted by Salz et al, (2012) it was noted that after reviewing survivorship care plans from 18 NCI designated cancer centers, only 8 (40%) of the sites included information recommended from the IOM about late and long term effects of treatment to their breast cancer populations.

A major theme reported by breast cancer survivors transitioning into early survivorship was having a sense that their lives as they once knew it, no longer exists (Allen, Savadatti & Levy, 2009). These survivors (similar to those participating in the current study) were diagnosed at an early stage and had completed treatment with radiation and/or chemotherapy within the past 12 months of study participation. They attributed their perception of the "new normal" to feeling forever changed and a struggle with resuming past roles. A sample of 113 BCS (stage I – III) evaluated 3 weeks and again 3 months after treatment with multiple treatment modalities, including chemotherapy and radiation, reported that attempts to return to and "create a 'new normal" was a source of stress that disrupted adjustment to life post treatment (Costanzo et al, 2007). Results of interviews conducted by Cappiello, Cunningham and Knobf (2007) with 18 BCS during early survivorship detail the women's struggle during the initial year post treatment to return to a "normal" life as challenging.



Early survivorship is a phase along the cancer care continuum that begins when treatment ends. It can be a challenging time for BCS. Emotional distress is commonly experienced due to concerns associated with uncertainty and fear of recurrence (Costanzo et al., 2007; Knobf, 2007; Lethborg et al., 2000). During this time, support, routinely provided by the healthcare team during treatment, is no longer immediately available; personal support systems are limited (Sadler-Gerhardt et al., 2010) and BCS are expected to provide more of their own self-monitoring. Healthcare clinicians will need to prepare these women to resume life after treatment.

Information is a rich, inexpensive source of social support that has a significant role with facilitating successful transitions (Schumacher & Meleis, 2010; Wilmoth, 2001). BCS experience lingering disease and treatment-related physiopsychosocial impairments that can be managed when appropriate information is provided. Further, patients who are satisfied with the information they receive may experience positive health benefits associated with PWB. Therefore, confirming satisfaction with information as a correlating factor to PWB will be helpful for these women long-term.

Limitations

Participants were asked to respond to open-ended survey questions so that the study investigator could gain an understanding of their perceived helpfulness of information received to transition. While the text-data provided a usable description, there were some returned comments that needed further clarification. Had the investigator had access to the responders, it is possible that the data would have been interpreted differently. Four participant responses were completely unclear and were excluded in the analysis.



Implications for Future Research and Practice

BCS are living longer with symptoms and side effects that could prevent them from fully engaging in life and experiencing optimal PWB. A correlate of positive mental health, satisfaction with information, may also be related to PWB. However, in order for BCS' to become satisfied with information it is important to fully understand the helpfulness of the information they receive. The current body of literature that addresses survivorship informational needs of BCS is growing. Yet, as demonstrated by results of this study and recently published studies, a gap between what the survivors need to be prepared to transition into survivorship and actual preparation by the healthcare team to successfully transition remains.



Table 3.1

Example of Manifest Content Analysis Using Selected Text Data

Meaning Unit	Condensed Unit	Code	
Fatigue is normal result of/reaction to radiation	Physical symptom(s) to expect	What to expect	
Information on how I will be treated in the future such as medical appointments for the next few years	Ongoing surveillance	Follow-up	

Table 3.2

Comparison of Frequency and Percentage of Meaning Units/Code (n = 52)

	BCS Satisf	ied (n = 43) %)	BCS not Satisfied $(n = 9)$ N(%)		
Code	Information most helpful	Information least helpful	Information that was provided	Information would have been helpful	
What to expect	19	3	3	6	
How to manage	4	1	1	1	
Resources for support	2	0	0	1	
Follow-up appointments	1	1	1	0	
New normal unaddressed	1	2	1	3	
Risk of recurrence	5	1	0	0	
Disease specific information	4	2	1	2	
Reconstructive surgery	1	0	1	0	
Hormone therapy	1	2	3	3	
Side effects of medication	0	1	0	0	
Financial counseling	0	1	0	0	
Prognosis/diagnosis	0	0	1	0	
Return to work	0	0	1	0	
Drugs received	0	0	0	1	



Chapter Four

Psychological Well-being among Breast Cancer Survivors: Factors that Influence Transition from Primary Treatment to Early Survivorship

