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Cancer-Related Symptoms And Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study

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CANCER-RELATED SYMPTOMS AND COGNITIVE INTERVENTION ADHERENCE AMONG BREAST CANCER SURVIVORS: A MIXED METHODS STUDY

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A DISSERTATION

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DOCTOR OF PHILOSPHY IN NURSING

ABSTRACT

Advancements in screening, early detection, and treatment have increased breast cancer survival. In the United States, the 5-year relative survival rate for breast cancer is 89%. With more women surviving breast cancer, there are now more than 3.5 million breast cancer survivors (BCS), a figure estimated to increase to 4.3 million by 2020. Survivors experience long-term symptoms of their cancer and treatment which may last years and even decades after diagnosis and treatment. This symptom experience may potentially have exacerbating effects on BCS' cognitive function as well as their ability to adhere to interventions aimed at improving cognitive function.

The intent of this study was to explore the relationship between selected cancer-related symptoms and adherence to the ***S****peed of Processing in Middle Aged and* ***O****lder Bre****a****st Cancer Su****r****vivors* (SOAR) web-based cognitive training intervention among BCS residing in Alabama by using a sequential Quan → QUAL mixed methods design. The goal of the quantitative phase of this study was to identify the relationship between selected cancer-related symptoms (i.e., perceived cognitive impairment, poor sleep quality, and depressive symptoms) and adherence to the SOAR intervention among BCS (n = 30) through self-reported questionnaire data (i.e., sociodemographic, Cognitive Failures Questionnaire (CFQ), Pittsburg Sleep Quality Index (PSQI), and Center for Epidemiologic Studies-Depression Scale (CES-D)). Data were analyzed using R Studio

3.3.1 software. Spearman's rho correlation suggested relationships between adherence and perceived cognitive impairment, depressive symptoms, and sleep quality. Results of the quantitative phase were used to inform the development of the interview protocol and participant selection for the second phase.

The goal of the qualitative phase of this study was to better understand how identified selected cancer-related symptoms contribute to or impede BCS' adherence to the SOAR intervention by conducting semistructured interviews with 15 purposefully selected SOAR intervention participants. Inductive thematic analysis yielded four themes that describe how cancer-related symptoms are related to adherence to SOAR among BCS, differences between adherent and non-adherent participants, and cultural aspects: (a) experiences of cancer-related symptoms; (b) influences of cognitive training; (c) adherence to cognitive training; and (d) environment for cognitive training. To describe the interrelationship of the emergent themes in their joint influence on BCS' adherence to cognitive training, a model was developed.

Integration of the findings identified that response to awareness of perceived cognitive impairment is critical to cognitive training adherence and that cognitive training exacerbates depressive symptoms among some BCS. Moreover, poor sleep quality can aggravate cognition and mood and negatively influenced cognitive training motivation and performance, creating a snowball effect. Yet, continued cognitive training may improve sleep, mood, and cognition among BCS.

Findings from this study illuminated the participant experience of cognitive training and cancer-related symptoms and their dynamic relationships with adherence. Experiences of and responses to cognitive training and cancer-related symptoms shape

adherence to cognitive training among BCS. BCS in this study who continued cognitive training experienced improved sleep, mood, and cognition. Further study and application of findings may potentially aid in self-management of concurrent cancer-related symptoms, delivery of cognitive interventions, and improved cognition and ultimately quality of life among BCS.

Keywords: breast cancer survivors, cognitive impairment, cognitive training, adherence, cancer-related symptoms, mixed methods research

DEDICATION

In memory of my Mother

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CHAPTER 1

INTRODUCTION

Breast cancer is the most common cancer in women, with more than 200,000 new cases diagnosed each year in the United States (American Cancer Society [ACS], 2016a). Advancements in screening, early detection, treatment, and symptom management have increased 5-year breast cancer survival rates to 89% (ACS, 2016a). Currently in the United States, there are approximately 3.5 million breast cancer survivors (BCS) (ACS, 2016a), a figure estimated to increase to 4.3 million by 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011; Parry, Kent, Mariotto, Alfano, & Rowland, 2011). This growing population of BCS has led to an increased focus on the management of cancer-related symptoms experienced following diagnosis and treatment (Dodd, Miaskowski, & Paul, 2001; Fiorentino, Rissling, Liu, & Ancoli-Israel, 2011; Lenz, Pugh, Milligan, Gift, & Suppe, 1997). One such cancer-related symptom is cognitive impairment.

Cognitive impairment, as defined by the Oncology Nursing Society (ONS), is a decline in function in one or multiple cognitive domains (i.e., attention, memory, executive function, and information processing speed) (ONS, 2016). Up to 75% of BCS in cancer treatment and 35% after treatment self-report cognitive impairment (Runowicz et al., 2016). Yet, BCS' self-reported (perceived) cognitive impairment is generally not concordant with neuropsychological measures (Hutchinson, Hosking, Kichenadasse,

Mattiske, & Wilson, 2012; Von Ah, Habermann, Carpenter, & Schneider, 2013). While cognitive impairment is thought to be multifactorial, a single specific cause is unknown. Recent studies among BCS indicate that cognitive impairment negatively impacts self-esteem, confidence, social relationships, work ability, and overall quality of life (Becker, Henneghan, & Mikan, 2015; Boykoff, Moieni, & Subramanian, 2009; Von Ah et al., 2013).

While the National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), and ONS indicate some evidence for cognitive training as treatment of cognitive impairment among survivors (Denlinger et al., 2015; LoBiondo-Wood et al., 2014; Runowicz et al., 2016), further study is needed. Thus, the President's Cancer Panel, the National Cancer Institute (NCI) Office of Cancer Survivorship, the NCCN Survivorship Panel, and ONS identified cognitive impairment among cancer survivors as a national research priority (Hewitt, Greenfield, & Stovall, 2005; Knobf, 2015; National Cancer Institute, 1999).

Some co-occurring cancer-related symptoms commonly reported by BCS include depressive symptoms and poor sleep quality (Dodd et al., 2001; Fiorentino et al., 2011; Lenz et al., 1997). These concurrent symptoms may potentially exacerbate cognitive impairment (Denlinger et al., 2015; Henneghan, 2016) and adherence to interventions aimed at improving cognitive function (Meneses, Azuero, Su, Benz, & McNees, 2014; Meneses, Benz, Azuero, Jablonski-Jaudon, & McNees, 2015; Vance et al., 2017; Wang et al., 2015). Yet, to date, no investigators report the relationship between cancer-related symptoms and adherence to a cognitive training intervention among BCS. The purpose of this chapter is to briefly introduce: (a) the problem of cognitive impairment; (b)

background and significance; (c) specific aims and research questions; (d) theoretical framework; (e) parent study; (f) definitions of terms used in the study; and (g) study assumptions, delimitations, and limitations.

Problem Statement

Cancer-related symptoms may be associated with BCS' adherence to the parent study (***S****peed of Processing in Middle Aged and* ***O****lder Bre****a****st Cancer Su****r****vivors* [SOAR]), a feasibility study of a web-based cognitive training intervention among BCS.

Background and Significance

Among BCS cognitive impairment, often called "chemobrain," is most commonly associated with chemotherapy. Recent evidence and reviews indicate that other cancer treatment such as endocrine therapy and radiation therapy may also be associated with cognitive impairment (Ahles, Root, & Ryan, 2012; Ahles et al., 2010; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Phillips et al., 2012; Vance et. al., 2017; Von Ah, 2015). Some studies have reported cognitive impairment occurring in BCS before treatment (Ahles et al., 2008; Jansen, Cooper, Dodd, & Miaskowski, 2011; Phillips et al., 2012), suggesting that the problem may be related to either the tumor itself and/or a response to the stress of diagnosis (Ahles et al., 2008; Denlinger et al., 2015; Jansen et al., 2011). The underlying mechanisms of cognitive impairment include stress, fatigue, depression, brain tissue injury, oxidative stress, inflammation, and vascular injury (Ahles & Saykin, 2007). Some mechanisms may be mediated by reduced levels of estrogen, which may impact BCS who experience acute menopause related to treatment

(Fallowfield & Jenkins, 2015). Other factors related to cognitive impairment include age, education, anxiety, and genetics (Ahles, 2012; Vance et al., 2017). While some investigators report cognitive impairment improved or even resolved over time (Fan et al., 2005; Weis, Poppelreuter, & Bartsch, 2009), others have found that cognitive impairment persisted for years, even decades, in survivorship (Koppelmans et al., 2012; Yamada, Denburg, Beglinger, & Schultz, 2010).

Mounting evidence indicate cognitive impairment in the domains of speed of processing, attention, memory, and executive function among BCS (Adams-Price, Morse, Cross, Williams, & Wells-Parker, 2009; Collins, Mackenzie, Tasca, Scherling, & Smith, 2014; Jansen et al., 2011; Koppelmans et al., 2012; Wefel, Saleeba, Buzdar, & Meyers, 2010). Investigators report BCS' performance on neuropsychological measures ranged from normal performance to significant cognitive impairment (Downie, Mar Fan, Houde-Tchen, Yi, & Tannock, 2006; Jansen et al., 2011; Koppelmans et al., 2012). Methodological differences (i.e., study design, type of cognitive testing, type of treatment, time since treatment, and definition of cognitive impairment) may account for this variability (Frank, Vance, Triebel, & Meneses, 2015; Vance et al., 2017), thus raising concerns that neuropsychological measures may not be sensitive to cognitive changes reported by BCS (Jansen, 2013). Recent imaging studies suggest that normal neuropsychological test results may mask the use of atypical neural processing to compensate for cognitive impairment (Hosseini & Kesler, 2014; Kesler, Kent, & O'Hara, 2011).

Compared to the frequency and severity of cognitive impairment measured by neuropsychological testing, self-reported (perceived) cognitive impairment is more

prevalent and severe (Bower, 2008; Frank, Vance, Jukkala, & Meneses, 2014; Hutchinson et al., 2012; Pullens, De Vries, & Roukema, 2010; Von Ah et al., 2013). BCS report forgetting appointments, misplacing items, not remembering why they had gone to a particular room, and difficulty with learning new information (Becker et al., 2015; Boykoff et al., 2009; Myers, 2012). Perceived cognitive impairment is frustrating and upsetting to BCS and may be poorly understood by family members and colleagues (Becker et al., 2015; Boykoff et al., 2009). Furthermore, perceived cognitive impairment, even if not documented through neuropsychological testing, negatively impacts BCS' self-esteem, confidence, social relationships, work ability, and overall quality of life (Becker et al., 2015; Boykoff et al., 2009; Von Ah et al., 2013).

Families and friends of BCS experiencing cognitive impairment often fail to understand their experiences, leading to BCS feeling misunderstood, embarrassed, frustrated, and lacking self-confidence in their cognitive abilities (Becker et al., 2015; Boykoff et al., 2009; Munir, Burrows, Yarker, Kalawsky, & Bains, 2010). Some BCS characterize family and friends as dismissive, belittling, and confused by their cognitive impairment and describe acts of being avoided or taken advantage of (Boykoff et al., 2009).

Employment plays a key role in financial and psychological well-being, quality of life, and a return to "normalcy" during or following treatment (Becker et al., 2015; Fenn et al., 2014; Kennedy, Haslam, Munir, & Pryce, 2007; Meneses, Azeuro, Hassey, McNees, & Pisu, 2012). Although 45% to 93% of BCS choose to return to work within 12 months of diagnosis (Becker et al., 2015; Islam et al., 2014; Munir et al., 2010; Player, Mackenzie, Willis, & Loh, 2014), cognitive impairment can make job-related duties more

difficult, requiring more time to complete such activities (Boykoff et al., 2009; Von Ah et al., 2013). Additionally, cognitive impairment may be a potential occupational safety issue (Calvio, Peugeot, Bruns, Todd, & Feuerstein, 2010; Player et al., 2014). Decision to return to work can be influenced by the level of cognitive impairment, self-awareness of cognitive impairment, and the impact of perceived cognitive impairment on their confidence to succeed at work (Munir et al., 2010). BCS are more likely to make changes in employment including retirement, reduction of hours, and change of position compared with their age-matched peers (Hauglann, Benth, Fossa, & Dahl, 2012). Some who are unemployed report lower physical and mental quality of life and higher levels of fatigue and anxiety than employed BCS (Lindbohm et al., 2014). Loss of employment greatly affects financial security and access to health insurance, especially for those who are sole family providers (Boykoff et al., 2009).

Effective interventions to enhance cognitive function in BCS with cognitive impairment are urgently needed. NCCN Survivorship Guidelines identifies occupational therapy (strategies focused on improvement of cognitive function) as a first-line intervention for cognitive impairment in cancer survivors (NCCN, 2017). In the ONS Putting Evidence into Practice (PEP), a guide that provides evidence-based interventions for patient care and teaching, the only recommendation deemed "likely to be effective" is cognitive training (ONS, 2016). ACSO's breast cancer survivorship care guidelines recommend cognitive training for the treatment of cognitive impairment (Runowicz et al., 2016). Recent literature reviews conducted on studies of interventions for cognitive impairment in BCS indicate that cognitive training interventions aimed at improving

speed of processing, attention, and memory are the most promising in BCS (Morean, O'Dwyer, & Cherney, 2015; Vance et al., 2017; Von Ah, Jansen, & Allen, 2014).

Cognitive training refers to a variety of methods of improving cognitive function through repeated practice of cognitive exercises that target specific cognitive skills such as attention, memory, speed of processing, or executive functioning (Sohlberg & Mateer, 2001). Within the framework of neuroplasticity, cognitive training produces actual neurological change either by neural strengthening of connections in the brain typically involved in performing a task or by creating new neural connections that result in improved performance (Vance et al., 2017). Cognitive exercises involved in cognitive training interventions are usually adaptive; the difficulty level of the training exercises increases as performance on the exercises improves while accuracy remains constant and the task remains engaging. Studies among healthy older adults demonstrate that computerized cognitive training produces physiological changes in the brain (Lampit, Hallock, Suo, Naismith, & Valenzuela, 2015), enhances cognitive function (Ball et al., 2002), sustains cognitive enhancement for up to 10 years (Rebok et al., 2014), reduces the incidence of dementia (Edwards, Xu, Clark, Ross, & Unverzagt, 2016), and improves other health-related outcomes (e.g., depressive symptoms, quality of life, self-rated health, and internal locus of control).

While NCCN, ASCO, and ONS identified the promise of cognitive training for the treatment of cognitive impairment among cancer survivors (Denlinger et al., 2015; LoBiondo-Wood et al., 2014; Runowicz et al., 2016), further study is needed. Thus, the President's Cancer Panel, the NCI Office of Cancer Survivorship, the NCCN Survivorship Panel, and ONS identified cognitive impairment among cancer survivors as

a national research priority (Hewitt et al., 2005; Knobf, 2015; National Cancer Institute, 1999).

Other cancer-related symptoms that co-occur include depressive symptoms and poor sleep quality (Fiorentino et al., 2011; Dodd et al., 2001; Lenz et al., 1997). Concurrent cancer-related symptoms may potentially exacerbate cognitive impairment (Denlinger et al., 2015; Henneghan, 2016) and adherence to interventions aimed at improving cognitive function (Meneses et al., 2014; Vance et al., 2017; Wang et al., 2015). Yet, to date, no research has been reported to examine the relationship between cancer-related symptoms and adherence to a cognitive training intervention among BCS.

In the parent study (***S****peed of Processing in Middle Aged and* ***O****lder Bre****a****st Cancer Su****r****vivors* [SOAR]), a feasibility study of a web-based cognitive training intervention among BCS, observations, including non-adherence to intervention protocol and verbal comments about cancer-related symptoms offered by participants, suggested that cancer-related symptoms may be related to BCS' adherence to a cognitive intervention. These observations lead to the development of the present study. A detailed description of the SOAR study is provided in chapter 2. To guide the delivery of future cognitive interventions in BCS, the present study explored the relationship between selected cancer-related symptoms and adherence to the SOAR intervention among BCS.

Purpose of the Study

The intent of this study was to explore the relationship between selected cancer-related symptoms and adherence to the SOAR web-based cognitive training intervention among BCS residing in Alabama by using a sequential Quan → QUAL mixed methods design. The goal of the quantitative phase of this study was to identify the relationship between selected cancer-related symptoms and adherence to the SOAR intervention among BCS through self-reported questionnaire data. The goal of the qualitative phase of this study was to better understand how identified selected cancer-related symptoms contribute to or impede BCS' adherence to the SOAR intervention by conducting semistructured interviews with 15 purposefully selected SOAR intervention participants. The rationale for integrating quantitative and qualitative methods in this study phase was to obtain validated meta-inferences to inform the delivery of future cognitive training interventions for BCS.

Specific Aims

The specific aims were:

1. Understand the relationship between selected cancer-related symptoms and adherence to the SOAR cognitive training intervention among BCS; and
2. Explore potential facilitators and/or barriers to SOAR and how identified symptoms contribute to/explain differences in adherence.

Research Questions

The integrated research question guiding this mixed methods study was:

1. How can quantitative instrument scores and interview themes jointly help understand the relationship between selected cancer-related symptoms and BCS' adherence to the SOAR cognitive training intervention?

For the quantitative phase of this study (Phase I), the guiding research question was: What is the relationship between selected cancer-related symptoms and adherence to the SOAR cognitive training intervention among BCS?

The specific research question for Phase I was:

1. What is the relationship between perceived cognitive impairment, depressive symptoms, and poor sleep quality, and adherence to the SOAR cognitive training intervention among BCS?

For the qualitative phase of this study (Phase II), the overarching research question was:

1. How do the selected cancer-related symptoms identified in Phase I contribute to or impede BCS' adherence to the SOAR cognitive training intervention?

Theoretical Framework

The Theory of Unpleasant Symptoms (TUS) was used to guide this study. The TUS provides a framework for understanding the complexity of the symptom experience and relationships to potential outcomes (Lenz, Suppe, Gift, Pugh, & Milligan, 1995). The TUS has been tested in a variety of clinical settings and "provides linkages with research and practice" (Lenz et al., 1997, p. 14). The overall symptom experience affects

health outcomes, and includes functional status, cognitive functioning, and physical performance.

Components of the Theory

The theory asserts that multiple symptoms can occur at one time, leading to interaction among symptoms and influencing factors that affect the individual's performance of physical, cognitive, and social activities (Lenz et al., 1997). The TUS focuses on symptoms and their interactions. The three components of the theory include (a) symptoms that the individual is experiencing, (b) influencing factors that give rise to or affect the nature of the symptom experience, and (c) consequences of the symptom experience (Lenz et al., 1997). The major concepts related to each component of the theory will be discussed separately for clarity; however, it is important to note here that each of the three components is reciprocal, each affecting every other component.

Symptoms. Symptoms are the central focus of the theory and are described as an individual experience. The original model (1995) depicted symptoms as somewhat isolated phenomena (see Appendix A). Revisions to the theory by Lenz et al. (1997) took into account the more complex nature of symptoms, specifically recognizing that multiple symptoms more often occur in combination and simultaneously (see Appendix A). Symptom dimensions include (a) intensity; (b) timing; (c) level of distress perceived;(d) and quality. Intensity refers to "the severity, strength, or amount of the symptom being experienced" (p. 15). Timing relates to the frequency with which symptoms occur, the duration of the symptom, and association of the symptom with activities. Quality of the

symptoms is “reflected by the vocabulary used to describe what the symptoms feel like” (Lenz et al., 1997, p. 17) and can indicate the seriousness of the symptom. The level of distress perceived “refers to the degree to which the person is bothered” (Lenz et al., 1997, p. 16) by the symptom.

For the purposes of this study, symptoms were operationalized as perceived cognitive impairment, depressive symptoms, and poor sleep quality (see Figure 1). The researcher measured perceived cognitive impairment using the 25-item self-report Cognitive Failures Questionnaire (CFQ). Depressive symptoms were measured via the 20-item self-report Center for Epidemiologic Studies-Depression Scale (CES-D). The study assessed sleep quality using the 11-item self-report Pittsburgh Sleep Quality Index (PSQI). Copies of the instruments appear in Appendix B.

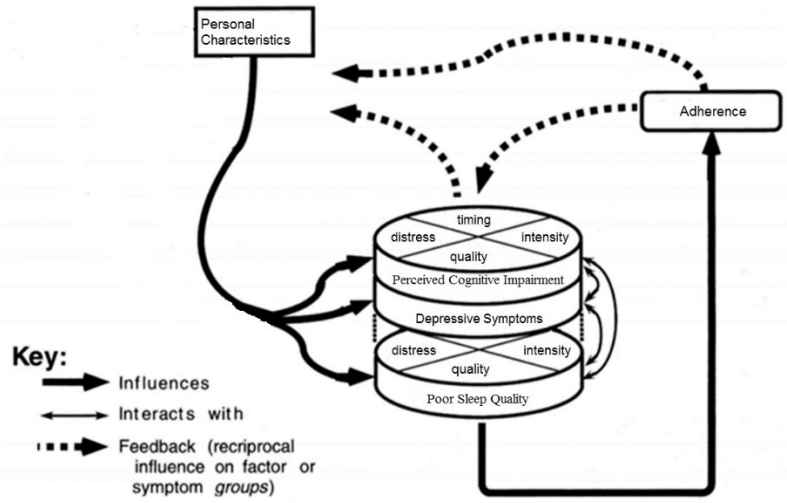

Figure 1. Illustration of how the Theory of Unpleasant Symptoms model informs the present study. Adapted from “The Middle-Range Theory of Unpleasant Symptoms: An Update,” by Lenz, et al., 1997, *Advances in Nursing Science*, *19*(3), 14-27.

Influencing factors. Influencing factors can lead to or affect the nature of the symptom experience and the consequences of the symptom experience (Lenz et al., 1997). Influencing factors include (a) physiologic, (b) psychologic, (c) and situational factors. Physiologic factors include "normally functioning body systems, existing pathology, disease, or trauma and the individual's nutritional status" (Lenz et al., 1997, p. 18). Psychologic factors include "mental state or mood" and "affective reaction to illness" (Lenz et al., 1997, p. 18). Therefore, psychologic factors encompass the degree of uncertainty about the symptoms, as well as knowledge about the symptoms and their meaning to the individual. Psychologic factors are made evident by symptoms such as stress, anxiety, and depression. Situational factors include the "social and physical environments that may affect the individual's experience" (Lenz et al., 1997, p. 18) of symptoms and their likelihood to report symptoms. These factors include employment status, marital and family support, social support, lifestyle behaviors such as diet and exercise, and the availability of and access to health care resources (Lenz et al., 1997).

Researchers using the TUS recognize that "people differ in their ability to discern symptoms" (Lenz et al., 1997, p. 17), and they may not all be able to clearly differentiate one symptom from another. However, one's long-term experience with a symptom may increase one's recognition of the sensations associated with it (Lenz et al., 1997). Nevertheless, when multiple symptoms are experienced together, it may be more difficult to differentiate among overlapping sensations, such as concurrent cancer-related symptoms (e.g., perceived cognitive impairment, depressive symptoms, and poor sleep quality) in BCS.

For the purposes of this study, influencing factors were operationalized as personal characteristics. The Sociodemographic and Treatment Questionnaire, a 20-item self-report questionnaire, was used to collect personal characteristics (see Appendix B).

Performance. Consequences of the symptom experience include performance, which is "the 'outcome' or 'effect' of the symptom experience" (Lenz et al., 1997, p. 19). Lenz et al. (1997) conceptualize performance to encompass functional and cognitive activities and their related behaviors. "Functional activities include physical activity, activities of daily living, social activity and interaction, and role performance activities related to work and role-related tasks" (Lenz et al., 1997, p. 20). For the purpose of this study, performance was operationalized as adherence (≥ 8 hr of cognitive training completed in 6-8 weeks) and was collected from the cognitive training website (www.BrainHQ.com). See Appendix B.

Summary

The TUS theorists originally depicted symptoms occurring in isolation from one another but soon after identified that symptoms more often occur in multiples experienced simultaneously. They further assert that the nature of multiple symptoms occurring together results in an experience that is not simply independent but is more likely to be synergistic. For example, cognitive impairment may be perceived as considerably worse when one is experiencing depressive symptoms or poor sleep quality and may be even more severe when all three symptoms occur together. Furthermore,

symptoms are seen as influencing adherence, and adherence is seen as affecting symptoms (Lenz et al., 1997).

Study Definitions

For the purposes of this research, the following terms were defined:

Adherence: Adherence to the SOAR cognitive training intervention was defined as completing ≥8 hr of cognitive training via Brain HQ over a period of 6-8 weeks.

Attention: Attention is the ability to selectively focus on one main object or idea while avoiding distraction from other objects or ideas (Frank et al., 2014).

Breast Cancer: Breast cancer is a malignancy that forms in tissues of the breast, usually the ducts and lobules (ACS, 2016b).

Cancer Survivor: Cancer survivor refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life (ACS, 2016b).

Cancer-related Symptoms: These are symptoms occurring as a result of cancer diagnosis and/or treatment (Dodd et al., 2001).

Coding: Coding is "identifying a meaningful statement of text [that] calls for some minimal representation of that meaning" (Guest, MacQueen, & Namey, 2012, p. 52).

Cognitive Impairment: Cognitive impairment is a decline in function, either objective or subjective, in one or multiple cognitive domains (i.e., attention, memory, executive function, and speed of processing) (ONS, 2017).

Cognitive Reserve: Cognitive reserve refers to the number and strength of neural connections in the brain (Vance et al., 2012).

Cognitive Training: Cognitive training refers to a variety of methods of improving cognitive function through repeated practice of cognitive exercises that target specific cognitive skills such as attention, memory, speed of processing, or executive functioning (Sohlberg & Mateer, 2001).

Computerized Cognitive Training: Computerized cognitive training refers to a method of cognitive training via a computer (Conklin et al., 2015).

Data Saturation: Data saturation is "the point in data collection and analysis when new information produces little or no change to the codebook" (Guest, Bunce, & Johnson, 2006, p. 65).

Depressive Symptoms: Depressive symptoms refer to depressed mood, loss of interest, and fatigability as measured by the Center of Epidemiologic Studies-Depression Scale (CES-D) and are not indicative of clinical depression (Aggarwal et al., 2008).

Executive Function: Executive function refers to working memory, cognitive flexibility, multitasking, planning, and attention (Kesler et al., 2013).

Inference Quality: Inference quality describes "standards for evaluating the quality of conclusions that are made on the basis of research findings" in a mixed methods study (Teddlie & Tashakkori, 2003, p. 287).

Memory: Memory is the capacity to retain and use information (Frank et al., 2014).

Meta-Inferences: A meta-inference is "a conclusion generated through an integration of the inferences that have been obtained from the results of the quantitative and qualitative strands of a mixed methods study" (Teddlie & Tashakkori, 2009, p. 152).

Mixed Methods Research: This approach requires "research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry" (Tashakkori & Creswell, 2007, p. 4).

Negative Neuroplasticity: Negative neuroplasticity is a process that inhibits the stimulation and health of neurons so that the connections between other neurons weaken and atrophy (Vance et al., 2012).

Neuroplasticity: Neuroplasticity refers to physiological changes that occur in neurons as a result of stimuli or lack thereof (Mahncke, Bronstone, & Merzenich, 2006).

Positive Neuroplasticity: Positive neuroplasticity is a process that enhances the stimulation and health of neurons so that they grow and form new or stronger connections to other neurons (Vance et al., 2012).

Qualitative Codebook: This is a list of codes and their emergent categories and themes (Guest et al., 2012).

Perceived Cognitive Impairment: Perceived cognitive impairment refers to the degree of cognitive difficulty that individuals perceive in their daily lives and their satisfaction with their cognitive functioning (Pullens, De Vries, Van Warmerdam, Van De Wal, & Roukema, 2013)

Poor Sleep Quality: Poor sleep quality refers to a disruption in the normal sleep-wake cycle or sleep architecture as measured by the Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989).

Speed of Processing: Speed of processing is the rate at which cognitive operations are performed (Vance, McNees, & Meneses, 2009).

Thematic Analysis: Thematic analysis is a "method for identifying, analyzing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79).

Assumptions

Assumptions of the study include:

1. Cognitive training may improve cognitive impairment.
2. SOAR participants aimed to adhere to the intervention protocol.
3. SOAR participants provided honest answers to self-reported questionnaires.
4. SOAR data were entered accurately.
5. Participants provided honest answers to interview questions.
6. The information obtained from the participants in this study represented their "truth space" (Onwuegbuzie & Teddlie, 2003, p. 369).

Delimitations

Delimitations of the study include:

1. The study was confined to the SOAR cognitive training intervention and participants.
2. Participants' responses were reflections of, and confined to, their personal experiences of SOAR.

Limitations

Limitations of the study included:

1. Due to the small sample size and the fact that convenience sampling was used in the quantitative phase of the study, the sample may not be representative of the larger population.
2. Quantitative data were limited to variables that were available from SOAR.
3. Due to an inherent researcher's bias, the data obtained in the second phase of the study may be subject to different interpretations.
4. There is a potential for bias in the qualitative results interpretation, because of the interpretative nature of the qualitative research and the researcher being a research assistant in the SOAR study and personally knew the participants of the study.
5. Due to the sequential Quan → QUAL mixed methods design, the quality of the inferences produced in the phase I may have influenced the quality of the inferences produced in Phase II, potentially affecting the quality of the generated meta-inferences from the entire study

Summary

This chapter presented the problem and its significance, research design, theoretical framework, parent study, assumptions, delimitations, and limitations of the study. The purpose, design, and research questions explored the relationship between selected cancer-related symptoms and adherence to the SOAR cognitive training intervention among BCS to inform the delivery of future cognitive interventions for BCS.

This study is the first step in developing a program of research and has potential to contribute to understanding and improving cognitive impairment in BCS.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this literature review was to gain an understanding of the state of the science of cognitive impairment among BCS and to guide the development of this study. This review examines the factors associated with cognitive impairment, affected cognitive domains, and impact on quality of life among BCS. Cognitive intervention studies, employing multiple intervention strategies, conducted with BCS over the past decade are discussed. Current gaps in knowledge, with primary emphasis on research to develop effective cognitive interventions aimed at improving cognitive function among BCS, are also discussed. This chapter presents (a) epidemiologic basis and concepts of interest; (b) literature search strategy; and (c) analysis of the literature relative to concepts.

Epidemiologic Basis and Concepts of Interest

Breast Cancer

Breast cancer is the most common cancer among women worldwide (World Health Organization [WHO], 2017). In the United States, one in eight women will be diagnosed with breast cancer in their lifetime (Centers for Disease Control and Prevention [CDC], 2017). Each year, more than 200,000 new cases of female breast

cancer are diagnosed, accounting for 29% of all new cancer cases in women (ACS, 2016a). In 2016, an estimated 246,660 new cases of female breast cancer were expected (ACS, 2016a; DeSantis et al., 2016; Siegel, Miller, & Jemal, 2016).

From 1975 until the turn of the millennium, female breast cancer incidence rates were the highest in Caucasians; however, from 2003-2012, breast cancer incidence rates were stable in Caucasian women and increased in African American women, resulting in the convergence of incidence rates in African Americans with those in Caucasians (ACS, 2016a; DeSantis et al., 2016; Siegel et al., 2016). While the median age at diagnosis is 61 years, 44% of women are over age 65 years and 19% are younger than age 50 years at diagnosis (ACS, 2016a).

From 2003-2012, due to improvements in early detection and treatment, breast cancer death rates decreased by 19% in Caucasian women and by 14% in African American women. Overall, breast cancer death rates declined 36% from 1989 to 2012, reducing breast cancer deaths by approximately 249,000 (ACS, 2016a; Miller et al., 2016). Yet, breast cancer is still the second most common cause of cancer death in women, second only to lung cancer, with 40,450 deaths expected in 2016 (ACS, 2016a; Siegel et al., 2016).

Since 1975, breast cancer survival in the United States has been increasing due to widespread mammography use and improvements in treatment (ACS 2016b; Berry et al., 2005; Howlader, Mariotto, Woloshin, & Schwartz., 2014). Currently, the 5-year, 10-year, and 15-year relative survival rates for breast cancer are 89%, 83%, and 78%, respectively (ACS, 2016b; Miller et al., 2016).

Breast Cancer Pathology

Breast cancer is an abnormality of cellular growth that initiates in the mammary tissue (ACS, 2015a; ACS, 2016a; Siegel et al., 2016). Most often, the cellular changes occur in the ductal and lobular regions of the breast. Less frequently, the cellular changes may initiate in alternate locations of the breast tissue. When breast cancer is detected and treated early, survival rate is greatly improved (ACS, 2016b; Miller et al., 2016; Siegel et al., 2016). While the cause of most breast cancers is unknown, there are associated risk factors. These risk factors include: family history of early-age breast cancer, early-onset menarche, late menopause, female gender, increasing age, late primigravida, never having children, hormone replacement therapy, increased density of breast tissue, history of irradiation of chest wall, and genetic mutations (ACS, 2015a; ACS, 2016a; Lacey et al., 2009). Lifestyle risk factors include: obesity, lack of physical activity, western diet (i.e., high in meat, fat, sugar, and processed foods), and alcohol consumption (ACS, 2015b; American Institute of Cancer Research [AICR], 2016; Bail, Meneses, & Demark-Wahnefried, 2016; Castello et al., 2015).

Breast Cancer Treatment

Treatment of breast cancer is dependent on multiple factors, including: stage of cancer at diagnosis, tumor characteristics, and patient menopausal status (ACS, 2016b; Siegel et al., 2016). Treatment regimens typically include surgery, radiation, chemotherapy, endocrine therapy, and/or biologic therapy (Runowicz et al., 2016; NCCN, 2017; Senkus et al., 2015).

Among women with early stage I or stage II breast cancer, 8% undergo breast-conserving surgery alone, 53% undergo breast-conserving surgery along with radiation and/or chemotherapy, and 36% undergo mastectomy along with radiation and/or chemotherapy (ACS, 2016b). In women with stage III breast cancer, 21% undergo breast-conserving surgery along with radiation and/or chemotherapy, 7% undergo mastectomy alone, and 65% undergo mastectomy along with radiation and/or chemotherapy (ACS, 2016b). As for women with metastatic disease (stage IV), 48% undergo radiation and/or chemotherapy without surgery, 25% receive surgery alone or in combination with other treatments, and 28% of patients receive no treatment (ACS, 2016b).

Women whose breast cancer tests positive for hormone receptors (about 84%) (DeSantis et al., 2016) are candidates for treatment with endocrine therapy. Endocrine therapy is generally started after chemotherapy and radiation are complete. For premenopausal women, the standard endocrine therapy is tamoxifen for at least 5 years. For those who are postmenopausal, endocrine therapy may include tamoxifen and/or an aromatase inhibitor for 5 to 10 years (Burstein et al., 2010). Women whose breast cancer tests positive for HER2 gene amplification or protein overexpression (about 14%) may be treated with targeted therapies either as single agents or in combination with chemotherapy or hormonal therapy (DeSantis et al., 2016).

Cancer-related symptoms. Cancer-related symptoms refer to symptoms occurring as a result of cancer diagnosis and/or treatment (Dodd et al., 2001). Cancer-related symptoms commonly experienced by BCS include cognitive impairment,

depressive symptoms, poor sleep quality, pain, fatigue, infertility, and lymphedema (Dodd et al., 2001; Fiorentino et al., 2011; Lenz et al., 1997). This review will specifically focus on cognitive impairment, depressive symptoms, and poor sleep quality.

Cognitive impairment. Cognitive impairment among BCS has been investigated since the 1990s with studies reporting cognitive impairment among 35% to 75% of BCS, with the most commonly affected domains of attention, memory, speed of processing, and executive function (Ahles & Saykin, 2002; Ahles et al., 2012; Ahles et al., 2010; Bender et al., 2006; Bower, 2008; Brezden, Phillips, Abdolell, Bunston & Tannock, 2000; Castellon et al., 2004; Jansen et al., 2011; Jenkins et al., 2006; Kreukels, van Dam, Ridderinkhof, Boogerd, & Schagen, 2008; Mar Fan et al., 2009;; Pullens et al., 2010; Schagen et al., 2006; Schagen et al., 1999; Scherwath et al., 2006; Vardy, Wefel, Ahles, Tannock, & Schagen, 2008; Von Ah, Russell, Storniolo, & Carpenter, 2009; Wefel, Lemzi, Theriault, Davis, & Meyers, 2004; Wefel & Schagen, 2012; Wieneke & Dienst, 1995). This wide incidence range may be related to the use of diverse methodological and sampling designs among these studies (Frank et al., 2014; Frank et al., 2015; Kreukels et al. 2008; Schagen et al., 2002; Vance et al., 2017; Von Ah et al., 2009; Wieneke & Dienst, 1995). While some investigators have reported an improvement and resolution of cognitive impairment over time (Fan et al., 2005; Weis et al., 2009), others have found cognitive impairment to persist for many years or even decades into survivorship (Collins et al., 2014; de Ruiter et al., 2011; Koppelmans et al., 2012; Vearncombe et al., 2009; Wefel et al., 2010; Yamada et al., 2010). Cognitive impairment may increase the brain's

vulnerability to the effects of aging, injury, and disease (e.g., dementia) (Kesler, Watson, & Blayney, 2015).

Depressive symptoms. Depressive symptoms refer to depressed mood, loss of interest, and fatigability as measured by the CES-D and are not indicative of clinical depression (Aggarwal et al., 2008). With the multiple stressors, vulnerabilities, and challenges they face, BCS are at a high risk for developing depressive symptoms (Denlinger et al., 2015). Depressive symptoms are the most common mood disturbance in BCS, and are experienced by up to 29% of BCS (Bower et al., 2005; Brem & Kumar, 2011). Depressive symptoms among BCS commonly stem from fear of reoccurrence (Harrison et al., 2011; Hodgkinson et al., 2007; Mehnert, de Boer, & Feuerstein, 2013). However, physical compromise, social isolation, or work and financial problems may also be related to depressive symptoms (Becker et al., 2015; Boykoff et al., 2009; Calvio et al., 2010; Munir et al., 2010; Myers, 2012; Player et al., 2014; Todd, Feuerstein, & Feuerstein, 2011; Von Ah et al., 2013).

Poor sleep quality. Poor sleep quality refers to a disruption in the normal sleep-wake cycle or sleep architecture as measured by the PSQI (Buysse et al., 1989). Poor sleep quality often goes unrecognized and/or untreated, which may potentially impair cognitive function (Vance, Heaton, Eaves, & Fazeli, 2011) and activities of daily living, such as driving (Heaton, 2009). Poor sleep quality typically start at diagnosis, occurs in 20% to 70% of BCS, and is often seen in combination with pain, fatigue, anxiety, or depressive symptoms (Alfano et al., 2011; Bower, 2008; Harrington, Hansen, Moskowitz,

Todd, & Feuerstein, 2010; Pinto & de Azambuja, 2011). Factors related to poor sleep quality among BCS include age, biologic changes (e.g., altered circadian rhythms, decreased estrogen), the stress of diagnosis and treatment, and side effects of therapy (e.g., pain, fatigue) (Carney et al., 2011; Flynn et al., 2010; Palesh et al., 2013). Among BCS, poor sleep quality may contribute to immunosuppression, negatively impact quality of life, and may even impact reoccurrence (Fiorentino & Ancoli, 2006; Palesh et al., 2013).

Cognitive Training

Cognitive training comprises a range of activities designed to increase cognitive function through practice exercises focusing on memory, speed of processing, attention, and executive function (Sohlberg, 2001). Computerized cognitive training (Conklin et al., 2015), in particular, has been used to improve neuroplasticity and cognitive reserve via exercises completed on a computer (Lampit et al., 2015; Vance et al., 2017). Neuroplasticity refers to the physiological changes to neurons either in response to a stimulus (positive neuroplasticity) or the absence of a stimulus (negative neuroplasticity) (Mahncke et al., 2006). Increasing positive neuroplasticity increases cognitive reserve, or the number and strength of the brain's neural connections (Vance et al., 2017). Greater cognitive reserve means a higher-functioning brain. Therefore, computerized cognitive training seeks to stimulate the creation of neurons and strengthen the connections among neurons for better brain health among those with cognitive impairment.

