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**THE EXPERIENCE OF COGNITIVE CHANGE IN WOMEN WITH
BREAST CANCER FOLLOWING CHEMOTHERAPY**

A Dissertation in

Nursing

by

Mary Louise Kanaskie

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The dissertation of Mary Louise Kanaskie was reviewed and approved* by the following:

Susan J. Loeb
Associate Professor of Nursing
Chair of Committee
Dissertation Advisor

Judith E. Hupcey
Associate Dean for Graduate Education
Associate Professor of Nursing

Margaret Cushman
Assistant Professor of Nursing

Elizabeth J. Tisdell
Professor of Adult Education
Adult Education Doctoral Program Coordinator
Penn State University - Harrisburg

*Signatures are on file in the Graduate School

Abstract

Background: Change in cognitive function is one side effect of chemotherapy that has been reported in some breast cancer survivors. Alarming reports indicate that between 16 to 50 percent of women receiving chemotherapy for breast cancer experience symptoms of cognitive impairment. These symptoms include subtle changes in memory, concentration, and some higher order processes that include psychomotor speed and executive functioning. In addition, it has been reported that these symptoms may persist even years after completion of treatment. Research is limited that has explored the lived experience of the phenomenon of chemotherapy-related cognitive change in breast cancer survivors.

Purpose: The purpose of this study was to uncover the meaning of cognitive change in women with breast cancer, how symptoms are experienced and become evident, how it impacts roles in personal and professional lives, and how women cope with these changes.

Methods: An interpretive phenomenological study was conducted with seven women with breast cancer, between the ages of 42-59, who had completed standard chemotherapy treatment within the past 12 months. Each woman participated in two in-depth semi-structured interviews one month apart and maintained a written journal. Reflective journaling and total immersion in the data enhanced the rigor of the methodology. In addition, a panel of three faculty members, with expertise in qualitative analysis, reviewed interview transcripts and provided insights which led to the refinement of essential themes and subthemes.

Results: Phenomenological analysis employing van Manen’s framework for interpretive phenomenology revealed five major essential themes: Noticing the difference, experiencing cognitive changes, interacting socially, coping, and looking forward. Subthemes, both essential and incidental, were identified within each major theme. Analysis provided a description of the phenomenon in relation to the lifeworld existentials of lived space, lived body, lived time, and lived human relation.

Conclusions: The experience of cognitive change could not be isolated nor studied separately from the greater context of the women’s reality of having breast cancer. This study provides clarity related to the impact of cognitive change and how women cope with these changes in relation to their daily roles and responsibilities. New knowledge is provided that is related to the impact on employment and professional life that can impact financial and social well being of women who are breast cancer survivors living with chemotherapy–related cognitive changes.

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DEDICATION

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Chapter 1

Introduction

Breast cancer survival rates have steadily improved in recent years (American Cancer Society, 2010a). The successful treatment of some stages of breast cancer is often dependent upon the administration of chemotherapy agents. Unfortunately, these life saving drugs are also known to cause a variety of side effects, some debilitating and others life threatening. Change in cognitive function is one side effect of chemotherapy that has been reported in some breast cancer survivors. Alarming reports indicate that between 16 to 50 percent of women receiving chemotherapy for breast cancer experience symptoms of cognitive impairment (Tannock, Ahles, Ganz, & van Dam, 2004). These symptoms include subtle changes in memory, concentration, and some higher order processes that include psychomotor speed and executive functioning (Ahles, 2003; Hess & Insel, 2007). In addition, it has been reported that these symptoms may persist even years after completion of treatment (Schagen et al., 1999).

In 1998, the President's Cancer Panel completed their review of survivorship issues related to the long term effects of cancer treatment. The consensus report, *Cancer Care Issues in the United States: Quality of Care, Quality of Life* identified "Systemic chemotherapies are associated with cognitive deficits such as memory and concentration. Some of these deficits may be subtle, but may...have a major impact on quality of life" (National Cancer Institute, 1999, p. 25). While the impact of cognitive change on daily activities is not completely understood, patient self-reports of cognitive difficulties suggest that it may lead to work absences and declines in productivity and job

performance. Moreover, the emotional stress this may cause for the individual can result in additional physical and psychological consequences.