The psychological well-being (PWB) of women with breast cancer is becoming increasingly important as women with this diagnosis are living longer. The influence of the diagnosis and treatment of breast cancer may have long lasting negative effects on well-being that can be diminished if appropriate interventions are not in place. In order to study PWB two major perspectives of this concept need to be considered. These perspectives include Hedonic (life satisfaction and happiness) and Eudaimonic (reaching one's life potential) well-being. Eudaimonic PWB refers to the extent that an individual is able to participate in lifelong activities that promote self-realization and actualization (Ryff, 1989). According to this perspective, Ryff designed the Scales of Psychological Well-being (SPWB) that included the following life activities: autonomy, purpose in life, self-acceptance, personal growth, positive relationships with others, and environmental mastery. Ryff posits that individuals who participate in these life activities to the greatest extent possible can experience optimal PWB. Ryff's view of PWB is used in this study.

The PWB of women surviving breast cancer can diminish due to the trauma frequently associated with diagnosis and treatment. Given the problems associated with the diagnosis and treatment of breast cancer, early survivorship can be a difficult time. Early survivorship is a stage along the cancer care continuum that begins when treatment ends. While the daily lives of these women are no longer disrupted due to medical and treatment appointments, the sudden loss of consistent contact, support and reassurance from their healthcare team can lead to distress (Allen, 2009; Lethborg et al., 2000). In



addition, there are multiple sources of stress attributed to the early phase of survivorship that women experience such as fear of recurrence, cancer worry, uncertainty about the future, less social support and concerns with adequately resuming pre-treatment roles (Costanzo et al., 2007; Knobf, 2007; Lethborg et al).

An immediate challenge for breast cancer survivors (BCS) during this time is to re-engage in life (Cappielle, Cunningham, Knobf & Erdos, 2007; Costanzo et al., 2007). Barriers to returning to a normal life style include both physical and psychological problems. Research shows that complications, such as fatigue, cognitive dysfunction, and lymphedema, related to treatment will ultimately limit their ability to complete home and work related tasks as well as affect their financial contribution to the household (Banning, 2011).

Background and Significance

Factors that negatively influence BCS' ability to successfully transition from primary treatment to early survivorship can impact their PWB. Physical symptoms commonly experienced by BCS were linked to PWB among samples of older survivors (Heidrich, 2006; Roiland & Heidrich, 2011). Roiland and Heidrich evaluated the relationship between 7 symptom clusters (musculoskeletal, neurocognitive, dryness, urinary, circulatory, sleep, and hormonal) and the ability of BCS to engage in activities that promoted two of Ryff's subscales: positive relationships with others and purpose in life. A significant negative relationship between symptom clusters and PWB was reported. Those women who reported experiencing more symptom clusters had lower levels of PWB.



Negative emotions can impact PWB as well. Egert (1999), utilizing the 6 subscales of Ryff's SPWB with BCS, found a moderate to strong negative significant relationship between PWB and psychological distress. Finally, education provided to BCS is viewed by healthcare providers and BCS themselves as an important component of their transition from primary treatment to survivorship (Meleis, et al., 2000; Mollica & Nemeth, 2014). While satisfaction with information that BCS receive to prepare for transitioning has been linked to mental health outcomes (Griggs et al., 2007; Mallinger, Griggs & Shield, 2005), the relationship between satisfaction with preparatory education and PWB has not been addressed.

Limited research has been conducted regarding PWB, factors that influence PWB and early breast cancer survivorship. The purpose of this study was to examine the relationship between PWB and a) cancer problems frequently experienced by early survivors of breast cancer, b) psychological distress during early survivorship, and c) satisfaction with the information women diagnosed and treated for breast cancer receive in order for them to transition from primary treatment to survivorship.

Methods

Design, Setting, and Sample

A prospective, cross sectional study design was used to evaluate the perceived PWB of BCS who (1) were at least 18 years old, (2) had received a primary diagnosis of breast cancer, (3) were able to read and write English, (4) were within 6 months of completing primary treatment, and (5) were without cognitive impairment. Women who remained on Herceptin and/or hormonal therapy as part of their treatment plan were



allowed to participate in this study. Approval from an Institutional Review Board was gained prior to participant enrollment.