Cognitive reserve and neuroplasticity. Examples of positive neuroplasticity, the process of building up and strengthening neural connections, include physical exercise, healthful nutrition, and good sleep. Meanwhile, negative neuroplasticity, the weakening of neural connections, occurs in response to cancer treatments such as chemotherapy, radiation, and endocrine therapy (Vance et al., 2017). Although they focus on healthy older adults, two recent studies illuminate how cognitive reserve, and thereby cognitive function, is increased with positive neuroplasticity and reduced by negative neuroplasticity (Boyke, Driemeyer, Gaser, Buchel, & May, 2008; Lampit et al., 2015).

Boyke at al. (2008) conducted a randomized controlled trial to determine whether 69 healthy other adults experienced physiological changes in the brain as a result of positive and/or negative neuroplasticity. Using a physical activity, juggling, the researchers assessed all participants, both the juggling group and the control group, before training; after three months of training, when participants could juggle three balls for 1 minute; and three months after training, when participants had not practiced juggling since the training. Magnetic resonance imaging (MRI) scans showed more gray matter in the mid-temporal area and the left posterior intraparietal sulcus for the participants who learned to juggle, demonstrating positive neuroplasticity. However, negative neuroplasticity occurred in the three months after training, when participants had not practiced juggling for three months.

Lampit et al. (2015) studied 80 healthy older adults, roughly half of whom completed computerized cognitive training, to assess physiological changes in the brain. In 36 one-hour training sessions over a period of 12 weeks, the training group's MRI

scans showed evidence between sessions 9 and 36 of physiological change in the form of significantly increased gray matter density in the right post-central gyrus, compared to the control group. Taken together, these two studies indicate that positive neuroplasticity can significantly increase cognitive reserve, improving cognitive function in the process (Boyke et al., 2008; Lampit et al., 2015).

Healthy older adults and computerized cognitive training. The largest longitudinal study involving computerized cognitive training, the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study gauged improvement in cognitive function of 2,832 healthy older adults recruited from six U.S. cities (Ball et al., 2002). Placed in either the no-contact control group (n = 704) or one of three intervention groups, participants were tasked with using computerized training to improve speed of processing (n = 712), memory training to learn mnemonic strategies (n = 711), or reasoning training to develop problem-solving strategies (n = 705). Over 5-6 weeks, participants completed ten 60-75 min group training sessions, with neurocognitive testing conducted at baseline, immediately post-intervention, 1-year follow-up, and 2-year follow-up. Immediately following the intervention, researchers observed substantial improvement in cognitive function for the area in which participants received training: specifically, 87% of computerized speed of processing, 26% of memory, and 74% of reasoning trained participants showed greater cognitive function than at baseline.

Researchers offered a random selection of participants from each of the three intervention groups booster training sessions 11 months post-intervention. This additional training (four 75-min sessions over 2-3 weeks) resulted in further gains in both

computerized speed of processing and reasoning skills. At 2-year follow-up—and even more impressively, at 10-year follow-up—computerized speed of processing (effect size, 0.66 [99% CI, 0.43-0.88]) and reasoning [effect size, 0.23 [99% CI, 0.09-0.38]) were found to be at similar levels. The speed of processing group showed the most dramatic positive effects of training (Rebok et al., 2014).

Furthermore, researchers for the ACTIVE study found that the speed of processing interventions resulted not only in improved cognitive function but also in greater self-rated health (Wolinsky, Mahncke, et al., 2010), increased internal locus of control (Wolinsky, Vander Weg, et al., 2010), higher quality of life (Wolinsky, Unverzagt, Smith, Jones, Stoddard, et al., 2006; Wolinsky, Unverzagt, Smith, Jones, Wright, et al., 2006), and fewer depressive symptoms (Wolinsky et al., 2009).

Computerized speed of processing training may even decrease one's likelihood of acquiring dementia, according to the most recent data from the ACTIVE study. That is, participants who finished up to 10 speed of processing training sessions were 12.1% less likely to incur dementia than those in the control group; participants completing 11-14 sessions showed a reduction of 48% in dementia incidence (HR = 0.52, 95% CI = 0.33-0.82, p = .005) (Edwards et al., 2016). Especially for BCS, for whom dementia incidence may be more likely than for healthy older adults (Kesler et al., 2015), this study's findings on the benefits of speed of processing training are significant.

Likewise, speed of processing training proved the most effective type of cognitive training for healthy older adults in a systematic review and meta-analysis of 51 computerized cognitive training randomized controlled trials (Lampit, Hallock, & Valenzuela, 2014). The 33 speed of processing training studies had a moderate and

statistically significant combined effect size (g = 0.31, 95% CI 0.11 to 0.50, p = 0.002), although training more than three times per week led to no additional gains in cognitive function.

Following the ACTIVE study, researchers have used computerized cognitive training in studies of populations other than healthy older adults. These include people with HIV (Cody, Fazeli, & Vance, 2015; Vance et al., 2012), stroke survivors (Park & Park, 2015; Yoo, Yong, Chung, & Yang, 2015), childhood cancer survivors (Conklin et al., 2015; Hardy, Willard, & Bonner, 2011), and BCS (Damholdt et al., 2016; Kesler et al., 2013; Von Ah et al., 2012).

Adherence

Adherence comes from the Latin word *adhere*, which means to cling to, keep close, or remain constant. The traditional definition of adherence is the extent to which individuals follow specific treatment instructions (Haynes, Taylor, & Sackett, 1978). While adherence has been studied at great length in other populations (i.e., people with diabetes and HIV), this section will focus specifically on adherence among BCS.

Adherence to cancer therapy. Adjuvant hormone therapy has contributed to significant reductions in recurrence and mortality in BCS. Yet, adherence to the full course of treatment (1 pill every day for at least 5 years) is necessary to obtain the full benefits. Despite these benefits, between 31% and 73% of survivors are non-adherent, thereby reducing treatment efficacy. Moreover, given the challenges in measuring adherence behaviors and the overestimation of adherence by doctors and patients,

published rates may underestimate true adherence rates (Hurtado-de-Mendoza, Cabling, Lobo, Dash, & Sheppard, 2016). Patient variables (e.g., age), social support, patient-provider communication, and health care factors (e.g., cost) are associated with BCS' adherence to therapies. Some research suggests that minority groups have lower adherence to adjuvant hormone therapy than Caucasians (Wells et al., 2016). A recent meta-analysis indicated that depressive symptoms were associated with decreased adherence to adjuvant therapy regimens (Fan et al., 2008). Studies suggest that the management of side effects (e.g., sleep and mood disturbances) is important to increase adherence to adjuvant hormone therapy (Wells et al., 2016).

Adherence to lymphedema self-management. Lymphedema is a condition caused by a blockage in the lymphatic system and is most commonly caused by lymph node removal or damage due to cancer treatment. Among BCS, lymphedema usually occurs in the arm and hand, but sometimes it affects the breast, underarm, chest, trunk, and/or back. Left unmanaged, lymphedema can worsen and cause severe swelling and permanent changes to the tissues under the skin, such as thickening and scarring. Despite these severe consequences, lymphedema self-management rates among BCS over the past 20 years remain between 40% and 50% (Boris, Weindirf, Lasinski, & Boris, 1994; Ridner, Dietrich, & Kidd, 2011). These low adherence rates are associated with psychological and psychosocial factors, including depressive symptoms and poor sleep quality.

Adherence to lifestyle behaviors. Two key modifiable risk factors in breast cancer recurrence are body weight and diet (ACS, 2016a; AICR, 2016; Bail, Meneses, & Demark-Wahnefried, 2016; Castello et al., 2015). Recently, DeNysschen and colleagues (2015) examined adherence to the ACS guidelines for healthy lifestyle behaviors among BCS. Results revealed adherence with meeting a healthy weight ranged from 52% (*n* = 33) to 61% (*n* = 31), adherence with physical activity guidelines ranged from 13% (*n* = 30) to 31% (*n* = 35), and adherence with guidelines for 5 servings of fruits and vegetables ranged from 36% (*n* = 28) to 39% (*n* = 36). Previously, the Women's Healthy Eating and Living (WHEL) study, aimed at improving dietary quality intake among 2,800 BCS, revealed that baseline depressive symptoms were associated with lower intervention adherence and suggested the inclusion of strategies aimed at minimizing depressive symptoms (Wang et al., 2015).

Search Strategy

To examine extant literature on cognitive impairment among BCS, the researcher conducted a review of English-language scientific literature. This review used applicable websites and multi-disciplinary academic databases (i.e., PubMed, Cumulative Index to Nursing and Allied Health Literature [CINAHL], and PsycINFO). The researcher searched for all full-text journal articles using the search string (breast cancer survi*) AND (cogniti*). Since cognitive impairment among BCS is a phenomenon only recently studied, search criteria were kept broad and were not restricted to publication dates. A reference librarian at the University of Alabama at Birmingham's Lister Hill Library of the Health Sciences reviewed the chosen databases and search terms prior to the search

being conducted. This search returned 866 articles: PubMed (*n* = 327), CINAHL (*n* = 289), and PsycINFO (*n* = 250). Of the 866 articles resulting from the initial search, 339 were duplicates. Removing these and adding 16 articles located through manual review of the reference lists of key articles produced 543 unique abstracts to be screened. Of the 543 screened abstracts, 377 did not meet the inclusion criteria and were excluded, resulting in 166 full-text articles to be assessed for eligibility. Inclusion criteria consisted of (a) factors associated with cognitive impairment; (b) affected cognitive domains; (c) measures of cognitive impairment; (d) impact on quality of life; and (e) interventions aimed at reducing cognitive impairment in BCS. One hundred thirteen studies (106 quantitative and 7 qualitative) were found to meet these criteria for a literature review of cognitive impairment among BCS. See Appendix C for consort.

Analysis of the Literature

This review presents factors associated with cognitive impairment among BCS, affected cognitive domains, and impact on quality of life. Next, cognitive intervention studies, employing multiple intervention strategies, conducted with BCS over the past decade will be presented. Finally, the current gaps in knowledge, with primary emphasis on research to develop effective cognitive interventions aimed at improving cognitive function among BCS, will be discussed.

Factors Associated with Cognitive Impairment

While "chemobrain," a colloquial term for cognitive impairment, is most often associated with physiological changes resulting from chemotherapy, investigators concur

that this phenomenon affects more than just the brain and may be connected to radiation and endocrine therapy as well (Ahles et al., 2012; Ahles et al., 2010; Hodgson et al., 2013; Hurria, Somlo, & Ahles, 2007; Phillips et al., 2012; Vance et. al., 2017; Von Ah & Tallman, 2015).

Because chemotherapy affects both cancer cells and healthy cells, DNA in both kinds of cells can be damaged. Although chemotherapeutical drugs generally do not cross the blood-brain barrier, cancer survivors have been found to possess unexpectedly higher levels of these in the central nervous system (CNS) (Ahles & Saykin, 2001). Furthermore, researchers have found in the CNS higher levels of cytokines, which are associated with post-treatment cognitive impairment, fatigue, depressive symptoms, chronic inflammation, and DNA damage (Ahles & Saykin, 2007). Besides cognitive impairment, cancer survivors may also struggle with depressive symptoms and difficulty sleeping well, both of which relate to brain function as well (Bower, 2008).

Interestingly, some studies have found cognitive impairment in BCS prior to treatment (Ahles et al., 2008; Jansen et al., 2011; Phillips et al., 2012). Pre-treatment cognitive impairment may be caused by the tumor itself, the stress of cancer diagnosis, or both (Ahles et al., 2008; Denlinger et al., 2015; Jansen et al., 2011). Although researchers do not fully understand the physiological and functional changes to the brain entailed in cognitive impairment, some related factors include stress, fatigue, depression, brain tissue injury, oxidative stress, inflammation, and vascular injury (Ahles & Saykin, 2007). Low levels of estrogen may also affect BCS who experience acute menopause (Fallowfield & Jenkins, 2015). Other factors related to cognitive impairment in BCS include age, education, anxiety, and genetics (Ahles, 2012; Vance et al., 2017).

Affected Cognitive Domains

Cognitive function encompasses multiple domains including attention, learning and memory, executive function, psychomotor efficiency, mental flexibility, visuospatial ability, and language. These cognitive domains are highly interrelated. Impairment in one domain can impair function in other domains (Bender et al., 2013). Among BCS with cognitive impairment, the most commonly affected domains include processing speed, memory, and executive function (Ahles et al., 2012; Boykoff et al., 2009; Frank et al., 2014; Jansen et al., 2011; Wefel et al., 2010; Wefel & Schagen, 2012).

Speed of processing. Speed of processing refers to the rate at which cognitive operations are performed (Vance et al., 2009). Even subtle impairment in speed of processing can affect other cognitive domains, impeding everyday functioning at work and home. BCS show impairment on neuropsychological tests of speed of processing (Adams-Price et al., 2009; Collins et al., 2014; Koppelmans et al., 2012). Speed of processing impairment is known to increase with aging (Vance & Wright, 2009).

Attention. Attention consists of the ability to selectively focus on one main object or idea while avoiding distraction from other objects or ideas (Frank et al., 2014). Approximately 64% of BCS experience problems with attention (Shilling & Jenkins, 2007; Shilling, Jenkins, Morris, Deutsch, & Bloomfield, 2005). The capacity to direct attention is necessary for cognitive functions such as learning new information, planning, and making decisions. BCS report difficulties with reading, paying bills, multitasking, driving, and learning new information (Myers, 2012). Impaired attention is associated

with poorer quality of life, including more depressive symptoms, poorer well-being, poorer physical functioning, and greater fatigue among BCS (Von Ah et al., 2009).

Memory. Memory is the capacity to retain and use information (Frank et al., 2014). Approximately 71% of BCS report problems with memory (Shilling & Jenkins, 2007; Shilling et al., 2005). BCS tend to self-report more severe impairment in memory compared with neuropsychological testing, where performance is often within normal limits (Downie et al., 2006). BCS report forgetting appointments, misplacing items, not remembering why they had gone to a particular room, and difficulty with learning new information (Myers, 2012). These experiences are frustrating and upsetting, and may be poorly understood by family members and colleagues (Boykoff et al., 2009).

Executive function. Executive function refers to working memory, cognitive flexibility, multitasking, planning, and attention (Kesler et al., 2013). Across both self-report and neuropsychological measures, BCS commonly demonstrate impaired executive function (de Ruiter et al., 2011; Ganz et al., 2013; Kesler et al., 2011; Schagen et al., 1999).

Measures of Cognitive Impairment

Increasing evidence shows cognitive impairment among BCS in the cognitive domains of speed of processing, attention, memory, and executive function (Collins et al., 2014; Jansen et al., 2011; Koppelmans et al., 2012). Impairment in these domains may

be measured either objectively (i.e., brain imaging and neuropsychological measures) or subjectively (i.e., self-report).

Brain imaging. Imaging studies support an association between cognitive impairment and structural damage to the brain and alterations in functional activity (de Ruiter et al., 2012). Although some studies found no differences following breast cancer treatment (Yoshikawa et al., 2005), many report significant changes in the structure and function of the brain in BCS for years or even decades following treatment (Deprez et al., 2012; Kesler et al., 2013; Koppelmans et al., 2014; Koppelmans et al., 2015; McDonald & Saykin, 2013).

Several investigators found an association between changes in white matter integrity and cognition following treatment for breast cancer (Abraham et al., 2008; Deprez et al., 2012; de Ruiter et al., 2012; Koppelmans et al., 2012; Koppelmans et al., 2014). These investigators report a consistent pattern of degradation in white matter integrity after treatment, which is often accompanied by cognitive impairment. Deprez and colleagues (2012) found a significant relationship between white matter integrity and neuropsychological measures of attention and processing speed (i.e., greater white matter integrity was related to better attention and faster response time in BCS). In a subsequent longitudinal follow-up, the investigators found that white matter integrity was related to change in attention and verbal memory scores (i.e., greater decline in white matter integrity following chemotherapy was related to greater decline in cognition) (Deprez et al., 2012). Ferguson and colleagues (2007) compared brain imaging of a BCS with self-reported cognitive impairment to her healthy twin. Findings revealed that the BCS had

both structural (i.e., degradation in white matter integrity) and functional (i.e., activation of atypical neural pathways) brain changes, but the healthy twin did not.

Neuropsychological. Neuropsychological measures are the gold standard in assessing cognitive impairment among BCS (Andreotti et al., 2016). Yet, investigators examining BCS' performance on neuropsychological measures report varying results, ranging from normal performance to significant cognitive changes (Donovan et al., 2005; Hermelink et al., 2008; Jansen et al., 2011; Quesnel, Savard, & Ivers, 2009; Wefel et al., 2010). Methodological differences (i.e., study design, type of cognitive testing, type of treatment, time since treatment, and definition of cognitive deficit) may account for this variability (Frank et al., 2015). Still, it is also possible that normal neuropsychological test results may mask the use of atypical neural processing to compensate for cognitive changes (Hosseini & Kesler, 2014; Kesler et al., 2011). The activation of atypical neural pathways is being explored through the use of imaging technology such as fMRI and positron emission tomography (Jung et al., 2016; Kam et al., 2015).

Neuropsychological tests are not always feasible or affordable (Lai et al., 2009). Administration of neuropsychological test batteries requires a trained and qualified professional and is often time intensive, which limits their use in practice (Jansen, 2013). In addition, administration of lengthy neuropsychological test batteries may lead to conflicting test results due to fatigue, loss of attention, or decreased motivation (Jansen, 2013; Ouimet, Stewart, Collins, Schindler, & Bielajew, 2011).

Concerns exist that neuropsychological measures may not be sensitive to the cognitive impairment experienced by BCS (Jansen, 2013). Changes in study design and

methods to improve the sensitivity of these measures are recommended (Andreotti et al., 2016).

Self-report. Self-reported cognitive impairment refers to the degree of cognitive difficulty that individuals perceive in their daily lives and their satisfaction with their cognitive functioning (Bender et al., 2008; Hutchinson et al., 2012; Pullens et al., 2010; Pullens et al., 2013; Tannock, Ahles, Ganz, & Van Dam, 2004) and is associated with poor self-esteem, confidence, social relationships, work ability, and overall quality of life (Becker et al., 2015; Boykoff et al., 2009; Frank et al., 2014; Munir et al., 2010; Myers, 2012; Von Ah et al., 2013).

Self-reported cognitive impairment is more prevalent and severe compared to the frequency and severity of cognitive impairment measured by neuropsychological testing (Hutchinson et al., 2012; Von Ah et al., 2013), ranging from 21% to 90% (Bower, 2008; Frank et al., 2014; Hutchinson et al., 2012; Pullens et al., 2010). While some researchers suggested that self-reported and neuropsychological measurements of cognitive impairment are not associated (Ahles & Saykin, 2002; Bender et al., 2006; Castellon et al., 2004; Donovan et al., 2005; Hermelink et al., 2007; Jansen, Dodd, Miaskowski, Dowling, & Kramer 2008; Schagen et al., 1999; Tchen et al., 2003; van Dam et al., 1998; Wefel et al., 2004), Von Ah and Tallman (2015) showed that self-reported cognitive impairment, as measured by the Functional Assessment of Cancer Therapy Cognitive Scale (FACT-Cog), was associated with neuropsychological measures of verbal memory, speed of processing, and executive function. Poorer functional outcomes and psychosocial well-being are associated with both neuropsychological and self-reported

measures (Bender et al., 2006; Biglia et al., 2012; Castellon et al., 2004; Donovan et al., 2005; Hermelink et al., 2007; Jansen et al., 2008; Jenkins et al., 2006; Schagen et al., 1999; Shilling & Jenkins, 2007; van Dam et al., 1998).

Study Design and Cognitive Impairment

Investigators, using both cross-sectional and longitudinal designs, examined cognitive impairment among BCS. Cross-sectional designs involve the collection of data at one time point and are appropriate for describing relationships at a fixed point in time (Polit & Beck, 2012). A longitudinal design involves data collection at more than one time point over an extended period of time and is appropriate for assessing changes over time (Polit & Beck, 2012).

Early cognitive impairment studies among cancer patients were primarily cross-sectional and did not account for pre-treatment assessments of cognitive function. Wefel and colleagues (2004) conducted the first prospective, longitudinal study to assess cognitive function among BCS using pre-treatment and post-treatment neuropsychological measures. While 46% of the post-treatment neuropsychological scores were within the normal range, 61% exhibited cognitive impairment post-treatment (i.e., a decline from pre-treatment neuropsychological scores), demonstrating the importance of pre-treatment assessments. In a cross-sectional design, it cannot be assumed that if post-treatment neuropsychological scores are within the normal range cognitive impairment has not occurred.

National Guidelines

NCCN and the ASCO provide evidence-based guidelines to assist health care providers in addressing cognitive impairment among BCS (NCCN, 2017; Runowicz et al., 2016). Guidelines recommend the following: 1) ask BCS if they are experiencing any cognitive difficulties and validate BCS' self-reported cognitive impairment; 2) screen for depression, pain, fatigue, and poor sleep quality; 3) review current medications and discuss any aspect of medication that interferes with cognition; 4) provide strategies for healthy living (e.g., physical activity, nutrition, good sleep hygiene, and stress reduction); 5) refer BCS with signs of cognitive impairment for neuropsychological assessment and cognitive training if available. While NCCN and ASCO guidelines recommend asking BCS if they are experiencing any cognitive difficulties and validating BCS' self-reported cognitive impairment, many health care providers do not (Boykoff et al., 2009; Buchanan et al., 2015; Fitch, Armstrong, & Tsang, 2008; Myers, 2012; Thorne & Stajduhar, 2012). Some BCS report feeling frustrated by not having their cognitive concerns validated (Becker et al., 2015; Von Ah et al., 2013) and unprepared to manage their cognitive impairment (Munir et al., 2010).

Impact on Quality of Life

Recent studies among BCS indicate that perceived cognitive impairment is associated with poor self-esteem, confidence, social relationships, work ability, and overall quality of life (Becker et al., 2015; Boykoff et al., 2009; Jenkins et al., 2006; Shilling & Jenkins, 2007; Steiner, Cavender, Main, & Bradley, 2004; Von Ah et al., 2013). Some BCS express feeling misunderstood, embarrassed, frustrated, and lacking

self-confidence in their cognitive abilities (Becker et al., 2015; Boykoff et al., 2009; Munir et al., 2010). Support from co-survivors (i.e., family and friends) ranges from "apathetic" to "supportive" (Von Ah et al., 2013). Many co-survivors do not understand BCS' cognitive impairment (Becker et al., 2015; Boykoff et al., 2009; Von Ah et al., 2013). Some BCS report co-survivors as being dismissive, belittling, and confused by their cognitive impairment and describe being avoided or taken advantage of (Boykoff et al., 2009).

Employment plays a key role in financial and psychological well-being and in a return to normalcy during or following treatment (Becker et al., 2015; Kennedy et al., 2007). The majority of BCS choose to return to work within 12 months of diagnosis (Becker et al., 2015; Islam et al., 2014; Munir et al., 2010; Player et al., 2014). However, cognitive impairment can make job-related duties more difficult and take longer to complete (Boykoff et al., 2009; Von Ah et al., 2013). Some BCS lack self-confidence in their cognitive abilities (Becker et al., 2015; Boykoff et al., 2009; Munir et al., 2010). In fact, cognitive impairment may be a potential occupational safety issue (Calvio et al., 2010; Player et al., 2014). The decision to return to work is influenced by cognitive impairment following treatment, self-awareness of cognitive impairment, and the impact of perceived cognitive impairment on BCS' confidence to succeed at work (Munir et al., 2010). Changes in employment including retirement, reduction of hours, and change of position are more likely to be faced by BCS than their age-matched peers (Hauglann et al., 2012). Some who are unemployed report lower physical and mental quality of life and higher levels of fatigue and anxiety than employed BCS (Lindbohm et al., 2014).

Furthermore, loss of employment affects financial security and access to health insurance, especially for those who are sole family providers (Boykoff et al., 2009).

Cognitive Interventions

To date, a variety of intervention methods have aimed to reduce cognitive impairment in BCS; these have been categorized as (a) cognitive remediation interventions; (b) physical activity interventions; and (c) pharmacological interventions. Studies using these approaches are summarized in Table D1 (Appendix D).

Cognitive remediation. Cognitive remediation is a theory-driven, systematic approach to maintaining, improving, or mitigating the loss of cognitive capacity (Vance, McNees, & Meneses, 2009). Cognitive remediation can produce actual neurological change by either strengthening the connections in the brain involved in performing a task or by creating new neural connections that result in improved performance (Lampit et al., 2015). Cognitive remediation interventions conducted with BCS include: EEG biofeedback (Alvarez, Meyer, Granoff, & Lundy, 2013), psycho-educational group (Dolbeault et al., 2009), cognitive rehabilitation group (Ercoli et al., 2013; Ercoli et al., 2015), Memory and Attention Adaptation Training (MAAT) (Ferguson et al., 2007; Ferguson et al., 2012), web-based cognitive training (Kesler et al., 2013), mindfulness-based stress reduction (MBSR) (Lengacher et al., 2015), meditation (Milbury et al., 2013), memory or computer-based speed of processing training (Von Ah et al., 2012), and neuropsychological or computer-based cognitive training (Weis et al., 2009).

While 9 of the 11 cognitive remediation interventions indicated improvement of either neuropsychological or self-reported measures of cognitive function (Alvarez et al., 2013; Ercoli et al., 2013; Ercoli et al., 2015; Ferguson et al., 2007; Ferguson et al., 2012; Kesler et al., 2013; Lengacher et al., 2015; Milbury et al., 2013; Von Ah et al., 2012), 2 demonstrated the most efficacy in alleviating cognitive impairment among BCS (Kesler et al., 2013; Von Ah et al., 2012).

Kesler and colleagues (2013) and Von Ah and colleagues (2012) conducted cognitive remediation interventions with BCS. Kesler implemented a web-based cognitive training program focused on executive function. Von Ah implemented an onsite-based cognitive training program that focused on either memory or speed of processing. Effects were seen in both executive function and memory training programs. Executive function training improved executive function performance. Likewise, memory training improved memory performance. In speed of processing training, improvements were seen in both speed of processing and memory performance. Findings suggested that speed of processing training may have broader cognitive benefits for BCS.

Physical activity. Increasing evidence suggests that physical activity may enhance cognitive function in attention and speed of processing (Smith et al., 2010). Physical activity interventions conducted with BCS include: yoga (Culos-Reed, Carlson, Daroux, & Hately-Aldous, 2006; Derry et al., 2015; Galantino et al., 2012), Tai Chi (Reid-Arndt, Matsuda, & Cox, 2012), medical Qigong (Oh et al., 2012), speed-feedback therapy (Miki et al., 2014), and the use of hip-worn accelerometers (Marinac et al., 2015).

Six of the seven physical activity interventions included in this review showed statistically significant findings, of which three were on objective measures (Marinac et al., 2015; Miki, Kataoka, & Okamura, 2014; Reid-Arndt et al., 2012) and three were on subjective measures (Culos-Reed et al., 2006; Derry et al., 2015; Oh et al., 2012). Of the interventions, two showed the most promise in alleviating cognitive impairment among BCS (Derry et al., 2015; Reid-Arndt et al., 2012).

Derry and colleagues (2015) and Reid-Arndt and colleagues (2012) conducted physical activity interventions with BCS with cognitive impairment. Derry implemented a 12-week yoga program that focused on the reduction of self-reported cognitive complaints in 100 BCS. Those in the yoga intervention reported fewer cognitive complaints. Data analysis revealed a correlation between practice frequency and reduction in cognitive complaints of BCS in the yoga intervention. Reid-Arndt implemented a 10-week Tai Chi program that focused on neuropsychological, psychological, and physical health with 24 cancer survivors, of which 16 were BCS. Improvement in immediate and delayed memory, verbal fluency, and executive function was demonstrated on objective measures. Improvement in memory and stress was self-reported. While Reid-Arndt showed significant results on objective and subjective measures of cognitive function, the study was comprised of just 16 BCS. Derry had 100 BCS participants, who self-reported all measures of cognition. Effectiveness of physical activity interventions for cognitive impairment in BCS shows encouraging preliminary results.

Pharmacological. Pharmacological therapy has been suggested as a possible intervention for cognitive impairment among BCS, based largely on its ability to improve cognitive function in other populations and in studies in animal models. Pharmacological interventions used to modify cognitive impairment in BCS include: Ginkgo biloba (Barton et al., 2013), methylphenidate (Escalante et al., 2014), dexmethylphenidate (Lower et al., 2009; Mar Fan et al., 2009), modafinil (Kohli et al., 2009), and epoetin alfa (Mar Fan et al., 2009; O'Shaughnessy et al., 2005).

With the exception of the study by O'Shaughnessy et al. (2005), which demonstrated improvement in self-reported cognitive function, none of the pharmacological interventions included in this review showed any statistically significant changes in cognition. Furthermore, six of the seven reported adverse events (Barton et al., 2013; Escalante et al., 2014; Lower et al., 2009; Mar Fan et al., 2009; O'Shaughnessy et al., 2005). The U.S. Food and Drug Administration issued a black box warning for epoetin alfa, which is no longer recommended for use in any cancer survivor (Charach, Kaysar, Grosskopf, & Rabinovich, 2009). The NCCN guidelines recommend pharmacological interventions only after all other options are exhausted (NCCN, 2017). Current evidence does not favor the use of pharmacological interventions for cognitive impairment in BCS.

Cognitive Intervention Adherence

Adherence to a cognitive intervention protocol is essential in determining whether the intervention is effective in alleviating cognitive impairment; however, to date only one study has addressed adherence among BCS. Damholdt and colleagues (2016)

reported a 65% adherence in their web-based 15-hr cognitive training intervention among 94 BCS. They reported no statistically significant change in either the primary or secondary cognitive outcomes. The researchers did not mention whether they examined the impact of lack of adherence on cognitive outcomes, nor did they report training effects by hours of training completed.

Symptom Cluster

Cancer-related symptoms experienced by BCS commonly form a symptom cluster and include cognitive impairment, depressive symptoms, and poor sleep quality (Dodd et al., 2001; Fiorentino et al., 2011; Lenz et al., 1997). Studies indicate significant associations among depressive symptoms, sleep, and cognition (Chen, Miaskowski, Liu, & Chen, 2012; Cheung, Tan, & Chan, 2012; Myers, Wick, & Klemp, 2015; Sanford et al., 2014; Von Ah & Tallman, 2015). Symptom clusters may exacerbate difficulties in cognitive function (Denlinger et al., 2016; Henneghan, 2016) and challenge adherence to interventions aimed at improving cognitive function (Meneses et al., 2014; Meneses et al., 2015; Vance et al., 2017; Wang et al., 2015).

Summary of the Literature

Breast cancer is a highly survivable disease. However, many BCS in cancer treatment and after treatment self-report challenging side effects such as cognitive impairment. Yet, BCS' self-reported cognitive impairment is not always concordant with neuropsychological measures.

While multifactorial, the specific mechanism of cognitive impairment is unknown. Some investigators reported cognitive impairment occurring in BCS before treatment, suggesting that the problem may be a result of the tumor itself and/or a response to the stress of diagnosis. Underlying mechanisms most likely include stress, fatigue, depression, brain tissue injury, oxidative stress, inflammation, and vascular injury. Some of these mechanisms may be mediated by low levels of estrogen, which may impact BCS who experience acute menopause related to treatment. Other factors that impact cognitive impairment include age, education, anxiety, and genetics. Although some investigators reported that cognitive impairment improved or even resolved over time, others found that cognitive impairment persisted for many years or even decades in survivorship.

Increasing evidence supports cognitive impairment among BCS in the cognitive domains of speed of processing, attention, memory, and executive function. Researchers have reported performances on neuropsychological measures varying from normal performance to significant cognitive impairment. Methodological differences (i.e., study design, type of cognitive testing, type of treatment, time since treatment, and definition of cognitive impairment) may account for this variability. Concerns exist that neuropsychological measures may not be sensitive to cognitive changes incurred by BCS. It is also possible that normal neuropsychological test results may mask the use of atypical neural processing to compensate for cognitive impairment. Neuropsychological tests are the gold standard in assessing cognitive impairment among BCS. A combination of brain imaging, neuropsychological testing, and self-reported measures may provide a more comprehensive assessment. While early cognitive impairment studies among

cancer patients were primarily cross-sectional, a longitudinal study design is needed to assess cognitive changes among BCS over time.

Within 12 months of diagnosis, majority of BCS choose to return to work. Many are faced with increased medical bills and the need for health insurance. Compared to age-matched controls, BCS are less likely to work outside their homes, demonstrate permanently reduced work ability, and are more likely to receive disability benefits. Returning to work is influenced by changes in cognitive ability following chemotherapy, self-awareness of cognitive impairment, and the impact of perceived cognitive impairment on BCS' confidence to succeed at work. Recent studies among BCS indicate that cognitive impairment is associated with poor self-esteem, confidence, social relationships, and work ability. It is also associated with depressive symptoms, poor sleep quality, and lower overall health status and quality of life.

Effective interventions to enhance cognitive function in BCS with cognitive impairment are needed. Recent studies and reviews indicate that cognitive training interventions aimed at improving speed of processing, attention, and memory are the most effective at alleviating cognitive impairment among BCS.

Gaps and Opportunities

This literature review reveals several gaps in knowledge regarding the best way to develop effective cognitive interventions to improve cognitive function among BCS. First, one study examined the use of speed of processing training in BCS; there is great need for further investigation. Given that cognitive impairment is multifactorial and that the specific cause is unknown, future studies should include all BCS, not just those who

were treated with chemotherapy. Inclusion of all BCS may improve our understanding of intervention response by allowing for comparison by treatment type. Second, studies lack racially and ethnically diverse samples of BCS. Diverse samples would aid researchers in understanding individual responses to cognitive interventions, which may lead to developing tailored cognitive interventions. Third, while MRI scans revealed physiological changes (positive neuroplasticity) in the brains of healthy older adults who underwent computerized cognitive training (Lampit et al., 2015), it is unknown if BCS experience these same changes. Inclusion of MRI scans in future studies may improve our understanding of neuroplasticity in BCS after treatment. Current neuropsychological measures of cognitive impairment are not adequate for BCS. Development of measures that are sensitive to the mild cognitive impairment experienced by BCS is needed. In summary, factors associated with BCS' adherence to cognitive interventions are unknown. The use of a mixed methods study design would aid in developing a comprehensive understanding of experiences, expectations, potential facilitators and/or barriers, and how cancer-related symptoms may impact adherence to cognitive interventions. Such a study may lead to improving adherence to cognitive interventions, thereby improving cognitive function among BCS.

Parent Study

This study was developed out of the parent study ***S****peed of Processing in Middle Aged and* ***O****lder Bre****a****st Cancer Su****r****vivors* (SOAR). SOAR was supported by the Edward Roybal Center at the University of Alabama at Birmingham (UAB) and funded by the

National Institute on Aging (P30 AG022838, project principal investigator: Karen Meneses). SOAR was a randomized feasibility study with the following aims:

Aim 1: To determine whether cognitive training improves performance on neuropsychological tests of speed of processing and other cognitive domains.

H1.1: BCS who receive cognitive training will demonstrate improved speed of processing.

H1.2: BCS who receive cognitive training will demonstrate improved memory and executive functioning.

Aim 2: To determine whether there are changes in self-rated measures of mood, sleep, and work performance.

H2.1: BCS who participate in cognitive training will self-report improved mood, sleep, and job performance.

IRB Approval

SOAR was reviewed and approved by the UAB Institutional Review Board (IRB), protocol #X141205005.

Design

SOAR was a randomized feasibility study. BCS were randomly assigned to either a home-based speed of processing training intervention group (n = 30) or a no-contact control group (n = 30).

Recruitment

Researchers recruited participants via UAB IRB-approved flyers, social media, websites, word of mouth, and referrals. The SOAR research assistant distributed study flyers, which provide a brief study description, eligibility criteria, and contact information, at community educational seminars for BCS, BCS support groups, annual BCS workshops, professional nursing organization local chapter meetings, and posted flyers at the UAB Comprehensive Cancer Center (CCC). Electronic flyers were posted on social media (i.e., Facebook) and websites (i.e., www.ThinkWell.tips, www.youngsurvivorsbhm.org, www.SurviveAL.org). Several participants were recruited by word of mouth from other participants. Additionally, health care professionals (e.g., oncologist, nurse practitioner, patient navigator) at the UAB CCC referred participants to the study.

The contact information provided by study flyers, social media, websites, word of mouth, or referrals directed interested participants to contact the SOAR research assistant via email and/or telephone. Once contacted, the research assistant explained the study in detail and screened interested participants, using the IRB-approved telephone screening protocol, for eligibility via telephone. The research assistant entered screening information (i.e., participant name, contact number, mailing address, eligibility status) into a secure password-protected database and assigned a sequential participant number used for all data collection. Once the research assistant determined eligibility and the participant gave verbal consent, participants were scheduled for a baseline assessment. To allow enough time for participants to receive a mailed copy of the IRB-approved consent form for consideration and complete study questionnaires (i.e.,

Sociodemographic and Treatment Questionnaire, Cognitive Failures Questionnaire, Pittsburgh Sleep Quality Index [PSQI], and CES-D, baseline assessments were scheduled for 7-10 days after the telephone screening. Using a consecutive sampling plan, 60 BCS residing in Alabama were recruited between June 2015 and October 2016.

Population

Inclusion criteria consisted of (a) diagnosed with breast cancer; (b) ≥ 21 years of age; (c) English speaking; 4) ≥ 6 months post primary breast cancer treatment; (d) computer and internet connection access; and (e) willing and able to participate in the intervention.

Exclusion criteria consisted of (a) significant neuro-medical comorbidities (e.g., schizophrenia, epilepsy, bipolar disorder, post-traumatic stress syndrome, Alzheimer's disease or related dementias, AIDS-related dementia, mental retardation); (b) diagnosed with metastatic breast cancer; or (c) conditions that could impact cognitive functioning or testing (e.g., currently enrolled in a residential substance abuse treatment, legally blind or deaf, currently undergoing radiation or chemotherapy, a history of brain trauma with a loss of consciousness greater than 30 min).

Intervention

Participants accessed the web-based cognitive training program using their home computer. The program did not enter or collect any personal health information. Cognitive training consisted of the commercially available "Double Decision" program (www.BrainHq.com), which was originally developed as part of the ACTIVE study and

then refined over time (Ball et al., 2002). This program systematically reduces the stimulus duration during a series of progressively more difficult information-processing tasks presented via computer. The exercises automatically adjust to user performance to maintain an 85% correct rate.

Dosage. The study asked participants to complete 2 hr of cognitive training per week and to complete a total of 10 hr within 6-8 weeks.

Adherence. In line with the ACTIVE study (Ball et al., 2002), those who completed ≥8 hr of cognitive training were considered adherent. The online program (www.BrainHQ.com) automatically recorded and stored the time and date, performance, and the duration of each training session.

Instruments

Sociodemographic and Treatment Questionnaire. Researchers used the sociodemographic questionnaire, a 20-item self-report questionnaire, to collect sociodemographic and breast cancer treatment data. Variables included: age, race, education, marital status, employment status, family income, survivorship months, surgery type, treatment type, endocrine therapy, weight gain, and use of support services.

Cognitive Failures Questionnaire. Perceived cognitive impairment was measured via the Cognitive Failures Questionnaire (CFQ), a 25-item self-report instrument that measures cognitive failures (i.e., memory, attention, and motor function)

on a 5-point Likert scale over a 6-month period (Broadbent, Cooper, FitzGerald, & Parkes, 1982). Scores range from 0 to 100, with higher scores indicating greater perceived cognitive impairment. Internal consistency and reliability are validated in cancer populations, with a Cronbach's alpha of .91 and test–retest reliability of .82 (Vom Hofe, Mainemarre, & Vannier, 1998).