Statement of the Problem

Breast cancer continues to be the most commonly diagnosed cancer in women in the United States, accounting for 28% of all new cases of cancer in women (American Cancer Society, 2010b). However, with advances in early detection and treatment, women diagnosed with breast cancer are living longer and more productive lives. Improved survival rates have resulted in an estimated 2.5 million women in the United States living as breast cancer survivors (National Cancer Institute, 2010a).

Treatment for breast cancer varies depending on many factors such as cell histology, genetic factors, and stage of the disease at diagnosis. For many women with breast cancer, chemotherapy is a prescribed treatment. Chemotherapy agents used in breast cancer treatment are known to cause significant side effects. These chemotherapeutic agents often include the following drug categories: anthracyclines, taxanes, alkylating agents, anti-metabolites, and targeted agents (Yackzan, 2007b). From these categories, the most common chemotherapeutic agents used in breast cancer treatment include doxorubicin, cyclophosphamide, paclitaxel, docetaxel, carboplatin and trastuzumab (Yackzan, 2007b).

The physical side effects of these chemotherapy agents are well documented and most are well understood. In fact, interventions to prevent common side effects become a major part of standard treatment protocols. In contrast, symptoms related to cognitive changes following chemotherapy are not well understood and early interventions have not been established (Schagen, Muller, Boogerd, Mellenbergh, & van Dam, 2006).

Furthermore, the potential for changes in cognition are seldom discussed with patients prior to treatment and patients receiving treatment with chemotherapy are not routinely evaluated for these changes (Staat & Segatore, 2005).

Although the symptoms are subtle, patients who report cognitive changes are very aware of the differences in their abilities to think clearly (Boehmke & Dickerson, 2005). Some of the symptoms of cognitive change may be frightening and lead to emotional distress (Simmons, 2009). In addition, the resulting physical and psychological consequences can negatively impact quality of life (Mitchell, 2007). Research focused on revealing the impact of cognitive change following chemotherapy and how women cope with these changes is needed to direct meaningful and timely interventions to improve quality of life for cancer survivors.

Purpose

The purpose of this study was to understand the lived experience of cognitive change following chemotherapy in women with breast cancer. Cognitive change is defined as the experience of symptoms related to memory loss, decreased ability to concentrate, decline in executive functioning (planning, sustained attention, and problem solving), and difficulty multitasking.

Specific Aims

The aim of this study was to uncover the meaning of cognitive change in women with breast cancer, how symptoms are experienced and become evident, how it impacts roles in personal and professional lives, and how women cope with these changes. It is important to give voice to women's experience of cognitive changes following chemotherapy to better understand the impact of the symptoms of the phenomenon and

how women cope with these changes in relation to their daily roles and responsibilities. This research contributes to knowledge that can lead to the development of strategies to help women adapt to living with cognitive changes. In addition, this research logically leads to next steps in the development of appropriate assessment tools to be used at post-treatment visits and improvement in patient education practices. An understanding of the experience of cognitive change following chemotherapy from the woman's perspective, including their coping strategies, is important to the improvement of quality of life for all breast cancer survivors.

Conceptual Framework

The Theory of Unpleasant Symptoms (TUS) provides a framework for understanding the complexity of the symptom experience and relationships to potential outcomes that affect quality of life. This middle-range theory advances a post-positivist perspective to understanding the symptom experience (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, Pugh, Milligan, Gift, & Suppe, 1997, p. 14). The theory was developed by a team of nurse researchers who share a holistic view of humans' experience with symptoms (Lenz et al., 1995). Physiological, psychological, and situational factors are presented as leading to the symptom or influencing the symptom experience. 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 (see Figure 1). The three components of the theory include the “symptoms that the individual is experiencing, the influencing factors that give rise to or affect the nature of the symptom experience, and the consequences of the symptom experience” (Lenz et al., 1997, p. 15). Effective coping strategies may positively influence outcomes or the perception of the symptom experience.