Hematology/Oncology and Radiation Oncology Physicians affiliated with two local community-based cancer programs in Kentucky were asked to identify a convenience sample of eligible BCS. Research packets were mailed to potential participants by a hospital staff member. Each packet included an IRB approved informed consent cover letter, study surveys and a self-addressed, stamped return envelope. Informed consent was implied upon return of the completed surveys to the study investigator. From a total of 220 mailed research packets, 56 completed surveys were returned yielding a 25% response rate. The study investigator received grant funds to compensate participants for their time completing the packets.

Measures

Demographic collection sheet. Participants were asked to provide the following demographic, disease and treatment-related information: age, race, marital status, level of education, employment status, household income, living arrangements, stage of disease at diagnosis, type of treatment received, and the amount of time (in months) since treatment had been completed.

Scales of Psychological Well-being (SPWB). Participants responded to the SPWB. This measure contains six 14-item subscales that capture an individual's selfreported level of PWB (SPWB): autonomy, self-acceptance, purpose in life, personal growth, positive relations with others and environmental mastery (Ryff, 1989). The scales consist of a mixture of negative and positive worded items. Scores for the negative items are reversed prior to computing the total score. Responders are provided a likert



type scale and are asked to determine the extent to which they either disagree (1 = strongly; 2 = somewhat; 3 = slightly) or agree (4 = slightly; 5 = somewhat; 6 = strongly) with each item; higher scores are reflective of higher levels of perceived PWB. The 20item parent and 14-item shortened scales are reported as reliable and valid measures from samples representing the general and BCS population (Carpenter, 1997; Carpenter, Brockopp & Andrykowski, 1999; Ryff; Ryff & Essex, 1992). For the current study, alpha coefficients are as follows: total score = .96, subscales range .80 to .88.

Cancer Problems in Living Scale (CPILS). The CPILS consists of 31 items and assesses common physical, psychological (including fear of recurrence), financial and employment related problems reported by cancer survivors (Baker, Denniston, Zabora & Marcellus, 2003). Participants respond to each item as follows: 0 no problem, 1 somewhat a problem, 2 a severe problem. Lower scores indicate less problem burden. Adequate internal reliability and convergent/divergent validity are reported from samples of bone marrow transplant recipients, hematology and solid tumor populations post treatment (Baker et al; Zhao, Portier, Stein, Baker & Smith, 2008). For this study Cronbach alpha = .94.

Depression, Anxiety and Stress Scales (DASS). The DASS is a 42 item questionnaire measuring the negative affect of depression, anxiety and stress. Based on the past week, responders are given the option to score each item from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time) with higher scores indicative of more severe negative symptomatology. Cut-off scores for mild, moderate and severe extremes of symptoms include 13, 20 and > 20 for depression and 9, 14 and > 14 for anxiety, respectively. Internal consistency, test-retest reliability, convergent and



discriminate validity of the DASS are reported as adequate in the adult general population as well as in samples of adults with clinical pathology (Crawford & Henry, 2003; Lovibond & Lovibond, 1995). For this study, Cronbach's alpha = .96 for depression scale, .90 for anxiety scale and .95 for stress scale.

Satisfaction with Preparation to Transition (SPT). An investigator developed questionnaire assessing BCS' satisfaction with information received from their healthcare team, including education on what to expect and how to manage ongoing side effects and symptoms was used for this study (Appendix A). Responses to the question, "Now that you have recently completed treatment, do you feel that you have been given the information you needed to transition into life after treatment?" included (1) Yes: I feel that I have been given <u>all</u> of the information I needed to transition into life after treatment; (2) Yes: I feel that I have been given <u>most</u> of the information I needed to transition into life after treatment; (3) No: I feel that I did not receive <u>some</u> of the information I needed to transition into life after treatment; or (4) No: I feel that I received very <u>little</u> to <u>no</u> information that I needed to transition into life after treatment.

Data Analysis

The purpose of this study was to examine relationships between PWB and factors thought to interfere with BCS' successful transition into early survivorship. Participant survey responses were analyzed using version 22 of the IBM Predictive Analytics Software. BCS' demographic, disease, treatment-related and study variables are reported using descriptive statistics.