Pittsburgh Sleep Quality Index. The study measured sleep quality using the Pittsburgh Sleep Quality Index (PSQI), an 11-item self-report instrument assessing sleep quality among adults over a 4-week period (Buysse et al., 1989). Scores range from 0 to 21, with a score of ≥5 indicative of poor sleep quality. Internal consistency and reliability are validated in cancer populations, with a Cronbach's alpha of .83 and test–retest reliability of .87 (Akman, Yavuzsen, Sevgen, Ellidokuz, & Yilmaz, 2015).

Center for Epidemiologic Studies-Depression Scale. Depressive symptoms were measured using the Center for Epidemiologic Studies-Depression Scale (CES-D), a 20-item self-report instrument that measures the occurrence of depressive symptoms on a 4-point Likert scale over a 1-week period (Radloff, 1977). Scores range from 0 to 60, with a score of ≥5 indicative of depressive symptoms (Aggarwal et al., 2008; Tuunainen, Langer, Klauber, & Kripke, 2001; Wassertheil-Smoller et al., 2004). Internal consistency and reliability are validated in cancer populations, with a Cronbach's alpha of .87 and test–retest reliability of .88 (Hann, Winter, & Jacobsen, 1999).

BrainHQ. The study assessed adherence (≥8 hr of cognitive training completed within 6-8 weeks) via the online cognitive training program BrainHQ (www.BrainHQ.com).

Data Collection

Data collection occurred at three time points (baseline, post-intervention, and 6-month follow-up). The baseline data collection consisted of one study visit in a private room on the UAB campus and lasted approximately 2 hr. Upon arrival for the baseline data collection, the research assistant reviewed the consent form with the participant and answered any questions. After the participant signed the consent form, the research assistant reviewed the participant's previously mailed study questionnaires for completeness. If any questionnaires were found to be incomplete, the participant was requested to complete them at that time. Next, the research assistant administered a neuropsychological test battery (i.e., National Institutes of Health [NIH] Toolbox Cognition Battery) to the participant. Before beginning each test, participants were given instructions and a chance to ask questions. Between each test, participants were given an opportunity to take a break and/or use the restroom. At the completion of the neuropsychological test battery, participants were informed of their randomization group (i.e., intervention group or control group). Using the same data collection procedures as the baseline assessment, two additional data collection time points occurred at post-intervention (approximately 6-8 weeks after baseline) and 6-month follow-up.

Summary

This review suggests that computer-based speed of processing training may enhance cognitive function in BCS with cognitive impairment, addressing an urgent and currently unmet need in BCS. In addition to cognitive impairment, other cancer-related symptoms commonly experienced by BCS include depressive symptoms and poor sleep quality. This cluster of cancer-related symptoms may exacerbate difficulties in cognitive function as well as inhibit adherence to interventions aimed at improving cognitive function. Further research is needed to gain a comprehensive understanding of experiences, expectations, potential facilitators and/or barriers, and to explore how cancer-related symptoms may impact adherence to cognitive interventions. Improving adherence to cognitive interventions may increase cognitive function in BCS, leading to greater quality of life during and after treatment. To inform the delivery of future cognitive interventions for BCS, the present study was developed out of the parent study SOAR.

CHAPTER 3

METHODOLOGY

Research Design

This study used a sequential Quan → QUAL mixed methods design, consisting of two distinct phases (Plano Clark & Ivankova, 2016; Teddlie & Tashakkori, 2009). In the first phase, the researcher analyzed the quantitative, numeric data from the parent study SOAR intervention participants (n = 30). The goal of the first, quantitative, phase was to identify the relationship between selected cancer-related symptoms and adherence to a web-based cognitive training intervention among BCS and to inform the development of the interview protocol for the second phase. In the second phase, a qualitative approach was used to explore participants' perspectives on their adherence to cognitive training through individual semistructured interviews with purposefully selected Phase I respondents to help explain why selected cancer-related symptoms, identified in the first phase, may impact BCS' adherence to a web-based cognitive training intervention. The rationale for this approach was that the quantitative data and results provide a general picture of the research problem (i.e., which selected cancer-related symptoms contributed to and/or impeded BCS' adherence to a web-based cognitive training intervention), while the qualitative data and its analysis would refine and explain those statistical results by exploring participants' views in more depth.

mixed methods is a procedure for collecting, analyzing, and "mixing" both quantitative and qualitative data within a single study to understand a research problem more completely (Creswell, 2002). In this study, "mixing," or integration of the quantitative and qualitative data, occurred in connecting the quantitative and qualitative phases and in the interpretation and reporting.

In selecting a mixed methods design, timing and priority should be considered and are dependent on the study purpose and research questions (Fetters, Curry, & Creswell, 2013; Ivankova, Creswell, & Stick, 2006). Timing of the data collection and analysis can be either concurrent or sequential and is determined by the study purpose and research questions. This study sought an in-depth explanation of the results from the quantitative measures; therefore, the researcher implemented sequential timing, where the quantitative data were collected and analyzed followed by the qualitative data collection and analysis.

Priority may be given to either the quantitative phase or qualitative phase or may be equal. In this study, because BCS who participated in SOAR provided in-depth knowledge of the experience of the selected cancer-related symptoms and adherence, priority was given to the qualitative phase. Notation for this study design is Sequential Quan→QUAL (Ivankova et al., 2006). The arrow (→) depicts the sequential nature of the design, and the capitalization (QUAL) depicts the priority given to the qualitative phase (Ivankova et al., 2006).

The quantitative and qualitative phases were connected by linking methods of data collection and analysis (Fetters et al., 2013). First, results from Phase I (quantitative) informed the development of the interview protocol for Phase II

(qualitative) to further elucidate the quantitative findings. Then, the researcher purposefully selected 15 interview participants from the Phase I respondents. Given that the results of the data analysis from Phase I inform data collection and participant selection for Phase II of a sequential design, connecting is a critical step (Teddlie & Tashakkori, 2009).

The researcher integrated the interpretation and reporting of the Phase I and Phase II results using joint display and narrative strategies (Fetters et al., 2013). Specifically, the researcher visually displayed the quantitative and qualitative results using a statistics-by-themes joint display to provide a visual comparison of participants to enhance interpretation of the findings. Integration through narrative occurred by using a weaving narrative by theme. This involved writing the findings of the quantitative data and qualitative data together by theme to answer the research questions.

Employing mixed methods was expected to yield complementary results (Greene, Caracelli, & Graham, 1989). In the quantitative phase, statistical data were used to identify cancer-related symptoms associated with adherence. Quantitative results informed the development of the interview protocol and participant selection for the qualitative phase. The interview protocol served as a means for following up on the quantitative results to understand them in more depth. Obtaining the best informants for understanding the quantitative results drove participant selection. In the qualitative phase, the themes (i.e., words and narratives) complemented (i.e., elaborated and clarified) the quantitative results. When used in combination, quantitative and qualitative methods complement each other and allow for a more complete understanding of the research problem (Greene et al., 1989; Tashakkori & Teddlie, 1998).

A sequential mixed methods study may be difficult to understand without a graphical representation (i.e., procedural diagram). A procedural diagram helps the researcher to visualize the sequence of the data collection, priority of the methods, and the connecting and "mixing" points (Creswell, 2005; Creswell, Plano Clark, Gutmann, & Hanson, 2003; Ivankova et al., 2006; Morse, 1991; Tashakkori & Teddlie, 1998). Figure 2 provides a procedural diagram of the study design. The rectangular boxes (▭) represent data collection or analysis. The arrows (→) represent the sequential nature of the design. The oval (⬭) represents the two phases being connected. The hexagon (⬡) represents the integration of the quantitative and qualitative for interpretation to develop meta-inferences.

Figure 2. Procedural diagram of proposed sequential Quan → QUAL mixed methods design. Adapted from "Using mixed-methods sequential explanatory design: From theory to practice" by N. V. Ivankova, J.W. Creswell, & S.L. Stick, 2006, *Field Methods, 18*(1), 3-20.

Phase I: Quantitative

Study Population and Sample

Participants were derived from the SOAR study. The researcher used convenience sampling to select intervention participants (n = 30) from SOAR (N = 60 [intervention group (n = 30); control group (n = 30)]). SOAR control group participants were excluded from the sample.

Data Collection

Quantitative data consisted of previously collected baseline data from SOAR intervention participants (n = 30) and participant adherence (i.e., ≥ 8 hr of cognitive training completed within 6-8 weeks). Baseline data included: (1) Sociodemographic and Treatment Questionnaire; (2) Cognitive Failures Questionnaire (CFQ); (3) Pittsburgh Sleep Quality Index (PSQI); and (4) Center for Epidemiologic Studies-Depression Scale (CES-D). Participant adherence was assessed via the online cognitive training program BrainHQ (www.BrainHQ.com). These instruments were discussed in detail in the Parent Study section of chapter 2. Appendix B contains copies of the instruments.

Data Analysis

Descriptive statistics and correlations among study variables were conducted and effect sizes were calculated. Data were analyzed using R Studio 3.3.1 software. Descriptive statistics were conducted for the sample characteristics. Frequencies and percentages were used to describe all variables. Means and standard deviations were generated for scores on all continuous variables (see Table 1). Correlations among study

variables were analyzed using Spearman's Rho (Field, 2009). Cohen's *d* was used to calculate effect sizes (measures of magnitude of the observed relationships, regardless of the sample size) (Field, 2009). Formal statistical inference was not conducted due to the exploratory rather than confirmatory nature of the investigation.

Table 1

Study Variables

Variable name	Instrument	Variable type	Range of scores	Score interpretation
Adherence	Cognitive Training Website (www.BrainHQ.com)	Categorical		Adherent Non-adherent
Perceived Cognitive impairment	Cognitive Failures Questionnaire (CFQ)	Continuous	0-100	Higher scores indicated greater perceived cognitive impairment
Sleep quality	Pittsburgh Sleep Quality Index (PSQI)	Continuous	0-21	≥5 indicative of poor sleep quality
Depressive symptoms	Center for Epidemiologic Studies-Depression Scale (CES-D)	Continuous	0-60	≥5 indicative of depressive symptoms

Reliability and Validity

The purpose of the quantitative phase of this study was to explore the relationship between cancer-related symptoms and adherence to a web-based cognitive training intervention among BCS. However, the use of inappropriate instruments and data

analysis procedures may result in inaccurate study results (Polit & Beck, 2012). The instruments identified for use in this study (Appendix B) have been validated in cancer populations (Akman et al., 2015; Hann et al., 1999; Vom Hofe et al., 1998) (see Table 2). In addition, data analysis procedures were appropriate for assessing for relationships between cancer-related symptoms and adherence (Field, 2009). Therefore, the use of psychometrically validated instruments and appropriate data analysis procedures aided in answering the research question of the quantitative phase of this study (Polit & Beck, 2012).

Table 2

Instrument Reliability and Validity

Instrument	Cronbach's alpha	Test-retest reliability
Cognitive Failures Questionnaire(CFQ)	.91	.82
Pittsburgh Sleep Quality Index (PSQI)	.83	.87
Center for Epidemiologic Studies-Depression Scale (CES-D)	.87	.88

To ensure consistency, the SOAR research assistant, a doctoral student trained by a doctorally prepared psychologist in administering the study instruments, performed all data collection. The SOAR research coordinator electronically entered all data into a password-protected database on a secure server. The research coordinator held a Master of Science degree in Nursing (MSN) and had more than 10 years of experience in data

entry and management. Additionally, all research methods and activities were recorded in a study log.

Connecting Phase I and Phase II

The quantitative results from Phase I informed the development of the interview protocol and participant selection for Phase II. The development of the interview protocol was based on quantitative results and probed for additional factors. The interview protocol (see Appendix B) consisted of nine open-ended questions to allow participants to fully express their viewpoints and experiences (DiCicco, Bloom & Crabtree, 2006). Follow-up prompts were used to further understanding (Turner, 2010). Interview questions sought to elicit potential facilitators and/or barriers to cognitive training and how and why selected cancer-related symptoms, explored in the quantitative phase, differentially impact BCS' adherence to the SOAR intervention. The protocol contained two introductory questions (i.e., icebreakers), two questions explored expectations and overall impression of the study, two questions explored experiences and influences of cancer-related symptoms , two questions explored experiences and influences of cognitive training, two questions explored facilitators/barriers to cognitive training and the environment for cognitive training, one question allowed for participants to further elaborate or to add anything that was not previously addressed. The interview protocol was approved via UAB IRB amendment (see Appendix E). After the researcher received IRB approval, two SOAR participants who were not part of the sample piloted the protocol.

Participants for Phase II were selected from those who participated in Phase I of the study (Ivankova et al., 2006). A systematic process for selecting participants for qualitative follow-up in Phase II was applied (Ivankova, 2014). The researcher used purposeful sampling to select a subset of Phase I participants who had been randomized to the SOAR intervention within the past 6 months (n = 13). The period of 6 months was chosen to aid in controlling for participant recall bias. Phase I descriptive statistics were re-analyzed on the selected interview group (n = 13), findings were consistent with the larger sample.

Phase II: Qualitative

Study Population and Sample

Participants for Phase II were purposefully selected from Phase I participants. A non-random maximum variation sampling strategy was applied to aid in understanding variations in experiences. The researcher conducted maximum variation purposeful sampling from the larger Phase I sample (n = 30), based on adherence and race, to select 13 interview participants for Phase II. To further explore Phase II (qualitative) findings, two additional participants, who had completed ≤ 1 hr of cognitive training, were purposefully selected for interviews. Data saturation occurred at 15 participants.

Recruitment

After the researcher received IRB approval, SOAR intervention participants were recruited via personal telephone calls using the recruitment script (see Appendix E). All telephone calls occurred from a private location. The researcher asked each potential

participant about their willingness to be interviewed about their cancer-related symptoms and views of the SOAR intervention. Recruitment continued until data saturation occurred (n = 15).

Data Collection

Each participant was asked to complete a one-time interview that took place at the UAB Holley-Mears Building - Center for Research on Applied Gerontology (CRAG). The researcher, who received training in interview techniques during her predoctoral work at UAB, conducted the interviews.

Prior to beginning the interview, each participant gave written informed consent (see Appendix E). The interview, guided by the interview protocol, lasted an average of 54 min (n = 15). With participant permission, the researcher audio recorded the interview. Interview questions asked participants to recall personal experiences of the SOAR intervention and cancer-related symptoms (e.g., perceived cognitive impairment, depressive symptoms, and poor sleep quality). Each participant was given an opportunity to comment on these experiences. At the end of the interview participants received a $25 gift card.

After completion of the interview, the researcher electronically sent the audio recording to a certified transcriptionist service for confidential, verbatim transcription of the interview. Upon receiving the completed transcript from the transcriptionist service, the researcher compared the transcript to the audio recording to verify accuracy. Once transcript accuracy was verified, the researcher generated a one-page summative report (see Appendix G), which was emailed to the participant to review for accuracy.

A follow-up telephone call occurred within 3 days of the interview. Follow-up calls lasted an average of 5 min (n = 15). Participants were asked to verify the accuracy of the summative report. In addition, the call allowed for (a) participants to further elaborate or to add anything they did not previously mention; and (b) researcher clarification. After completion of the follow-up phone call, participants were mailed another $25 gift card.

Data Analysis

Data analysis was conducted via inductive thematic analysis and occurred simultaneously with data collection (Creswell, 2012). Analyzing the data during the data collection process gives the researcher a general sense of the collected data, may guide future data collection (i.e., modification of the interview protocol or additional probing), and aids in determining when data saturation has been reached (Ivankova, 2015). Thematic analysis is a "method for identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). An inductive approach is data driven and is directed at organizing the data into categories and themes from the specific to the general (Braun & Clarke, 2006; Creswell, 2014). The use of an inductive thematic approach allows for the qualitative findings (i.e., themes, categories, or codes) to be connected to the quantitative results and aids in the integration of the two (Ivankova, 2015).

Data analysis followed Creswell's (2009) step-by-step approach: 1) organizing and preparing data for analysis; 2) reading and getting familiar with the data; 3) coding the data; 4) synthesizing the codes to develop themes; and 5) interpreting the meaning of

the themes. These steps were iterative and were repeated until data interpretation was sufficient to answer the research question.

First, data were organized and prepared for analysis. A professional transcription service transcribed the interviews verbatim. The researcher imported audio recordings and transcripts into Qualitative Software and Research (QSR) NVivo 11Pro© software for qualitative data analysis.

Second, the researcher became familiar with the data. This was accomplished by listening and listening again to interview audio recordings, reading and re-reading transcripts, making notes, and developing a one-page summative report for each interview.

Third, data were coded. Coding is "identifying a meaningful statement of text [that] calls for some minimal representation of that meaning" (Guest et al., 2012, p. 52) with the purpose of generating meaningful inferences (Koshy, Koshy, & Waterman, 2010; Strauss & Corbin, 1998). Richards and Morse (2012) describe coding as linking: "It leads you from the data to the idea and from the idea to all the data pertaining to that idea" (p. 137). The process of inductive coding was data driven and involved "segmenting sentences (or paragraphs) into categories and labeling those categories" (Creswell, 2009, p. 186). To preserve the voices of the participants, the strategy of in vivo coding (i.e., using the participants' own words as code labels) was implemented. The researcher developed a codebook, a list of codes and their categories and themes. The use of a codebook is considered critical in inductive analysis and aids in sorting the coded text into "categories, types and relationships of meanings" (Guest et al., 2012, p. 52). Using the constant comparative method, the researcher compared each new segment

of data to other similar segments before creating a new code (Strauss & Corbin, 1998). This iterative process continued until data saturation was met (n = 15). Data saturation is "the point in data collection and analysis when new information produces little or no change to the codebook" (Guest et al., 2006, p. 65).

Fourth, the researcher synthesized the codes to develop themes. Codes were examined for overlap and the number of codes was then reduced. The researcher then grouped codes together into broader categories and themes. Themes were then reviewed and further refined to ensure that the codes were relevant to each theme. As recommended, four themes with sub-themes were generated (Creswell, 2014).

Fifth, the meaning of the themes was interpreted. The researcher created a tree display using NVivo 11 Pro© to explore patterns across themes. Themes and sub-themes were reviewed to verify that the depth and breadth of the data were captured. A model was developed to describe the interrelationship of the themes and sub-themes. Finally, the researcher wrote a thorough narrative to answer the research question.

Trustworthiness

The terms reliability and validity traditionally are associated with quantitative research; however, in qualitative research the term used is "trustworthiness" (Lincoln & Guba, 1985). Trustworthiness was established following Lincoln and Guba's (1985) criteria of 1) credibility, 2) transferability, 3) dependability, and 4) confirmability.

Credibility refers to the believability of the findings. Strategies for establishing credibility include spending prolonged time with participants and member checking

(Lincoln & Guba, 1985). In this study, spending prolonged time with the participants provided an in-depth understanding of how identified selected cancer-related symptoms contributed to or impeded BCS' adherence to the SOAR intervention. The researcher achieved this by conducting an in-person interview with each participant, which lasted an average of 54 min (n = 15). Member checking ensured data accuracy (Hinchey, 2008). The researcher accomplished this by conducting a follow-up phone call with each participant, which lasted an average of 5 min (n = 15). During the phone call participants were asked to verify the accuracy of the summative report and were given an opportunity to further elaborate or to add anything they did not previously mention. In addition, the follow-up phone call allowed for researcher clarification.

Transferability refers to the applicability of the findings to other research contexts. To facilitate comparison with other contexts, the researcher (a) collected detailed descriptive data via in-depth in-person interviews; and (b) generated a detailed description of the study setting and participants (i.e., "rich, thick description"). Rich, thick description developed from a detailed narrative of the themes and sub-themes that emerged from the analysis of the participant interviews.

Dependability refers to the consistency and repeatability of the findings. Strategies for establishing dependability include audit trail, peer review, and dissertation committee audit (Lincoln & Guba, 1985). For this study, audit trail consisted of keeping a record/log of research methods and activities to ensure consistency in data collection and analysis. Peer review entailed asking a peer to review and explore interview

transcripts, data analysis, and emerging themes. Dissertation committee audit consisted of a review of all data collection, storage, and analysis procedures of the study by the dissertation committee.

Confirmability refers to the objectivity of the findings. Confirmability ensures findings are shaped by the participants' views and not researcher bias. Strategies for establishing confirmability include audit trail and clarifying researcher bias (Lincoln & Guba, 1985). The researcher shared the audit trail, described above, with the dissertation committee. Researcher bias was clarified by practicing reflexivity to reveal any underlying assumptions and/or biases. Reflexivity is a process of reflecting on emergent themes in the data and checking these observations with the researcher's own perceptions (Mills, 2006).

Mixed Methods Research Quality Assurance

Ensuring quality in mixed methods research is difficult due to the integration of quantitative and qualitative approaches to obtain credible meta-inferences; in fact, this has been the most debated topic in mixed methods research over the past decade (Ivankova, 2014). A Meta-inference is "a conclusion generated through an integration of the inferences that have been obtained from the results of the quantitative and qualitative strands of a mixed methods study" (Teddlie & Tashakkori, 2009, p. 152). The generation of meta-inferences may be impacted by the timing of data collection and analysis (i.e., concurrent or sequential). For example, in a sequential Quan → QUAL mixed methods design the quality of the inferences produced in the first phase may significantly impact

the quality of the inferences produced in the second phase (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009), potentially affecting the quality of the generated meta-inferences from the entire study (Ivankova, 2014).

To ensure the generation of high-quality meta-inferences from the study, the researcher used separate procedures, previously discussed in this chapter, to assess the reliability and validity of the quantitative results and trustworthiness of the qualitative results (Bryman, Becker, & Semptik, 2008; Creswell & Plano Clark, 2011; Dellinger & Leech, 2007; Greene, 2007; Onwuegbuzie & Leech, 2006; Teddlie & Tashakkori, 2009). Additionally, to address the specific quality issues of a sequential Quan → QUAL design, the researcher applied a systematic process for selecting participants for qualitative follow-up (Ivankova, 2014). This systematic process included (a) controlling for participant recall bias by selecting Phase I participants who were randomized to the SOAR intervention within the past 6 months; and (b) verifying that selected Phase II participants were reflective of the larger Phase I sample by checking for consistency among the quantitative findings.

Integration of Quantitative and Qualitative Results

Integration of the quantitative and qualitative results aids in explaining the statistical results, emphasizing the explanatory purpose of a sequential Quan → QUAL mixed methods design (Creswell, 2003; Greene et al., 1989; Ivankova et al., 2006). The overarching mixed methods research question addressed in this study was, "How can quantitative instrument scores and interview themes jointly explain the relationship between selected cancer-related symptoms and BCS' adherence to the SOAR cognitive

training intervention?" Answering this question required study of the qualitative themes in terms of their ability to explain the quantitative results. Then the qualitative findings were integrated with the quantitative findings to answer the question using quality inferences. The rationale for integrating quantitative and qualitative methods in this study was to obtain validated meta-inferences to inform the delivery of future cognitive training interventions for BCS.

Ethical Considerations

The study protocol received expedited approval by the UAB IRB (see Appendix E). Ethical issues were addressed at each phase in the study. Phase I quantitative results (i.e., questionnaire responses) were linked to Phase II participants. Recruitment of Phase II participants minimized the possibility of coercion or undue influence by the researcher informing potential participants, during the recruitment call, that while they agreed to be contacted for future research, they were under no obligation to participate in this separate dissertation study. A lag time of at least 48 hr occurred between recruitment and the first interview. Prior to beginning the interview, written informed consent was obtained from each participant. The researcher reviewed the consent form with each participant, answered any questions the participant had, and confirmed participant understanding by asking relevant questions (i.e., "What is the purpose of this study?," "What is your role as a participant?," "Who can you call if you want to report an ethical issue?," "What are the risks and benefits of participating in this study?," and "Do you have the right to drop out of this study?"). Upon decision to participate, participants signed the consent form and received a copy of their signed form.

Once written informed consent was obtained, the individual was considered an enrolled participant. The researcher ensured privacy by conducting the informed consent protocol in a private room at the UAB Holley-Mears Building - CRAG, which was reserved to prevent any interruptions. The researcher monitored for emotional harm during each of the individual interviews. In addition, the researcher sought to avoid risk of emotional harm by stating at the outset of the interview that sharing information may have an unintended consequence of causing emotional upset. The anonymity of participants was protected by assigning participant numbers for use in their description and reporting the results. The researcher reviewed the description of findings to ensure that too much information was not disclosed and that participant identities were not revealed. Participants were informed that information from the study may be published for scientific purposes; however, no individual will be identified.

Data were stored to maintain confidentiality. All audio and paper files of study data were stored in a locked file in a locked office of a restricted access research area. All identifiable data with participants' names and contact information were stored electronically with restricted access in the study file, which was located on a centrally-maintained computer. Access to identified study data was restricted to the researcher only.

Role of the Researcher

The researcher's role differed in the two phases of this study. In the first, quantitative, phase the researcher analyzed data collected at baseline in the SOAR study. In the second, qualitative phase, the researcher collected qualitative data through semi-

structured in-person interviews. In this second phase, the researcher assumed a more participatory role due to the "sustained and extensive experience with participants" (Creswell, 2003, p. 184) and personal involvement with the SOAR study. The researcher was a doctoral student/research assistant at the UAB School of Nursing. She was IRB-approved personnel on the SOAR study. Her duties as a research assistant for SOAR included recruitment, enrollment, and data collection. She has a developed rapport with SOAR participants. This may create a potential for bias. Extensive quality assurance procedures, including clarifying researcher bias, developing rich, thick descriptions, maintaining an audit trail, member checking, peer review, and dissertation committee audit were used to establish the trustworthiness of the findings and to control bias.

Summary

An IRB-approved, sequential Quan → QUAL mixed methods study explored the relationship between selected cancer-related symptoms and adherence to the SOAR web-based cognitive training intervention among BCS residing in Alabama. Phase I consisted of analyzing self-reported questionnaire data for SOAR intervention participants (n = 30). The quantitative results from Phase I informed the development of the interview protocol and participant selection for Phase II. Fifteen Phase I respondents were purposefully selected for Phase II. Phase II participants participated in a one-time face-to-face interview and follow-up telephone call (n = 15). Data were analyzed using inductive thematic analysis. Results from Phase I and II are presented in chapter 4.

CHAPTER 4

RESULTS

This study sought to explore the relationship between selected cancer-related symptoms and adherence to the SOAR cognitive training intervention among BCS residing in Alabama by using a sequential Quan → QUAL mixed methods design. The goal of the quantitative phase was to identify the relationship between selected cancer-related symptoms and adherence to SOAR using self-reported questionnaire data. The goal of the qualitative phase was to better understand how identified selected cancer-related symptoms contribute to or impede BCS' adherence to SOAR by conducting semi-structured interviews with 15 purposefully selected SOAR participants. This chapter presents results for the quantitative (Phase I) and qualitative (Phase II) phases of this sequential Quan → QUAL design mixed methods study.

Phase I: Quantitative

This section presents the results of the first, quantitative, phase of the study guided by the research question: What is the relationship between perceived cognitive impairment, depressive symptoms, sleep quality, and adherence to the SOAR cognitive training intervention among BCS? What follows is the description of sample characteristics and results of the quantitative data analysis.

Sample Characteristics

The quantitative sample consisted of SOAR intervention participants (*n = 30*). Participants had a mean age of 54 years and the majority were African American (see Table 3). Overall, these women were well educated, most having attended or graduated from college, married, and living with other family members. Retirement and disability were common among participants. While income varied, many had a family income of more than $50,000 per year.

Mean survivorship time of participants was 6 years (see Table 4). Surgery, chemotherapy, radiation therapy, and/or hormonal therapy were received by participants for breast cancer treatment. Many of these women experienced weight gain since treatment. Almost all participants had health insurance and the majority attended a breast cancer support group.

Results

Means and standard deviations for scores on all continuous study variables are displayed in Table 5. Mean scores indicated poor sleep quality, depressive symptoms, and perceived cognitive impairment among participants. Four participants had PSQI scores <5, indicating good sleep quality; and 24 participants had PSQI scores ≥5 indicating poor sleep quality. One participant had a CES-D score <5, indicating that they were not likely to be experiencing depressive symptoms; 11 participants had CES-D scores ≥5 indicating depressive symptoms; and 18 participants had CES-D scores ≥16,

Table 3

*Sociodemographic Characteristics (*N = *30)*

Variables	Mean (*SD*) Range	*n* (%)
Age (Years)	53.69 (10) 35-71	
Race		
African American		16 (53%)
Caucasian		14 (47%)
Education years	15.10 (2.9) 12-20	
High school or less		6 (20%)
Some college		9 (30%)
College graduate		15 (50%)
Marital status		
Married		18 (60%)
Divorced		6 (20%)
Never married		6 (20%)
Living with others*		25 (83%)
Spouse		15 (50%)
Children	1.17 (1.4) 0-5	17 (57%)
Parents		2 (7%)
Other relatives		3 (10%)
Friend		1 (3%)
Employment status		
Employed		14 (46.6%)
Unemployed		4 (13.4%)
Retired		7 (23.3%)
Disabled		5 (16.7%)
Household income		
<$10,000		1 (3%)
>$10,000 -$30,000		6 (20%)
>$30,000-$50,000		5 (17%)
>$50,000		12 (40%)
No response		6 (20%)

* *Does not equal 100%*

Table 4

*Cancer Treatment and Survivorship Characteristics (*N *= 30)*

Variables	Mean (*SD*) Range	*n* (%)
Survivorship (years)	6.1 (5.69) 1-25	
Health insurance		
Insured		29 (97%)
Uninsured		1 (3%)
Type of surgery*		
Lumpectomy		15 (50%)
Mastectomy		6 (20%)
Bilateral mastectomy		8 (27%)
Chemotherapy		
Yes		26 (87%)
No		4 (13%)
Radiation		
Yes		24 (80%)
No		6 (20%)
Endocrine therapy		
Yes		20 (67%)
No		10 (33%)
Weight gain*		15 (50%)
Pounds of weight gain	23 (14) 0-50	
Current weight	192 (40.5) 123-274	
Breast cancer support group		
Yes		17 (56.7%)
No		13 (43.3%)

** Does not equal 100%*

Table 5

*Descriptive Statistics for Cancer-Related Symptoms (*N = *30)*

	Range of possible scores	Range of scores in sample	*M*	*SD*
Perceived cognitive impairment[a]	0 - 100	29 - 80	55.60	12.64
Depressive symptoms[b]	0 - 60	2 - 43	17.87	9.89
Sleep quality[c]	1 - 21	1 - 19	8.87	4.38

[a] *Measured by the CFQ, with higher scores indicative of worse perceived cognitive function*
[b] *Measured by the CES-D, with a score of ≥5 indicative of depressive symptoms; ≥16 high depressive symptoms*
[c] *Measured by the PSQI, with a score of ≥5 indicative of poor sleep quality*

indicating high depressive symptoms. CFQ scores ranged from 29 to 80 indicating worse perceived cognitive function. Sample (N = 30) mean scores were comparable to the parent study, SOAR, sample (N = 60).

Descriptive statistics were used to determine adherence to the cognitive training intervention (see Table 6). The mean duration of cognitive training was 7.17 hr. Adherence was defined as ≥8 hr of cognitive training. Based on this definition, 17 participants were considered adherent and 13 were considered non-adherent.

T-tests were conducted to compare adherent and non-adherent groups. Between group comparisons for sleep quality resulted in a medium effect size (d = 0.55, p = 0.15). No relevant differences for perceived cognitive impairment (d = 0.05, p = 0.89) or depressive symptoms (d = 0.05, p = 0.89) were seen. See Table 7.

Table 6

*Descriptive Statistics for Cognitive Training Hours (*N *= 30)*

	Mean (*SD*)	Range	Adherent	Non-adherent
Cognitive training hours	7.17 (4.07)	0-14	17	13

Adherent = completed ≥8 hours of cognitive training
Non-adherent = completed <8 hours of cognitive training

Table 7

*Difference Between Groups for Cancer-Related Symptoms (*N *= 30)*

Variables	Adherent (*n* = 17)		Non-adherent (*n* = 13)		Difference	Effect size
	Mean (*SD*)	Min. - Max.	Mean (SD)	Min. - Max.	*p*	Cohen's *d*
Perceived cognitive impairment[a]	55.88 (14.54)	29 - 80	55.23 (10.21)	41 - 78	0.89	0.05
Depressive symptoms[b]	17.65 (11.07)	2 - 43	18.15 (8.55)	9 - 39	0.89	0.05
Sleep quality[c]	7.82 (3.96)	1 - 14	10.23 (4.67)	3 - 19	0.15	0.55

[a] *Measured by the CFQ, with higher scores indicative of worse perceived cognitive function*
[b] *Measured by the CES-D, with a score of ≥5 indicative of depressive symptoms; ≥16 high depressive symptoms*
[c] *Measured by the PSQI, with a score of ≥5 indicative of poor sleep quality*
Cohen's d*: small ~0.2; medium ~0.5; large ~0.8 or greater*

Spearman's rho correlation suggested the presence of relationships between adherence and perceived cognitive impairment, depressive symptoms, and sleep quality (see Table 8). A small to medium inverse correlation occurred with sleep quality and adherence (r_s = -0.24, p = 0.19). Non-relevant correlations were seen with depressive symptoms and adherence (r_s = -0.03, p = 0.87) and perceived cognitive impairment and

adherence (r_s = 0.04, p = 0.85). In addition, sleep quality had a medium correlation with perceived cognitive impairment (r_s = 0.29, p = 0.12) and depressive symptoms (r_s = 0.29, p = 0.11).

Table 8

Correlation with Adherence among Cancer-Related Symptoms (N = 30)

		1	2	3	4
1	Adherence		0.04	-0.03	-0.24
2	Perceived cognitive impairment			0.03	0.29
3	Depressive symptoms				0.29
4	Sleep quality				

Spearman's rho correlation (absolute value): small ~0.1; medium ~0.3; large ~0.5 or greater

Summary of Quantitative Results

The following quantitative results apply to the study sample. Due to the inherent uncertainty of exploratory analyses in small samples, no formal inferential statements to a larger population are made. Poor sleep quality, depressive symptoms, and perceived cognitive impairment were present among participants. Poorer sleep quality was seen in the non-adherent group (*d = 0.55*). Adherence to SOAR was moderately inversely correlated with sleep quality (r_s = *-0.24*). Sleep quality was moderately correlated with depressive symptoms (r_s = *0.29*) and perceived cognitive impairment (r_s = *0.29*). Results suggest that sleep quality may be related to BCS' adherence to SOAR.

Phase II: Qualitative

This part of the chapter presents the results of the second, qualitative, phase of the study, which aimed to address the qualitative research question: How do the selected cancer-related symptoms identified in Phase I contribute to or impede BCS' adherence to the SOAR cognitive training intervention? What follows is the description of (a) participants; (b) themes that emerged from the qualitative data analysis, organized by themes and subthemes and supported by participants' quotes; and (c) the interrelation of themes to explain how cancer-related symptoms are related to adherence to SOAR among BCS.

Participants

The qualitative phase of the study involved interviewing 15 participants selected from the quantitative phase. Participant characteristics appear in Table 9. Six of these participants were adherent to the SOAR cognitive training protocol, while nine were non-adherent. The following section describes each of these participants.

Table 9

*Qualitative Participant Characteristics (*N *= 15)*

Participant ID	CT hours	Age	Race	Work status	House-hold size	House-hold support	CFQ score	CES-D score	PSQI score
Adherent (*n* = 6)									
2	10	42	CAU	Home-maker	4	Yes	57	13	3
5	10	40	CAU	Employed	4	Yes	56	27	13
6	10	45	AA	Un-employed	3	Yes	47	10	4
7	10	51	AA	Un-employed	8	Yes	60	16	8
8	10	39	CAU	Employed	2	No	53	11	7
10	10	64	CAU	Retired	2	Yes	78	12	9
Non-adherent (*n* = 9)									
1	3	41	AA	Employed	6	No	44	21	7
3	3	50	CAU	Disabled	3	No	57	13	3
4	7	61	AA	Retired	1	No	56	27	13
9	3	71	AA	Retired	1	No	47	10	4
11	0	65	AA	Employed	5	No	60	16	8
12	7	68	CAU	Retired	7	Yes	53	11	7
13	0.5	55	AA	Employed	1	No	78	12	9
14	0.72	55	AA	Employed	1	No	43	9	10
15	0.33	62	CAU	Employed	2	No	67	39	10

Note. AA=African American, CAU=Caucasian; CES-D=Center for Epidemiologic Studies-Depression Scale; CFQ=Cognitive Failures Questionnaire; CT=Cognitive Training; PSQI= Pittsburgh Sleep Quality Index

Participant 1. Participant enrolled in the study to learn more about "chemobrain" because she had noticed some changes in how she was thinking. She found the cognitive training to be helpful as it made her more aware of the mental delays that she was experiencing. She felt that she was previously in denial about any cognitive changes. Since becoming more aware of her cognitive changes, she began using reminder strategies (e.g., planner, lists, large key chain). Challenges she experienced in doing the cognitive training consisted of her environment and the lack of mobility of the training. She did not receive any emotional support from those in her household and felt that household support may have aided her in completing the training. She recommended that other BCS (a) take full advantage of the cognitive training, (b) make it a priority, (c) schedule frequent short cognitive training sessions, (d) do as many hours as they can, and (e) keep a journal (i.e., how you feel, what is on your mind).

Participant 2. Participant was informed about the study at a community event for BCS. She thought that the cognitive training program was easy to use and navigate, and she liked the convenience and flexibility to be able to do it at home on her own schedule. However, she found the cognitive training to be repetitive and would have preferred more variety. Overall, though, she found the training to be helpful and felt that her memory was sharper, her brain was less foggy, and she was experiencing less frustration than before the doing the cognitive training. She did not necessarily schedule her cognitive training; rather, she just worked it in when she could, usually in the morning. Completing her training in the kitchen, which was not necessarily free from distractions, still worked better for her than locking herself away in another room and

being inaccessible to her family. The emotional support she received from her husband encouraged her to complete all 10 hr of the cognitive training. Suggested improvements to the program included being able to gauge one's advancement more clearly and having more variety in the training.

Participant 3. Participant was informed about the study at her support group meeting. She did not complete all 10 hr of cognitive training and did not feel that the number of hours that she did was sufficient. Still, she enjoyed doing the cognitive training, finding it engaging and challenging, and felt like she was doing something good for herself. However, she found the game to be primitive; it could get boring and she preferred more of a variety cognitive games. She noticed that her cognitive training performance would vary on different days, but was not sure why and thinks it would have been helpful to keep a journal during the training to record how she was feeling (i.e., mood, sleep, and cognitive and physical status). She recommended this program for other BCS and advised them to "just give it a try" and to do the cognitive training when it's quiet and they're in a good mood, well rested, and pain free.

Participant 4. Although this participant felt that the study was difficult at times, it met her expectations of stimulating her brain. She found the training to be helpful, as it made her more aware of her thought process. Since becoming more aware of her thought process, she has felt more focused and mindful of what she is doing. She mentioned being more likely to remember why she went to a particular room, instead of forgetting. Things that helped her with the cognitive training included (a) receiving reminders and

encouragement from the research assistant, (b) a personal sense of commitment and responsibility, and (c) doing her training in a comfortable place (e.g., on her couch in her living room). Personal responsibilities (e.g., running errands) and fatigue would sometimes interfere with doing her cognitive training. Being provided a tablet with the cognitive training loaded on it would have made it easier for her. She genuinely enjoyed the study and is proud to have been part of it.

Participant 5. Participant found out about the study by being "tagged" on Facebook. Her main reason for enrolling in the study was to help other BCS. Although participants were instructed to complete the cognitive training on a computer, she completed it on her phone, which allowed her the flexibility to complete the 10 hr. While she felt that the 10 hours was sufficient, she thought that some people may benefit from doing more. Things that would have made it easier include (a) making it mobile (i.e., phone app, iPad), (b) more colorful graphics, (c) more variety of training, (d) more positive feedback, and (e) a display that shows the user the hours of training completed. She considers herself a procrastinator, which she felt made it more challenging for her to get the training completed. She felt that her ability to focus, her sleep quality, and mood did have some impact on her cognitive training.