Figure 1. Updated Version of the Middle-Range Theory of Unpleasant Symptoms

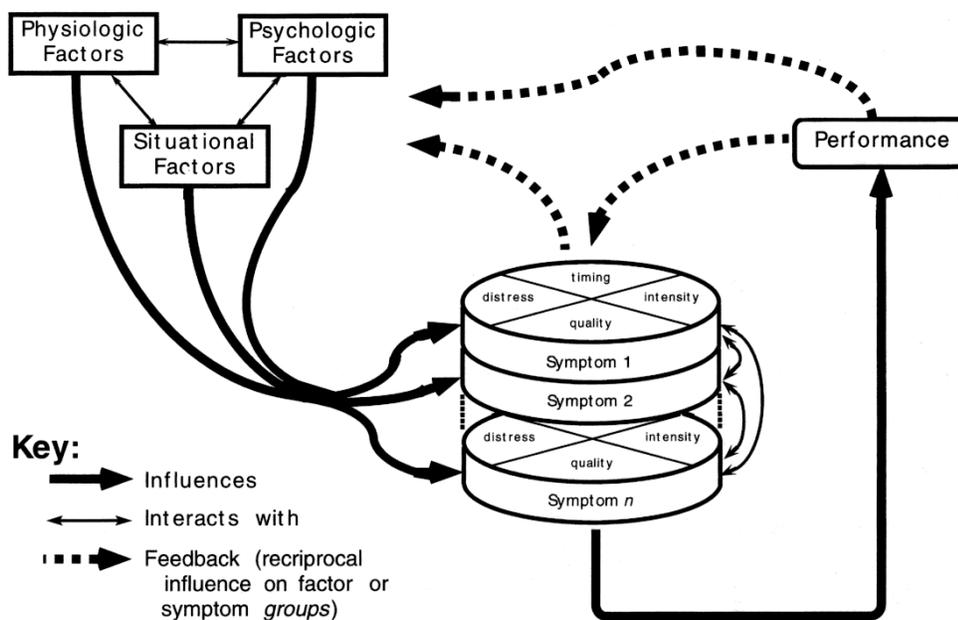


Figure 1. From “The middle range theory of unpleasant symptoms: An update,” by E.R. Lenz, L.C. Pugh, R.A. Milligan, A.G. Gift, & F. Suppe, 1997, *Advances in Nursing Science*, 19 (3), pp. 14-27. Reprinted with permission from Wolters Kluwer Health.

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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. Revisions to the theory (1997) have taken into account the more complex nature of symptoms, specifically recognizing that multiple symptoms more often occur in combination and simultaneously. The theory does not differentiate signs from symptoms; however, Pugh (personal communication, December 3, 2008) describes symptoms as subjective in nature and typically measureable. In addition, others have made the claim that symptoms are subjective; whereas, signs are detectable not only by self but also by others (Hutchinson, 1998).

Although symptoms are different, it is recognized that they likely possess common dimensions. These dimensions include intensity, timing, level of distress perceived, and quality. These dimensions can clearly be seen in the characteristics of pain and fatigue, and may also be seen in characteristics of some symptoms of cognitive change. Lenz et al. (1997) describe intensity as referring “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 and therefore is useful in determining medical and nursing diagnoses. The level of distress perceived “refers to the degree to which the person is bothered” (Lenz et

al., 1997, p. 16) by the symptom. This may determine whether one seeks treatment and what coping strategies they call upon to manage the day to day difficulties in living with persistent symptoms (Lenz et al., 1997).

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 physiologic, psychologic, 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). In addition, psychologic factors include the degree of uncertainty about the symptoms, as well as, the 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).

It is recognized in the TUS that “people differ in their ability to discern symptoms” (Lenz et al., 1997, p. 17); therefore, they may not all be able to identify a label that clearly differentiates one symptom from another. Additionally, it is recognized that one’s long term experience with a symptom may increase one’s recognition of the sensations associated with it (Lenz et al., 1997). However, when multiple symptoms are experienced together it may be more difficult to differentiate among overlapping

sensations. An example relevant to this study includes a neuropsychological cluster of symptoms in patients with breast cancer. These overlapping experiences or sensations were reported as depressed mood, cognitive disturbance, fatigue, insomnia, and pain (Kim, Barsevick, & Tulman, 2009).

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). Cognitive functioning, also viewed as a consequence of symptoms, includes concentrating, thinking, and problem-solving abilities. Cognitive impairment in this clinical context includes memory loss, decreased ability to concentrate, and decline in executive functioning related to activities such as planning, sustained attention, and problem solving. The inability to stay focused on task, to plan agendas, or remember names can be very frightening. Moreover, the emotional stress this may cause for the individual can result in additional psychological consequences.