Pearson r correlation coefficients were calculated to evaluate the relationship between PWB (total score of the SPWB and total scores of the six subscales of the



SPWB) and the total score of the CPILS and DASS subscales. Prior to calculating the point biserial correlation coefficient to evaluate a relationship between PWB and satisfaction with information received to transition from treatment, the four responses to the SPT questionnaire were recoded into a dichotomous variable (yes, no). Since multiple correlations were simultaneously conducted on the data, a bonferroni-like correction was applied to the original critical value (set at 0.05). Therefore, correlations reaching ≤ 0.01 were considered to be statistically significant.

Results

Characteristics of the 56 study participants are included in Table 4.1. This sample consisted primarily of Caucasian BCS who were on average 59 years old, married and living with a partner or spouse, college educated, and worked either full-time or were retired with an annual household income \geq 40,000.00. Seventy-seven percent of the sample reported having an early stage of cancer at diagnosis. While the most common treatment was radiation alone, the participants also received single modality treatment with chemotherapy and combination modality with both radiation and chemotherapy. The median time since completing treatment for these BCS was 2 months. Mean scores and counts appropriate for measures used in this study are listed in Table 4.2.

PWB was noted to have a relationship with factors thought to be negative influences on BCS during early survivorship (Table 4.3). Medium to strong negative relationships between PWB and CPILS were found; higher levels of PWB were associated with physical symptoms, psychological dysfunction, fear of recurrence, financial and employment concerns being perceived as less burdensome by BCS during reintegration into life. As well, higher scores of PWB were related to less



symptomatology associated with depression, anxiety and stress experienced by these women. Finally, except for the subscales of autonomy and personal growth, PWB had a small to medium negative relationship with satisfaction with preparatory information to transition into early survivorship. Results from the point biserial correlation between these two variables demonstrate that lower scores of positive relationships with others, environmental mastery, purpose in life and self-acceptance co-occur among the group of BCS who are not satisfied with information preparing them to transition into survivorship.

Discussion

Eudaimonic PWB refers to a lifelong process of purposeful engagement in goaldriven tasks or activities that enables an individual to discover and perfect their potential in life; subsequently, positive psychological functioning results (Ryff, 1989). For this study, PWB was measured using SPWB which consist of six dimensions of life activities proposed by Ryff to characterize positive psychological functioning: autonomy, purpose in life, self-acceptance, personal growth, positive relationships with others and environmental mastery (Ryff, 1989). Mean scores for PWB (total SPWB score and total scores for each subscale) reported by BCS enrolled in this study are listed in Table 4.2. Compared to mean scores of PWB (positive relations with others X = 70.21; personal growth X = 70.13; self-acceptance X = 66.27; purpose in life X = 68.53; autonomy X =64.55; and environmental mastery X = 65.13) reported from a sample of healthy female participants recruited from a community breast imaging center (Moe, 2012), BCS enrolled in this study are comparable as far as their ability to engage in activities that



reflect positive functioning in spite of the abrupt disruption breast cancer has caused in their life.

This study was designed to explore relationships among PWB and physical, psychological, and social barriers BCS face during early survivorship as a result of diagnosis and treatment. Among this sample of BCS, each dimension of PWB was noted to have a significant negative relationship with a) cancer problems frequently experienced by BCS during early survivorship and b) depression, anxiety, and stress. Four of the six PWB dimensions (positive relationships with others, environmental master, purpose in life and self-acceptance) had a significant negative relationship with satisfaction with information survivors received to transition into survivorship.

Prior research has demonstrated that during early survivorship, BCS live with multiple cancer problems that are a direct or indirect result of the tumor itself, treatment for the disease, and stress that is uniquely associated with this phase of survivorship (Banning, 2011; Barnes, Robert & Bradley, 2014; Cappielle et al, 2007; Costanzo et al., 2007; Ganz, Kwan, Stanton, Bower & Belin, 2011; Klimmek, Snow & Wenzel, 2010; Lauzier et al., 2008; Mollica & Nemeth, 2014). Participants in this study were asked to respond to a set of problems commonly experienced by early survivors as they reintegrate into life immediately after treatment. These problems covered physical, psychosocial, financial and employment-related concerns.

While higher levels of PWB were associated with less problem burden among this group of BCS, six of the 31 problems were reported by \geq 50% of the BCS to be more of a burden (somewhat or a severe burden) than not (Table 4.4): fatigue, sleep difficulty, being fearful that their illness will return, concern about relapse, difficulty concentrating



and fears about the future. These findings can be explained by the fact that more than half of this sample of BCS were treated with chemotherapy alone or chemotherapy in combination with radiation therapy. Past study results have attributed receipt of chemotherapy as a treatment modality for breast cancer to a more severe physical and psychological symptom profile compared to those BCS who received other types of treatment (Bender et al., 2005; Costanzo et al., 2007; Ganz et al., 2011; Janz et al., 2007).