Participant 6. Participant enjoyed the cognitive training, which she characterized as engaging and challenging, and easy to use and navigate. Cognitive training consisted of doing the same task over and over, which made it easy for her. Although the training was repetitive, she did not find it boring and actually looked forward to doing it. She

found the training to be helpful as it made her aware of "chemobrain," confirming that it was a real thing. Her daughters supported her to do the cognitive training by assisting her with logging onto the computer, having a positive attitude about the training, and by not disrupting her when she was doing her training sessions. She recommended this program for other BCS. She felt that it is good for BCS to be aware of "chemobrain" and that they should give cognitive training a try because it may help them.

Participant 7. Participant enjoyed the cognitive training and would have liked to do even more. She found the cognitive training to be engaging and challenging, and this motivated her to improve her score and "beat this thing." At first she experienced some difficulty with logging into the computer, but after her son helped her, she was self-sufficient. The most difficult thing for her was finding quiet time to be able to sit and focus on the cognitive training like she wanted to. She generally did her cognitive training at night when everyone was in bed or during the day when her grandkids were in school. She found that the training helped her to learn how to stay focused on what she was doing and to really listen to what someone was saying to her. Since doing the cognitive training, her confidence has increased, she feels good, smiles more, she is more socially active, and just enjoys life so much more. She reported experiencing improvements in memory, mood, and sleep.

Participant 8. Participant felt that the study was easy; however, the time management to complete all 10 hr of the cognitive training was challenging. While she felt that the 10 hr was sufficient for this study, she thought that there should be guidance

for how much people should do to receive benefit (i.e., duration of sessions, number of sessions, and number of weeks/months). Overall, she felt that the cognitive training had a positive effect on her life. She felt more focused and was able to find her words better while doing the training. Things that helped her complete the cognitive training included (a) previous knowledge of and experience with cognitive training, (b) receiving reminders and encouragement from the research assistant, and (c) a personal sense of commitment and responsibility. She did not schedule cognitive training. She considers herself a procrastinator, which led to her doing the majority of the training in the last week of the intervention.

Participant 9. Participant decided to enroll in the study to help other BCS and to possibly help improve her focus. Also, the compensation was helpful to her. She thought that the computer program was easy to use and navigate. She did not complete the 10 hr of cognitive training; she felt that the number of hours that she did was not sufficient and thought that she should have done more. Despite this, she found the cognitive training to be easy, fun, and challenging, and she liked that it made her sit and focus. She did her cognitive training in the morning in the living room while sitting on the sofa. She did not feel that her ability to focus, her mood, or sleep quality influenced doing her cognitive training. Since doing the cognitive training, she has not experienced any improvements in cognition, mood, or sleep. However, she felt that while she was doing the cognitive training, it was helping her to be a little more focused. She would have liked to continue the cognitive training.

Participant 10. Participant liked the convenience and flexibility of being able to do the training at home on her own time. Making the cognitive training a priority, she generally did 15-30 min every morning in her spare bedroom, which was free from distractions. While on vacation she made daily trips to the local library to do her cognitive training. No daily activities or responsibilities interfered with doing her cognitive training. She did not feel that her mood or sleep quality influenced doing her cognitive training, because she was determined to do it anyway. However, she felt that her lack of ability to focus did influence her cognitive training in a positive way, because she wanted to do something to improve it. Since doing the cognitive training, she has felt more focused, more energetic, more socially active, and has experienced fewer incidences of "forgetfulness" (e.g., leaving the stove on). She has also experienced improvements in memory, mood, and sleep.

Participant 11. At her initial study appointment, this participant had difficulty with the cognitive testing, which led to her feeling vulnerable and like she was falling apart. She can still remember feeling very tense and wanting to leave the appointment. This experience made her more aware of her cognitive functioning and confirmed that she was having some memory and attention issues, which was frustrating and uncomfortable. She considers herself a perfectionist and likes to get things right. Being an African American woman, she has always felt like she had to do twice as much as others in order to be accepted. She felt that if perhaps she had aced all the cognitive testing at the first appointment, she would have felt more comfortable. However, she ended up not logging into the website at home or doing any cognitive training. She felt

like she let herself down, because it was an opportunity to possibly help herself that she did not take. On the other hand, she did not want to see herself failing again. Doing the study brought awareness to the fact that she was having more cognitive difficulty than she thought, which was distressing.

Participant 12. Participant felt that the study met her expectations of helping her memory. As a result of the cognitive training, she has experienced fewer incidences of losing her train of thought while having a conversation, which has improved her mood and confidence. She is now able to carry on a discussion better, which has led to her being more socially active. Additionally, she is more apt to remember the items on her grocery list. While her sleep has improved, she is not sure if it is due to the cognitive training (her husband began using a CPAP around the same time). She did not necessarily schedule her cognitive training; rather, she just worked it in when she could, usually in the evening after the children were in bed. She received encouragement and support from her husband, daughter, friends, and others at her monthly social groups. At times, she experienced difficulty with focusing, fatigue, or sadness, which influenced her cognitive training performance (poor performance), and sometimes she was not up to doing the training and just skipped that day. She advised other BCS to do it, schedule it, and make it a priority.

Participant 13. Participant decided to enroll in the study because she was experiencing some cognitive changes and was hoping to improve her cognition. However, she felt that the study was much harder and more time consuming than she

expected. She did not schedule her cognitive training; rather, she just worked it in when she could, usually in the evenings after her 10-hour work day. After a long day at work, she was physically tired, and the cognitive training seemed to make her more mentally tired. She would think, "Oh, I'll do it tomorrow, or I'll do it on the weekend when I have more time," but the time never came around. She did not feel that the cognitive training helped her and has not experienced any improvement in cognition, sleep, or mood since the cognitive training. However, she felt that this may partly be due to her not putting in enough hours.

Participant 14. At her initial study appointment, this participant was afraid that her "brain was not going to do as expected" and she "would not do it right," which was "frightening." She can still remember her stomach getting queasy, her heart beating fast, and thinking, "Oh God, I'm just going to faint." Since she did not have a home computer, she tried doing her cognitive training at the office before work, which was difficult. The office was a stressful environment and full of distractions. While she has not experienced any improvement in cognition, sleep, or mood since the cognitive training, knowing that "someone on the other end really cared about the study results" and that it may "help some other woman" made it all worthwhile. While she told her son about being in the study, she chose not to share with others, because "it can be shaming." She feared they would say, "Oh, she's just trying to explain why she's so stupid." Nevertheless, she feels that it was an "awesome" study that made her rethink things, gave her the desire to go back to school, and gave her hope. The only regret she has is that she couldn't complete it.

Participant 15. Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some cognitive changes and difficulties with her thinking and reading abilities. However, she felt that the study was difficult and anxiety producing. She did not like the type of brain activities it entailed. Furthermore, she felt that it was not germane to the cognitive changes she was experiencing. It did not help her with the things she needed help, which were reading comprehension and commitment to something that she had pre-planned. Instead, it just made her anxious about things that she wasn't anxious about before, and it seemed self-defeating. If given a choice, she would prefer a cognitive intervention with a more holistic perspective and slower pace. She would be interested in trying something psychophysical, in which she would be working her body with her brain, or maybe meditation. For her, the best part of the study was having social interaction with the research assistant. She expressed that “sometimes it's good just to be with people who have some awareness that you've been through some shit and understand that you've had breast cancer, you've had chemo, and you have some issues."

Themes

Inductive thematic analysis yielded four themes that describe how cancer-related symptoms are related to adherence to SOAR among BCS, differences among adherent and non-adherent participants, and cultural aspects: 1) experiences of cancer-related symptoms; 2) influences of cognitive training; 3) adherence to cognitive training; and 4) environment for cognitive training. Table 10 lists the themes, subthemes, and codes.

Table 10

Themes, Subthemes, and Codes

Theme		Subtheme		Codes	
I.	Experiences of cancer-related symptoms	a.	Experience of perceived cognitive impairment	1)	An uncontrollable brain
				2)	A safety issue
				3)	Life interfering
				4)	Coping mechanisms
				5)	A loss of sense of self
				6)	Nobody knows how it feels
		b.	Experience of depressive symptoms	1)	Self-doubt
				2)	Constant frustration
				3)	Unhappiness
				4)	Being a survivor and a co-survivor
				5)	Managing depressive symptoms
		c.	Experience of poor sleep quality	1)	Unable to fall asleep
				2)	Disrupted sleep
				3)	Napping
				4)	Crashing
				5)	Managing poor sleep quality
II.	Influences of cognitive training	a.	Raised Awareness	1)	About cancer and treatment
				2)	Perceived cognitive impairment
				3)	Depressive symptoms
		b.	Positive influence	1)	Improved cognition
				2)	Improved mood
				3)	Improved sleep
		c.	Negative influence	1)	Anxiety
				2)	Frustration
				3)	Self-defeating thoughts
III.	Adherence to cognitive training	a.	Influence of perceived cognitive impairment	1)	Hindrance
				2)	Determination
		b.	Influence of depressive symptoms	1)	Poor performance
				2)	Not in the mood
		c.	Influence of poor sleep quality	1)	Unmotivated
				2)	Too tired
IV.	Environment for cognitive training	a.	Computer access	1)	Assistance from others
				2)	Unable to access computer
		b.	Household dynamics	1)	Extended family
				2)	Unexpected to changes
				3)	Living alone
		c.	Support system	1)	Felt supported
				2)	Keeping to self

The remainder of this chapter describes the emergent themes and their interrelationship to explain how cancer-related symptoms influence adherence to SOAR among BCS. Theme descriptions and interpretations are supported by participants' illustrative quotes. To provide as much anonymity as possible, BCS are referred to by their participant number (e.g., PT 01). In addition, to aid in identifying differences and/or similarities among participant responses and in the integration of the findings, identifiers of adherent/non-adherent and Caucasian/African American are used.

Theme 1: Experiences of Cancer-Related Symptoms

The BCS in this study had varied experiences of cancer-related symptoms that influenced their adherence to cognitive training in different ways. These varied experiences are related to perceived cognitive impairment, depressive symptoms, and poor sleep quality and are described below.

Experience of perceived cognitive impairment. All participants reported experiencing perceived cognitive impairment since cancer and tended to refer to it as "chemobrain." Six codes related to this subtheme emerged from the interviews: 1) an uncontrollable brain, 2) a safety issue, 3) life interfering, 4) coping mechanisms, 5) a loss of sense of self, and 6) nobody knows how it feels.

An uncontrollable brain. Participants described not being able to remember things that they normally would have before cancer, forgetting names, difficulty finding words, and feeling "foggy" (PT 05 and 08) or "cotton headed" (PT 02). The majority of

BCS were not informed by their health care provider about cognitive impairment, which led to some BCS fearing that they were "going crazy" (PT 07). One participant expressed, "I felt like I was just crazy. I couldn't remember anything" (PT 07). Perceived cognitive impairment was described as an "uncontrollable brain" (PT 01 and 02) that made participants feel out of control. One non-adherent participant described it this way: "Just constantly thinking about, what? Just random thoughts, no point of reference, not what I wanted to think about. It's like I was out of control of controlling this brain" (PT 01). This experience was echoed by an adherent participant: "I feel like it makes you feel out of control or something when your mind is not working right" (PT 02).

A safety issue. The "uncontrollable brain" was a safety issue for some BCS. One participant spoke of repeatedly leaving on the stove or oven. "I've left the stove on, I can't tell you how many times, or the oven, and I used to never do that" (PT 10). Another participant described not remembering driving to her office: "I don't know how many times I had driven and didn't remember from the time I left the driveway to the time I got the car in my parking spot" (PT 14). Difficulties in remembering regularly traveled routes, following directions, and observing road signs make driving problematic for many BCS. One adherent participant remarked, "I would go somewhere and couldn't remember exactly how to get back home" (PT 07). One non-adherent Caucasian participant explained having difficulties with comprehending directions: "If my husband is telling me directions to a place, and he gives me more than three or four directions at a time, I can't process it" (PT 15). A non-adherent African American participant, who

lived near a school, started to become concerned about her ability to observe road signs and children's safety:

> I could have ran a stop sign or stop light because now my short-term memory doesn't remember it being there. What about that one day when that one child decides to run to get to the other side, thinking they can catch the light, and that person being in a hurry, and that person in a hurry is me and I hurt somebody's child because my brain has decided it wants to be lazy because of a few dead cells have been affected by chemotherapy. (PT 14)

Life interfering. The "uncontrollable brain" interferes in the daily lives of these BCS. For some, it is the greatest interference: "You can have problems with anything in your body, but when it's your brain, that can be the most life interfering thing" (PT 02). Participants reported interferences at work, school, and daily activities. These interferences ranged from not being able to find car keys to having to drop out of graduate school. One participant observed, "It's the first time in my life that I ever started being late for work, because I couldn't find the car keys" (PT 14). One non-adherent Caucasian participant, who is a teacher, began having difficulties in carrying out her pre-planned classes:

> I would make out a list, a plan, what I was going to do in the class that day, and I would get in there and would be, "I can't do this, I've got to improv and do something different other than what I had planned." It was almost like I was unable to follow through on my logical pre-planning of the class. (PT 15)

Several BCS described feeling incompetent, overwhelmed, and/or unable to keep up at work. One non-adherent African American participant described this experience:

> When I'm at work and the phone is ringing and I'm trying to read and email and someone is talking to me, someone has said something and I know what they said is important and I have to go back because I didn't think to write it down, and when I write it down I can't read my own handwriting. It goes a little bit bigger than just remembering. It's translating it to other ways where I could go back to it, but I can't read my own handwriting when I'm in a hurry or I'm in a rush or I'm misspelling words and then I don't know what the word was supposed to be. I didn't write it down and I have to go ask the boss, "What did you say?" Then it makes me look like I'm stupid. (PT 14)

Others spoke of interferences in daily activities. Staying focused on household chores was challenging for some: "I would just start something and I didn't finish it because I got distracted with something else and just totally forgot I was doing ... Maybe cleaning up the bathroom or the kitchen and I may walk out for something and just forget that I was doing that" (PT 07). One non-adherent African American participant described the challenges of remembering to pay bills on time: "I need to be more focused on things in my life that I shouldn't let happen. Like paying bills on time, 'I'll get that tomorrow.' Then your due date or you passed your due date, because you kept putting off, didn't stay focused on it" (PT 09). Remembering children's school schedules and assignments was difficult for some BCS. One adherent African American participant recalls, with great angst, forgetting to pick up her granddaughter from school: "I just left my grandbaby at

school. My daughter called me ... She was like, 'Did you pick her up?' and I was like, 'Oh my God!' I just forgot" (PT 07).

Some of these life interferences were demoralizing for BCS. A non-adherent participant spoke of how, as an African American woman, education had always been very important to her, and not being able to pursue a graduate degree, due to her "uncontrollable brain," was devastating:

> I have two classes and I got to read 50 pages today and then 50 pages two days from now and then write a paper. I'm not going to remember the first two pages, much less 100 pages. My first semester I had to withdraw from a class, because I just couldn't keep up. That grade brought me down below a graduate-level grade and so now I'm on academic probation, because I can't remember the information. Before I let them kick me out, I might have to drop out of graduate school. (PT 14)

Coping mechanisms. For some BCS, making adjustments in daily life and using coping mechanisms aided in dealing with perceived cognitive impairment. Reported coping mechanisms included writing a grocery list, using a planner, and setting reminders. One non-adherent participant described incorporating coping mechanisms in her life, "Just doing little things different. I now see the need of a grocery list versus back before. I have to have a planner, and have to see the vision. Have to see what I need to do. Where's priority? I put it on a sheet of paper somewhere in my office and now I cross it out" (PT 01). Setting reminders was essential for remembering appointments and activities among BCS. One adherent participant described the

importance of setting reminders on her phone: “Things that I do every week, I have to set a reminder on my phone. If I don't set the reminder, I will not remember it” (PT 05).

A loss of sense of self. Many BCS saw their mental ability as an essential part of themselves. One adherent participant captured this view when she observed, “Your mental ability can almost be more important than your physical abilities in a way. If you can't think straight, then you can't do anything” (PT 02). Some BCS expressed no longer being themselves after cancer. One adherent participant noted, “Before I went through all this breast cancer stuff, I wasn't really one of those forgetful kind of people. Then after all of that, I was” (PT 05). A non-adherent African American participant spoke of losing one of her greatest assets: “I started off telling you that I felt like my brain, my mind, was one of my best assets or something to that effect, and that if that starts to dysfunction, that's me” (PT 11). A loss of sense of self was a fear voiced by many BCS. For one adherent Caucasian participant it was terrifying, “I've always had a quick memory and an easy ... I catch on to things easily and I'm able to retain and function cognitively very easy, and so it was not only frustrating, but also a little bit terrifying to feel like that part of what's been my identity was slipping away” (PT 08).

Nobody knows how it feels. Some BCS felt that there was a lack of public knowledge of cognitive impairment. This lack of public awareness was frustrating. One adherent participant described how reactions from other people frustrate her: “They think it’s a joke when you tell them you got chemobrain or you can’t think of something and you say, ‘Well, it’s the chemobrain,’ and they like, ‘What? Chemo shouldn’t affect your

brain.' People don't realize all the side effects that chemo have on your body" (PT 10). Many BCS felt that family, friends, and co-workers underestimate the magnitude of cognitive impairment. For one non-adherent African American participant, this caused her much distress at work:

> I tell people now, I said I still kind of suffer a little bit from, you know, chemobrain ... it doesn't go away overnight. It's very real and people in my department don't show true compassion. When I tell them I'm trying to get them to understand why I can't remember something or why I keep asking. When I explain, they look at me like I really don't care, just don't ask me again. Or that I'm saying that because I'm trying to elicit sympathy. (PT 14)

Some BCS reported that attempts, from family and friends, to comfort them were not always comforting. One non-adherent participant described these attempts as being "uncomforting" due to the inability for other people to understand the severity of her cognitive difficulties:

> People say, 'Oh, I know, I do that all the time.' It's different because you start getting older and you start having memory lapses and memory problems, and you forget stuff. It's not anywhere near the same thing. I appreciate them saying it because they're comforting, the people who say this. They're trying to comfort, but at the same time, nobody knows about that black hole that swallows up all of your information if they've not been there. (PT 12)

Overall, BCS felt that "nobody knows how it feels" (PT 07 and PT 12) to experience cognitive impairment. For one adherent African American participant this

was distressing: “I tell my children, ‘You just really don't know how I feel. You just really don't.’ They still don't. They still just don't know how I feel” (PT 07).

Experience of depressive symptoms. All BCS reported experiencing depressive symptoms since cancer. Five codes related to this subtheme emerged from the interviews: 1) self-doubt, 2) constant frustration, 3) unhappiness, 4) being a survivor and a co-survivor, and 5) managing depressive symptoms.

Self-doubt. Experiencing self-doubt, particularly in social situations, was expressed by several BCS. One non-adherent Caucasian participant described withdrawing from friends:

> A lot of times out in a group I'm careful about what I start saying. Am I going to be able to remember all the way through in order to say this? I was afraid I would make a fool of myself by not being able to finish what I was gonna say. It undermined my confidence. Now, if you're quiet because you're quiet, that's one thing. But, if you're quiet because you don't think you can finish a sentence, that's just very depressing. Worthless isn't the right word, but when you just feel like ... you don't feel good about yourself. (PT 12)

An adherent Caucasian participant reported a history of self-doubt before cancer, which has intensified since cancer:

> I also have social anxiety, which I had before cancer. It did get worse, much worse after with the chemobrain because it was like not only was there the self-doubt of talking to people in groups and those social anxieties, but then there was

> the fear that if I started talking, I wasn't going to be able to find the words. (PT 08)

For some BCS, these feelings of self-doubt resulted in social isolation. One adherent African American participant experiencing self-doubt described how feelings of inadequacy exacerbated her introverted tendencies:

> I was never really an outgoing person, just really, really outgoing, but it made me kind of shy back because I couldn't remember things and I just felt inadequate. I didn't feel like I had anything to offer because a lot of times I just couldn't remember things. It was just embarrassing. I just didn't want to do that to myself. I would rather stay in the background. Don't look at me, don't say anything to me. (PT 07)

A history of self-doubt, related to being an African American woman, was noted among some non-adherent African American participants. One non-adherent African American participant described her history of self-doubt in this way:

> Being an African American woman, I have always felt like I needed to do twice as much as other people in order to be accepted. Not feeling good enough unless you just come across as being perfect and having all the answers. (PT 11)

Constant frustration. Most BCS reported experiencing constant frustration. Perceived cognitive impairment constituted a major trigger of frustration for BCS. Because perceived cognitive impairment made daily activities difficult and resulted in frustration, one participant reported, “I had lost sharpness and just everyday things were difficult, and it was really frustrating” (PT 02). Even leisure activities (e.g., reading)

became frustrating for some: “I used to love to read and I can't do that anymore because it's frustrating” (PT 14). Many BCS described becoming frustrated more quickly and over little things that would not have previously bothered them. One non-adherent African American participant voiced this experience:

> I was more frustrated after the chemo treatment; just things aggravated me a little faster than normal. My mood was a little bit more... I was more slow to think and slow to speak. Because, if you knew how you used to be able to do something and then now all of a sudden it's different, it is frustrating. (PT 01)

Constant frustration became distressing for many BCS and even paralyzing for one adherent African American participant:

> When you can't remember things it's frustrating and you get angry and you feel bad. I would just cry because some things were just important. Like the day I just left my grandbaby at school. I just forgot. I felt horrible and angry and frustrated. All I wanted to do was just lay in the bed and that's what I did. I just laid in the bed and just cover my head. (PT 07)

Unhappiness. Many BCS described feelings of unhappiness. Sources of unhappiness varied. For some, not being able to enjoy leisure activities made them feel sad. Reading was one leisure activity that BCS reported not getting pleasure from anymore. Difficulties with focus and memory were key factors in their displeasure with reading: “I didn't have the brain to read long passages anymore, especially if it was a book where I was supposed to carry a lot of names in my mind to get clear who people were later in the book. That made me sad” (PT 15). For others, social activities were no

longer joyful. Social activities were now seen as stressful, dreaded, and were avoided. One adherent African American participant characterized the distress of socializing this way: “I didn't enjoy it when I went out, I just didn’t. I didn't have any joy” (PT 07). A source of unhappiness was not always identifiable for BCS. For some BCS, unhappiness was just a way of being: “I find myself sad and I don't know why I'm sad” (PT 14). One non-adherent African American participant captured the experience of being unhappy:

> My goal is to be happy. I'm not always happy but I try not to be negative. When I'm not happy, I may not talk a lot. I may isolate myself. I do a lot of self-examination and blaming because I think I'm responsible for the whole condition of the world, so I do a lot of, there's a lot of guilt. There may be some shame. There may be some fears. Really when I'm not, I'm more silent and isolated. (PT 11)

Being a survivor and a co-survivor. Some BCS were also co-survivors. For some, experiencing depressive symptoms stemmed more from the cancer diagnosis of a loved one than themselves. Being both a survivor and a co-survivor was distressing. Those who reported being a co-survivor had multiple cancers in the family. Being a co-survivor came with the responsibility of caregiving, which was mentally and physically exhausting. One non-adherent African American participant, who was a caregiver for four of her family members with cancer, expressed with angst her desire to be able to put herself first: “You've helped your mother, your two brothers go through cancer, you've helped your daughter, you've been through it yourself, at what point in your life do you say, ‘It's about you?’ When does it come to be about you?” (PT 09). Some BCS

described being more able to cope with their own cancer than their family members' cancer. Being a co-survivor was more of an emotional strain than being a survivor. For one non-adherent African American participant, the diagnosis of her daughter and sister was devastating: "I think the depression then, though, was not just my cancer but my daughter's. Then shortly thereafter, my sister was diagnosed with cancer, so it was like, 'This is all getting too crazy'" (PT 11).

Managing depressive symptoms. Approaches for managing depressive symptoms varied. While some BCS used medications, others preferred non-pharmacological methods. BCS reported using both depression and anxiety medications. For some BCS, these medications aided in keeping their mood steady; however, this required being adherent to the dosage. Some BCS spoke of not always remembering to take their medications. Missed doses of medications resulted in mood changes, which were apparent to BCS and others. One adherent Caucasian participant described:

> If I don't take my antidepressant, and if I don't take my anxiety medicine, I tend to be a little snappy. I can only tell that with my kids and my husband. They're the ones I snap at. At work, my boss will get on my ever loving last nerve if I'm not taking my medicine. Sometimes I'll forget it for a day, and then I'm like, why am I so grumpy. Oh, I forgot to take my medicine. I forget simple little things like that. (PT 05)

Some BCS had a dislike for medications in general and were not willing to use medications to manage depressive symptoms. Instead, they relied on spirituality. One non-adherent African American participant remarked:

> I don't like pills, so I don't like any medicine dealing with my mood, pain, or anything like that. I've never adhered to a real medication regiment. I'm not compliant, but I have taken it. Probably not long enough to even get any benefits. I do a lot of praying and that's been my salvation in terms of finding peace inside. (PT 11)

Overall, adherent and non-adherent participants experienced difficulty with activities that they normally did before cancer, which made them feel "frustrated" (PT 01, 02, 07 and 14). Leisure activities were no longer a source of happiness for these participants. Some non-adherent African American participants had a history of self-doubt, related to the cultural aspect of "being an African American woman." The additional emotional and physical burden of being a co-survivor was distressing for some non-adherent African American participants.

Experience of poor sleep quality. All BCS reported experiencing poor sleep quality since their cancer diagnosis. Five codes related to this subtheme emerged from the interviews: 1) unable to fall asleep, 2) disrupted sleep, 3) napping, 4) crashing, and 5) managing poor sleep quality.

Unable to fall asleep. Many BCS expressed difficulty falling asleep due to constant random thoughts. One participant noted, "Part of the chemobrain is not being able to sleep" (PT 03). Participants described the experience of constant random thoughts as "my mind won't shut down" (PT 01 and 05) or "my brain won't shut up" (PT 15). Trying to force themselves to sleep and tossing and turning until 3:00 in the

morning was an ongoing problem for some BCS. One adherent African American participant captured this experience:

> A million thoughts going through my head. Just over and over and all, I couldn't rest because my mind just wouldn't shut down. I would twist and turn and maybe read or play a game until I could fall asleep and just really try not to think about things, trying to force myself to go to sleep. (PT 07)

Some BCS described not being able to fall asleep due to worry. One adherent Caucasian participant, who is a mother of two, described how worries about her children and work kept her awake at night:

> I think I've got a bunch of stuff on my mind, and my mind won't shut down. Because I have a lot of things going on at work, and a lot of things going on at home with my daughter and school, and I think that's it. On the weekends, I rest better because my son is home from school so I know where he is. If all mama's birds are in the nest, she can rest. If not, I don't get to rest. (PT 05).

Difficulty falling asleep affected daily activities and work performance for many BCS. One non-adherent Caucasian participant who works as a teacher explained, "A lot of times, I don't get to sleep until three or four o'clock in the morning, so I'm tired, lagging and lacking energy a lot during the day" (PT 15).

Disrupted sleep. Participants described having 3 to 6 hours of disrupted sleep per night. For most BCS, waking up numerous times per night was due to restlessness, hot flashes, and worrying thoughts. For some BCS, disrupted sleep was due to sleeping with the TV on at night. Two non-adherent African American participants, who were older

and lived alone, (PT 04 and 09) described sleeping with the TV on at night to make them feel safer, but acknowledged that it disturbed their sleep:

> My problem with sleeping is that I keep the TV on at night. I live alone so in order for me not to hear the creeping and the creaks and wondering what those sounds are, I keep the TV on. The TV tends to wake you up because I keep the sound on moderately. (PT 09)

Some BCS described being able to fall asleep and sleeping for several hours, but then waking up and not be able to go back to sleep. For one non-adherent African American participant, this was a daily occurrence: “I literally wake up at 2:00 a.m. and can't go back to sleep” (PT 13).

Napping. Poor sleep quality led to napping for some BCS. Ability and opinions about napping varied among participants. Some reported requiring a nap to get through the day. One non-adherent African American participant who worked full-time explained, “I still wake up sometimes two, three o'clock in the morning and can't go back to sleep. Usually by the end of the day I have to go home and take a nap” (PT 13). Other BCS had difficulty with being able to nap. One adherent African American participant stated, “In the day time I can't sleep. Anything disturbs me. The phone, if I hear something. I lay down and I'm going to sleep maybe about 10 to 15 minutes and I'm up. Napping, I don't do well at all at napping” (PT 06). While some BCS reported being fatigued, they believed that napping was inappropriate. One non-adherent African American participant, who is employed full-time, described not taking naps due to her need to be constantly working: “I don't take naps. I feel like it's always something to do

and I need to be on 100% of the time" (PT 11). For some African American BCS, napping was viewed as being "lazy" (PT 11 and PT 01). One non-adherent African American participant explained how her culture shaped her belief of napping being lazy:

> Now in my personality I'm not a person who loves the bed. I was raised and I think it was my culture; we had to get up out of bed by nine o'clock. If you were in bed past nine, something must be wrong with you. That's the only way you have the right to stay in there, but you're getting up, cleaning up, doing something. My culture was that. So staying in the bed, napping, oh to me that looked lazy. (PT 01)

Crashing. Several consecutive days of poor sleep quality lead to exhaustion and eventually "crashing" (PT 01, 03, and 15) for some BCS. One non-adherent Caucasian participant captured this experience as follows:

> I don't sleep good. I don't sleep good at all. I will be so tired because I don't sleep all night. I wake up during the night. I have hot flashes. I don't ... I just get up all through the night. If I hear anything, it wakes me up, so I don't sleep good at all. Then what happens is, I stay awake for so long, and I don't sleep so good, then about 3 or 4 nights in, I just crash and nothing wakes me up and I sleep all night, but I only do that like twice a week, because I just can't sleep. (PT 03)

Managing poor sleep quality. Approaches for managing poor sleep quality varied. While some BCS used medications, others preferred non-pharmacological methods. Participants reported using both prescription and over-the-counter medications.

Even with sleep medications, some BCS still experienced poor sleep quality. Additionally, some BCS suffered side effects of medication. One non-adherent African American participant who experienced side effects of an over-the-counter medication remarked, “I was taking Benadryl to go to sleep, but that was causing some heart palpitations or whatever so I had to get off the Benadryl” (PT 13). Some BCS felt that they were already taking enough medications and did not want to add any medications to manage poor sleep quality. One non-adherent Caucasian participant explained:

> I went to the doctor. He put me on a sleeping medication. I just told him, ‘You know what? I don't want drugs. I don't want ... I have enough medicine I have to take. I don't want nothing else to help me do what I have to do normally. I will figure it out some way.’ If I have to have a glass of wine at night or run around the block twice. I'll figure it out. I will get the sleep that I need sooner or later. (PT 03)

In addition to medications, one adherent Caucasian participant with sleep apnea used continuous positive airway pressure (CPAP) therapy to manage her poor sleep quality: “I have sleep apnea, so I sleep with a mask” (PT 08).

Overall, BCS experienced difficulty falling asleep and/or staying asleep, which led to fatigue for many BCS. Napping was viewed as being “lazy” by some African American participants. Exhaustion, due to lack of sleep, resulted in “crashing” for several non-adherent participants.

Summary of Theme 1. To summarize this theme, BCS reported varied experiences of cancer-related symptoms. These experiences were distressing. The

description of these experiences included cultural aspects of "being an African American woman" among some non-adherent African American participants. Other people (i.e., family, friends, and co-workers) did not always understand BCS' experiences of cancer-related symptoms and were not always supportive. Notably, cancer-related symptoms did not occur in isolation; they were often concurrent and exacerbated difficulty in cognition. The frequency of reporting experiencing cancer-related symptoms was similar between adherent and non-adherent participants. However, non-adherent participants' descriptions of experiencing cancer-related symptoms tended to be more emotionally charged with angst and despair than those of adherent participants. Although poor sleep quality was noted to exacerbate other cancer-related symptoms, participants underestimated the importance of sleep for mental and physical well-being.

Theme 2: Influences of Cognitive Training

The influence of cognitive training on cancer-related symptoms varied among the BCS in this study. These varied influences are related to raised awareness, positive influence, and negative influence and are described below.

Raised awareness. Many BCS experienced a raised awareness related to cognitive training. Three codes related to this subtheme emerged from the interviews: 1) about cancer and treatment, 2) perceived cognitive impairment, and 3) depressive symptoms.

About cancer and treatment. Some BCS emphasized that they were not aware that cancer and its treatment could affect their cognition. One non-adherent Caucasian participant exclaimed, "I had no idea there was such a thing as so-called chemobrain" (PT 15). One older non-adherent African American participant, who was unaware of chemobrain, had attributed her perceived cognitive impairment to old age: "It [cognitive training] made me more aware of what was going on and how the things worked. I always contributed memory loss to something, old age and stuff, because I am 62 now. So I contribute memory loss to old age, but I can see how it's really the chemobrain" (PT 04). For one non-adherent participant, who was in denial, this raised awareness led to acceptance:

> I'm no longer in denial. I understand that with the chemo treatment and things of that nature, I believe there are side effects. I think I was in denial. Denial thinking that nothing's wrong. This is normal, this thinking, this feeling. After this study, I've realized, no, these are some of the side effects of it. (PT 01)

Perceived cognitive impairment. Cognitive training raised awareness of perceived cognitive impairment for some BCS, who described becoming more aware of difficulties with memory, attention, and speed of thinking. One older African American participant reflected, "It [cognitive training] has made me more aware of something going on in terms of my memory and attention. I'm not what I used to be, and so I think in terms of awareness, it made me more aware" (PT 04). A younger African American participant stated, "For me with the study, I really wasn't aware that I was experiencing some delays. It allowed me to realize, okay there is some, so yeah. I felt it gave me

awareness that there was some delays, there were some issues" (PT 01). While most participants described experiencing a raised awareness of perceived cognitive impairment as beneficial, for one non-adherent African American participant, it was distressing:

> I think the study kind of made me realize that there are indeed some holes that are starting to show up and that's kind of scary. It's recognition, the confirmation that was hard for me. It's like, "I don't want to feel like this. I don't want to know this." I'm using abilities on my job that this study made me believe that they're going away, those abilities are going away. That's hard to accept. Just let me be ignorant. Fall apart in ignorance. (PT 11)

Depressive symptoms. For some BCS, cognitive training raised awareness of depressive symptoms. These participants described becoming more aware of frustration and anxiety. One non-adherent African American participant elucidated her experience of becoming more aware of her frustration:

> It's just being aware, that study made me more aware of myself in more ways that I didn't think I would get out of it. I've learned that I'm very impatient now. I want to learn it now. I'm 57 years old. Time is not waiting on my side, so I don't want to spend 10 years trying to learn something that maybe five years ago I knew before I had cancer. Maybe I forgot it, maybe it's not needed. I just know, I want to learn it now! I want to remember it now! (PT 14)

An adherent participant, who experienced a raised awareness of her anxiety, described with concern, "It [cognitive training] made me more aware of my anxiety. When I would

drive I was getting anxious and it just made me more aware. I just thought, 'Should I drive today?' I don't even remember the stop sign" (PT 07).

In summary, several BCS were unaware of the cognitive effects of cancer and its treatment. Cognitive training was noted, among some BCS, to raise awareness of perceived cognitive impairment. Most BCS viewed this raised awareness as beneficial; however, for one non-adherent African American participant, it was distressing.

Positive influence. Many BCS reported cognitive training had a positive influence on their cancer-related symptoms. Three codes related to this subtheme emerged from the interviews: 1) improved cognition, 2) improved mood, and 3) improved sleep.

Improved cognition. Several BCS experienced improved cognition since completing the cognitive training. BCS described experiencing improved cognition as being able to think more clearly, staying focused, and being able to remember.

An adherent African American participant described the experience of thinking more clearly as, "I could just think clearly now. It's not such a fog" (PT 07). This experience was echoed by an adherent Caucasian participant, who observed, "I feel like some of the cotton has been cleared a little bit. A little clearer is how I feel" (PT 02).

Staying focused aided BCS with calming the mind, completing daily activities, and communicating effectively. One non-adherent African American participant described experiencing a calming effect from cognitive training:

> It [cognitive training] helped me to stay focused. All I was thinking about was what I was doing at the moment, instead of a million other things. It made me sit, focus only on that. It was like going fishing where your only concern was just fishing. Your mind is at peace. (PT09)

Another non-adherent African American participant described staying focused when going to another room of the house: “It [cognitive training] made me more aware to say go back into the room to get something then it made me think about so I'm going to ... It got me to focus on what I was going there for. Before, I'd walk in a room and forget” (PT 04). For one adherent African American participant, staying focused strengthened her listening skills and aided in communicating with others: “It helped me to just really think and focus and concentrate. That's what I learned from that. Now I'm more intentional with listening when someone is speaking to me. Just focusing in on their words” (PT 07). For a non-adherent Caucasian participant, staying focused allowed for maintaining a train of thought when communicating with others:

> I do feel like I am able to retain my train of thought a little bit better and a lot of times in conversations when I'm kind of wandering around I will flash back on the screens where they show you something, and then you'd click on stuff. I will flashback to some of those, and it seems like that gives me ... It's kind of like it gives me strength to hold onto my train of thought and finish what I was gonna say. (PT 12)

Several BCS experienced a new ability to remember. For one participant, this was thrilling: “Going through the exercises and knowing, the ones that I got right, knowing that I was remembering where they were and are the ones and clicking on them

and seeing that that was right meant I was being able to remember. Anytime I can remember is exciting" (PT 12). Participants noted improvements in memory with continuing cognitive training. One adherent Caucasian participant described, "I could see a difference as I went along with the study. The more I put in the time I could see the improvement in my cognitive thinking. My memory was better, my forgetfulness was better" (PT 10). Being able to remember aided some BCS with work-related tasks. An adherent Caucasian participant reflected:

> I actually feel a little more, a bit sharper than I did before. For example, my husband has his own business. I help him, answer the phone, do stuff. Before the study, I just couldn't ... He would ask me to do something, and literally I would forget immediately. That has gotten better as far as not feeling ... I can actually remember something for longer than a hair now. (PT 02)

Some BCS described being able to remember items on their grocery list. One non-adherent Caucasian participant described how cognitive training helped her remember her grocery list by connecting the items: "I tend to connect them with something. I think that's part of the study where you remember where these things were. I have been very pleased with that" (PT 12). Marked improvement in memory was described by an adherent African American participant who previously was not able to remember her grocery list at all: "My memory has improved a lot. I made a grocery list and I didn't look at it, but I got everything but two things on it. There was a time where I couldn't remember anything on my grocery list" (PT 07).

Improved mood. Several BCS experienced improved mood since completing the cognitive training. These participants reported feeling a sense of decreased frustration, increased confidence, and hope.