Symptom Multiplicity

The theorists originally depicted symptoms occurring in isolation from one another and 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 additive but is more likely to be multiplicative. For example, pain may be perceived as considerably worse when one is

fatigued or depressed and may be even more severe when all three symptoms occur together. Furthermore, symptoms are seen as influencing performance, and performance is seen as affecting symptoms (Lenz et al., 1997).

Although the complex nature of the symptom experience is clearly recognized in the theory, the complexity of the relationships between symptoms, influencing factors and performance comes into question. In particular, alterations in cognitive performance raise important questions about the identification of “What is a symptom?” “What is an influencing factor?” and “What constitutes a symptom consequence or outcome?” For example: Are concentrating, remembering, and problem-solving unique and isolated symptoms or are they outcomes of a symptom such as fatigue or anxiety? The usefulness of the TUS to this study is subject to the significance of the theory’s identification of cognitive factors as performance outcomes rather than symptoms. It has been acknowledged that cognitive factors, as well as, other symptoms may have blurred boundaries and even overlap (Hutchinson & Wilson, 1998). In some instances, cognitive change related to chemotherapy may be a group of symptoms, and in other contexts, it may be a situational factor or symptom outcome. Rather than dismissing the theory’s usefulness for this population, I argue that the TUS provides an excellent framework for understanding this complex multidimensional phenomenon that can best be understood by considering the individual’s experience of chemotherapy-related cognitive change within the unique context of psychological and social factors.

Conceptual Components of Chemotherapy-Related Cognitive Change

Conceptual components attributed to the concept of chemotherapy-related cognitive change include influencing factors, the symptom experience of cognitive

change, and consequences or outcomes. Influencing factors may be those antecedent events or factors that occur prior to the symptoms of cognitive change or those that affect the symptom experience or outcome. An important aspect of chemotherapy-related cognitive change is the meaning of the experience to patients and how that meaning may influence the perceived distress that the individual experiences and the perceived impact of these symptoms on performance in daily life.

Influencing Factors

Influencing factors relative to chemotherapy-related cognitive change include individual factors, disease factors, and treatment factors. Individual factors, particularly age and gender, may play an important role in identifying conceptual boundaries of chemotherapy-related cognition. Disease factors encompass the specific cancer diagnosis, and other factors such as pre-existing cognitive impairment and history of emotional distress. Lastly, treatment factors include the specific treatment, either chemotherapy or hormonal therapy alone, or a combination of the two, as well as, the dose and duration of therapy.

Symptom Experience

The individual's perception of the symptom of cognitive change is based on self-report in the absence of objective measures. This may include the attributes commonly reported by patients such as forgetfulness, absent-mindedness, and the inability to focus, plan agendas, and remember tasks. The perception of symptoms also includes the frequency, intensity, type and amount of distress caused by the experience. Patients receiving chemotherapy for a cancer diagnosis may have multiple symptoms occurring

together at any given time. Furthermore, when symptoms co-exist the perception of cognitive difficulties may increase.

Consequences or Outcomes

Consequences or outcomes of the experience of chemotherapy-related cognitive change include adjustment to illness, generation of coping skills, impact on quality of life, and potential for emotional stress. Adjustment to illness may include reassigning family roles and responsibilities which can lead to subsequent role strain. In addition, common symptoms of cognitive change, such as poor concentration and inability to focus may affect performance making it difficult to carry out normal daily activities in one's personal and professional life. Moreover, emotional stress, resulting from the impact of cognitive change on everyday activities, may contribute to further fear, anxiety, or depression.

Theoretical Definition

Chemotherapy-related cognitive change is a multidimensional phenomenon that follows a diagnosis of cancer and chemotherapy treatment and involves the patient's perception of change in cognitive abilities. Cognitive changes may follow adjuvant treatment with chemotherapy alone or with chemotherapy and hormonal therapy. Symptoms of cognitive change may last for the duration of treatment or may persist for months or years. Changes in cognition following chemotherapy treatment are often subtle but clearly recognizable by the individual experiencing them. An individual may perceive changes in cognition that do not correlate with objective measures of cognitive impairment (Paraska & Bender, 2003). Psychosocial factors such as fatigue, depression, and anxiety may be associated with the symptom experience. The exact relationship of

these factors to cognitive change is not clear; however, there is evidence that patients still experience cognitive change when these factors are controlled (Castellon, et al., 2004). Some of the symptoms of cognitive change may be frightening and lead to emotional stress. The resulting physical and psychological consequences can generate coping skills that can significantly impact the performance of daily activities including those related to personal and professional roles and responsibilities.