Depression, anxiety and stress are common responses to being diagnosed and treated for cancer. Higher levels of PWB were found to be related to lower levels of depression, anxiety and stress reported by BCS participants enrolled in the current study. Inquiry into how PWB relates to psychological distress dates back to the initial development of Ryff's SWPB (Ryff, 1989). Using the Self-Rating Depression Scale, she reported a significant negative relationship between these two variables using a sample of healthy adults. One study, conducted by Egert (1999), evaluated the correlation between PWB and psychological distress using a severity general index associated with the Brief Symptom Inventory among a sample of 113 BCS who were within 9 to 15 months of being diagnosed. Again, a significant moderate to strong negative relationship between PWB and distress was reported. The current study used the DASS subscales to measure distress levels among PWB.

Preparing BCS with information on what to expect and how to manage challenges is an important factor in facilitating the transition process from primary treatment to early survivorship (Meleis, et al., 2000; Mollica & Nemeth, 2014). It is important that BCS are satisfied with information provided by their healthcare team to prepare for early survivorship. Responding to an investigator developed questionnaire assessing



satisfaction (Appendix A), 82% of the sample reported being satisfied with the information received in preparation to transition while 18% reported not being satisfied (Table 4.2). The relationship between PWB and satisfaction with information received by this sample of BCS demonstrates that high and low levels of PWB are associated with corresponding levels of satisfaction and dissatisfaction with information, respectively.

The current body of literature is limited as to describing how satisfaction with information will affect actual PWB of BCS, however satisfaction with treatment and survivorship information has been reported in prior research to be positively related to mental functioning and vitality and negatively related to negative affect in BCS (Bergenmar, Johansson, & Sharp, 2014; Griggs et al., 2007; Mallinger, Griggs & Shields, 2005). The fact that the subscales of autonomy and personal growth did not reach significance is difficult to interpret as well. Using the original p-value set at .05, both of these subscales would have been considered statistically significant. However, the bonferroni-like correction, which was applied to minimize the chance of making a type I error as a result of simultaneous statistical analysis, prevented these two subscales from reaching significance.

There is a paucity of literature available that addresses PWB from a Eudaimonic perspective among BCS. This study was designed to add to this limited body of evidence. BCS are living longer with multiple challenges that can impact their PWB. Several studies have reported the physical and psychological health benefits that accompany the experience of PWB (Kimiecik, 2011; Rafanelli & Ruini, 2012; Ruini & Fava, 2012; Wood & Joseph, 2010). It is important to gain an understanding of PWB



among BCS and factors that influence the ability of these women to transition into survivorship.

Study Limitation

To address the threat to external validity, it would have been helpful to report characteristics of those BCS who chose not to participate. To prevent undue coercion, the research procedure (described earlier in this manuscript) was developed specifically to maintain anonymity of the responders. The procedure, however, made it impossible to capture the characteristics of those BCS who chose not to participate.

In addition, the sample characteristics may be problematic in terms of generalizing the results. Participants were largely Caucasian, educated, financially viable survivors who were diagnosed with cancer in the early stage. Level of education is associated with PWB. Therefore, evaluating these variables among a sample of BCS less educated would have most likely yielded different study results.

Conclusion

A seminal report distributed by the Institute of Medicine (IOM, 2006) raised public awareness regarding two key issues pertinent to the BCS population. One, in spite of known physical and psychosocial post-treatment effects, the functioning and wellbeing of these women do not receive the proper amount of attention needed. And two, the phase of early survivorship presents barriers in and of itself that BCS will need to overcome but this time is also "critical to long-term health" and should be used as an opportunity to provide information and education as a means to promote wellness (IOM, page 1).



This study addresses primary concerns noted within the 2006 IOM report. While the majority of BCS in the current study experienced strong PWB, at least half of the sample reported severe physical and psychological symptomatology capable of limiting their day to day functioning. Findings from a national survey demonstrates that BCS are vulnerable to experiencing more mood disturbances and an increased number of physical symptoms while engaging in the same routine life activities and associated stressors as their healthy peers (Costanzo et al., 2012). This finding was gathered from a sample of survivors who reported being anywhere from 1 to 59 years post diagnosis, suggesting that a threat for BCS to maintain positive psychological functioning can remain throughout the balance of their life.