Decreased frustration enhanced mood for some BCS. One non-adherent African American participant explained experiencing less frustration due to using more coping strategies: “After the brain training I knew how to cope a little bit better, and my mood was able to change a little bit instead of getting so aggravated and frustrated” (PT 01). For an adherent Caucasian participant her decreased frustration was due to improvements in her thinking: “I just feel less frustrated, because I feel like it makes you feel out of control or something when your mind is not working right. I feel less frustrated with that than I did before. That's a positive in the mood realm” (PT 02). One non-adherent Caucasian participant characterized cognitive training as a confidence builder:

> It really makes me feel good to be able to remember where I'm going to with a thought, verbalizing it and getting to the very end and not forgetting where I was going. Like I said, I think this [cognitive training] has been helpful with that. It [cognitive training] was a very confidence building activity. (PT 12)

For one adherent African American participant, increased confidence facilitated increased social interactions, feelings of happiness, and better quality of life:

> It [cognitive training] has made my confidence level come up. I haven't shied back as much and I'm just really enjoying life, now. It has helped me to just enjoy life so much better. I am. I feel good. I feel good every day. I smile more. I feel like I'm getting my life back and I'm happy about that. (PT 07)

Some BCS experienced a renewed sense of personal hope, hopefulness for others, and hope for future research. One non-adherent African American participant, who had been close to despair, expressed her feelings of renewed hope:

> I think the study really was my beginning of hope, because I still didn't believe that chemobrain was real. The study gave me a lot of food for thought and rethinking things. In fact, it gave me the desire to want to go back to school. That's the one great positive thing, that it gave me hope. My hope has been renewed. (PT 14)

A non-adherent Caucasian participant described being hopeful that future BCS would be helped as a result of the SOAR study:

> Most the time I was working on this [cognitive training], I would be thinking about I hope this is going to be helpful for future survivors and reveal some input for them to have some help, to get some help to be able to learn to remember. (PT 12)

A hope for future research aimed at improving cognition among BCS was raised. One non-adherent Caucasian participant voiced, “I hope they continue to study it [cognitive training]” (PT 15). One non-adherent African American participant, who regretted not completing the cognate training, hopefully remarked, “I pray that there will be another study” (PT 14).

Improved sleep. Several BCS experienced improved sleep since completing the cognitive training. Sleeping better was attributed to fewer “random thoughts” (PT 01),

less “restlessness” (PT 10 and 12), and a “calmer mind” (PT 07). For one non-adherent African American participant, fewer random thoughts dramatically improved her sleep:

> I know literally I sleep so much better. My brain used to be on fire, it just seemed like it was always moving. I could not stop thinking. I was thinking about like, why a dog drinks milk? Random things and random thoughts. My sleeping has improved tremendously. (PT 01)

Less restlessness was also noted for promoting better quality sleep. One adherent Caucasian participant, who was previously restless and moving around in the night, described experiencing better quality sleep:

> My sleep has improved a lot. Instead of being up and down three or four times a night, I just get up one time now. Before I was getting up, I guess, being restless I would get up. Get on the couch then get up. Just move around during the night. Now, I am not feeling restless. I’m just sleeping, and I get up one time a night now. (PT 10)

For one adherent African American participant, improved sleep increased her motivation to be more active in her life:

> It [cognitive training] has made my sleep a lot better. Now, my mind is much calmer. I can just lay my head down and I'm out. That feels so good. I feel myself just falling asleep instead of trying to force myself to go to sleep. I feel rested when I wake up in the morning. I get up and I'm motivated to do things around the house or to go somewhere or to pay bills. It has helped a lot. (PT 07)

To sum, many participants described experiencing improvements in cognition, mood, and sleep. These improvements renewed confidence and feelings of hope and

aided participants in communicating effectively and completing daily activities. While both adherent and non-adherent participants described experiencing improvements, differences were seen in duration and magnitude. Non-adherent participants tended to experience short term improvements that occurred while doing the cognitive training or lasted for a short time after completion. Whereas, adherent participants tended to experience long-term improvements, which were noted to improve their quality of life.

Negative influence. Several BCS reported that cognitive training had a negative influence on their cancer-related symptoms. Three codes related to this subtheme emerged from the interviews: 1) anxiety, 2) frustration, and 3) self-defeating thoughts.

Anxiety. Cognitive training triggered feelings of anxiety for several BCS, which incapacitated them from doing cognitive training. One non-adherent African American participant referred to cognitive training as "frightening" (PT 14). Cognitive training produced psychological and physical reactions of anxiety. For one non-adherent Caucasian participant, who experienced both of these reactions, cognitive training was distressing and reminded her of unpleasant childhood experiences:

> The program itself made me nervous and anxious. My breath stops, my heart races, it reminds me of having to play volleyball or basketball in 8th grade, "Look here, look here, look here!" I couldn't do it, I couldn't commit to it. It [cognitive training] made me anxious. (PT 15)

Noted anxiety triggers of the cognitive screening were the speed and flashing screen. One non-adherent African American participant captured the experience of these anxiety triggers in the following way:

> The exercise itself [cognitive training] was more difficult than I guess I thought it was going to be. It was stressful. It's just that ... I don't know ... It's like it was so fast and ... I couldn't seem to ... I could get the pictures as fast as it was flashing ... and I'm thinking, "Oh, I got to do this again!" (PT 13)

Anxiety led to panic for some BCS. One non-adherent African American participant described feeling trapped: "I can still remember feeling very tense, very ... its like, 'Oh, my God!' when I was going through this [cognitive training] and, 'Let me out of here!' That's what I felt" (PT 11). For one non-adherent African American participant, the anxiety was paralyzing:

> It [cognitive training] was frightening. You get ready, you get set, and then all of the sudden my stomach would get queasy, my heart would beat fast and I'm looking all over the screen. The anxiety came along with I'm not going to do well, because I'm not going to do well. My brain is just not going to do as expected. I got fearful, I would sit there and I would just go, "Oh God, I'm just going to faint! (PT 14)

Frustration. Cognitive training kindled feelings of frustration for several BCS. Frustration was primarily related to the difficulty of cognitive training and participants' poor performance. Feelings of frustration discouraged some BCS from doing cognitive training. The experience of frustration, due to the difficulty of cognitive training, was

summarized by one non-adherent African American participant as follows: “It was a lot harder than what I thought it was going to be and it was kind of frustrating. It was hard, it was frustrating and uncomfortable. It was hard. I'll just say it was hard” (PT 11). One adherent Caucasian participant, who experienced frustration due to poor performance, stated:

> I would get agitated. Because I was like, what? I knew that that is what that was. I didn't mean to click that, or … you know. I thought I should've done better than I did. I get aggravated if I do something wrong. If I know I made a mistake, especially if I knew the right answer and just clicked the wrong thing. It's like, I can't go back and fix that. I really meant that, but you can't. Yeah, it frustrated me. I got a little frustrated. (PT 05)

Poor performance triggered frustration and resulted in mental exhaustion for one non-adherent African American participant:

> It's like after I did it a few times, it's like well I'm not getting my score any higher. And then it's like when I was doing it, it's like ... Almost like my brain hurt ... It's like ... It was making me ... I guess it was just frustrating and it's like I was getting exhausted mentally. (PT 13)

Self-defeating thoughts. Cognitive training induced self-defeating thoughts for several BCS. Similar to frustration, self-defeating thoughts were sparked by the perceived difficulty of cognitive training: “I wasn't expecting it to be as hard as it was, so I was hesitant to keep doing it” (PT 13). Several non-adherent African American participants conveyed thoughts of being “not smart enough” (PT 11 and 14) and “failing”

(PT 11 and 14). Consequently, self-defeating thoughts thwarted BCS from doing cognitive training. One non-adherent African American participant explained, “I just didn't like it, because I wasn't going to be able to remember. I had already set myself up to fail, thinking there was way too many things for my memory to prioritize. I became unsure of my own ability” (PT 14). All BCS who communicated self-defeating thoughts were employed highly educated women. The experience of self-defeating thinking was summarized by one non-adherent African American participant: “I didn't want to see myself failing, not comfortable with failing. That this is going to be so hard that I'm not going to be able to do it and I'm going to feel worse about myself when I finish” (PT 11). One non-adherent Caucasian participant described cognitive training as a self-defeating activity: “The only thing I got to was those first two, and I hated them. It kept getting harder, so I quit after that. It [cognitive training] seemed self-defeating to me, because it made me feel bad about myself like, ‘I can't do this, I don't like it!’” (PT 15).

Several non-adherent participants reported that cognitive training induced feelings of anxiety, frustration, and self-defeating thoughts. The intensity of these reactions were incapacitating to cognitive training among these participants. In addition, some non-adherent African American participants described not feeling smart enough for cognitive training and expressed fears of failing.

Summary of Theme 2. The influence of cognitive training on cancer-related symptoms varied among the BCS in this study. Many BCS experienced a raised awareness of perceived cognitive impairment and/or depressive symptoms. For one non-adherent African American participant, this raised awareness was unsettling. Participants

reported experiencing both positive and negative influences of cognitive training on cancer-related symptoms. While adherent participants tended to experience positive influences of cognitive training (e.g., improvement in cognition, mood, and/or sleep), non-adherent participants tended to experience negative influences (e.g., anxiety, frustration, and/or self-defeating thoughts). Although some Caucasians participants described experiencing anxiety, frustration, and self-defeating thoughts, these experiences were largely described by African American participants.

Theme 3: Adherence to Cognitive Training

Adherence to cognitive training among the BCS in this study was influenced by their experiences of cancer-related symptoms. These experiences are related to influence of perceived cognitive impairment, influence of depressive symptoms, and influence of poor sleep quality and are described below.

Influence of perceived cognitive impairment. Most BCS reported perceived cognitive impairment influencing adherence to cognitive training. Participants tended to refer to cognitive training as "brain training." The two codes related to this subtheme that emerged from the interviews were hindrance and determination.

Hindrance. Perceived cognitive impairment, specifically inability to focus, was a hindrance to cognitive training adherence for some BCS. Participants noted that cognitive training required the ability to focus: "You have to be able to focus. If you can't focus, then there's no way you could do it. There's no way because you have to do

so quick that you have to be focused" (PT 04). One non-adherent Caucasian participant described her difficulty with focusing this way:

> I would have to concentrate on concentrating. I would have to make a conscious effort to focus. I can remember sitting down at the computer, or something, and thinking about something else, and not even seeing that I missed a whole screen, and I'm like, "Oh, we're doing something here!" (PT 12)

For one non-adherent African American participant, the inability to focus resulted in feelings of anger and ultimately in quitting the cognitive training sessions:

> I was easily distracted and very hard to go back and refocus. I was trying to watch where everything was, but I wasn't sure because I wasn't focused on the brain training. Then I turn it off, it made me mad, because I can't finish my brain training. (PT 14)

One non-adherent Caucasian participant described not even attempting cognitive training if she was unable to focus: "I wouldn't have tried to do the training if I couldn't concentrate well enough to sit down" (PT 03).

Determination. While the experience of perceived cognitive impairment constituted a hindrance for some BCS, for others it gave rise to a determination to improve it. For these BCS, perceived cognitive impairment motivated them to be "proactive" (PT 08) in their brain health, and they viewed cognitive training as a tool to improve cognition. One adherent Caucasian participant wanting to improve her cognition explained, "It [perceived cognitive impairment] did influence me doing my brain training. I knew there was something that the chemo had did, and I needed something to

improve it" (PT 06). Improving cognition served as a driving force for cognitive training among these BCS. One adherent Caucasian participant, who experienced cognitive improvement, described her resolve: "I was just determined to complete it [cognitive training] because I seen I was improving" (PT 10). Determination kindled adherence to cognitive training. One adherent African American participant captured the essence of determination:

> Not being afraid and accepting the fact that I did have a problem and not just saying, "Oh, it'll go away." It's just accepting it and having the courage to want to do something about it. You just have to have a willingness to stick with it [cognitive training] or it won't work. You can't give up. You just have to stick with it. You can sit back and get frustrated and say I don't want to do it [cognitive training] and give up, or you can just go on and just persevere and just say, "I'm not going to let this beat me." That's what I did with the cancer. That's what I did with the brain training. Just determined that I will beat this [perceived cognitive impairment]. (PT 07)

In summary, cognitive training required the ability to focus. Inability to focus was irritating and hindered cognitive training among non-adherent participants. For adherent participants, the experience of perceived cognitive impairment ignited a determination to improve cognition. For these determined participants, cognitive training was viewed as a tool to achieve their goal.

Influence of depressive symptoms. Most BCS reported depressive symptoms influencing adherence to cognitive training. The two codes related to this subtheme that emerged from the interviews were poor performance and not in the mood.

Poor performance. Depressive symptoms influenced cognitive training performance for many BCS. Participants reported poor performance on days they were experiencing depressive symptoms. One non-adherent Caucasian participant remembered, "Depending on how I felt, some days, I wouldn't do any good at all. I would do terrible. I would be like, 'Surely I can do better than that!'" (PT 03). Another non-adherent Caucasian participant, with a history of anxiety, remarked, "If I'm anxious or stressed out, I can't sit down and get the same results" (PT 08). Mood and cognitive training performance fluctuated for some BCS. One non-adherent Caucasian participant described how mood fluctuations affected her performance:

> When I felt good, and everything, I could concentrate better and I felt like I was more accomplished. When I was really sad about something, it just kind of takes you down and you just don't do as well on what you're working on at the time. (PT 12)

Not in the mood. Experiencing depressive symptoms, especially frustration, impeded cognitive training adherence for most BCS. Some BCS described not being in the mood to be "fooling" (PT 05) or "fiddling" (PT 08) with cognitive training, and sometimes they "just didn't do it" (PT 13 and 12). A non-adherent Caucasian participant explained, "If I was frustrated, I couldn't do it [cognitive training]. I couldn't concentrate

if I was not in a good mood. I wouldn't have even tried" (PT 03). One adherent Caucasian participant vividly recalled skipping cognitive training when she was feeling frustrated: "I didn't do it if I was in a particular mood. I just didn't do it because I was like, 'I'm not fooling with you today!'" (PT 05). Personal relationships were noted as a source for not being in the mood for cognitive training. One non-adherent African American participant described boyfriend issues interfering with cognitive training: "If I was in a bad mood, I didn't do it. Like if I was going through a bad day with my boyfriend ... I just didn't do it" (PT 13).

In summary, depressive symptoms influenced cognitive training performance and motivation among some adherent and non-adherent participants. Although some African American participants described experiencing poor performance or motivation due to depressive symptoms, these experiences were largely described by Caucasian participants.

Influence of poor sleep quality. Most BCS reported poor sleep quality influencing adherence to cognitive training. The two codes related to this subtheme that emerged from the interviews were unmotivated and too tired.

Unmotivated. Lack of motivation for cognitive training was experienced, due to poor sleep quality, by several BCS. One non-adherent African American participant explained, "If I had a poor night's sleep, I was not as determined to do it as I would normally" (PT 04). One adherent Caucasian participant described her experience of being unmotivated:

> I feel like it [poor sleep quality] interferes with everything, but I don't know what to do about it. I don't feel rested or energized. Some mornings I wake up and I'm like, “Oh, please give me a cup of coffee!” or I'm not going to make it. It makes it difficult to be motivated to do things. (PT 05)

Being tired and unmotivated made cognitive training more difficult for some BCS. One adherent Caucasian participant described, “Whenever I was tired and didn’t feel like doing it [cognitive training], it would be more challenging. I wouldn't be doing as well” (PT 08). For some, participants’ poor performance, stemming from being tired, was aggravating. One non-adherent African American participant described her poor performance with much aggravation: “Because I was extra tired, I did not want to do it [cognitive training]. My score didn't get better. It got worse!” (PT 13).

Too tired. Due to poor sleep quality, several participants were “too tired” (PT 03 and 08) to attempt the cognitive training and just “skipped it” (PT 13). One non-adherent African American participant described how poor sleep quality prevented doing cognitive training due to fatigue: “I still don't ... I sleep, but it's not a restful sleep. I really would want to do it, but ... just feeling fatigued and it just has a snowball effect” (PT 14). Being too tired was described as being “physically tired” (PT 04, 11, 12, and 13), “mentally tired” (PT 08, 11, and 13), and “emotionally tired” (PT 07 and 12). One non-adherent African American participant who was employed recounted, “By the time I did have time to actually do it, I was tired already, physically tired, and then the exercises seemed to make me more mentally tired. And so it was like a bad combination” (PT 13). This was echoed by a non-adherent Caucasian participant who cared for her four grandchildren: “If

I had a really, really bad night, then the next day by the time I was able to have time to sit down, I was really getting tired physically and emotionally, so that worked against me" (PT 12). One non-adherent Caucasian participant described being too tired to even concentrate or focus on the computer screen:

> When I didn't have any sleep, I couldn't even ... I couldn't focus. I couldn't even finish it. It was like ... there was a couple times that I couldn't follow through because I was just tired and didn't realize how tired I was until I started looking at that computer screen. I think it had a lot to do with the sleep. At least once or twice, I had to stop because I just could not focus because I was just too tired. I would try to do it on days ... I didn't do it every single day. I tried to do at least every other day, because I knew that I didn't sleep. The nights that I didn't sleep good, I was like, "Oh, I can't do it now. I can't do that today. I can't even concentrate, much less focus on what they're doing on this screen. (PT 03)

In summary, poor sleep quality influenced cognitive training performance and motivation among most non-adherent participants and some adherent participants. Although some Caucasian participants described experiencing poor cognitive training performance or motivation due to poor sleep quality, these experiences were largely described by African American participants.

Summary of Theme 3. The influence of cancer-related symptoms on adherence varied among the BCS in this study. While the experience of perceived cognitive impairment hindered adherence for non-adherent participants, for adherent participants it was a source of determination to complete the training. Differences in frequency of

describing influences of depressive symptoms and poor sleep quality on cognitive training adherence were seen between Caucasian and African American participants. That is, Caucasians tended to more frequently describe the influence of depressive symptoms and African Americans tended to more frequently describe the influence of poor sleep quality. Depressive symptoms and poor sleep quality were noted to negatively influence cognitive training motivation and performance among non-adherent and some adherent participants. Not being in the mood or being too tired made focusing more difficult and cognitive training frustrating. Feelings of frustration and exhaustion resulted in non-adherent participants, and occasionally some adherent participants, not wanting to be bothered with cognitive training and just skipping it.

Theme 4: Environment for Cognitive Training

Environment influenced cognitive training adherence for the BCS in this study. These environmental influences are related to computer access, household dynamics, and support system and are described.

Computer access. Computer access was instrumental to cognitive training. The two codes related to this subtheme that emerged from the interviews were location and assistance from others.

Location. The location of cognitive training varied. For the majority of BCS, cognitive training was done at home. Areas of the home used included the living room,

kitchen, basement, and bedroom. Location selection was based on personal preferences, comfort, and computer availability.

The kitchen was a place of physical comfort for some BCS. Sitting in a chair that provided back support was essential for one adherent African American participant: “I did it in the kitchen at the kitchen table because it was easier for me to sit up straight. I had to get somewhere where I could have support for my back” (PT 06). While the kitchen was a place of physical comfort, for one adherent Caucasian participant it was emotionally isolating: “It was an area of the house that we don't typically use. It limited the distractions, but you’re not involved with whatever else is going on in the house at that time” (PT 08).

Some BCS did not want to be isolated from their families and chose to do cognitive training in the living room, amongst the household activity. One adherent Caucasian participant described, “I did it [cognitive training] in the recliner, because it's my comfort spot. I could have my dog in my lap, my phone in my lap, and my family there and just do what I wanted to do” (PT 05). One adherent Caucasian participant, who initially planned to do the cognitive in her spare bedroom, explained that being isolated from her family would have been worrisome and needed to be easily accessible to take care of family matters:

> At first I thought it would be better to just lock myself away, but that's just not doable all the time. I would have been just worried the whole time about what else was going on where I was not at. So it's really better to be right there. Then if somebody needs something, I can pause it, and then deal with it, and then come

back to it. That I thought was ... Being able to pause it and then resume sometimes was helpful too" (PT 02).

The bedroom was a place of retreat and emotional comfort for some BCS. One non-adherent Caucasian participant explained, "I did it sitting on my bed. That's the least disturbing place, and that's where I go when everything's done in the evening. I go lie on my bed and watch a little bit of TV and call it a night" (PT 03). One adherent African American participant described choosing her bedroom because it was a safe and comfortable place: "I actually did it [cognitive training] in my room. That's where I feel safe. It's just a place of comfort to me" (PT 07).

Computer availability influenced cognitive training location for some BCS. One non-adherent African American participant, who did not own a home computer, chose to do cognitive training at her work place, which negatively influenced her ability to focus, "I only did it [cognitive training] at work, because I didn't own a home computer. Not being able to actually be in my own environment and find a space where I could really focus. Work environment is not a good place to do that" (PT 14). The library was an alternate location for cognitive training. While on vacation, one adherent Caucasian participant went to the library to stay on track with her cognitive training, "We took a vacation and I'd go to the library and do it. I just had to be dedicated and motivated to complete it. I didn't let anything deter it" (PT 10).

Assistance from others. Employed Caucasian and African American participants were very "comfortable using the computer" (PT 13 and 14), since they "do it all the time" (PT 05 and 08), and were able to access the cognitive training without any

difficulties. One employed non-adherent African American participant described accessing the cognitive training as, “It was easy. The software was easy, self-explanatory, not a problem” (PT 01).

Unemployed, disabled, and retired African American BCS needed assistance to access the cognitive training. For these participants, using the computer was not a regular activity. Assistance was required in connecting to the Internet and navigating the cognitive training website. However, once receiving assistance, participants were self-sufficient and able to manage on their own. For most African American BCS, assistance was provided by children living in the household. One retired non-adherent African American participant described, “I'm not that computer literate, but my daughter helped me. Then after that, it was a go! Once you got started, there was no problem” (PT 09). This was echoed by a disabled adherent African American participant: “At first I had to get used to it because it was my son's computer. Once I got the hang of it, it was really easy” (PT 07). Similarly, a younger unemployed adherent African American participant described, “At first it was a little difficult getting on there, because my daughter had to help me. Then, I got right to where I need to go to and everything. It wasn't hard at all” (PT 06). For one retired participant, who lived alone, assistance was provided by the SOAR research assistant: “I had difficulty at first until she [research assistant] had to help me through this stuff. Once she help me through it, I was able to do it” (PT 04).

To sum, computer access was instrumental to cognitive training. While Caucasian and employed African American participants were able to access the cognitive training easily, unemployed, disabled, and retired African American BCS needed

assistance to access the cognitive training. For those requiring assistance, once assistance was received they were self-sufficient.

Household dynamics. Household dynamics varied and were influential to cognitive training among BCS. The two codes related to this subtheme that emerged from the interviews were household size and unexpected changes.

Household size. Household size varied among BCS and ranged from living alone to eight people in the home. Some households also included pets. For those who lived alone, there was a sense of solitude and quietness. One participant, who lived alone, remarked, "I live alone, so my whole house is quiet" (PT 13). For those that had several people and/or pets in the home, there was" a lot of energy" (PT 12) and "buzzing" (PT02). One adherent Caucasian participant described this energy:

> It's me, my husband, my son, my daughter, and our two dogs. It's usually buzzing with people around. If the husband calms down, then the kids are buzzing around. If they settle down, then the dogs or something, so it's usually something buzzing around all the time. (PT 02)

For one non-adherent Caucasian participant who had seven people living in the home, all the household energy was exhausting: "A lot of energy in the house that sucks the energy out of the house and the individuals, the grown up individuals" (PT 12).

Having younger children in the house, at the time of cognitive training, was sometimes disruptive and required working around the children's schedules. One non-

adherent African American participant described doing cognitive training before the children were awake:

> My kids were 14 and 9. The youngest always wanted my attention, so by me being at the computer I couldn't do it successfully when she was up, so I had to do it early in the morning. Try to do it early before she came down, asking me, "Hey what you doing?" Then you had to explain it, so it was just a delay. (PT 01)

A non-adherent Caucasian participant had to do cognitive training when her granddaughter was at school, because she was too much of a distraction:

> I'm like, "Stop. I have to do this [cognitive training]!" I need to do this with no disturbances," and she's like, "but Nana, I want to ask ... I want to do this." I'm like, "Go away! I'm trying to do something." I tried to do it [cognitive training] when she wasn't around or at school or something because she's just too big of a distraction. (PT 03)

Pets were another form of "energy" around the house. For some participants, pets were very therapeutic. One non-adherent African American participant described the excitement of coming home from work and being with her dogs: "I get home, it's been a long day, I'm playing with the dogs!" (PT 14). One adherent Caucasian participant's household had more pets than people: "There are five pets in the house. There's three dogs. A Bulldog, a Chihuahua, and a Yorkipoo who's very needy. Then there's two cats that just kinda hang around" (PT 08).

Unexpected changes. Due to "life events" (PT 01 and 12), some BCS had unexpected changes in the household. Unexpected changes of having extended family

members moving in changed the normal household environment, causing some BCS to get sidetracked. The stress and additional responsibilities of having four grandchildren move in, disrupted cognitive training for one non-adherent Caucasian participant: “Due to everything that was going with the grandkids in the house I was strapped for time when I could really get into it and work on it [cognitive training] without interruptions” (PT 12). One non-adherent Caucasian participant, whose 7-year-old granddaughter moved in, became distracted and frustrated:

> My grandbaby, she's precious, but she does get on my nerves sometimes. She wants to ask questions or wants me to come here. "Come here, Nana. Come here, Nana." I'm like, "Look, you are the little child. You come ... When I say, 'Come here,' that means you come over here to me. I don't come to you when you call me. You come to me. I don't need you calling me every 5 minutes, 'Nana, come here. I want you to look at this.' I don't want to come to you and see what you want me to look at. I'm doing other things. You cannot disturb me while I'm doing other things." She just didn't grasp that concept. (PT 03)

Computer access became a problem for non-adherent African American participant when her brother-in-law moved into her basement, which is where the computer was located:

> Now this situation was a little different for me, for my environment. My computer was in my basement and I had someone living in my basement. I had my brother-in-law. He worked early in the morning so I could not go down in the basement; I just didn't want to disturb him so that was a challenge for me. That was the only challenge and I wasn't able to move my computer to a different

space. My situation, the environment, didn't allow me to use my desktop the way I needed to, when I needed to. (PT 01)

To sum, household dynamics varied and were influential to cognitive training among adherent and non-adherent participants. Unexpected changes in the household were disruptive for non-adherent participants and for one non-adherent African American participant lead to the computer no longer being accessible for cognitive training.

Support System. Support system was advantageous to cognitive training among BCS. The two codes related to this subtheme that emerged from the interviews were felt supported and kept it to myself.

Felt supported. Support from others facilitated cognitive training. Having emotional support from other people was encouraging and motivational. One adherent Caucasian participant who felt supported by her family members described:

> Honestly, even just having, just knowing that people are behind you. It is helpful when somebody helps with hands on things, but having their emotional support, just knowing that they are behind you in it and that they think it's a good idea, not just a lame waste of time, I feel like that was very encouraging. It helped me to do it [cognitive training]. It helped me to continue to do it. (PT 02)

Explaining personal significance of the study facilitated receiving support from others. One non-adherent Caucasian participant who shared her personal significance of the study with her family members and received their support described:

> I explained to them about what it was for and what I felt about it contributing and being a part of offering something to help people. They were totally on board and supportive of me doing that because they knew it was important to me. (PT 12)

Several BCS felt supported at home by family members providing encouragement, computer assistance, and help with household chores. One adherent African American participant, with 8 people in her household, described feeling supported at home by her family:

> All of them supported me. They knew when I would say, "I'm getting ready to get on the computer." My son, he still had school work, but he would let me use his computer to do my brain training. My oldest daughter would cook and make sure things were clean. She cleaned up the living room, the bathroom and things like that, the kitchen, just so I didn't have to be frustrated about those things and trying to focus in on doing the training. Yeah, I really had a lot of help with that. (PT 07)

In addition to household support, some BCS reported receiving support from their support group and/or the SOAR research assistant. One adherent Caucasian participant described receiving support at her weekly support group meeting: “We have a group meeting. There’s not very many. Me and another lady's started, but everybody supported me doing this training” (PT 10). One adherent Caucasian participant, who does not attend a support group, described receiving support, in the form of encouragement and reminders, from the SOAR research assistant:

> She would say, "You've made it this far," and it was an uplifting text, not a come on now you’ve only done two hours. You've got eight more to go. There's a

sense of, oh I'm halfway there. Oh I can do this. It's that. Or you've only got this much further to go. I guess I need encouragement. If it wasn't for her, and her encouragement, I wouldn't have finished it. (PT 05)

Kept it to myself. Several African American BCS revealed not sharing, with others outside the household, about participating in the study. Instead, they "kept it to myself" (PT 01, 04, 09, 13, and 14). They felt cognitive training was something personal and were not comfortable telling others. One non-adherent African American participant remarked, "I'm kind of private on stuff like that. They didn't know" (PT 04). One non-adherent African American participant explained how in her culture "you do not tell these things; it is better to keep it to yourself" (PT 01). A non-adherent African American participant described the stigma of "chemobrain" as "shaming" (PT 14). This act of "kept it to myself" impeded African American participants from receiving support from others.

While African American BCS informed household members of study participation, some did not share how significant the study was to them. Instead, they kept it to themselves. In turn, household members were not always supportive. One non-adherent African American participant, who did not share the importance of the study and did receive any household support, described how having support at home matters and how it may have made a difference in her completing the cognitive training:

A lot of things might have changed, or might have worked better where I could have been able to use the computer. He probably could have moved the computer upstairs. Could have asked my brother-in-law to leave, because he stayed in that

> place, in the basement where the computer was. To realize how important that was for me. Yeah, maybe I could have completed those 10 hours. Yeah, support at home matters. (PT 01)

To sum, having a support system was advantageous to cognitive training among adherent participants. Receiving support for cognitive training required sharing about the study and its personal significance. The cultural aspect of "keeping it to self" influenced comfort and willingness to share and in receiving support among non-adherent African American participants.

Summary of Theme 4. In summary, cognitive training was influenced by the personal environment in which it occurred. Environmental influences included computer access, household dynamics, and support system. Cognitive training was easily accessible from home for most adherent and non-adherent participants. Personal preferences determined room selection for cognitive training. Unexpected changes in the household were disruptive for non-adherent participants. Adherent participants found household support advantageous to cognitive training. Due to the cultural aspect of "keeping it to self", non-adherent African American participants did not confide in others, which impeded receiving cognitive training support.

Interrelation of Themes

The analysis of the interview data revealed the interrelationship of the emergent themes in their joint influence on BCS' adherence to cognitive training. This interrelationship of the themes and subthemes is illustrated in Figure 3. All BCS in this

study experienced cancer-related symptoms and these cancer-related symptoms influenced, in different ways, adherence to cognitive training. Cancer-related symptoms, in their turn, are influenced by cognitive training, adherence to cognitive training, and the environment in which cognitive training occurs. Therefore, cancer-related symptoms appear at the core of the figure.

The themes also interact with each other. Experiences of cancer-related symptoms shape how cognitive training influences cancer-related symptoms. The influences of cognitive training on cancer-related symptoms influence adherence to cognitive training. Adherence to cognitive training influences how cancer-related symptoms are experienced. The arrows in the figure capture the dynamic character of how the themes influence each other. Within each theme is a dynamic relationship among subthemes. The experience of one cancer-related symptom shapes the experience of other cancer-related symptoms. The influence of cognitive training is informed by awareness of perceived cognitive impairment. The influence of one cancer-related symptom on cognitive training shapes the influence of other cancer-related symptoms on cognitive training. Household dynamics impact computer access and support.

The way that BCS experience cognitive training is shaped, to a great extent, by how cancer-related symptoms are experienced and influenced and by the environment in which cognitive training occurs. Computer access, household dynamics, and support system constitute the cognitive training environment. The model presented in Figure 3 is a first attempt to describe how cancer-related symptoms are related to adherence to cognitive training among BCS.

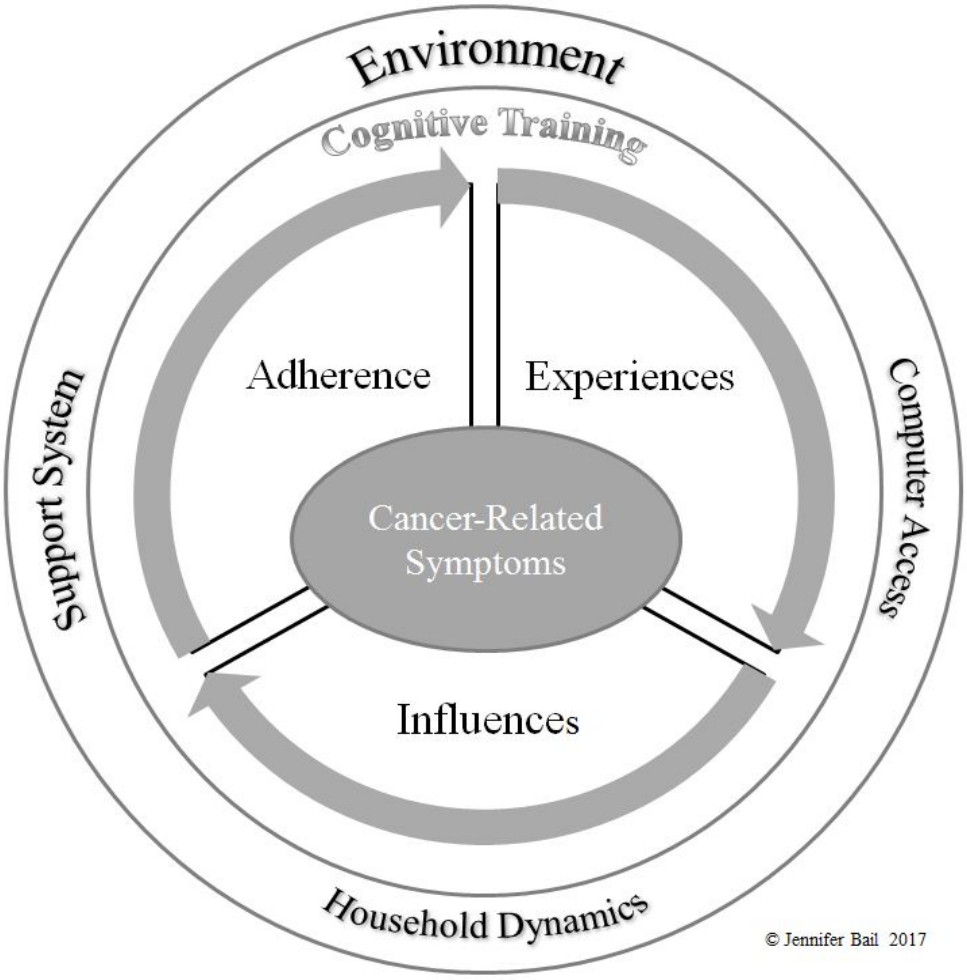

Figure 3. Interrelationship of themes and subthemes. Adapted from "Theory and Practice of Using Mixed Methods in Translational Research: A Cross-Disciplinary Perspective," by N. V. Ivankova, I. Herbey, & L. Roussel, 2017, *International Journal of Multiple Research Approaches, 10*(1).

Summary of Qualitative Results

Four themes describing the relationship between cancer-related symptoms and adherence to SOAR among BCS, differences among adherent and non-adherent participants, and cultural aspects emerged in the inductive thematic analysis: 1) experiences of cancer-related symptoms; 2) influences of cognitive training; 3) adherence to cognitive training; and 4) environment for cognitive training. However, they differed in the number of and similarity of codes comprising them. The experience of perceived cognitive impairment was the most discussed theme. Participants were less likely to elaborate about the influence of cancer-related symptoms on cognitive training, but spoke at great lengths about the advantages and/or disadvantages of cognitive training. There were differences in experiences, influences, and behaviors between the adherent and non-adherent participants. Specific cultural aspects of "being an African American woman" and "keeping it to self" also influenced adherence among African American participants. Essential factors deemed important for these 15 participants, as related to their adherence to SOAR, were as follows.

Experiences of cancer-related symptoms. This included participants' experiences of perceived cognitive impairment, depressive symptoms, and poor sleep quality. The frequency of reporting experiencing cancer-related symptoms was similar between adherent and non-adherent participants. However, non-adherent participants' descriptions of experiencing cancer-related symptoms tended to be more emotionally charged with angst and despair than those of adherent participants. A history of self-doubt, related to the cultural aspect of "being an African American woman", was noted

among some non-adherent African American participants, poor sleep quality was noted to exacerbate other cancer-related symptoms among adherent and non-adherent participants. The description of these experiences elucidated the state of participants, relating to their mental and physical ability to attend to cognitive training.

Influences of cognitive training. Differences in influences of cognitive training, as well as responses to these influences, were seen between adherent and non-adherent participants. While adherent participants tended to experience positive influences of cognitive training (e.g., improvement in cognition, mood, and/or sleep), non-adherent participants tended to experience negative influences (e.g., anxiety, frustration, and/or self-defeating thoughts). Although some Caucasians participants described experiencing anxiety, frustration, and self-defeating thoughts, these experiences were largely described by African American participants.

Adherence to cognitive training. Differences in views of cognitive training, as well as perseverance to complete it, were seen between adherent and non-adherent participants. Non-adherent participants tended to view cognitive training as frustrating. These feelings of frustration impaired participants' ability to focus, made cognitive training mentally exhausting, and led to avoidance. In contrast, adherent participants viewed cognitive training as a tool to improve their cognition. In order to improve their cognition, they persevered through cognitive difficulties, frustration, and sleeplessness to complete the cognitive training.

Environment for cognitive training. Environmental influences included computer access, household dynamics, and support system. While Caucasian and employed African American participants were able to access the cognitive training easily, unemployed, disabled, and retired African American participants needed assistance to access the cognitive training. Unexpected changes in the household were disruptive for non-adherent participants. Adherent participants found household support advantageous to cognitive training. The cultural aspect of "keeping it to self" hindered non-adherent African American participants in receiving cognitive training support.

CHAPTER 5

DISCUSSION

A mixed method sequential Quan → QUAL study was conducted to explore the relationship between selected cancer-related symptoms and adherence to the SOAR cognitive training intervention among BCS residing in Alabama. The goal of the quantitative phase of this study was to identify the relationship between selected cancer-related symptoms and adherence to the SOAR intervention among BCS. To meet this goal, self-reported questionnaire data were collected and analyzed. Based on the statistical results of the quantitative phase of the study, a purposeful sample of 15 BCS from SOAR was selected for follow-up interviews. The goal of the qualitative phase of this study was to better understand how identified selected cancer-related symptoms contribute to or impede BCS' adherence to the SOAR intervention by conducting semistructured interviews with 15 purposefully selected SOAR intervention participants.

Summary of Major Findings

Phase I: Quantitative

Analysis of data from the self-reported questionnaires (i.e., CFQ, PSQI, CES-D) provided information to answer the guiding research question: What is the relationship between adherence to the SOAR cognitive training intervention and perceived cognitive

impairment, depressive symptoms, and poor sleep quality among BCS? The data revealed poorer sleep quality in the non-adherent group, which were inversely associated with adherence to SOAR. In addition, poor sleep quality was associated with depressive symptoms and perceived cognitive impairment. The quantitative analysis provided an indication that poor sleep quality may be pivotal in BCS' adherence to SOAR.

Phase II: Qualitative

Inductive thematic analysis yielded four themes that describe how cancer-related symptoms are related to adherence to SOAR among BCS, differences between adherent and non-adherent participants, and cultural aspects: 1) experiences of cancer-related symptoms; 2) influences of cognitive training; 3) adherence to cognitive training; and 4) environment for cognitive training. These themes provided information to answer the central qualitative (Phase II) question: How do the selected cancer-related symptoms identified in Phase I contribute to or impede BCS' adherence to the SOAR cognitive training intervention? BCS in this study had varied experiences of cancer-related symptoms that were distressing. Cognitive training raised awareness of and influenced, both positively and negatively, cancer-related symptoms. While the experience of perceived cognitive impairment hindered adherence for non-adherent participants, it was a source of determination for adherent participants. Depressive symptoms and poor sleep quality were noted to negatively influence cognitive training motivation and performance, which was detrimental to adherence. Cognitive training was impacted by the personal environment in which it occurred. While support from others was

advantageous to cognitive training adherence, the cultural aspect of being an African American woman prevented some BCS from receiving support.

Integration of Quantitative and Qualitative Results

The overarching mixed methods research question addressed in this study was, "How can quantitative instrument scores and interview themes jointly explain the relationship between selected cancer-related symptoms and BCS' adherence to the SOAR cognitive training intervention?" To answer this question, it was necessary for the researcher to understand the qualitative themes in terms of their ability to explain the quantitative results.