Research Questions

- What meaning do women with breast cancer ascribe to cognitive change following chemotherapy?
- How does cognitive change following treatment with chemotherapy impact personal relationships and roles?
- How does cognitive change following treatment with chemotherapy impact professional relationships and roles?
- How do women cope with cognitive change following chemotherapy?

Definitions

Adjuvant Chemotherapy

Chemotherapy administered after the primary treatment. The purpose of adjuvant therapy is to eradicate cancer cells lowering the risk of cancer reoccurrence (National Cancer Institute, 2010b).

Breast Cancer

Breast cancer is a malignancy that forms in tissues of the breast, usually the ducts and lobules (National Cancer Institute, 2010c):

Stage I. Stage 1 breast cancer is an early stage of invasive breast cancer characterized by a tumor that is no more than two centimeters that has invaded the breast tissue but has not spread beyond the breast.

Stage II. Stage II breast cancer is divided into four subgroups characterized by the size of the tumor and determination of spread to the axillary lymph nodes.

Stage III. Stage III breast cancer is locally advanced cancer that has grown into the chest wall or has spread to breast and regional lymph nodes

Stage IV. Stage IV breast cancer has metastasized to one or more parts of the body such as the bones, liver, lung, or central nervous system.

Chemotherapy

Chemotherapy is a broad term that refers to antineoplastic agents that inhibit cancer cell reproduction. Classifications of chemotherapeutic agents include: alkylating agents, antitumor antibiotics, antimetabolites, vinca alkaloids, and miscellaneous agents consisting of nitrosureas, steroids, and hormonal agents (Shields, 2009).

Hormonal Therapy

Hormonal therapy, also referred to as endocrine therapy, is a treatment that is administered to slow or stop the growth of breast cancer. Synthetic hormones and other drugs may be given to block the body's natural hormones inhibiting cancer growth (National Cancer Institute, 2010b).

Assumptions

1. A subset of women with breast cancer experience cognitive changes following treatment with chemotherapy.

2. Cognitive changes following chemotherapy may persist throughout the treatment phase and beyond.
3. In some patients, the symptoms of cognitive change may persist indefinitely.
4. Estrogen depletion is believed to contribute to cognitive change in some women.
5. Breast cancer treatment may consist of hormonal therapy which depletes estrogen stores in the body.
6. Some women receive hormonal therapy in conjunction with chemotherapy and as sole therapy once chemotherapy treatment ends.
7. Some women may experience emotional distress as a result of the cancer experience.

Significance

The concept of chemotherapy-related cognitive change is of interest to researchers and clinicians worldwide. As described earlier, the President's Cancer Panel consensus report on survivorship issues identified that cognitive deficits such as memory and concentration following chemotherapy treatment may have a major impact on quality of life (National Cancer Institute, 1999). In addition, in an effort to increase awareness and understanding of chemotherapy-related cognitive change, the "Oncology Nursing Society 2009-2013 Research Agenda" calls for studies in cognitive function as a research priority.

Oncology professionals are increasingly interested in understanding these symptoms in order to provide patient and family counseling and education. There is a recognized need to develop reliable assessment tools to identify those individuals with cognitive changes following chemotherapy and to determine how long cognitive changes

persist following treatment (Myers, Pierce, & Pazdernick, 2008). Furthermore, as survival increases with new cancer therapies, knowledge concerning long term cognitive changes will become an important part of the informed consent process, may impact individuals' treatment decisions (Hess & Insel, 2007), and may inform health care policy concerning follow-up screening for cancer survivors.

Summary

Research is limited that has explored the lived experience of the phenomenon of chemotherapy-related cognitive change in breast cancer survivors. Most researchers have studied cognitive change following chemotherapy by exploring causal relationships related to physiologic responses to drug, dose, and time since treatment (Vardy, Wefel, Ahles, Tannock, & Schagen, (2008). Some have studied chemotherapy-related change by exploring possible contributing factors such as anxiety, fatigue, and depression (Downie, Mar Fan, Houede-Tchen, Yi, & Tannock, 2006; Hess & Insel, 2007). Vardy et al. (2006) studied patients' perceptions of cognitive changes following chemotherapy but did so using quantitative methods. These studies do not explore the meaning of the lived experience beyond "what" they experienced.