PWB is negatively related to common problems associated with cancer, psychological distress and satisfaction with preparatory information. In addition, BCS report that some of the common problems present a severe burden to them during early survivorship. The knowledge gap identified in this study is a starting point for healthcare teams providing care to BCS.

Implications for Nursing Practice

Nurses are engaged on a continuous basis in the care of BCS and are increasingly utilized in the post-treatment care of these women (Grunfeld, 2009; Lewis et al., 2009; Mayer et al., 2012; O'Brien, et al., 2013). This places them in a key position, from the moment the survivor is diagnosed, to (1) monitor the women's physical and psychosocial response to treatment from a Eudaimonic perspective of well-being throughout treatment into early survivorship and (2) implement and follow-up with effective strategies,



especially those involving education that will prepare BCS to successfully transition into life after treatment.



Table 4.1

Variable Re		
Age	ge <u>X(S</u> 59.1(1	
	N (%)
Race	Caucasian	54(96.4)
	African American	2 (3.6)
Marital Status	Married	38(67.9)
	Divorced	10(17.9)
	Widowed	6(10.7)
	Single	2 (3.6)
Education	Elementary/HS	25(44.6)
	College/University	22(39.3)
	Graduate School	9(16.1)
Employment Status	Full-time	24(47)
(N = 51)	Retired	20(39)
	Part-time	5 (10)
	Other	2 (4)
Household Income	< \$20,000	5 (9)
(<i>N</i> =54)	\$20,001 - \$40,000	13(24)
	\$40,001 - \$80,000	20(37)
	\geq \$80,000	16(30)
Living Arrangements	Partner/spouse	32(57.1)
	Family	14(25.0)
	Alone	10(17.9)
Stage at diagnosis	Stage 0	3 (5.4)
(<i>N</i> =51)	Stage I/II	43(76.8)
	Stage IIIA	4 (7.1)
	Stage IV	1 (1.8)
Treatment	Radiation only	25(44.6)
	Chemo & Radiation	19(33.9)
	Chemotherapy only	12(21.4)

Study Participant Characteristics (N = 56 unless noted otherwise)

Time since completing treatment

<u>M (R)</u> 2 months (5)



Table 4.2

Descriptive Statistics: SPWB, CPILS, DASS, And SPT

			Min/	Max
Measure			Potential	Actual
	Mean	SD		
Scales of Psychological Well-being				
Total scale score ($N = 47$)	409.75	54.78	84-504	254-491
Autonomy ($N = 56$)	66.71	9.55	14-84	39-84
Self-acceptance ($N = 52$)	67.93	10.89	14-84	35-83
Personal Growth $(N = 55)$	68.86	10.46	14-84	37-84
Purpose in Life $(N = 54)$	67.52	10.89	14-84	42-83
Positive relations with others $(N=54)$	71.67	10.27	14-84	44-84
Environmental Mastery $(N = 53)$	65.94	10.98	14-84	32-83
	Median	Range		
Cancer Problems In Living Scale $(N = 50)$	8.5	47	0-62	0-47
Depression Anxiety Stress Scales				
Depression $(N = 56)$	3.5	34	0-42	0-34
Anxiety $(N = 54)$	4.0	33	0-42	0-33
Stress $(N = 55)$	4.0	33	0-42	0-33
	Counts	%		
Satisfaction Preparation to Transition (n = 56)				
Yes, all	32	57.1	N/A	N/A
Yes, most	14	25	N/A	N/A
No, some	5	8.9	N/A	N/A
No, little to none	5	8.9	N/A	N/A



Table 4.3

	Total SPWB	PR	PL	EM	AU	SA	PG
Factors							
CPILS	695*	487*	541*	637*	563*	670*	455*
Depression	726*	474*	675*	683*	439*	703*	565*
Anxiety	709*	505*	578*	639*	468*	679*	504*
Stress	605*	424*	533*	602*	396*	639*	402*
SPT	470*	406*	389*	404*	321	454*	266