Results of the quantitative and qualitative phases were integrated to more fully answer the research questions and to provide a more in-depth understanding of the research problem. Consistent with the sequential Quan → QUAL mixed methods design, the results from the quantitative phase were interpreted first to answer the research question of "What is the relationship between adherence to the SOAR cognitive training intervention and perceived cognitive impairment, depressive symptoms, and sleep quality among BCS?" The interpretation of the qualitative results followed to answer the guiding qualitative research question of "How do the selected cancer-related symptoms identified in Phase I contribute to or impede BCS' adherence to the SOAR cognitive training intervention?" Presenting the finding in this order allowed for the qualitative findings to further elucidate and explain the statistical results from the quantitative phase.

The integrated findings are discussed as they are related to the three cancer-related symptoms (i.e., perceived cognitive impairment, depressive symptoms, and poor

sleep quality) that collectively influence BCS' adherence to cognitive training. The quantitative and qualitative results are jointly displayed in Table H1 (see Appendix H) to enhance the interpretation. A statistics-by-themes joint display provides a visual comparison of adherent and non-adherent participants. Headings are organized by quantitative and qualitative results. Quantitative data displayed include number of cognitive training hours completed and cancer-related symptom measurement scores (i.e., CFQ, PSQI, CES-D). Qualitative data (i.e., representative quotes) are organized by themes.

The integrated findings are discussed in detail in the following sections using a weaving narrative strategy (Fetters et al., 2013) and are grouped by cancer-related symptom. The discussion is augmented by discussing the findings within the context prior research, which reflects both quantitative and qualitative published studies on the topic.

Perceived Cognitive Impairment

The first integrated finding is that the relationship between perceived cognitive impairment and adherence to cognitive training among BCS may be understood through BCS' description of the experience of perceived cognitive impairment, influence of cognitive training, and personal determination. Results from the analysis, conducted during the quantitative phase of the study, revealed the presence of perceived cognitive impairment among participants. A correlational analysis identified a non-relevant correlation between perceived cognitive impairment and adherence.

In this study, BCS described the experience of perceived cognitive impairment as having an "uncontrollable brain" that often distressed them and interfered with the tasks of daily life. Participants reported finding cognitive training challenging, and said it raised awareness of perceived cognitive impairment among BCS. While this raised awareness was a hindrance to cognitive training for non-adherent participants, for adherent participants it kindled a personal determination to complete it. Non-adherent participants tended to view cognitive training as frustrating. Feelings of frustration impaired BCS' ability to focus, made cognitive training mentally exhausting, and led to non-adherence. However, adherent participants viewed cognitive training as a tool to improve their cognition. They described first accepting that they had a problem with their cognition and then resolving to do something about it. For them, that something was cognitive training. Even if they were tired, in a poor mood, or on vacation, they persevered to complete the cognitive training. Continuing cognitive training was noted to improve cognition among adherent and non-adherent participants. Participants described experiencing improved cognition as being able to think more clearly, stay focused, and remember more. While non-adherent participants tended to experience temporary cognitive improvements, adherent participants tended to experience lasting improvements.

The qualitative findings complemented and expanded the quantitative findings. The qualitative data elucidated that cognitive training challenged participants and raised their awareness of perceived cognitive impairment, and confirmed that BCS' response to this raised awareness differed. Personal determination was pivotal in how BCS responded to the difficulty of cognitive training, the raised awareness of perceived

cognitive impairment and, consequently, in their willingness to persevere to complete the cognitive training. Those who persevered reported experiencing improved cognition.

These findings are supported by cognitive studies among other populations. In a study of older adults with mild cognitive impairment, Werheid and colleagues (2010) reported that participants with more awareness of their cognitive impairment were less likely to participate in a cognitive intervention. However, in a study of traumatic brain injury patients, Flashman and McAllister (2002) found that the more aware the patients were of their cognitive impairment, the more likely they were to participate in cognitive interventions. According to Hill and colleagues (2014), this difference in response may be related to personality type. That is, participants who ordinarily would be high-achieving goal setters but are aware of their cognitive impairment might be less willing to risk participation in cognitive interventions where they might not meet their own high expectations.

In addition, findings are consistent with cognitive training studies among BCS. Becker and colleagues (2017) reported a 0% adherence rate to their web-based cognitive training intervention among BCS. This lack of adherence was attributed to BCS' verbal reports of being unmotivated due to awareness of poor cognitive training performance. Von Ah and colleagues (2013) reported that 17% of BCS indicated that cognitive training was difficult. Yet, evidence exists that continued cognitive training improves perceived cognitive function among BCS (Damholdt et al., 2016; Kesler et al., 2013; Von Ah et al., 2012).

Together, the quantitative and qualitative findings extend knowledge of cognitive training interventions among BCS. Findings from this study illuminated that BCS'

response to their awareness of perceived cognitive impairment is critical to cognitive training adherence and ultimately improving cognition.

Depressive Symptoms

The second integrated finding is that the relationship between depressive symptoms and adherence to cognitive training among BCS may be understood through BCS' description of the experience of depressive symptoms, influence of cognitive training, and exacerbation of depressive symptoms. Results from the analysis, conducted during the quantitative phase of the study, revealed the presence of clinically relevant depressive symptoms (CES-D $\geq$16) among participants. A correlational analysis identified a non-relevant inverse correlation between depressive symptoms and adherence.

In this study, BCS described the experience of depressive symptoms as feelings of self-doubt, constant frustration, and unhappiness. Cognitive training raised awareness of the depressive symptoms of frustration and anxiety among BCS. For non-adherent participants, cognitive training tended to induce anxiety, frustration, and self-defeating thoughts, especially among African American women. Depressive symptoms were noted to negatively influence cognitive training motivation and performance, which was detrimental to adherence. Continuing cognitive training improved mood among adherent participants. Adherent participants described experiencing improved mood as feelings of decreased frustration, increased confidence, and hope.

The qualitative findings complemented and expanded upon the quantitative findings. The qualitative data elucidated that cognitive training exacerbated depressive

symptoms among some BCS, resulting in not being in the mood to be "fooling" with cognitive training and just not doing it. Yet, those who persevered experienced improved mood.

An inverse relationship between depressive symptoms and adherence is supported by intervention studies aimed at improving quality of life among BCS. Lack of adherence in these interventions often was attributed to depressive symptoms (Courneya et al., 2008; Meneses et al., 2014; Somerset, Graham, & Markwell, 2011; Wang et al., 2015). BCS who had higher levels of depressive symptoms at baseline were less likely to comply with the intervention protocol than those who did not. For example, Wang and colleagues (2015) found that baseline depressive symptoms were associated with lower intervention adherence to the WHEL study, a dietary intervention among 2,800 BCS. In the Rural Breast Cancer Survivors Study (RBCS), a population-based psychoeducational support interventions among 432 rural BCS, Meneses and colleagues found that depressive symptoms were a significant predictor of attrition (Meneses et al., 2014).

The experience of improvements in mood is supported by findings from other cognitive training interventions among BCS and healthy older adults. BCS report an improvement in depressive symptoms after cognitive training (Becker et al., 2017; Damholdt et al., 2016; Kesler et al., 2013; Von Ah et al., 2012). Among healthy older adults, cognitive training has been demonstrated to reduce the risk of depression (Wolinsky et al., 2009) and improve internal locus of control (Wolinsky et al., 2010). These improvements in mood may be due to the nature of cognitive training as a procedural task that has a broad pattern of regional brain activation (Wolinsky, Unverzagt, Smith, Jones, Wright, et al., 2006; Wolinsky et al., 2009).

Together, the quantitative and qualitative findings extend knowledge of cognitive training interventions among BCS. Von Ah and colleagues (2012) reported that some BCS indicated, via a Likert-based Client Satisfaction Questionnaire, not enjoying cognitive training (23%) and preferring a different cognitive intervention (20%). Reported adherence rates to cognitive training among BCS have been as low as 0% (range 0% to 97%), with attrition rates as high as 22% (range 3% to 22%) (Becker et al., 2017; Damholdt et al., 2016; Kesler et al., 2013; Von Ah et al., 2012). Yet, participant reactions to cognitive training and influences on depressive symptoms among these studies are unreported and unknown. Qualitative findings from this study illuminate that cognitive training exacerbates depressive symptoms among some BCS, hindering adherence.

Poor Sleep Quality

The third integrated finding is that the relationship between sleep quality and adherence to cognitive training among BCS may be understood through BCS' description of the experience of poor sleep quality, influence of cognitive training, and being too tired to complete the training. Results from the analysis, conducted during the quantitative phase of the study, revealed the presence of poor sleep quality (PSQI $\geq$5) among participants. A correlational analysis identified a moderate, non-significant inverse correlation between sleep quality and adherence. In addition, sleep quality had a moderate, non-significant correlation with perceived cognitive impairment and depressive symptoms. Although statistically non-significant, a *t*-test revealed a

difference, with a medium effect size, in sleep quality between the adherent and non-adherent groups.

In this study, BCS described the experience of poor sleep quality as being unable to fall asleep, having disrupted sleep, and occasionally crashing due to exhaustion. Due to poor sleep quality, adherent and non-adherent participants were often physically, mentally, and/or emotionally tired. Additionally, poor sleep quality was noted to aggravate other cancer-related symptoms, resulting in an inability to focus and feelings of frustration. Poor sleep quality negatively influenced cognitive training motivation and performance, which was detrimental to adherence. For non-adherent participants, poor sleep quality had a snowball effect. Feelings of frustration and exhaustion resulted in not wanting to be bothered with cognitive training and sometimes just skipping it. While adherent participants did report poor sleep quality, they felt that they were manageable and did not interfere with cognitive training. Continuing cognitive training was noted to improve sleep. Participants attributed improved sleep to fewer random thoughts, less restlessness, and a calmer mind. For adherent participants, improved sleep resulted in improved mood and ambition.

The qualitative findings complemented and expanded upon the quantitative findings. The qualitative data elucidated that poor sleep quality aggravated cognition and mood and negatively influenced cognitive training motivation and performance, creating a snowball effect for non-adherent participants. Those who continued cognitive training experienced improved sleep, mood, and ambition.

Previous quantitative studies among BCS indicate significant associations among sleep quality, depressive symptoms, and cognitive function (Chen et al., 2012; Cheung et

al., 2012; Myers et al., 2015; Von Ah & Tallman, 2015). Recently, Johns and colleagues (2016) reported that baseline sleep quality was significantly correlated with depressive symptoms and perceived cognitive impairment among BCS in their MBSR intervention. Vance et al. (2011) describe sleep, mood, and cognition as having a dynamic relationship and posit that their interactions influence daily functioning and ability to perform tasks. Consistent with this idea, Prigozin and colleagues (2010) found sleep, mood, and cognitive function were significantly associated with interference in daily activities (e.g., housework, employment, socializing, and physical activity) among BCS. Qualitative studies confirm this finding through BCS' descriptions of concurrent cancer-related symptoms interfering with their ability to perform activities of daily living (Becker et al., 2015; Boykoff et al., 2009; Kanaskie & Loeb, 2015; Munir et al., 2010; Myers, 2012; Player et al., 2014; Von Ah et al., 2013). In addition, concurrent cancer-symptoms have been shown to interfere with intervention participation among BCS. Derry and colleagues (2015) found BCS who dropped out of their 12-week yoga intervention reported greater perceived cognitive impairment and depressive symptoms and poorer sleep quality at baseline compared to those who completed the study. McChargue and colleagues (2012) found sleep quality and depressive symptoms significantly impacted BCS' adherence to their behavioral therapy sleep intervention. Yet, the influence of concurrent cancer-related symptoms on cognitive training adherence among BCS has not been reported.

Together, the quantitative and qualitative findings from this study suggest that concurrent cancer-related symptoms hindered cognitive training adherence among BCS. In addition, this study illuminated that poor sleep quality tends to exacerbate depressive

symptoms and perceived cognitive impairment among some BCS, indicating that sleep quality may be pivotal in cognitive training adherence among BCS.

Summary of Integrated Findings

To summarize, integration of the findings identified that response to awareness of perceived cognitive impairment is critical to cognitive training adherence and that cognitive training exacerbates depressive symptoms among some BCS. Moreover, poor sleep quality can aggravate cognition and mood and negatively influenced cognitive training motivation and performance, creating a snowball effect. Yet, continued cognitive training may improve sleep, mood, and cognition among BCS.

Implications

To date, a comprehensive cognitive intervention, addressing the concurrent cancer-related symptoms of perceived cognitive impairment, depressive symptoms, and poor sleep quality, for BCS does not exist. This section discusses the potential uses of research findings from this study to inform research, clinical practice, and health care policy.

Future Research

Four important considerations for the future of cognitive research among BCS emerged: 1) the state of BCS, 2) being a survivor and a co-survivor, 3) the cultural aspect of being an African American woman, and 4) the process of adherence.

First, the state of BCS must be taken into consideration when planning cognitive interventions. This study revealed that BCS struggling with concurrent cancer-related symptoms (e.g., perceived cognitive impairment, depressive symptoms, and poor sleep quality) may be mentally and/or physically unable to attend to cognitive training. This finding raises the question of how to improve BCS' ability to attend to cognitive training. One possibility is healthy living strategies. Healthy living strategies include: physical activity, nutrition, good sleep hygiene, and stress reduction. Healthy living strategies, as a form of symptom self-management, may improve BCS' mental and physical well-being. Combining healthy living strategies with cognitive training may aid in the self-management of concurrent cancer-related symptoms and improve BCS' ability to attend to cognitive training. Future cognitive studies may consider such an approach.

Second, this study revealed that some BCS are also co-survivors. In this study being a co-survivor was more distressing than being a survivor. This finding identified a need to explore and understand the experience of being a survivor and a co-survivor. Given the additional burden and distress of being a caregiver to family members with cancer (Kim et al., 2016), research on these women's concerns and unmet needs should be further explored.

Third, this study revealed that cultural aspects hindered cognitive training adherence and support among African American BCS. In this study the specific cultural aspect of "being an African American woman" and "keeping it to self" were noted in having a history of self-doubt, not feeling smart enough for cognitive training, fears of poor cognitive training performance, discomfort in sharing with other people about their cancer-related symptoms, and lack of support. This finding identified a need to explore

and understand how to provide needed support for African American BCS. Given that African American BCS view cancer and cancer-related symptoms as a stigma (Adams et al., 2015), culturally relevant approaches should be utilized in exploring this issue.

Last, this study revealed that cognitive training tended to improve sleep, mood, and cognition among adherent BCS. Yet, only 58% of the participants in this study were adherent. This finding identified a need to explore and understand the process of cognitive training adherence among BCS. Given the varied adherence rates to cognitive training among BCS in this study as well as in others (Becker et al., 2017; Damholdt et al., 2016; Kesler et al., 2013; Von Ah et al., 2012), research on the adherence process should be explored further.

Clinical Implications

Three important considerations for clinical practice emerged: 1) promoting healthy living after cancer; 2) applying survivorship guidelines; and 2) addressing the entire symptom experience.

First, it is essential that healthy living (physical activity, nutrition, good sleep hygiene, and stress reduction) education and support begin at diagnosis and continue across the survivorship continuum (NCCN, 2017; Runowicz et al., 2016). To facilitate the adoption of healthy behaviors among BCS, healthy living strategies should be inclusive of co-survivors (Howell, Brockman, et al., 2013; Howell, Sinicrope, et al., 2013). The inclusion of co-survivors may also serve as a teaching moment for cancer-risk reduction (Bail et al., 2016; Demark-Wahnefried, Rock, Patrick, & Byers, 2008) and provide needed support for co-survivors (Davey, Tubbs, Kissil, & Nino, 2011; Haynes-

Maslow, Allicock, & Johnson, 2016). Health care professionals can encourage the benefits of a healthy lifestyle and serve as role models for BCS by adopting a healthy lifestyle themselves (Bail et al., 2016).

Second, the NCCN survivorship guidelines should be applied. These guidelines recommend routinely assessing cognitive function, sleep, mood, and distress and encouraging healthy living strategies for self-management (NCCN, 2017). Guidelines recommend the following: (a) ask BCS if they are experiencing any cognitive difficulties and validate BCS' self-reported cognitive impairment; (b) screen for depression, pain, fatigue, poor sleep quality, and distress; (c) review current medications and discuss any aspect of medication that interferes with cognition; (d) provide strategies for healthy living (e.g., physical activity, nutrition, good sleep hygiene, and stress reduction); and (e) refer BCS with signs of cognitive impairment for neuropsychological assessment and cognitive training if available.

Last, given that BCS experience concurrent cancer-related symptoms, health care providers need to shift focus from one symptom to the entire experience. It is important to note that the symptom experience may vary among BCS and may be related to who they are rather than just their disease (Matthews, Schmiege, Cook, & Sousa, 2012). In addition, awareness of the exacerbating effect that some cancer-related symptoms (e.g., poor sleep quality) may have on the entire symptom experience is crucial.

Limitations

Limitations of the study included:

1. Due to the small sample size and the fact that convenience sampling was used in the quantitative phase of the study, the sample may not be representative of the larger population.
2. Quantitative data were limited to variables that were available from SOAR.
3. Due to an inherent researcher's bias, the data obtained in the second phase of the study may be subject to different interpretations by different researchers.
4. There is a potential for bias in the qualitative results interpretation, because of the interpretative nature of the qualitative research and the researcher being a research assistant in the SOAR study and personally knew the participants of the study.
5. Due to the sequential Quan → QUAL mixed methods design, the quality of the inferences produced in the phase I may have influenced the quality of the inferences produced in Phase II, potentially affecting the quality of the generated meta-inferences from the entire study.

Strengths

This study has several strengths. First, the researcher was well suited to study cognitive training adherence among BCS. As lead research assistant on the parent study SOAR, the researcher had first-hand knowledge of cognitive training and had an established rapport with participants. The researcher was experienced in quantitative and qualitative data collection, analysis, and dissemination. In addition, the researcher's

coursework included numerous courses on quantitative, qualitative, and mixed methods research design and statistical analyses.

Second, the researcher used psychometrically validated instruments and appropriate data analysis procedures. Study instruments (i.e., CFQ, PSQI, CES-D) were validated in cancer populations (Akman et al., 2015; Hann et al., 1999; Vom Hofe et al., 1998). Spearman's Rho correlation was appropriate for assessing for relationships between cancer-related symptoms (continuous variables) and adherence (categorical variable) (Field, 2009). The use of psychometrically validated instruments and appropriate data analysis procedures support the reliability and validity of the presented quantitative findings (Polit & Beck, 2012).

Third, the researcher used strategies to improve the trustworthiness of findings based on Lincoln and Guba's (1985) concepts of credibility, dependability, confirmability, and transferability. The researcher addressed credibility by spending prolonged time with participants and member checking. The researcher addressed dependability by audit trail, peer review, and dissertation committee audit. The researcher addressed confirmability by audit trail and clarifying researcher bias. The researcher addressed transferability by collecting detailed descriptive data via in-depth in-person interviews and generating a detailed description of the study setting and participants (i.e., "rich, thick description"). The use of these strategies, infer trustworthiness of the presented qualitative findings.

Finally, to ensure the generation of high-quality meta-inferences from the study, the researcher used separate procedures, previously discussed in this section, to assess the reliability and validity of the quantitative results and trustworthiness of the qualitative

results (Bryman et al., 2008; Creswell & Plano Clark, 2011; Dellinger & Leech, 2007; Greene, 2007; Onwuegbuzie & Leech, 2006; Teddlie & Tashakkori, 2009). Additionally, to address the specific quality issues of a sequential Quan → QUAL design, the researcher applied a systematic process for selecting participants for qualitative follow-up (Ivankova, 2014). This systematic process included controlling for participant recall bias, by selecting Phase I participants who were randomized to the SOAR intervention within the past 6 months, and verifying that selected Phase II participants were reflective of the larger Phase I sample, by checking for consistency among the quantitative findings. The uses of these procedures strengthen the quality of the meta-inferences presented in this study.

Conclusion

This study is the first to document an understanding of cancer-related symptoms and cognitive training among BCS. The findings from this study illuminate the participant experience of cognitive training and cancer-related symptoms and their dynamic relationships with adherence. Experiences of and responses to cognitive training and cancer-related symptoms shape adherence to cognitive training among BCS. BCS in this study who continued cognitive training experienced improved sleep, mood, and cognition. This study brought forward implications for future research, clinical practice, and health care policy. Further study and application of findings may potentially aid in self-management of concurrent cancer-related symptoms, delivery of cognitive interventions, and improved cognition and ultimately quality of life among BCS.

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APPENDIX A

THEORETICAL FRAMEWORK

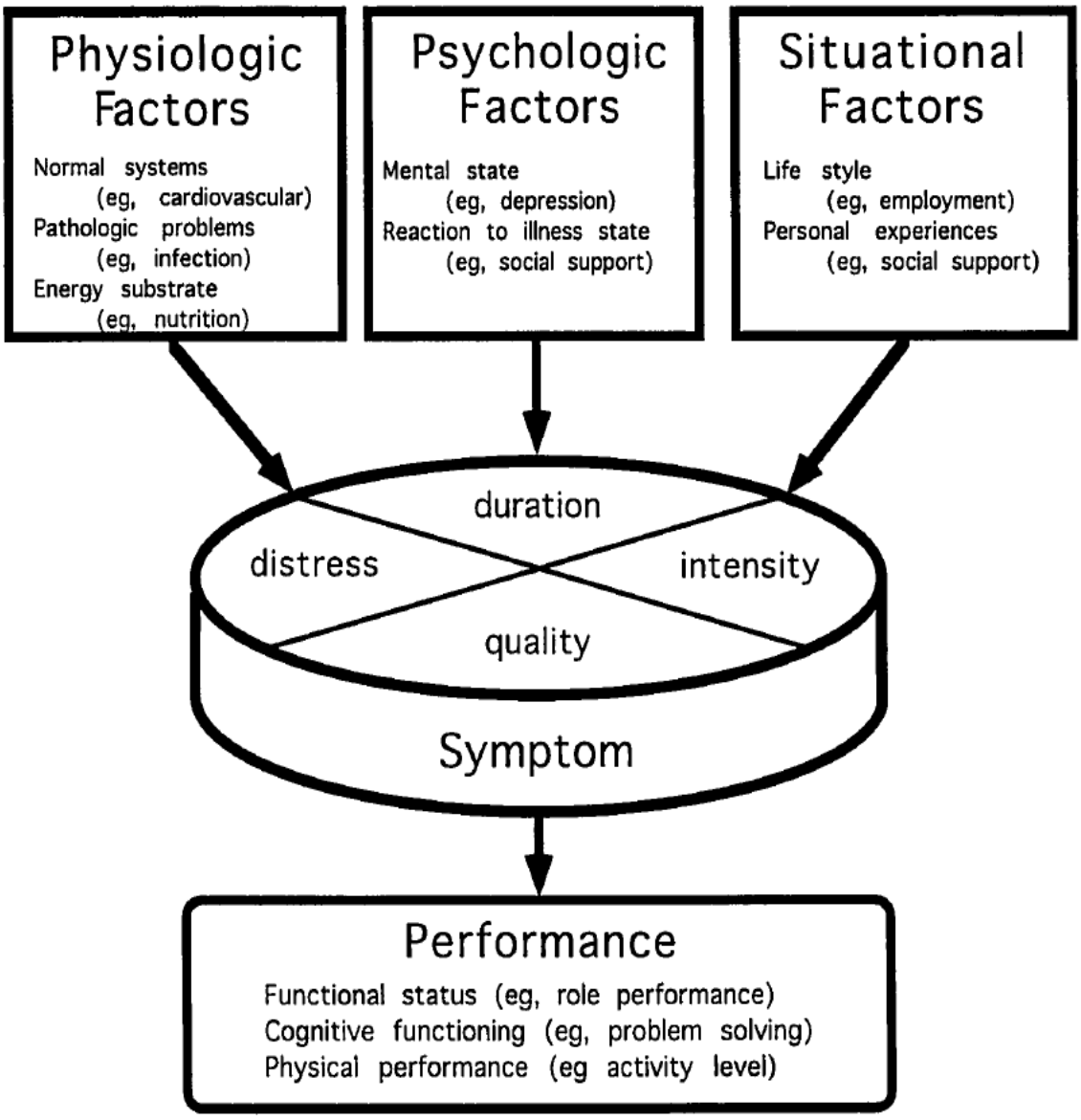


Figure A1. From "Collaborative Development of Middle-Range Nursing Theories: Toward a Theory of Unpleasant Symptoms," by E.R. Lenz, F. Suppe, A.G. Gift, L.C. Pugh, & R.A. Milligan, 1995, Advances in Nursing Science, 17(3), p. 10. Copyright 1995 by Lippincott Williams and Wilkins. Reprinted with permission

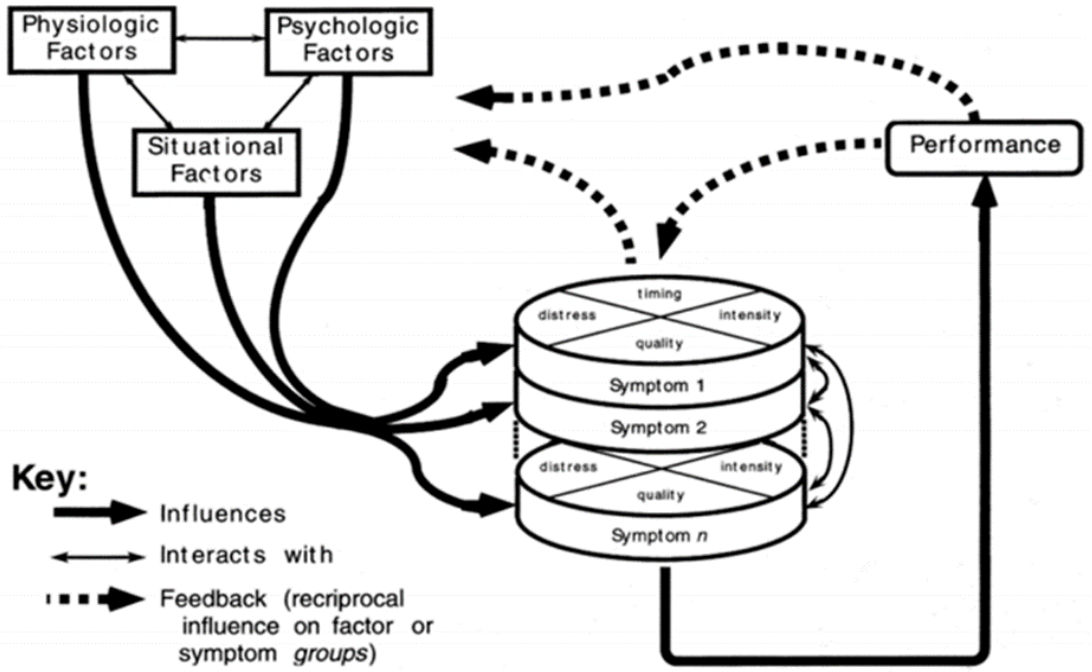


Figure A2. From "The Middle Range Theory of Unpleasant Symptoms: An update," by E.R. Lenz, L.C. Pugh, R.A. Milligan, A.G. Gift, & F. Suppe, 1997, *Advances in Nursing Science*, 19 (3), pp. 14-27. Reprinted with permission from Wolters Kluwer Health.

APPENDIX B

INSTRUMENTS AND DATA COLLECTION TOOLS

Sociodemographic Form

1. What is your date of birth? _____

2. What is your race?

African American -- Native American -- Native Alaskan -- Asian -- Caucasian – Other

3. Are you Hispanic or Latina? Yes – No

4. What is your primary language? English – Spanish – Other

5. What is the highest grade of school you completed?

Grade School (grades 1-8)

High School (grades 9-11)

High School graduate (12)

Technical or trade school

Some college

College graduate

Post graduate degree (Masters, JD, PhD, MD)

6. What is your religious preference?

Christian – Jewish – Muslim – Other (specify: _____) – Agnostic – Atheist

7. What is your marital status?

Never married – Married – Living with partner – Separated – Divorced – Widowed

8. How many people do you live with? _____

8a. Who are the other members of your household?

Spouse – Parents (# of parents ____) – Children (# of children ____) – Friends/Significant Other (# of friends/significant other ____) – Other relatives (# of other relatives _____) – None

9. What is your current employment?

Employed full time – Employed part time – Retired – Student – Homemaker – Unemployed looking for work – Unemployed through disability/illness

10. What is the range of your family income?

$10,000 or less -- $10,001 to $20,000 -- $20,001 to $30,000 -- $30,001 to $40,000 -- $40,001 to $50,000 – Greater than $50,000 – Do not care to respond

11. Do you have health insurance? Yes – No

12. When was your breast cancer first diagnosed? _____

13. Have you had any other type of cancer before?

None – Breast – Skin (basal/squamous/melanoma) – Cervical – Ovarian – Colon – Other (specify: _____)

14. What type of surgery did you have? Lumpectomy – Mastectomy – Bilateral mastectomy

15. Did you have chemotherapy? Yes – No

15a. If yes, which chemotherapy drugs did you take?

Cytoxan – Methotrexate – Adriamycin – Taxol – Taxotere – Herceptin – Xeloda – Other (please specify

_____

____) –Don't know

16. Did you have radiation therapy? Yes – No

16a. If yes, what type?

Primary- After lumpectomy – Post-operative- After Mastectomy – Mammosite radiation

17. Are you on anti-hormonal medication? Yes – No

17a. If yes, what type?

Arimidex (Anastrozole) – Aromasin (Exemestane) – Femara (Letrozole) – Tamoxifen – Zoladex – Fareston (Synthetic tamoxifen) – Other (please specify: _____)

18. When did you finish primary treatment? _____

19. Have you gained weight while on cancer treatment? Yes – No

19a. If yes, how much weight did you gain (in pounds)? _____

19b. What is your current weight? _____

20. What type of support services did you or do you use?

Breast cancer-specific support group – Non-breast cancer specific support group – Counseling – Electronic care page on a blog – None

The Cognitive Failures Questionnaire (Broadbent, Cooper, FitzGerald & Parkes, 1982)

The following questions are about minor mistakes which everyone makes from time to time, but some of which happen more often than others. We want to know how often these things have happened to your in the past 6 months. Please circle the appropriate number.

		Very often	Quite often	Occasion-ally	Very rarely	Never
1.	Do you read something and find you haven't been thinking about it and must read it again?	4	3	2	1	0
2.	Do you find you forget why you went from one part of the house to the other?	4	3	2	1	0
3.	Do you fail to notice signposts on the road?	4	3	2	1	0
4.	Do you find you confuse right and left when giving directions?	4	3	2	1	0
5.	Do you bump into people?	4	3	2	1	0
6.	Do you find you forget whether you've turned off a light or a fire or locked the door?	4	3	2	1	0
7.	Do you fail to listen to people's names when you are meeting them?	4	3	2	1	0
8.	Do you say something and realize afterwards that it might be taken as insulting?	4	3	2	1	0
9.	Do you fail to hear people speaking to you when you are doing something else?	4	3	2	1	0
10.	Do you lose your temper and regret it?	4	3	2	1	0
11.	Do you leave important letters unanswered for days?	4	3	2	1	0
12.	Do you find you forget which way to turn on a road you know well but rarely use?	4	3	2	1	0
13.	Do you fail to see what you want in a supermarket (although it's there)?	4	3	2	1	0
14.	Do you find yourself suddenly wondering whether you've used a word correctly?	4	3	2	1	0

		Very often	Quite often	Occasion-ally	Very rarely	Never
15.	Do you have trouble making up your mind?	4	3	2	1	0
16.	Do you find you forget appointments?	4	3	2	1	0
17.	Do you forget where you put something like a newspaper or a book?	4	3	2	1	0
18.	Do you find you accidentally throw away the thing you want and keep what you meant to throw away – as in the example of throwing away the matchbox and putting the used match in your pocket?	4	3	2	1	0
19.	Do you daydream when you ought to be listening to something?	4	3	2	1	0
20.	Do you find you forget people's names?	4	3	2	1	0
21.	Do you start doing one thing at home and get distracted into doing something else (unintentionally)?	4	3	2	1	0
22.	Do you find you can't quite remember something although it's "on the tip of your tongue"?	4	3	2	1	0
23.	Do you find you forget what you came to the shops to buy?	4	3	2	1	0
24.	Do you drop things?	4	3	2	1	0
25.	Do you find you can't think of anything to say?	4	3	2	1	0

References

Broadbent, D.E., Cooper, P.F., FitzGerald, P., & Parkes, K.R. (1982). The Cognitive Failures Questionnaire (CFQ) and its correlates. *British Journal of Clinical Psychology*, *21*, 1-16.

Pittsburg Sleep Quality Index – (PSQI)

The following questions relate to your usual habits of sleep during the **past month only**. Your answers should indicate the accurate reply for the majority of days and night in the past month. Please answer all the questions.

1. **When have you usually gone to bed?**

   Usual bedtime ___ ___:___ ___

2. **How long (in minutes) does it take you to fall asleep?**

   Number of minutes ___ ___ ___

3. **When do you usually get up for work?**

   Getting-up time :

4. **How many hours of actual sleep do you get?**
   (may be different than when you went to bed.)

   Hours of sleep last night ___ ___:___ ___

5. **(Please check the one best response.) How often have you had trouble sleeping because you;**

   a. Cannot get to sleep within 30 minutes
   - **Not during the past month**
   - **Less than once a week**
   - **1-2 times per week**
   - **3 or more times per week**

   b. Wake up in the middle of the night
   - **Not during the past month**
   - **Less than once a week**
   - **1-2 times per week**
   - **3 or more times per week**

   c. Have to get up to go to the bathroom
   - **Not during the past month**
   - **Less than once a week**
   - **1-2 times per week**
   - **3 or more times per week**

d. Cannot breathe comfortably
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

e. Cough or snore loudly
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

f. Feel too cold
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

g. Feel too hot
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

h. Have bad dreams
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

i. Have pain
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

j. Other reasons you can't sleep
- Not during the past month
- Less than once a week
- 1-2 times per week
- 3 or more times per week

6. During the past month, how would you rate your sleep quality overall?

Very good

Fairly good

Fairly bad

Very bad

7. During the past month, how often have you taken medication to help you sleep (prescribed or over the counter)?

   Not during the past month

   Less than once a week

   Once or twice a week

   3 or more times a week

8. During the past month, how often have you had trouble staying awake while driving?

   Not during the past month

   Less than once a week

   Once or twice a week

   3 or more times a week

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

   No problem at all

   Only a very slight problem

   Somewhat of a problem

   A very big problem

10. Do you have a bed partner or roommate?

    No bed partner or roommate

    Partner or roommate in the other room

    Partner in the same room but not in the same bed

    Partner in the same bed

11. If you have a bed partner or share a room, how often in the past month have you had...

a. Loud snoring
   - ○ Not during the past month
   - ○ Less than once a week
   - ○ 1 or 2 times a week
   - ○ 3 or more times a week

b. Long pauses between breaths while asleep
   - ○ Not during the past month
   - ○ Less than once a week
   - ○ 1 or 2 times a week
   - ○ 3 or more times a week

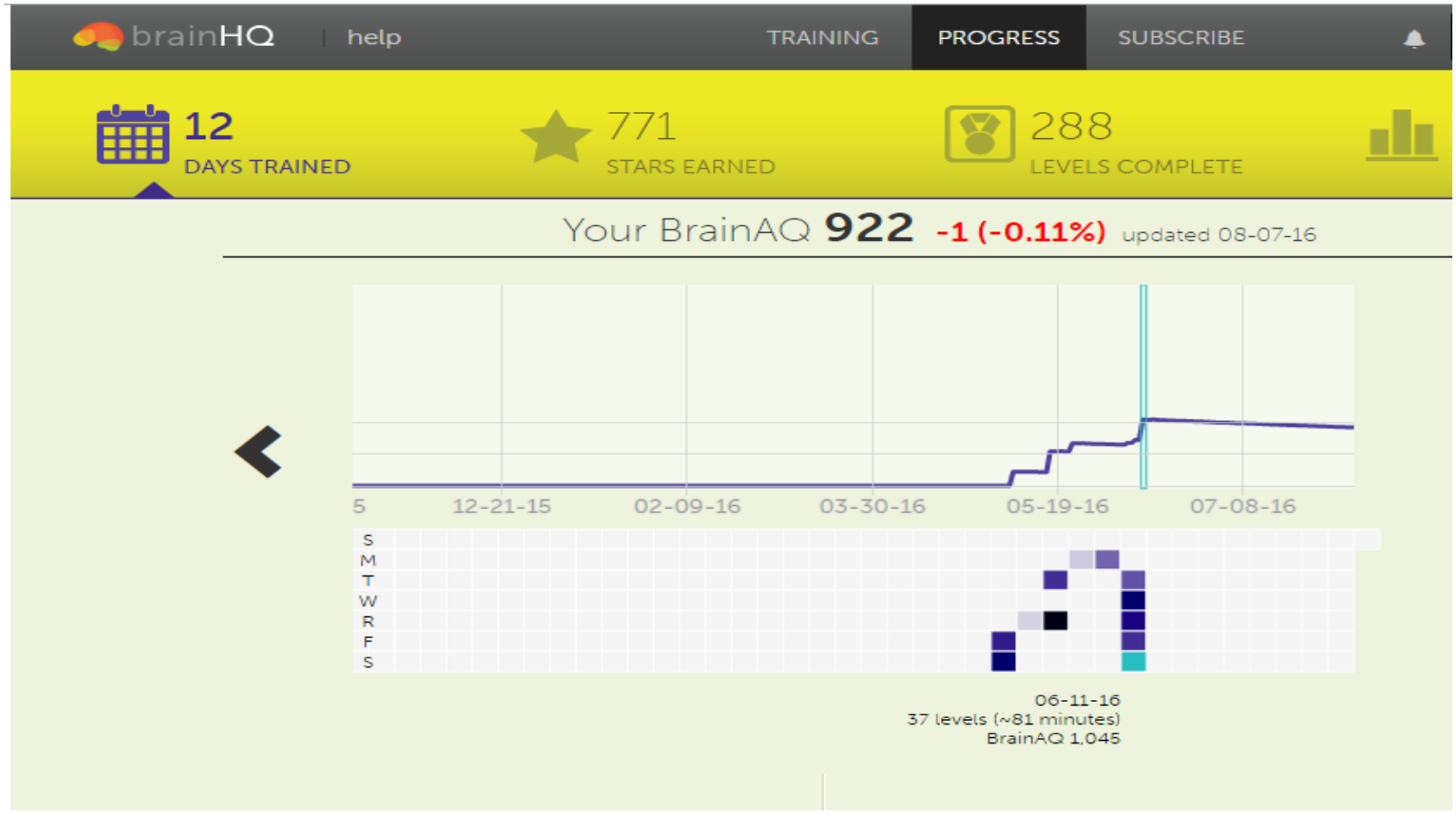
c. Legs twitching or jerking while you sleep
   - ○ Not during the past month
   - ○ Less than once a week
   - ○ 1 or 2 times a week
   - ○ 3 or more times a week

d. Episodes of disorientation or confusion during sleep
   - ○ Not during the past month
   - ○ Less than once a week
   - ○ 1 or 2 times a week
   - ○ 3 or more times a week

e. Other restlessness while you sleep
   - ○ Not during the past month
   - ○ Less than once a week
   - ○ 1 or 2 times a week
   - ○ 3 or more times a week

Please describe:

CES-D **How often did you feel this way in the past week?**	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time **(5-days)**
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating: my appetite was poor.				
3. I felt that I could not shake off the blues even with help from others.				
4. I felt that I was just as good as other people				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people disliked me.				
20. I could not get "going".				


brainHQ
help
TRAINING
PROGRESS
SUBSCRIBE
12
DAYS TRAINED
771
STARS EARNED
288
LEVELS COMPLETE
Your BrainAQ 922 -1 (-0.11%) updated 08-07-16
5
12-21-15
02-09-16
03-30-16
05-19-16
07-08-16
S
M
T
W
R
F
S
06-11-16
37 levels (~81 minutes)
BrainAQ 1,045

Interview Protocol
Cancer-Related Symptoms and Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study
(Cognitive Deficits in Breast Cancer Survivors)

Date: _____ Time: _____

Location: _____

Interviewer: _____

Interviewee: _____

Introduction: (Interviewee name), thank you for taking the time to talk with me today. I would like to learn about your experience of participating in the "***S****peed of Processing in Middle Aged and* ***O****lder Bre****a****st Cancer Su****r****vivors*" (SOAR) study. I will be asking you questions about difficulties you may have experienced with the brain training and things that helped you with the brain training. You will also be asked about your mood, sleep, and mental abilities. I expect that this interview will last approximately 60-90 minutes. With your permission, I will be audio-recording this interview and writing notes. If you wish to stop recording at any time, please let me know.

I. Icebreaker Questions:

Icebreaker #1: How did you hear about the SOAR study?

Icebreaker #2: What led you to enroll in the SOAR study?

II. Main Questions:

- What expectations did you have when you enrolled in the SOAR study?
    a. How did the study meet your expectations?
    b. How easy was the study?
    c. How difficult was the study?

- Now, let's talk about the brain training that you did in the SOAR study.
    a. What is your overall impression of brain training?
    b. Do you think the number of training hours were sufficient? Why or why not?
    c. What did you like about the brain training?
    d. What did you dislike about the brain training?
    e. How helpful do you think the brain training was for you?
- What changes have you noticed after completing the brain training?

a. How do you think that your mental abilities have improved? Why? Can you give an example?
b. How do you think that your mood has improved? Why? Can you give an example?
c. How do you think that your sleep has improved? Why? Can you give an example?

- Tell me what helped you complete the brain training.

    a. How did you schedule your brain training? What day/time worked best? Why?
    b. Where did you do your brain training? Was it free from distractions?
    c. How comfortable were your using the computer? Did you have assistance from others?

- Tell me about any challenges you faced with brain training.

    a. Were you able to overcome these challenges? How or why not?
    b. What difficulties did you experience in accessing/navigating the brain training?
    c. How did daily activities/responsibilities interfere with the brain training?
    d. What physical challenges did you experience with the brain training?
    e. How was it sitting at the computer for a training session?
    f. What would have made the brain training easier for you?

- What support did you receive from others?

    a. Please describe what your household looks like.
    b. Did anyone in your household support you? How so?
    c. Did anyone at work support you? How so?
    d. Did anyone in your community/church/support group support you? How so?

- What other factors helped or challenged you with the brain training?

    a. How do you feel that your ability to focus influenced completing the brain training?
    b. How do you feel that your sleep quality influenced completing the brain training?
    c. How do you feel that being in a particular mood influenced completing the brain training?

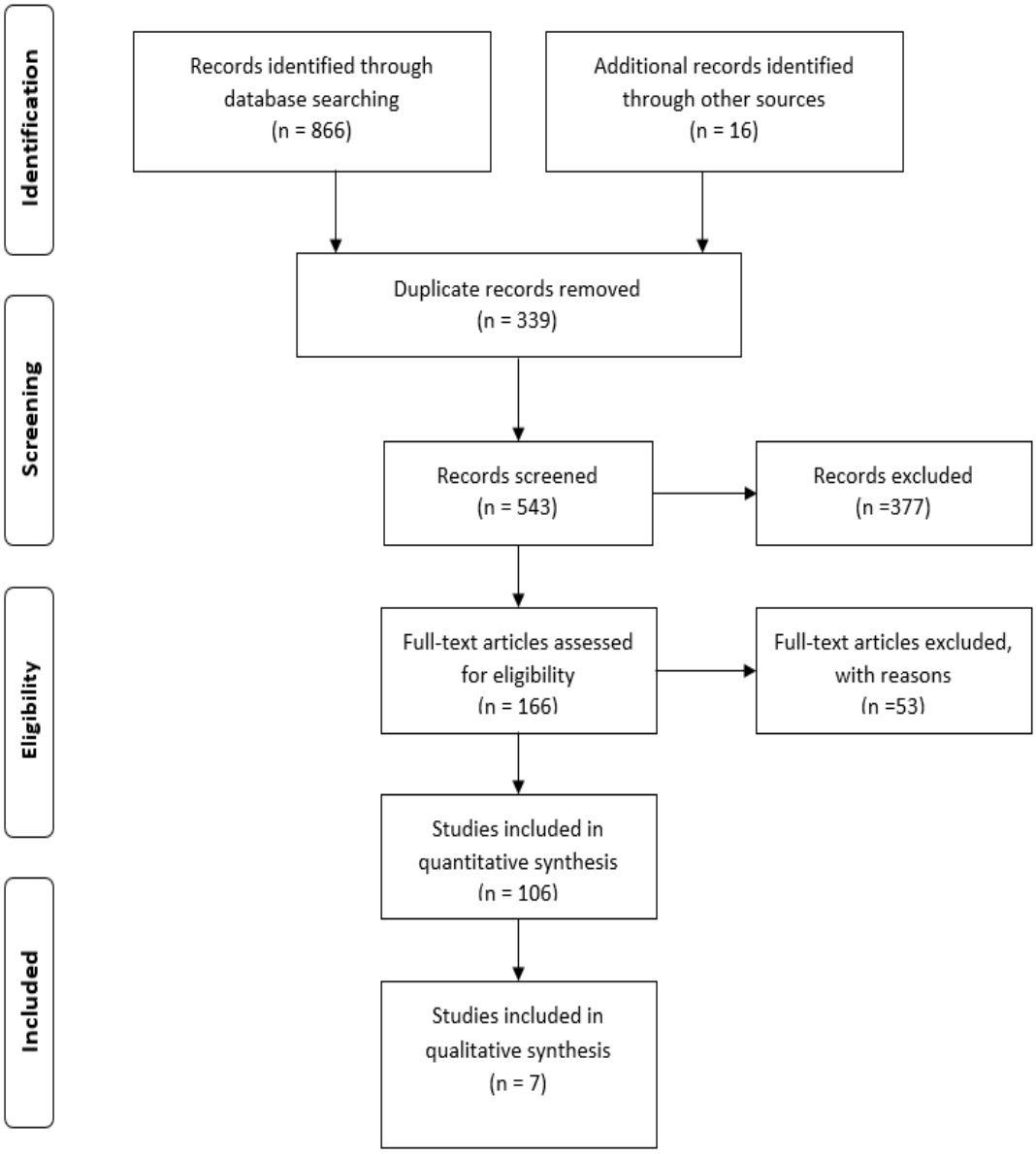
- What advice would you give to other breast cancer survivors about this program?

- Is there anything else that would you like to share?

III. Closing: Thank you so much for your time today and for sharing your experience with me. Your input is very important and much appreciated.

APPENDIX C

CONSORT



Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, and D. G. Altman, The PRISMA Group, 2009, *PLOS Medicine 6*(7): e1000097. doi:10.1371/journal.pmed1000097

APPENDIX D

COGNITIVE INTERVENTION STUDIES

Table D1. Cognitive Intervention Studies for Cognitive Impairment in Breast Cancer Survivors

Author, Date, & Title	Participants	Design & Procedure	Findings	Strengths & Limitations
Cognitive Remediation Interventions				
Alvarez et al 2013 USA The Effect of EEG Biofeedback on Reducing Postcancer Cognitive Impairment	23 chemotherapy-treated BCS (M_{age} = 56 years, Race = 100% Caucasian, $M_{months\ post\text{-}treatment}$ = 24)	• BCS participated in a 10-week wait-list control period followed by a 10-week EEG biofeedback intervention. • Biofeedback sessions (20 sessions) occurred twice a week for 10 weeks. • Questionnaires were administered 3 times during each 10-week session (wait-list and intervention) and once at 4-weeks post-biofeedback.	• Significant improvement was observed on all four domains of the Functional Assessment of Cancer Therapy – Cognitive Function over the course of the 10-week intervention.	**Strengths** • Pilot study of potential cognitive improvement following biofeedback intervention • No adverse effects **Limitations** • Participants acted as their own wait-list control group • BCS all Caucasian • Exclusion of BCS <40 years old • Subjective outcome measures only
Dolbeault et al 2009 France The Effectiveness of a Psycho-educational Group After Early-stage Breast Cancer Treatment: Results of a Randomized French Study	203 BCS treated with radiation or radiation and chemotherapy Time post-treatment ranged from 15 days to 1 year. • 2 Randomized Groups: 1. Psycho-educational (N = 102, M_{age} = 55 years) 2. Wait-list Control (N = 101, M_{age} = 52 years)	• Psycho-educational group intervention program • BCS in the intervention group received 8 weekly 2-hour sessions led by two therapists. • Outcome measures consisted of a set of questionnaires administered at baseline, immediately post-intervention, and 1-month follow up.	• BCS showed no statistical significance for improvement in cognitive function. • BCS showed significant reduction in anxiety.	**Strengths** • RCT • Large sample size **Limitations** • Participant race/ethnicity not reported • Subjective outcome measures only
Ercoli et al 2013 USA Assessment of the Feasibility of a Rehabilitation Intervention Program for Breast Cancer Survivors with Cognitive Complaints	27 chemotherapy-treated BCS (M_{age} = 54 years, Race = 85% Caucasian, $M_{months\ post\text{-}diagnosis}$ = 33.6)	• Intervention consisted of five weekly 2-hour group sessions and homework exercises that focused on attention, memory, and executive function challenges. • Outcome measures consisted of a neurocognitive test battery and self-report questionnaires administered at baseline, immediately	• BCS showed significant improvement on tests of speed of processing and executive functioning. • Significant reductions in self-reported cognitive deficits were found immediately post-intervention and were greatest for memory deficits. • Reductions in self-	**Strengths** • Intervention rooted in evidence-based cognitive rehabilitation • Extended post-intervention follow-up • Neurocognitive test battery **Limitations** • Single arm study

		post- intervention, and 2- and 4-months follow up.	reported deficits of executive functioning became apparent at the 4-month follow-up.	• Lack of racial diversity in participants.
Ercoli et al 2015 USA Cognitive Rehabilitation Group Intervention for Breast Cancer Survivors: Results of a Randomized Clinical Trial	48 chemotherapy, radiation, or Herceptin treated BCS • 2 Randomized Groups: 1. Cognitive Rehabilitation (N = 32, M_{age} = 54.5 years, Race = 88% Caucasian, $M_{months\ post\text{-}diagnosis}$ = 34) 2. Wait-list control (N =16, M_{age} = 52.4 years, Race = 94% Caucasian, $M_{months\ post\text{-}diagnosis}$ = 34.8)	• Intervention consisted of five weekly 2-hour group sessions and homework exercises that focused on attention, memory, and executive function challenges. • Outcome measures consisting of neurocognitive test battery and self-report questionnaires were collected at baseline, immediately post-intervention, and at 2-month follow-up.	• BCS in the intervention group showed significant improvement in self-reported cognitive functioning immediately following the intervention which was sustained at 2-month follow-up. • BCS in the intervention group showed significant improvement on neuropsychological tests of memory	**Strengths** • RCT • Incorporation of exploratory EEG measures • Neurocognitive test battery **Limitations** • Longer term follow-up required • Lack of racial diversity in participants
Ferguson et al 2007 USA Cognitive-behavioral Management of Chemotherapy-related Cognitive Change	29 chemotherapy-treated BCS (M_{age} = 56 years, Race = 100% Caucasian, $M_{months\ post\text{-}treatment}$ = 96)	• Memory and Attention Adaptation Training (MAAT) with workbook • BCS attended 4 individual monthly visits of 30-50 minutes, and phone calls. • Outcome measures consisted of self-rating questionnaires and a cognitive battery administered at baseline, immediately post-intervention, and at 2- and 6-month follow-up.	• BCS self-reported improved cognitive functioning from baseline to immediately post-treatment which was sustained at 2 and 6 months. • Improvement on measures of executive function, verbal skills, and quality of life were also sustained.	**Strengths** • High intervention satisfaction • Neurocognitive test battery **Limitations** • Single arm study • BCS all Caucasian • Subjective outcome measures only
Ferguson et al 2012 USA Development of CBT for Chemotherapy-related Cognitive Change: Results of a Waitlist Control Trial	29 chemotherapy-treated BCS (> 18 months post-treatment, Race = 98% Caucasian) • 2 Randomized Groups: 1. MAAT (N = 19, M_{age} = 51 years) 2. Wait-list Control (N = 21, M_{age} = 50 years)	• MAAT with workbook • BCS attended 4 individual monthly visits of 30-50 minutes, and phone calls. • Outcome measures consisted of self-rating questionnaires and a cognitive battery administered at baseline, immediately post-intervention, and at 2- and 6-month follow-up.	• BCS in the MAAT group showed significant improvement on a test of verbal memory. • BCS in the MAAT group reported significantly improved spiritual well-being on a quality of life questionnaire. • BCS in the MAAT group did not show the expected improvement on a questionnaire of daily cognitive problems.	**Strengths** • RCT • Neurocognitive test battery • High intervention satisfaction. • Only four visits required **Limitations** • Sample was small, • Lack of racial diversity in participants
Kesler et al 2013 USA	41 chemotherapy-treated BCS • 2 Randomized Groups:	• BCS completed online computerized exercises targeting executive functioning	• BCS in the intervention group demonstrated some transfer to verbal	**Strengths** • RCT • Demonstrates efficacy of a home-

Cognitive Training for Improving Executive Function in Chemotherapy-Treated Breast Cancer Suvivors	1. Cognitive Training (N = 21, M_{age} = 55 years, $M_{months\ post\text{-}treatment}$ = 72) 2. Wait-list Control (N = 20, M_{age} = 56 years, $M_{months\ post\text{-}treatment}$ = 72)	at home. • Sessions lasted 20-30 minutes for 12 weeks • Outcome measures consisted of a cognitive battery administered at baseline and within 3 days of intervention completion.	memory and showed improved cognitive flexibility, speed of processing, set shifting, and verbal fluency compared to the control group. • BCS in the intervention group self-reported improvement in executive behaviors.	based training program for cognitive deficits in BCS • Neurocognitive test battery **Limitations** • No extended follow-up • No auditory component • Exclusion of BCS <40 years old • Home computer and internet access required • Participant race/ethnicity not reported
Lengacher et al 2015 USA Moderating Effects of Genetic Polymorphisms on Improvements in Breast Cancer Survivors Participating in a 6-Week Mindfulfulness-Based Stress Reduction Program	72 chemotherapy, radiation, or surgery treated BCS • 2 Randomized Groups: 1. Mindfulness-Based Stress Reduction Program (MBSR) (N = 37, M_{age} = 59 years, Race = 76% Caucasian, $M_{months\ post\text{-}treatment}$ = 7.3) 2. Usual Care (N = 35, M_{age} = 57 years, Race = 80% Caucasian, $M_{months\ post\text{-}treatment}$ = 6.7)	• BCS in the MBSR group attended 6 weekly 2-hour sessions and also practiced at home for 15-45 minutes a day. • Usual Care consisted of standard post-treatment clinic visits. • Everyday Cognition (ECog) questionnaire was administered at baseline, immediately post-intervention, and at 12-week follow-up. • All BCS had 5 ml of blood drawn for genotyping.	• Four of the eight ECog outcomes (Language, visuospatial, planning, and divided attention) demonstrated a significant interaction between MBSR and genotype. • The gene ANKKI modulates improvement in cognitive function in response to and MBSR intervention.	**Strengths** • RCT • Demonstrates potential for personalized cognitive treatment programs for BCS **Limitations** • Small sample size • Lack of racial diversity in participants • Subjective outcome measures only
Millbury et al 2013 USA Tibetan Sound Meditation for Cognitive Dysfunction: Results of a Randomized Controlled Pilot Trial.	42 BCS undergoing hormonal therapy • 2 Randomized Groups: 1. Tibetan Sound Meditation (N = 23, M_{age} = 53 years, Race = 74% Caucasian) 2. Wait-list Control (N = 24, M_{age} = 54 years, Race = 63% Caucasian)	• The BCS in the meditation intervention group attended twice-weekly 60-minute sessions for six weeks, and were also encouraged to practice at home. • BCS completed a self-report assessment prior to, immediately following, and 1-months post-intervention. • Cognitive performance measures were administered at baseline and at the 1-month follow-up.	• BCS in the intervention group reported significantly fewer cognitive deficits than BCS in the wait-list control group immediately post-intervention but not at the 1-month follow-up. • BCS in the intervention group performed significantly better than those in the wait-list control group at the 1-month follow-up on a verbal memory test with a trend for improved performance on tests of memory and processing speed.	**Strengths** • RCT • Neurocognitive test battery • High intervention satisfaction • Intervention feasible for patients suffering from physical limitations or fatigue **Limitations** • Small effect sizes • Lack of racial diversity in participants
Von Ah et al 2012 USA Advanced	82 chemotherapy-treated BCS • 3 Randomized Groups: 1. Memory Training (N = 26, M_{age} = 55 years,	• BCS in the training protocols received ten 1-hour training sessions over a 6-8 week period. • Outcome measures consisted of a	• BCS in both the memory and speed of processing training groups improved on the cognitive battery both immediately post-intervention and	**Strengths** • RCT • Both interventions were effective and satisfactory to participants. • Neurocognitive

Cognitive Training for Breast Cancer Survivors: A Randomized Controlled Trial	Race = 81% Caucasian, $M_{months\ post\text{-}treatment}$ =59.5) 2. Speed of Processing Training (N = 27, M_{age} = 57 years, Race = 96% Caucasian $M_{months\ post\text{-}treatment}$ = 78 3. Wait-list Control (N = 29, M_{age} = 57 years, Race = 90% Caucasian $M_{months\ post\text{-}treatment}$ = 59)	cognitive battery administered at baseline, immediately post-intervention, and at a 2-month follow-up.	at the 2-month follow-up. • The memory training group showed significant improvement on memory testing at the 2-month follow-up. • The speed of processing training group showed significant improvement in both speed of processing and memory at both time points.	test battery **Limitations** • Exclusion of BCS <40 years old • Lack of racial diversity in participants
Weis et al 2011 Germany Rehabilitation of Therapy-Related Cognitive Deficits in Patients with Breast Cancer	96 chemotherapy-treated cancer survivors (M_{age} = 49.2 years, $M_{months\ post\text{-}diagnosis}$ = 9, $M_{months\ post\text{-}treatment}$ = 2.1) • 2 Randomized Groups: 1. Neuropsychological Training 2. Computer-based Training • Non-Randomized Control Group	• BCS in both interventions received four 1-hour training sessions per week over a 3-week period during their in-patient stay at a rehabilitation center. • Activities of both interventions focused on the cognitive domains of memory and attention. • Outcome measures consisted of computerized neuropsychological testing and self-report questionnaires administered at baseline, immediately post-intervention, and at 6-month follow-up.	• Significant improvement on neurocognitive tests were seen in all three groups. • Since the control group improved in the same manner as the 2 interventions, no specific intervention effects were demonstrated.	**Strengths** • Neurocognitive test battery **Limitations** • Non-randomized control group • Participant race/ethnicity not reported
Physical Activity Interventions				
Culos-Reed et al 2006 Canada A Pilot Study of Yoga for Breast Cancer Survivors: Physical and Psychological Benefits	38 chemotherapy-treated cancer survivors (BCS = 32, M_{age} = 51 years, $M_{months\ post\text{-}diagnosis}$ = 56) • 2 Randomized Groups: 1. Yoga (N = 20) 2. No-contact Control (N = 24)	• Participants in the yoga group attended one 75- minute class per week for 7 weeks. • Outcome measures consisted of a set of psychological and physical questionnaires and physiological and fitness measurements administered pre-intervention, and immediately following the intervention.	• As compared to the control group, the yoga group showed a reduction in confusion immediately post intervention.	**Strengths** • RCT **Limitations** • Small sample size • Short program duration • Participant race/ethnicity not reported • Subjective outcome measures only • Not all BCS
Derry et al 2014 USA Yoga and Self-Reported Cognitive Problems in Breast Cancer Survivors: A Randomized Controlled Trial	200 chemotherapy, radiation, or surgery treated BCS • 2 Randomized Groups: 1. Yoga (N = 100 (59 treated with chemotherapy), M_{age} = 52 years, Race = 88%	• BCS in the yoga intervention group attended 24 twice-weekly 90-minute sessions, and were also encouraged to practice at home. • BCS completed a symptom checklist prior to, immediately following, and 3-months post-	• Participants in the yoga condition did not differ from wait-list controls on self-rated cognitive complaints at baseline or immediately following the intervention. • At the 3-month follow-up, BCS in	**Strengths** • RCT • High retention • Home practice was tracked. **Limitations** • Lack of racial diversity in participants • Subjective outcome measures

	Caucasian, $M_{months\ post\text{-}treatment}$ = 16.3) 2. Wait-list Control (N = 100, 53 treated with chemotherapy, M_{age} = 51 years, Race = 88% Caucasian, $M_{months\ post\text{-}treatment}$ = 18.3)	intervention.	the treatment condition reported significantly fewer cognitive symptoms. • There was a significant correlation between practice frequency and reduction in cognitive symptoms. • Differences remained significant after controlling for mood, fatigue, and sleep quality.	only
Galantino et al 2012 USA Longitudinal Impact of Yoga on Chemotherapy-related Cognitive Impairment and Quality of Life in Women with Early Stage Breast Cancer: A Case Series	4 BCS undergoing chemotherapy (M_{age} = 55 years, Race = 100% Caucasian)	• BCS attended a modified Iyengar yoga program twice a week for 6 weeks and then once a week for 6 weeks. • Cognitive testing consisted of a questionnaire of self-reported cognition and a computerized cognitive battery, and was administered before onset of chemotherapy, 6 and 12 weeks into chemotherapy, and 1 and 3 months post-chemotherapy.	• Performance on the computerized cognitive battery was variable and fluctuated over time.	**Strengths** • Pilot study of potential cognitive improvement following yoga intervention both during and post-chemotherapy • Neurocognitive test battery **Limitations** • Small sample size • No control group • BCS all Caucasian
Marinac et al 2015 USA Objectively-Measured Physical Activity and Cognitive Functioning in Breast Cancer Survivors	136 BCS (50% post-chemotherapy, 70% undergoing endocrine therapy, M_{age} = 62.6 years, Race = 79% Caucasian, $M_{months\ post\text{-}diagnosis}$ = 25.2)	• 7-day physical activity of BCS was assessed using hip worn accelerometers.	• Moderate to vigorous physical activity was associated with information processing speed. This association was significant in overweight and obese BCS, but not leaner BCS.	**Strengths** • Objective measurement of physical activity • Neuropsychological test battery **Limitations** • Cross-sectional data • Short program duration • Lack of racial diversity in participants
Miki et al 2014 Japan Feasibility and Efficacy of Speed-feedback Therapy With a Bicycle Ergometer on Cognitive Function in Elderly Cancer Patients in Japan	38 chemotherapy-treated cancer survivors (55% BCS) • 2 Randomized Groups: 1. Speed-feedback therapy (N = 38, BCS = 21, M_{age} = 73, $M_{months\ post\text{-}diagnosis}$ = 56.6) 2. No-contact Control (N = 40, BCS = 22, M_{age} = 75, $M_{months\ post\text{-}diagnosis}$ = 68.9)	• Cancer survivors in the speed-feedback therapy intervention group participated in four weekly sessions. • Frontal Assessment Battery (FAB), Instrumental Activities of Daily Living (IADL), and Functional Assessment of Cancer Therapy-General (FACT-G) were administered at baseline and immediately post-intervention.	• Compared to the control group, intervention participants showed significant improvement in executive and motor function immediately post-intervention.	**Strengths** • RCT • Highly acceptable intervention • Neurocognitive testing **Limitations** • No exercise control • No extended follow-up • Excluded cancer survivors <65 years old • Participant race/ethnicity not reported • Only 55% BCS

Oh et al 2012 Australia Effect of Medical Qigong on Cognitive Function, Quality of Life, and a Biomarker of Inflammation in Cancer Patients: A Randomized Controlled Trial	81 Cancer Survivors (65% post-chemotherapy, 34% undergoing chemotherapy) • 2 Randomized Groups: 1. Medical Qigong (N = 37, BCS = 12, M_{age} = 65 years) 2. Usual Care Control (N = 44, BCS = 13, M_{age} = 61 years)	• Participants in the Medical Qigong group attended at least one (with the option of a second) 90 minute class per week for 10 weeks. • Two measures of self-reported cognitive function were administered at baseline and following the 10-week intervention.	• As compared to the control group, the Medical Qigong group showed significant improvement on 2 questionnaires of self-reported cognitive function.	**Strengths** • Pilot study of potential cognitive improvement following Medical Qigong intervention **Limitations** • No exercise control group • Only 31% BCS • Subjective outcome measures only
Reid-Arndt et al 2012 USA Tai Chi Effects on Neuropsychological, Emotional, and Physical Functioning Following Cancer Treatment: A Pilot Study	24 chemotherapy-treated cancer survivors (BCS = 16, M_{age} = 62 years, $M_{months\ post\text{-}chemotherapy}$ = 78)	• Cancer survivors participated in a 1-hour Tai Chi class twice a week for 10 weeks. • Cognitive tests and a questionnaire of self-reported cognitive function were administered prior to and within 1-month following the intervention.	• Statistically significant improvement was found on tests of immediate and delayed memory, verbal fluency, and executive functioning, as well as on the self-report questionnaire of cognitive function.	**Strengths** • Potential for cognitive improvement following Tai Chi intervention • Neurocognitive testing **Limitations** • No exercise control group • Small sample size • Only 67% BCS • Participant race/ethnicity not reported
Pharmacological Interventions				
Barton et al 2013 USA The Use of Ginkgo Biloba for the Prevention of Chemotherapy-related Cognitive Dysfunction in Women Receiving Adjuvant Treatment for Breast Cancer	210 BCS undergoing chemotherapy • 2 Randomized Groups: 1. Ginkgo biloba (N = 107, Age ≥ 50 = 50%, Caucasian = 93%) 2. Placebo Control (N = 103, Age ≥ 50 = 50%, Caucasian = 95%)	• BCS received either 60 mg of Ginkgo biloba twice daily or a placebo. • Intervention began at the onset of the second cycle of chemotherapy and continued until 1-month after the completion of chemotherapy. • High Sensitivity Cognitive Screen (HSCS), Trail Making tests A and B, Profile of Mood States, and Perceived Health Scale administered at baseline, during chemotherapy, and at completion of chemotherapy.	• There was no significant group difference on any of the measures at any time point.	**Strengths** • Randomized double-blind placebo-controlled trial • Objective and Subjective measures utilized • Data collected over 24 months **Limitations** • Adverse side effects • HSCS known for practice effects. • Lack of racial diversity
Escalante et al 2014 USA A Randomized, Double-blind, 2-Period, Placebo-Controlled Crossover Trial of a Sustained-	33 BCS undergoing chemotherapy (M_{age} = 57 years)	• BCS undergoing chemotherapy received sustained release methylphenidate for two weeks and placebo for two weeks. • Cognitive performance measures administered at baseline, crossover,	• BCS performed significantly better on tests of verbal learning, memory, visual perception, and scanning speed in the methylphenidate condition.	**Strengths** • Double-blind, 2-period, placebo-controlled crossover trial **Limitations** • Small sample size • Short treatment period

Release Methylphenidate in the Treatment of Fatigue in Cancer Patients		and final visit. • Primary outcomes of interest were scores on tests assessing fatigue, depression, sleep, and mood.		• Low dose of methylphenidate • No long-term follow-up testing • Lack of racial diversity
Kohli et al 2009 USA The Effect of Modafinil on Cognitive Function in Breast Cancer Survivors	68 chemotherapy-treated BCS • 2 Randomized Groups: 1. Modafinil (N = 34, M_{age} = 52 years, Race = 97% Caucasian, $M_{months\ post-\ treatment}$ = 22.1) 2. Placebo Control (N = 34, M_{age} = 56 years, Race = 100% Caucasian, $M_{months\ post-treatment}$ = 22.1)	• All 68 BCS participated in an open label 4-week trial of modafinil and had initial good response on fatigue. • Post open label trial, BCS received either 4 weeks of modafinil or placebo. • Cognitive assessment was administered prior to any modafinil treatment, after the 1st 4 weeks of treatment, and after the 2nd 4 weeks of treatment.	• The modafinil treated group showed significant improvement compared to the placebo group on speed and quality of memory and attention after 4 weeks of treatment. • Treatment of 8 weeks resulted in greater improvement than 4 weeks on some measures.	**Strengths** • RCT • Fewer side effects than other stimulants **Limitations** • Secondary data analysis • Lack of pre-chemotherapy baseline • Lack of racial diversity
Lower et al 2009 USA Efficacy of Dexmethylphenidate for the Treatment of Fatigue After Cancer Chemotherapy: A Randomized Clinical Trial	154 chemotherapy-treated cancer survivors • 2 Randomized Groups: 1. Methylphenidate (N = 76, BCS = 59, M_{age} = 53 years, Race = 83% Caucasian, $M_{months\ post-chemotherapy}$ = 28) 2. Placebo Control (N = 78, BCS = 59, M_{age} = 53 years, Race = 77% Caucasian, $M_{months\ post-chemotherapy}$ = 25)	• 1-week single-blind placebo run-in period followed by randomized double-blind trial • Treatment phase lasted 8 weeks. • Primary outcome measure consisted of change from baseline on Functional Assessment of Chronic Illness Therapy-Fatigue Subscale. • Secondary outcome measure was change from baseline on HSCS	• There was no significant change on the HSCS in either group as compared to baseline.	**Strengths** • Randomized double-blind design **Limitations** • Adverse side effects • Low dose • Non BCS participants • HSCS known for practice effects. • Only 77% BCS • Lack of racial diversity
Mar Fan et al 2008 Canada A Randomized, Placebo-controlled, Double-blind Trial of the Effects of d-methylphenidate on Fatigue and Cognitive Dysfunction in Women Undergoing Adjuvant Chemotherapy for Breast Cancer	57 BCS undergoing chemotherapy • 2 Randomized Groups: 1. Methylphenidate (N = 29, M_{age} = 50 years) 2. Placebo Control (N = 28, M_{age} = 51 years)	• BCS in intervention group received methylphenidate throughout chemotherapy. • Primary outcome measure consisted of proportion of BCS with moderate to severe cognitive dysfunction on the HSCS at the end of chemotherapy and 4-6 months post-intervention.	• There was no significant group difference on the HSCS at any time point.	**Strengths** • Randomized placebo-blind design **Limitations** • Small sample size • HSCS known for practice effects. • Participant race/ethnicity not reported
Mar Fan et al 2009 Canada The Influence of Erythropoietin on Cognitive Function	87 BCS undergoing chemotherapy • 2 Randomized Groups: 3. Epoetin alfa (N = 45, M_{age} = 53 years) 4. Placebo Control	• BCS received either epoetin alfa during chemotherapy or standard care. • HSCS, Revised Hopkins Verbal Learning Test, and fatigue and quality of life questionnaires	• There was no group effect on either of the two cognitive tests. • The epoetin alfa group reported a higher overall quality of life than the standard care group.	**Strengths** • Examined long-term effects of epoetin alfa on cognition • Neurocognitive Testing **Limitations**

in Women Following Chemotherapy for Breast Cancer	(N = 42, M_{age} = 50 years)	were administered 12-30 months post-chemotherapy.		• Only BCS with moderate-severe impairment • Sub-study design precluded randomization • HSCS known for practice effects. • Participant race/ethnicity not reported
O' Shaughnessey et al 2005 USA Feasibility of Quantifying the Effects of Epoetin Alfa Therapy on Cognitive Function in Women with Breast Cancer Undergoing Adjuvant or Neoadjuvant Chemotherapy	94 BCS undergoing chemotherapy • 2 Randomized Groups: 1. Epoetin alfa (N = 47, M_{age} = 53 years) 2. Placebo Control (N = 47, M_{age} = 54 years)	• BCS received either epoetin alfa or a placebo subcutaneously once per week at the beginning of 4 weeks of chemotherapy lasting for a total of 12 weeks. • Cognitive function was evaluated with the EXIT25 and clock drawing tasks at baseline, 1 week before chemotherapy cycle 4 and 6 months post-chemotherapy.	• BCS treated with epoetin alfa during chemotherapy performed better than a placebo control group on a questionnaire of executive functioning. • There was no difference between the two groups 6-months post-treatment.	**Strengths** • Randomized double-blind placebo-controlled trial • Epoetin alfa was well tolerated • Neurocognitive Testing **Limitations** • Performance on the clock drawing task was near ceiling at baseline. • Participant race/ethnicity not reported

Note: BCS = Breast Cancer Survivors; HSCS = High Sensitivity Cognitive Screen; MAAT = Memory and Attention Adaptation Training; RCT = Randomized Control Trial.

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APPENDIX E

IRB APPROVAL, RECRUITMENT, AND CONSENT DOCUMENTS

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on November 8, 2021. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator:	BAIL, JENNIFER REBECCA
Co-Investigator(s):	HEATON, KAREN L VANCE, DAVID E
Protocol Number:	**X161101001**
Protocol Title:	*Cancer-Related Symptoms and Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study (Cognitive Deficits in Breast Cancer Survivors)*

The IRB reviewed and approved the above named project on 11/28/16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 11/28/16

Date IRB Approval Issued: 11/28/16

IRB Approval No Longer Valid On: 11/28/17

HIPAA Waiver Approved?: Yes

Expedited Reviewer
Member - Institutional Review Board
for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

470 Administration Building
701 20th Street South
205.934.3789
Fax 205.934.1301
irb@uab.edu

The University of
Alabama at Birmingham
Mailing Address:
AB 470
1720 2ND AVE S
BIRMINGHAM AL 35294-0104

Recruitment Script

Hello. My name is Jennifer Bail. I am a PhD student at the UAB School of Nursing. I am conducting a research study for my dissertation to examine the relationship between mood, sleep, mental abilities, and cognitive training among breast cancer survivors in Alabama. You participated in the "Speed of Processing in Middle Aged and Older Breast Cancer Survivors" (SOAR) cognitive training study through the UAB School of Nursing and agreed to be contacted regarding future research opportunities.

WOULD YOU LIKE TO PROCEED WITH THIS PHONE CALL? ***YES / NO***

- **IF NO,** "Thank you for your time, I will remove your name from my list."
- **IF YES, CONTINUE WITH SCRIPT**.

We are asking you to take part in a study to learn about your experience in the SOAR cognitive training study. The information that you share may help us better understand how to improve mental abilities and everyday functioning in breast cancer survivors in the future. This study will enroll up to 20 participants from the SOAR study.

If you choose to participate, you will complete two audio-recorded interviews at a private location of your choosing. The first interview will be conducted in person. During this interview, we will ask you questions about difficulties you may have experienced with the cognitive training and things that helped you with the cognitive training. You will also be asked about your mood, sleep, and mental abilities. This interview may last up to 90 minutes. After the first interview you will be asked to review a written summary of the first interview for accuracy. The second interview will be over the phone and will occur within one week of the first interview. During the second interview you will be given an opportunity to further elaborate or to add

anything you did not mention in the first interview. This interview may last up to 30 minutes. At the completion of each interview you will receive a $25 gift card, for your time and travel.

If you agree to participate, your identity will be protected and all of your information held confidential. Any information or responses will be coded in a way that does not identify you, and any publications resulting from the study will not include any personal identifying information.

ARE YOU INTERESTED IN PARTICIPATING? ***YES / NO***

- **IF NO,** "Thank you for your time."
- **IF YES, SCHEDULE BOTH INTERVIEW APPOINTMENTS.**

Interview #1 Appointment (*in person*):

Date:_____

Time:_____

Location:_____

Interview #2 Appointment (*telephone*):

Date:_____

Time:_____

Phone number:_____

CONSENT FORM

TITLE OF RESEARCH:	Cancer-Related Symptoms and Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study (Cognitive Deficits in Breast Cancer Survivors)
IRB PROTOCOL NO.:	X161101001
INVESTIGATOR:	Jennifer Bail, BSN, RN
SPONSOR:	**American Cancer Society**

Purpose of the Research

We are asking you to take part in a research study to learn about your experience of participating in the "*Speed of Processing in Middle Aged and Older Breast Cancer Survivors*" (SOAR) cognitive training study. The purpose of this study is to examine the relationship between mood, sleep, mental abilities and cognitive training among breast cancer survivors in Alabama. The information that you share will help inform the development of future cognitive interventions for breast cancer survivors. This study will enroll up to 20 participants from the SOAR study.

Explanation of Procedures

If you enter the study, you will complete two audio-recorded interviews at a private location of your choosing. The first interview will be conducted in person. During this interview, we will ask you questions about difficulties you may have experienced with the cognitive training and things that helped you with the cognitive training. You will also be asked about your mood, sleep, and mental abilities. This interview may last up to 90 minutes. After the first interview you will be asked to review a written summary of the first interview for accuracy that we will send you. The second interview will be over the phone and will occur within one week of the first interview. During the second interview you will be given an opportunity to further elaborate or to add anything you did not mention in the first interview. This interview may last up to 30 minutes.

Risks and Discomforts

The risks associated with this project are very small. You may feel some stress or emotional discomfort discussing your cancer-related symptoms. You are free to end the discussion at any point.

Benefits

You will not benefit directly from taking part in this study. However, this study may help us better understand how to improve mental abilities and everyday functioning in breast cancer survivors in the future.

Alternatives

The alternative to enrolling in this study is choosing not to participate.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with the UAB Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to research including the Office for Human Research Protections (OHRP), and the American Cancer Society. The information from the research, at the group level, may be published for scientific purposes; however, no individual will be identified.

Consent forms will be kept in a locked file within a secure office at the UAB School of Nursing Office of Research and Scholarship and will be available only to study staff. You will not be identified to anyone outside the project staff without your permission, and your name will be removed from all results prior to analysis. The door to the research office where data files (audio recording and transcripts of interviews) are kept locked when no one is present. After the recordings are transcribed, they will be password protected and stored on the UAB School of Nursing secure server. Audio recordings will be destroyed at the completion of the study.

Voluntary Participation and Withdrawal

Whether or not you take part in this study is your choice. There will be no penalty if you decide to not be in the study. If you decide not to be in the study, you will not lose any benefits you are otherwise owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this institution. You may be removed from the study without your consent if you are not following the study rules.

If you are a UAB student or employee, taking part in this research is not a part of your UAB class work or duties. You can refuse to enroll, or withdraw after enrolling at any time before the study is over, with no effect on your class standing, grades, or job at UAB. You will not be offered or receive any special consideration if you take part in this research.

Cost of Participation

There will be no cost to you for taking part in this study.

Payment for Participation in Research

You will receive $25 for each interview that you complete. Payments will be made at the completion of interview. The method of payment that will be used for this study is in the form of a gift card. The first one will be given to you in person, and the second one will be mailed to you.

Questions

If you have any questions, concerns, or complaints about the research, you may contact Jennifer Bail. She will be glad to answer any of your questions. Jennifer Bail may be reached at 205-975-2391.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB (OIRB) at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

Signatures

Your signature below indicates you that you have read the information provided above and agree to participate in this study. You will receive a copy of this signed consent form.

Signature of Participant Date

Signature of Principal Investigator Date

University of Alabama at Birmingham

AUTHORIZATION FOR USE/DISCLOSURE OF PROTECTED HEALTH INFORMATION (PHI) FOR RESEARCH

Participant Name: _____

UAB IRB Protocol Number: 161101001

Research Protocol: Cancer-Related Symptoms and Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study (Cognitive Deficits in Breast Cancer Survivors)

Principal Investigator: Jennifer Bail, BSN, RN

Sponsor: American Cancer Society

What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your protected health information for research. Participation in research is voluntary. If you choose to participate in the research, you must sign this form so that your protected health information may be used for the research.

Why do the researchers want my protected health information? The researchers want to use your protected health information as part of the research protocol listed above and as described to you in the informed consent.