Pearson r Correlation Coefficients between PWB and Influencing Factors

Legend: SPWB = Scales of Psychological Well-being; PR = positive relations with others PL = purpose in life EM = environmental mastery; AU = autonomy SA = self-acceptance PG = positive growth; CPILS = cancer problems in living scales; SPT – satisfaction with preparation to transition; bonferroni-like correction was applied to the original level of significance to prevent a type I error associated with the simultaneous analysis of data therefore only correlations with *p = ≤ 0.01 are considered statistically significantly



Table 4.4

CPILS Item Frequencies

Item	Not a problem	Somewhat a problem	Severe problem
	N (%)	N (%)	N (%)
unable to change jobs for fear losing health	48(91)	1(1)	4(8)
insurance ich discrimination	51(06)	0	2 (4)
job discrimination	51(96)		2(4)
concern about relapse	21(38)	27(49)	7(13)
fatigue	12(21)	32(57)	12(21)
uncomfortable with changes in physical appearance	31(55)	20(36)	5(9)
preoccupation with being ill	35(64)	16(29)	4(7)
eating difficulties	40(73)	12(22)	3(5)
concern about being physically unable to have children	50(94)	0	3(6)
difficulty concentrating	24(44)	24(44)	6(11)
sleep difficulties	17(30)	27(48)	12(22)
feeling dependent	40(73)	12(22)	3(5)
being less physically able to have sexual	40(74)	11(20)	3(6)
intercourse			0(0)
fears about the future	27(49)	21(38)	7(13)
guilt feelings	43(78)	10(18)	2(4)
feeling angry	37(67)	15(27)	3(6)
having difficulty making long term plans	39(71)	13(24)	3(5)
feeling isolated	47(86)	4(7)	4(7)
feeling helpless	41(75)	9(16)	5(9)
feeling vulnerable	33(60)	18(33)	4(7)
being treated as different from others	45(82)	9(16)	1(2)
being concerned about infection and crowds	36(66)	16(29)	3(5)
problems with family/children	48(87)	5(9)	2(4)
difficulty in returning to former roles	40(73)	11(20)	4(7)
problems communication with my spouse or	41(76)	11(20)	2(4)
partner difficulty in meeting medical expenses	30(56)	14(26)	10(18)
fearful that my illness will return	18(33)	29(53)	8(14)
being less able to provide financially	37(67)	12(22)	6(11)
difficulty obtaining adequate insurance	48(89)	4(7)	2(4)
difficulties pursuing career of my choice	48(89)	3(5)	3(5)
continued major problems with my health	40(73)	11(20)	4(7)
unable to get information I need about cancer	51(93)	4(7)	0

Note: Due to rounding, not all percentages equal 100



Chapter Five

Conclusion

Eudaimonic PWB, operationalized by Ryff into the SPWB, is a theoretical framework that covers the spectrum of functioning which includes positive psychological functioning (Ryff, 1989). It is a more accurate reflection of BCS' ability to engage in life while experiencing cancer-related problems than evaluating how they respond to the sequealae of cancer and it treatment using traditional approaches such as extremes of illness or degrees of physical impairment. According to Ryff (1989), optimal PWB results from being fully engaged in activities of life associated with being independent, having a purpose in life, self-acceptance, personal growth and development, having positive relationships with others, and mastering one's environment (Table 1.1). While it is suggested that the experience of PWB has the potential to promote wellness, its absence has been linked to depressive symptomatology in adults without cancer (Wood & Joseph, 2010). As more BCS are living longer with disease and treatment-related negative effects it will become increasingly important to monitor their functioning and well-being as early after treatment as possible.

The literature review presented in Chapter Two summarized PWB among BCS in terms of factors that were either associated with or factors that predicted levels of functioning using the SPWB. Forms of coping mechanisms and social support were factors most frequently evaluated. This is not surprising since coping strategies and resources are necessary for managing the stress associated with cancer (Franks & Roesch, 2006). Three other factors determined to be associated with PWB from the literature review included self-esteem, post traumatic growth and symptom experience.