What protected health information do the researchers want to use? All medical information, including but not limited to information and/or records of any diagnosis or treatment of disease or condition, which may include sexually transmitted diseases (e.g., HIV, etc.) or communicable diseases, drug/alcohol dependency, etc.; all personal identifiers, including but not limited to your name, social security number, medical record number, date of birth, dates of service, etc.; any past, present, and future history, examinations, laboratory results, imaging studies and reports and treatments of whatever kind, including but not limited to drug/alcohol treatment, psychiatric/psychological treatment; financial/billing information, including but not limited to copies of your medical bills, and any other information related to or collected for use in the research protocol, regardless of whether the information was collected for research or non-research (e.g., treatment) purposes.

Who will disclose, use and/or receive my protected health information? All individuals/entities listed in the informed consent documents, including but not limited to, the physicians, nurses and staff and others performing services related to the research (whether at UAB or elsewhere); other operating units of UAB, HSF, UAB Highlands, Children's of Alabama, Eye Foundation Hospital, and the Jefferson County Department of Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees and agents, including any CRO; and any outside regulatory agencies, such as the Food and Drug Administration, providing oversight or performing other legal and/or regulatory functions for which access to participant information is required.

How will my protected health information be protected once it is given to others? Your protected health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.

Can I cancel this Authorization? You may cancel this Authorization at any time by notifying the Principal Investigator, in writing, referencing the research protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However, researchers may continue to use the protected health information that was provided before you cancelled your authorization.

Can I see my protected health information? You have a right to request to see your protected health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

Signature of participant: _____ Date: _____

or participant's legally authorized representative: _____ Date: _____

Printed Name of participant's representative: _____

Relationship to the participant: _____

Project Revision/Amendment Form

Form version: June 26, 2012

In MS Word, click in the white boxes and type your text; double-click checkboxes to check/uncheck.

- Federal regulations require IRB approval before implementing proposed changes. See Section 14 of the IRB Guidebook for Investigators for additional information.
- Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.). See Item 4 for more examples.

1. Today's Date	December 16, 2016	29689

2. Principal Investigator (PI)

Name (with degree)	Jennifer Bail, BS,RN	Blazer ID	jbail
Department	School of Nursing	Division (if applicable)	
Office Address	MT 504	Office Phone	205-975-2391
E-mail	jbail@uab.edu	Fax Number	

Contact person who should receive copies of IRB correspondence (Optional)

Name		E-Mail	
Phone		Fax Number	
Office Address (if different from PI)			

3. UAB IRB Protocol Identification

3.a. Protocol Number	X161101001
3.b. Protocol Title	Cancer-Related Symptoms and Cognitive Intervention Adherence Among Breast Cancer Survivors: A Mixed Methods Study (Cognitive Deficits in Breast Cancer Survivors)

3.c. Current Status of Protocol—Check ONE box at left; provide numbers and dates where applicable

- ☒ Study has not yet begun — No participants, data, or specimens have been entered.
- ☐ In progress, open to accrual — Number of participants, data, or specimens entered:
- ☐ Enrollment temporarily suspended by sponsor
- ☐ Closed to accrual, but procedures continue as defined in the protocol (therapy, intervention, follow-up visits, etc.)
  - Date closed:
  - Number of participants receiving interventions:
  - Number of participants in long-term follow-up only:
- ☐ Closed to accrual, and only data analysis continues
  - Date closed:
  - Total number of participants entered:

4. Types of Change

Check all types of change that apply, and describe the changes in Item 5.c. or 5.d. as applicable. To help avoid delay in IRB review, please ensure that you provide the required materials and/or information for each type of change checked.

- ☐ **Protocol revision (change in the IRB-approved protocol)**
  In Item 5.c., if applicable, provide sponsor's protocol version number, amendment number, update number, etc.
- ☒ **Protocol amendment (addition to the IRB-approved protocol)**
  In Item 5.c., if applicable, provide funding application document from sponsor, as well as sponsor's protocol version number, amendment number, update number, etc.
- ☐ **Add or remove personnel**
  In Item 5.c., include name, title/degree, department/division, institutional affiliation, and role(s) in research, and address whether new personnel have any conflict of interest. See "Change in Principal Investigator" in the IRB Guidebook if the principal investigator is being changed.
  - ☐ **Add graduate student(s) or postdoctoral fellow(s) working toward thesis, dissertation, or publication**
    In Item 5.c., (a) identify these individuals by name; (b) provide the working title of the thesis, dissertation, or publication; and (c) indicate whether or not the student's analysis differs in any way from the purpose of the research described in the IRB-approved HSP (e.g., a secondary analysis of data obtained under this HSP).
- ☐ **Change in source of funding; change or add funding**
  In Item 5.c., describe the change or addition in detail, include the applicable OSP proposal number(s), and provide a copy of the application as funded (or as submitted to the sponsor if pending). Note that some changes in funding may require a new IRB application.

☐ **Add or remove performance sites**
In Item 5.c., identify the site and location, and describe the research-related procedures performed there. If adding site(s), attach notification of permission or IRB approval to perform research there. Also include copy of subcontract, if applicable. If this protocol includes acting as the Coordinating Center for a study, attach IRB approval from any non-UAB site added.

☐ **Add or change a genetic component or storage of samples and/or data component—this could include data submissions for Genome-Wide Association Studies (GWAS)**
To assist you in revising or preparing your submission, please see the IRB Guidebook for Investigators or call the IRB office at 934-3789.

☐ **Suspend, re-open, or permanently close protocol to accrual of individuals, data, or samples (IRB approval to remain active)**
In Item 5.c., indicate the action, provide applicable dates and reasons for action; attach supporting documentation.

☐ **Report being forwarded to IRB (e.g., DSMB, sponsor or other monitor)**
In Item 5.c., include date and source of report, summarize findings, and indicate any recommendations.

☐ **Revise or amend consent, assent form(s)**
Complete Item 5.d.

☐ **Addendum (new) consent form**
Complete Item 5.d.

☐ **Add or revise recruitment materials**
Complete Item 5.d.

☐ **Other (e.g., investigator brochure)**
Indicate the type of change in the space below, and provide details in Item 5.c. or 5.d. as applicable.
Include a copy of all affected documents, with revisions highlighted as applicable.

▶

5. Description and Rationale

In Item 5.a. and 5.b, check Yes **or** No **and see instructions for** Yes **responses.**
In Item 5.c. and 5.d, describe—and explain the reason for—the change(s) noted in Item 4.

☐Yes ☒No **5.a. Are any of the participants enrolled as normal, healthy controls?**
If yes, describe in detail in Item 5.c. how this change will affect those participants.

☐Yes ☒No **5.b. Does the change affect subject participation, such as procedures, risks, costs, location of services, etc.?**
If yes, FAP-designated units complete a FAP submission and send to fap@uab.edu. Identify the FAP-designated unit in Item 5.c.
For more details on the UAB FAP, see www.uab.edu/cto.

5.c. Protocol Changes: In the space below, briefly describe—and explain the reason for—all change(s) to the protocol.

▶ We request the addition of an Individual Interview Protocol (**See the attached *Individual Interview Protocol***) which will be utilized in individual interview #1. This protocol was developed based on the secondary data analysis results from the first phase of this sequential mixed methods study.

5.d. Consent and Recruitment Changes: In the space below,
(a) describe all changes to IRB-approved forms or recruitment materials and the reasons for them;
(b) describe the reasons for the addition of any materials (e.g., addendum consent, recruitment); and
(c) indicate either how and when you will reconsent enrolled participants or why reconsenting is not necessary (not applicable for recruitment materials).

Also, indicate the number of forms changed or added. For new forms, provide 1 copy. For revised documents, provide 3 copies:
- **a copy of the currently approved document (showing the IRB approval stamp, if applicable)**
- **a revised copy highlighting all proposed changes with "tracked" changes**
- **a revised copy for the IRB approval stamp.**

▶

Signature of Principal Investigator Jennifer Bail Date 12/16/2016

FOR IRB USE ONLY

☐ Received & Noted ☑ Approved Expedited* ☐ To Convened IRB

Marilyn Doss 1-3-17

Signature (Chair, Vice-Chair, Designee) Date

DOLA 11/28/16

Change to Expedited Category Y / N / NA

*No change to IRB's previous determination of approval criteria at 45 CFR 46.111 or 21 CFR 56.111

APPENDIX F

CONSENT TO CONTACT FOR FUTURE RESEARCH

CONSENT FORM

TITLE OF RESEARCH:	Speed of Processing in Middle Aged and Older Breast Cancer Survivors
IRB PROTOCOL NO.:	X141205005
INVESTIGATOR:	Karen Meneses, Ph.D., RN, FAAN
SPONSOR:	**National Institute on Aging/**National Institutes of Health

Purpose of the Research

Some breast cancer survivors report changes with their memory, attention, concentration and other mental abilities important in everyday life. We are asking you to take part in a research study to test whether training on a computer task similar to a video game changes performance on tests of these abilities. The study involves testing that will consist of completing several questionnaires about your mood and health, as well as tests of mental abilities. The study also involves training for approximately 1/2 of participants who are randomly selected to receive training. Training consists of a total of ten total hours over the course of four to six weeks on a computerized program called RoadTour™. This study will enroll 60 participants from the Birmingham area, 30 of whom will complete the training at home while 30 participants will be randomized to a control group and will not receive training. Ten to 12 weeks after the first visit participants will repeat the same questionnaires and mental tests as given prior to the training. You will also be asked to come back about 6 months later and repeat these tests.

Explanation of Procedures

If you enter the study, you will complete three testing sessions. Thirty of the 60 participants will also complete 10 hours of training . The first step is completion of a testing session which will involve questionnaires on your physical and psychological health and general well-being. The questionnaires will be followed on the same visit by several tests of mental abilities such as memory and attention. The first visit will be conducted at the Roybal Center for Research on Applied Gerontology at UAB and will last approximately two to two and one-half hours.

After the first testing, you will be randomly picked (like the flip of a coin) by a computer to complete the training program either at home, at the Roybal Center, or receive no training.

- For those assigned to training at home, user name and password with instructions for logging onto the Posit training website and a telephone help line number will be given to you for use on your home computer. Your progress will be remotely monitored by the research staff after you have installed and created a user profile within the software. You will be asked to complete 2 hours per week of training on this software at home.

- Those assigned to the no contact control group will be scheduled for follow-up after their baseline visit and will do no training between these testing visits.
- Within two weeks of completing the computer training or about 10-12 weeks after your first testing session, you will be scheduled for a second testing session at UAB which will be identical to the first session. Every participant will also be called to schedule a follow-up appointment approximately 6 months after your first testing visit.

Risks and Discomforts

The risks associated with this project are very small. You may feel some stress or emotional discomfort discussing your breast cancer experience. You are free to end the discussion at any point. The testing or the training may cause fatigue or frustration which will resolve with rest.

You will be assigned by chance to complete the training sessions in your home or not at all.

Benefits

You may not benefit directly from taking part in this study. However, this study may help us better understand how to improve mental abilities and everyday functioning in breast cancer survivors in the future.

Alternatives

The alternative to enrolling in this study choosing not to participate.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with the UAB Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to researchincluding the people on behalf of the NIA/NIH and the Office for Human Research Protections (OHRP). The information from the research may be published for scientific purposes; however, your identity will not be given out.

Voluntary Participation and Withdrawal

Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you are otherwise owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this institution. You may be removed from the study without your consent if you are not following the study rules.

If you are a UAB student or employee, taking part in this research is not a part of your UAB class work or duties. You can refuse to enroll, or withdraw after enrolling at any time before the study is over, with no effect on your class standing, grades, or job at UAB. You will not be offered or receive any special consideration if you take part in this research.

Cost of Participation

There will be no cost to you for taking part in this study.

Payment for Participation in Research

You will receive $50 for each testing session and $20 for each training hour that you complete (up to $200). If you quit the study, you will be paid for each session you have completed. Payments will be made at the completion of the second testing session and the 6 month follow-up testing session, or at the time you decide to end participation. If you complete 3 testing sessions and 10 training hours you will receive a total of $350. If you are assigned to the no contact control group and complete the 3 testing sessions, you will receive $150. Ask the study staff about the method of payment that will be used for this study (e.g., check, cash, gift card, direct deposit).

Payment for Research-Related Injuries

UAB has not provided for any payment if you are harmed as a result of taking part in this study. If such harm occurs, treatment will be provided. However, this treatment will not be provided free of charge.

Questions

If you have any questions, concerns, or complaints about the research or a research-related injury including available treatments, you may contact Dr. Karen Meneses. She will be glad to answer any of your questions. Dr. Meneses may be reached at 205-996-7038.
If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB (OIRB) at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

Data Storage

Consent forms will be kept in a locked file within a secure office at the UAB School of Nursing and will be available only to study staff. You will not be identified to anyone outside the project staff without your permission, your name will be removed from all results prior to analysis. The door to the research office where data files (the results from your testing and training sessions) are kept will remain locked when no one is present.

Consent to Contact for Future Research

☐ I would like to be contacted for future research for which I may be eligible.

☐ I do not want to be contact for future research.

Signatures

Your signature below indicates you that you have read (or been read) the information provided above and agree to participate in this study. You will receive a copy of this signed consent form.

Signature of Participant Date

Signature of Person Obtaining Informed Consent Date

Reviewed by:

Signature of Principal Investigator Reviewing Consent Document Date

University of Alabama at Birmingham
AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION FOR RESEARCH

What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your health information for research. Participation in research is voluntary. If you choose to participate in the research, you must sign this form so that your health information may be used for the research.

Participant Name: _____

Research Protocol: Speed of Processing in Middle Aged and Older Breast Cancer Survivors

UAB IRB Protocol Number: X141205005

Principal Investigator: Karen Meneses, Ph.D.

Sponsor: National Institutes of Health.

What health information do the researchers want to use? All medical information and personal identifiers, including past, present, and future history, examinations, laboratory results, imaging studies and reports and treatments of whatever kind related to or collected for use in the research protocol.

Why do the researchers want my health information? The researchers want to use your health information as part of the research protocol listed above and described to you in the Informed Consent document.

Who will disclose, use and/or receive my health information? The physicians, nurses and staff working on the research protocol (whether at UAB or elsewhere); other operating units of UAB, HSF, UAB Highlands, Children's of Alabama, Eye Foundation Hospital and the Jefferson County Department of Public Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees; and outside regulatory agencies, such as the Food and Drug Administration.

How will my health information be protected once it is given to others? Your health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.

Can I cancel the Authorization? You may cancel this Authorization at any time by notifying the Principal Investigator, in writing, referencing the Research Protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However, researchers may continue to use the health information that was provided before you cancelled your authorization.

Can I see my health information? You have a right to request to see your health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

Signature of participant: _____ Date: _____

or participant's legally authorized representative: _____ Date: _____

Printed Name of participant's representative: _____

Relationship to the participant: _____

APPENDIX G

QUALITATIVE INTERVIEW SUMMATIVE REPORTS

Qualitative Interview Summative Reports

Participant 1

Participant enrolled in the study to learn more about "chemobrain" because she had noticed some changes in how she was thinking. She felt that the study was easy and met her expectations of learning more about the effects of her cancer treatment. She did not complete all 10 hours of cognitive training and did not feel that the number of hours that she did was sufficient. However, she enjoyed doing the cognitive training, which she found engaging and challenging. She thought that the computer program was easy to use and navigate, although she would have preferred for the training to be more mobile (i.e., mobile app). She found the training to be helpful as it made her more aware of the mental delays that she was experiencing. In fact, she felt that she was previously in denial of any cognitive changes. Since becoming more aware of her cognitive changes, she has begun utilizing coping strategies (e.g., planner, lists, large key chain). She has not experienced any improvements in mood but has experienced more feelings of frustration as she has to cope with new things. Her sleep has improved; her thoughts race less and she is up less in the night, resulting in more of a solid night's sleep. She tried to schedule cognitive training early on Saturday mornings while the kids were sleeping; however, the computer was set up in the basement where an extended family member was temporarily staying. Challenges she experienced in doing the cognitive training consisted of her environment and the lack of mobility of the training (i.e., it had to be completed on a personal computer). She did not receive any support from those in her household. She felt that household support may have aided her in completing the training. She would recommend that other BCS: 1) take full advantage of the cognitive training, 2) make it a priority, 3) schedule frequent short cognitive training sessions, 4) do

as many hours as they can, and 5) keep a journal (i.e., how you feel, what is on your mind). She loved the program and felt that it was simple and easy for anyone to do. Improvements to the program would include making the training more mobile and adding participant journaling.

Participant 2

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some changes in her memory and wanted to help other BCS. The study was easy for her and met her expectations of helping her memory. She both completed all 10 hours of cognitive training and felt that the number of hours that she did was sufficient. She thought that the cognitive training program was easy to use and navigate, and she liked the convenience and flexibility to be able to do it at home on her own schedule. However, she found the cognitive training to be repetitive and would have preferred more variety. Overall, though, she found the training to be helpful and feels that her memory is sharper, her brain is less foggy, and she is experiencing less frustration than before the doing the cognitive training. She did not necessarily schedule her cognitive training; rather, she just worked it in when she could, usually in the morning. Fitting it in rather than trying to make it so rigid worked better for her. Completing her training in the kitchen, which was not necessarily free from distractions, still worked better for her than locking herself away in another room and being inaccessible to her family. The convenience and flexibility to be able to do the training at home, on her own schedule, and knowing that it could benefit her helped her in completing the cognitive training. Furthermore, the emotional support she received from her husband encouraged her to do the cognitive training. She would recommend

that other BCS doing cognitive training set weekly goals, be flexible, and not get discouraged. Improvements to the program would include being able to gauge one's advancement more clearly and having more variety in the training.

Participant 3

Participant was informed about the study at her support group meeting. She decided to enroll in the study because she was experiencing some changes in her memory and wanted to help other BCS. She thought that the computer program was easy to use and navigate. She did not complete all 10 hours of cognitive training and did not feel that the number of hours that she did was sufficient. Still, she enjoyed doing the cognitive training, finding it engaging and challenging, and felt like she was doing something good for herself. However, she found the game to be primitive; it could get boring and she would have preferred more variety. She noticed that her cognitive training performance would vary on different days, but she is not sure why and thinks it would have been helpful to keep a journal during the training to record how she was feeling (i.e., mood, sleep, and cognitive and physical status). She did her cognitive training in her room on her bed, preferably in the evening, when everything was calmed down and quiet so that she could sit down and concentrate. She felt that her ability to focus, mood, and sleep quality may have influenced doing her cognitive training. Since doing the cognitive training, she has not experienced any improvements in cognition, mood, or sleep. Her household at the time of the cognitive training consisted of her husband and 7-year-old granddaughter. While she did not receive any support in doing her cognitive training from those in her household, she did receive emotional support from her sister. She would recommend this program for other BCS and would tell them to "just give it a try,"

advising them to do the cognitive training when it's quiet and they're in a good mood, well rested, and pain free. Also, they should have all their ducks in a row before sitting down to complete the cognitive training. Improvements to the program would include making the training less primitive, with more variety, and adding participant journaling.

Participant 4

Participant was informed about the study at her support group meeting. She decided to enroll in the study to learn more about "chemobrain," since she was noticing some changes in how she was thinking, and to help other BCS. She did not complete all 10 hours of cognitive training and did not feel that the number of hours that she did was sufficient. Although she felt that the study was difficult at times, it met her expectations of stimulating her brain. She found the training to be helpful, as it made her more aware of her thought process. Since becoming more aware of her thought process, she has felt more focused and mindful of what she is doing. She mentioned being more likely to remember why she went to a particular room, instead of forgetting. She has not experienced any changes in mood or sleep since doing the cognitive training. Things that helped her with the cognitive training included: 1) receiving reminders and encouragement from the research assistant, 2) a personal sense of commitment and responsibility, and 3) doing her training in a comfortable place when she was home alone. She did not schedule cognitive training. It was easier to do the training whenever she had a free moment. She tended to do the training at home on her couch in the living room, which was a comfortable spot for her. Personal responsibilities (e.g., running errands) and fatigue would sometimes interfere with doing her cognitive training. Being provided a tablet with the cognitive training loaded on it would have made it easier for her. While

she lived alone and did not have any household support, she received emotional support from her support group. She would recommend that other BCS: 1) make the time to do the cognitive training, 2) create a schedule for cognitive training, 3) take baby steps and not get overwhelmed, and 4) find a quiet space where they can concentrate. She genuinely enjoyed the study and is proud to have been part of it.

Participant 5

Participant was noticing some changes in her attention and memory. She found out about the study by being "tagged" on Facebook. Her main reason for enrolling in the study was to help other BCS. She did not have any expectations when she enrolled. At the beginning of the study she had a little difficulty getting started, due to the lack of mobility. While participants were instructed to complete the cognitive training on a computer, she completed it on her phone. The flexibility of doing it on the phone allowed her to complete the 10 hours. While she felt that the 10 hours was sufficient, she thought that some people may benefit from doing more. Although she thought that the cognitive training program was easy to use and navigate, she found it to be repetitive and boring and would have preferred more variety. She has not noticed any changes since doing the cognitive training and has not experienced any improvements in cognition, mood, or sleep. Things that helped her complete the cognitive training included receiving reminders and encouragement from the research assistant and a personal sense of commitment and responsibility. She did not schedule cognitive training. It was easier to do the training on her phone whenever she had a free moment. She tended to do the training at home in her recliner in the living room, which was a comfortable spot for her. The challenge she experienced in doing the cognitive training was repetitiveness, which

made it boring and made it seem to take forever to complete. Things that would have made it easier include: 1) making it mobile (i.e., phone app, iPad), 2) more colorful graphics, 3) more variety of training, 4) more positive feedback, and 5) a display that shows the user the number of hours they have trained. While she received emotional support from her daughter, she did not receive any support from other household members. She considers herself a procrastinator, which she felt made it more challenging for her to get the training completed. She felt that her ability to focus, her sleep quality, and mood did have some impact on her cognitive training. She would recommend that other breast cancer survivors doing the cognitive training, not procrastinate, and not get frustrated with the repetitiveness.

Participant 6

Participant was experiencing difficulty with her attention and memory. She decided to enroll in the study to learn more about "chemobrain" and to see if the study could help improve her attention and memory. She felt that the study was easy and met her expectations of learning more about the effects of her cancer treatment. She completed all 10 hours of cognitive training and felt that the number of hours that she did was sufficient. She enjoyed doing the cognitive training, which she characterized as engaging and challenging, easy to use, and navigate. The fact that the cognitive training consisted of doing the same task over and over made it easy for her. Even though the training was repetitive, she did not find it boring and actually looked forward to doing it. She did not find anything difficult about the study. She found the training to be helpful as it made her aware of "chemobrain" and that it was a real thing. She has not noticed any changes since doing the cognitive training and has not experienced any

improvements in cognition, mood, or sleep. She didn't necessarily schedule her cognitive training, but she tried to log on every day. She generally did her cognitive training at the kitchen table because it made it easier for her to sit up straight and remain mostly free from distractions. At first she experienced some difficulty with logging into the computer, but after her daughter helped her, she was able to do the training on her own. She felt that her training sessions went by quickly and she did not experience any physical discomfort during the sessions. Her household consisted of her and her two teenage daughters. Her daughters supported her in doing the cognitive training by assisting her with logging onto the computer, having a positive attitude about the training, and by not disrupting her when she was doing her training sessions. She would recommend this program for other BCS. She felt that it is good for BCS to be aware of "chemobrain" and that they should give cognitive training a try because it may help them.

Participant 7

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some changes in her memory. The study was easy for her and exceeded her expectations of helping her improve her memory. Her acceptance of the fact that she had a problem with her memory and taking personal responsibility to do what she needed to do to improve her brain health helped her in completing all 10 hours of cognitive training. She enjoyed doing the cognitive training and would have liked to do even more. In fact, she found the cognitive training to be engaging and challenging, and this motivated her to improve her score and "beat this thing." The computer program was a little difficult to use and navigate at first, but it got easier over time. She liked the convenience and flexibility of being able to do

the training at home on her own time. She did her cognitive training in her room, which was a room of comfort and privacy for her. At first she experienced some difficulty with logging into the computer, but after her son helped her, she was self-sufficient. The most difficult thing for her was finding quiet time to be able to sit and focus on the cognitive training like she wanted to. She generally did her cognitive training at night when everyone was in bed or during the day when her grandkids were in school. She found the training to be helpful as it helped her to learn how to stay focused on what she was doing and to really listen to what someone was saying to her. Since doing the cognitive training, her confidence has increased, she feels good, smiles more, she is more socially active, and just enjoys life so much more. She reported experiencing improvements in memory, mood, and sleep. She received emotional support and assistance with household chores from her household, which consisted of her three daughters, one son, and three grandkids. In addition, her son supported her by lending her his computer and helping her with logging on and getting the right webpage. She would recommend this program for other BCS and would tell them to "just give it a try" and don't give up, because it's worth every moment.

Participant 8

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some changes in her memory and wanted to help other BCS. She felt that the study was easy; however, the time management to complete all 10 hours of the cognitive training was challenging. While she felt that the 10 hours was sufficient for this study, she thought that there should be guidance for how much people should do to receive benefit (i.e., duration of sessions,

number of sessions, and number of weeks/months). She thought that the cognitive training program was easy to use and navigate. She enjoyed doing the cognitive training and having a sense of doing something proactive for her brain health. She also liked advancing levels and improving her score. However, after a period of time it felt like there was no advancement; rather the training was just repeating and at times boring. She would have preferred more variety and for it to be available on a mobile device. Overall, she felt that the cognitive training had a positive effect on her life. She felt more focused and was able to find her words better while doing the training. Things that helped her complete the cognitive training included: 1) previous knowledge of and experience with cognitive training, 2) receiving reminders and encouragement from the research assistant, and 3) a personal sense of commitment and responsibility. She did not schedule cognitive training. She considers herself a procrastinator, which led to her doing the majority of the training in the last week of the intervention. She chose to do her training at home at her kitchen table, which was not where she normally sat in the house and therefore felt a little isolated. The challenge she experienced in doing the cognitive training was repetitiveness, which made it boring and at times could even be agitating. Things that would have made it easier include: 1) making it mobile (i.e., phone app, iPad), 2) more colorful graphics, 3) more variety of training, 4) more positive feedback, and 5) incentives to improve one's score and advance levels. She felt that her ability to focus, sleep quality, and mood did have some impact on her cognitive training performance and motivation to do cognitive training. She would recommend that other BCS doing cognitive training: 1) make a schedule, 2) be flexible, 3) set goals, 4)

experiment with different days and times, and 5) be informed about the purpose of cognitive training and what it does.

Participant 9

Participant decided to enroll in the study to help other BCS and to possibly help improve her focus. Also, the compensation was helpful to her. She thought that the computer program was easy to use and navigate. She did not complete the 10 hours of cognitive training and felt that the number of hours that she did was not sufficient and thought that she should have done more. Despite this, she found the cognitive training to be easy, fun, and challenging, and she liked that it made her sit and focus. At first she experienced some difficulty with logging into the computer, but her daughter helped her, and then she could do it on her own. Her biggest obstacle was the fact that she considers herself a procrastinator and just kept thinking, "tomorrow, tomorrow, tomorrow," but then she ran out of time. She did her cognitive training in the morning in the living room while sitting on the sofa. She did not feel that her ability to focus, her mood, or sleep quality influenced doing her cognitive training. Since doing the cognitive training, she has not experienced any improvements in cognition, mood, or sleep. However, she felt that while she was doing the cognitive training, it was helping her to be a little more focused. She would have liked to continue the cognitive training. While she lived alone and did not have any household support, her daughter supported her by helping her log into the computer and by encouraging her to do the cognitive training. Suggestions for making the program easier for others included providing a tablet with the program already loaded. She would recommend this program to other BCS and would tell them to

put their whole heart into it, follow the schedule, don't procrastinate, and listen to the messages that your research coordinator sends.

Participant 10

Participant was informed about the study at a community event for BCS. She was experiencing "chemobrain," so she decided to enroll in the study to see if it could help improve her memory and because she wanted to help other BCS. She felt that the study was easy and exceeded her expectations of helping her improve her cognition. She completed all 10 hours of cognitive training, but would have liked to do more. She enjoyed it and felt that doing it longer would be more beneficial. However, she would like more of a variety of brain exercises (e.g., crossword puzzles). While doing the cognitive training, which engaged and challenged her, she could see that she was improving. She thought, "If it helped me, it might help somebody else," and was motivated to complete the training to help herself and others. She liked the convenience and flexibility of being able to do the training at home on her own time. Making the cognitive training a priority, she generally did 15 - 30 minutes every morning in her spare bedroom, which was free from distractions. While on vacation she made daily trips to the local library to do her cognitive training. No daily activities or responsibilities interfered with doing her cognitive training. She did not feel that her mood or sleep quality influenced doing her cognitive training, because she was determined to do it anyway. However, she felt that her lack of ability to focus did influence her cognitive training in a positive way, because she wanted to do something to improve it. Since doing the cognitive training, she has felt more focused, has more energy, is more socially active, and has experienced fewer incidences of "forgetfulness" (e.g., leaving the stove on). She

has also experienced improvements in memory, mood, and sleep. She received emotional support and encouragement in doing her cognitive training from bot h her husband and daughter. She would recommend this program to other BCS because she has experienced a positive effect in herself and she would tell them to: 1) "do it," 2) "put yourself first," and 3) make the time. She thought that this was a good study and she was glad to be able to participate in it.

Participant 11

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some cognitive changes and was hoping to learn some strategies or skills that could help. She felt that the study was much harder than she expected. At her initial study appointment she had difficulty with the cognitive testing, which led to her feeling vulnerable and like she was falling apart. She can still remember feeling very tense and wanting to leave the appointment. This experience made her more aware of her cognitive functioning and confirmed that she was having some memory and attention issues, which was frustrating and uncomfortable. She considers herself a perfectionist and likes to get things right. Being an African American woman, she has always felt like she had to do twice as much as others in order to be accepted. She felt that if perhaps she had aced all the cognitive testing at the first appointment, she would have felt more comfortable. Her initial impression of the cognitive training, from the demonstration and practice at her initial appointment, was positive, and she was enthusiastic about trying it. She was eager to try something to help improve her memory and focus, and she felt optimistic that this was something that could help. However, she ended up not logging into the website at home or doing any cognitive

training. She felt like she let herself down, because it was an opportunity to possibly help herself that she did not take. On the other hand, she did not want to see herself failing again. She was concerned that the training might be so hard that she wouldn't be able to do it and then she might feel worse about herself. She would tell other BCS that the study is hard and to "be prepared to be stressed out." She has always felt that one of her biggest assets was her thinking and ability to reason. From the time she was a little girl, she had the reputation of being "the smart girl," having all the answers. Doing the study brought awareness to the fact that she was having more cognitive difficulty than she thought, which was stressful and frustrating. If she had the opportunity to do it over again, she would not have participated in the study because she would prefer not to have the awareness and the confirmation of her memory and attention issues. She would have preferred to be ignorant of these changes.

Participant 12

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some changes in her memory and wanted to help other BCS with similar struggles. She thought that the cognitive training program was easy to use and navigate. Additionally, she liked the convenience and flexibility to be able to do it at home on her own schedule. Her sense of personal accountability and being part of something to help future survivors helped her complete the study. In fact, she found the training to be helpful and would have liked to do more. She felt that the study met her expectations of helping her memory. As a result of the cognitive training, she has experienced fewer incidences of losing her train of thought while having a conversation, which has improved her mood and confidence. She is now

able to carry on a discussion better, which has led to her being more socially active. Additionally, she is more apt to remember the items on her grocery list. While her sleep has improved, she is not sure if it is due to the cognitive training (her husband began using a CPAP around the same time). She did not necessarily schedule her cognitive training; rather, she just worked it in when she could, usually in the evening after the children were in bed. She did her training in the kitchen, which was generally free from distractions after the children were asleep. She was very comfortable using the computer and didn't need any assistance to access or navigate the cognitive training program. She received encouragement and support from her husband, daughter, friends, and others at her monthly social groups. At times, she experienced difficulty with focusing, fatigue, or sadness, which influenced her cognitive training performance (poor performance), and sometimes she was not up to doing the training and just skipped that day. She would advise other BCS to do it, schedule it, and make it a priority.

Participant 13

Participant decided to enroll in the study because she was experiencing some cognitive changes and was hoping to improve her cognition. However, she felt that the study was much harder and more time consuming than she expected. She did not complete all 10 hours of cognitive training and did not feel that that the number of hours that she did was sufficient. She found the cognitive training to be frustrating and mentally exhausting. She considers herself to be competitive, and her scores never quite got where she thought they should, which made her a hesitant to continue. She did not necessarily schedule her cognitive training; rather, she just worked it in when she could, usually in the evenings after her 10-hour work day. After a long day at work, she was physically

tired, and the cognitive training seemed to make her more mentally tired. She would think, "Oh, I'll do it tomorrow, or I'll do it on the weekend when I have more time," but the time never came around. She did not feel that the cognitive training helped her and has not experienced any improvement in cognition, sleep, or mood since the cognitive training. However, she felt that this may partly be due to her not putting in enough hours. She felt that her ability to focus, sleep quality, and mood did have some impact on her cognitive training performance and motivation to do cognitive training. Overall, she felt that the cognitive training was difficult, lacked variety, and had no sense of advancement or achievement, which created feelings of frustration. Things that would have made the cognitive training easier would be 1) starting off at a lower level of cognitive training, 2) having a mouse, 3) daily encouragement, and 4) having an accountability partner. The biggest challenges she experienced in doing the cognitive training consisted of making the time to do it and the fact that it was more difficult than she had anticipated. She would advise other BCS to "Give it a try, it couldn't hurt. It might give you some benefit."

Participant 14

Participant decided to enroll in the study to have a better understanding of "chemobrain" and to improve her cognitive function. At her initial study appointment, she had difficulty with the cognitive testing. She was afraid that her "brain was not going to do as expected" and she "would not do it right," which was "frightening." She can still remember her stomach getting queasy, her heart beating fast, and thinking, "Oh God, I'm just going to faint." Since she did not have a home computer, she tried doing her cognitive training at the office before work, which was difficult. The office was a

stressful environment and full of distractions. It was the one time that she really wished she could have afforded a home computer so that she could do the cognitive training at home. She did not complete all 10 hours of cognitive training and did not feel that the number of hours that she did was sufficient. However, she found the cognitive training to be helpful, because it stimulated her brain and increased her self-awareness. She is now more aware of her brain functioning, impatience, and frustration. Physically she could feel "something going on in the front of her brain," which gave her hope. While she has not experienced any improvement in cognition, sleep, or mood since the cognitive training, knowing that "someone on the other end really cared about the study results" and that it may "help some other woman" made it all worthwhile. She felt that her ability to focus, sleep quality, and mood did have some impact on her cognitive training performance and ability to do the cognitive training. The biggest challenge she experienced in doing the cognitive training was not having a home computer. Being provided a tablet with the cognitive training pre-loaded would have made it easier for her. While she did tell her son about being in the study, she chose not to share with others, because "it can be shaming," they'll say, "Oh, she's just trying to explain why she's so stupid." She would advise other BCS, "If they have all the resources that they need to complete the study, complete it. What do they have to lose?" She feels that it was an "awesome" study that made her rethink things, gave her the desire to go back to school, and gave her hope. The only regret she has is that she couldn't complete it.

Participant 15

Participant was informed about the study at a community event for BCS. She decided to enroll in the study because she was experiencing some cognitive changes and

difficulties with her thinking and reading abilities. However, she felt that the study was difficult and anxiety producing. She did not like the type of brain activities it entailed. Furthermore, she felt that it was not germane to the cognitive changes she was experiencing. At her initial study appointment, she had difficulty with the cognitive testing that was geared toward quick responses, which led to her feeling nervous and anxious. While she did log into the cognitive training website at home and attempted to do the cognitive training, it caused her too much anxiety and she was not able to do any additional training. She felt that the cognitive training was useless because it did not help her with the things she needed help with, which were reading comprehension and commitment to something that she had pre-planned. Instead, it just made her anxious about things that she wasn't anxious about before, and it seemed self-defeating. She considers herself a people person and a word person, definitely not a computer person, and left to her own devices, would not use computers at all. If given a choice, she would prefer a cognitive intervention with a more holistic perspective and slower pace. She would be interested in trying something psychophysical, in which she would be working her body with her brain, or maybe meditation. She feels the best part of the study was having social interaction with her tester. She feels that “sometimes it's good just to be with people who have some awareness that you've been through some shit and understand that you've had breast cancer, you've had chemo, and you have some issues."

APPENDIX H

JOINT DISPLAY OF INTEGRATED FINDINGS

Table H1

Integrated Findings by Cancer-Related Symptom

Quantitative			Qualitative			
Adherence	Hours	Score	Experiences of cancer-related symptoms	Influences of cognitive training	Adherence to cognitive training	Environment for cognitive training
Perceived cognitive impairment[a]						
Adherent	10	78	“Before I was sharp as a tack. I’ve left the stove on I can’t tell you how many times and I used to never do that.”	“I was just determined to complete it because I could see the improvement in my thinking.	“It [ability to focus] did influence me doing my brain training. I knew there was something that the chemo had did and I needed something to improve it.”	“My daughter and my husband really encouraged me to do it.”
Non-adherent	3	57	“I used to be pretty sharp. I know that these things that I'm forgetting, I shouldn't be forgetting. I just can't remember anything.”	“It was pretty difficult. I felt like I was stressing, because I was trying so hard to get them right. Then it would be over. Thank goodness!”	“You have to be able to focus. If you can't focus, then there's no way you could do it. You can't do it with people walking in, talking to you, and asking you questions. At least once or twice, I had to stop because I just could not focus”	“I had a grandchild that I was taking care of at the time. My husband was out of town working, which didn't help a whole lot.”
Depressive symptoms[b]						
Adherent	10	16	“When you can't remember things it's frustrating and you get angry and you feel bad. I would just cry because some things were just important.”	“It really has helped me. Before I couldn't remember things, I just felt inadequate. Now my confidence has come back and I just feel good. I'm happier now. I smile more.”	“Some days, yeah, it frustrated me. I got a little frustrated. I wanted to beat it. I didn't want it to beat me, so I kept on and kept on. I was determined that it wasn't going to beat me.”	“My son let me use his computer. My daughter cooked and made sure things were clean so I could do the training. I really had a lot of help.”

Non-adherent	0.33	39	"If my husband is telling me directions to a place, and he gives me more than three or four directions at a time, I can't process it, it makes me nervous."	"The program itself made me nervous and anxious. My breath stops, my heart races."	"I couldn't do it, I couldn't commit to it. It made me anxious."	"I didn't receive any support. I told my husband it made me anxious and crazy. I think his response was, 'Ooh, that sounds awful.'"
Sleep quality[c]						
Adherent	10	4	"I do get up in the night. Sometimes I can't go back to sleep. Sometimes I'm feeling tired during the day."	"When I was doing it I was staying focused. It was awesome. I just seen that it could help. It helped. It was just good"	"I still do it. I was still motivated to do it. If I was tired or sleepy I was like let me get on here."	"My daughters were like, 'Mama, you doing your brain training? How long you going to stay on today?' They wanted me to do it."
Non-adherent	0.5	9	"I still wake up sometimes two, three o'clock in the morning and can't go back to sleep. Usually by the end of the day I have to go home and take a nap."	"When I was doing it, it's like my brain hurt. I didn't get a headache per se, but it made me mentally exhausted."	"By the time I did have time to actually do it, I was tired already, physically tired, and then the exercises seemed to make me more mentally tired. And so it was like a bad combination."	"I live alone. Nobody knew I was doing it. I didn't see the need to share]."

Hours=Cognitive training hours completed and ranged from 0 to 10, with ≥ 8 considered as adherent
[a] *Measured by the CFQ, with higher scores indicative of worse perceived cognitive function*
[b] *Measured by the CES-D, with a score of ≥5 indicative of depressive symptoms; ≥16 high depressive symptoms*
[c] *Measured by the PSQI, with a score of ≥5 indicative of poor sleep quality*