The transition from cancer treatment into early survivorship can be difficult and information was found to be a key facilitator for a successful transition by this sample of BCS. As pointed out in Chapter Three, regardless of whether these women were satisfied or not satisfied with the information they were given to transition, they described information on what to expect once treatment ends and how to manage it as being the most helpful. It was resoundingly apparent that cancer care clinicians should spend more time and effort emphasizing how the physiopsychosocial effects of cancer and its treatment will result in the life of the BCS after treatment being unlike their life prior to being diagnosed. Several of the women called this difference a "new normal" yet the feedback they provided about this phenomenon was superficial. Future research should focus on gaining deeper insight into the "new normal" to help cancer care clinicians engage in more effective discussions with BCS.

Finally, the burden associated with cancer problems, psychological distress and satisfaction with preparatory information were found to be significantly negatively correlated with Eudaimonic PWB among this sample of BCS. While coping mechanisms, social support, self-esteem and post-traumatic growth were factors noted to be associated with PWB in Chapter Two, the burden associated with problems cancer patients typically face during early survivorship (physical symptoms, psychological, financial and employment) and satisfaction with preparatory information to transition into survivorship were selected for this dissertation for two reasons. One, the IOM (2006) published recommendations that information should be provided to survivors as they transition into early survivorship; this includes information on the after effects of cancer treatment. Two, these factors are pertinent to survivors being cared for in the real world



setting which is where this sample of BCS were drawn from. An important finding worth further investigation is to identify the exact reason why, with the existence of strong levels of PWB among BCS, certain cancer problems remain a severe burden to these women.

In conclusion, as this sample of BCS was transitioning into early survivorship they had strong levels of PWB. Higher levels of PWB were noted to be significantly correlated with lower levels of burden of cancer problems and psychological distress; lower levels of PWB co-existed with those BCS who were not satisfied with preparatory information they were given to transition into survivorship. Information learned from this dissertation can be used by healthcare teams to promote or maintain positive psychological functioning among these survivors, focusing initially on preparing them for life immediately after treatment.



Appendix A

Satisfaction with Preparation to Transition

Women who have completed treatment for breast cancer may feel that they have to return to a normal life rather quickly. However, it may be more difficult than one would think. Being prepared to transition from living with cancer while receiving treatment to surviving cancer after treatment can be beneficial. **Information on what to expect and how to manage the transition** is helpful to prepare most survivors. Now that you have recently completed treatment, do you feel that you have been given the information you needed to transition into life after treatment?

Please check the appropriate box below.

- □ **YES:** I feel that I have been given <u>all</u> of the information I needed to transition into life after treatment.
- \square **YES:** I feel that I have been given <u>most</u> of the information I needed to transition into life after treatment.
- □ **NO:** I feel that I did not receive <u>some</u> of the information I needed to transition into life after treatment.
- □ **NO:** I feel that I received very <u>little to no information that I needed to transition into life after treatment.</u>



If YES:

What information was most helpful to you?

What information was least helpful to you?

If **NO:** What information were you provided?

What additional informational would have been helpful to you?



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VITA

Celestine G. Gochett

Education

2006 - 2008	University of Kentucky Master of Science in Nursing Adult Health Clinical Nurse Specialist
2003 - 2006	University of Kentucky Bachelor of Science in Nursing
1986 – 1988	Purdue University Associate of Arts (Nursing)

Professional Experience

2009 - Present	KentuckyOne Health/Saint Joseph Health System, Kentucky Oncology Clinical Nurse Specialist
2000 - 2009	Manager, Research Center Oncology Clinical Research Coordinator Registered Nurse, Hematology/Oncology
1994 – 1996	Cleveland Clinic Foundation, Ohio Registered Nurse, BMT/Hematology/Oncology
1988 – 1994	University of Maryland Cancer Center, Maryland Registered Nurse, Hematology/Oncology

Honors

American Cancer Society Doctorate in Nursing Scholarship (2009 – 2011) Lillian Yeager Memorial Nursing Scholarship (2009) University of Kentucky College of Nursing Alumni Association Presidential Award (2008) Lyman T. Johnson Torch of Excellence Award (2007) Roberta Scofield Memorial Certification Award (2005) Nursing Educational Scholars Award (2005) Estelle Massey Osbourne Scholarship (2005)



Professional Publication

Roach, A.R., Lykins, E.L., Gochett, C.G., Brechting, E.H., Graue, L.O., & Andrykowski, M.A. (2009). Differences in cancer information seeking behavior, preferences, and awareness between cancer survivors and healthy controls: A national, population-based survey. *Journal of Cancer Education*, 24(1), 73-79.

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Celestine G. Gochett Student Name