Only a few researchers have studied cognitive change following chemotherapy using qualitative methods. Boykoff, Moieni, and Subramanian (2009) described interview responses related to the impact of cognitive change on work, social networks, and health care response among breast cancer survivors but did not explore the depth of those relationships. Myers (2012) conducted a qualitative study that provided descriptions of the experience of chemotherapy-related cognitive impairment in women with breast cancer and identified how women need to receive information before and

after treatment. A descriptive phenomenological study was conducted by Thielen (2008) which validated the existence of cognitive change and its impact on everyday living. Descriptive phenomenological methods uncover the essence of phenomena but do not explore the influence of context in which it is experienced. Consequently, most research related to cognitive change in breast cancer patients falls short of exploring the meaning of the lived experience from the perspective of the coping strategies that women use to fulfill their multiple roles and responsibilities. By using interpretive phenomenological methods, this study fills a gap in the current research by exploring the contextual features of the phenomenon, revealing the impact of cognitive change following chemotherapy, and elucidating the strategies that women use to cope with these changes in everyday life. These findings can guide current practice and provide recommendations for new practice strategies.

Chapter 2

Review of the Literature

Introduction

Cognitive change-related to chemotherapy is an important complication of cancer treatment that has only recently been recognized. Studies report that between 16 to 50 percent of women receiving chemotherapy for breast cancer experience some symptoms of cognitive change (Tannock et al., 2003). These symptoms include memory loss, decreased ability to concentrate, decline in executive functioning (planning, sustained attention, and problem solving), and difficulty multitasking (Jansen, Miaskowski, Dodd, & Dowling, 2005a). Although the symptoms are subtle, patients are very much aware of the differences in their thinking (Staat & Segatore, 2005). In fact, patients who experience these symptoms commonly use the phrase “chemo brain” to describe this phenomenon (Evens & Eschiti, 2009).

The study of cognitive change related to chemotherapy is in its infancy. The earliest research that focused directly on the effect of standard dose chemotherapy on cognition was published only 15 years ago (Wieneke & Dienst, 1995). Since then, the majority of publications have focused on attempts to identify the causative mechanisms and to predict the variables that make one susceptible to these changes. In some cases, the aim has been to validate whether the symptoms are real and separate from other related symptoms experienced by cancer patients. Despite research efforts to better explain this phenomenon, much is still unknown. A few studies have tested intervention strategies; but until the impact of cognitive change following chemotherapy is better understood, meaningful and timely interventions cannot be developed.

A concern is that cognitive change may negatively impact quality of life for cancer survivors leading to problems with performance and productivity.

The purpose of this review is to present the state of the science about chemotherapy-related cognitive change. The review begins with the concept's early stages of discovery and moves towards its emergence as an identifiable, serious complication of chemotherapy. The next section, "Meeting the Problem Head On," presents the most important studies of the last decade where researchers confronted multiple scientific questions. The investigators addressed identifying characteristics, putative causes, measurement, and prediction of susceptibility. Finally, the last section presents the current gaps in knowledge with primary emphasis on research to improve understanding of the challenges in living day to day with chemotherapy-related cognitive change and its potential impact on daily functioning and role performance.

Cognitive Changes in Cancer Patients

Early Studies – 1980 to 1999

The earliest study related to cognitive change in patients with cancer was published in 1980. Psychiatrists, Silberfarb, Philibert, and Levine (1980), were called to evaluate cancer patients for emotional problems on an inpatient medical oncology unit. They administered a battery of cognitive tests to the first 50 patients admitted during the study period. The tests administered were standard at the time for detecting mental status and brain damage and included Cognitive Capacity Screening Test, Digit Symbol Test, and Trail Making B Test. Silberfarb et al. (1980) reported that the results of the cognitive tests were significantly lower ($p < .01$) in the chemotherapy group compared to the non-chemotherapy control group. They concluded that there was a significant association

between cognitive impairment and several categories of chemotherapy agents regardless of cancer diagnosis.

Silberfarb et al. (1980) also recognized that individuals experiencing depression or anxiety could have difficulty in performing cognitive testing. Specifically, individuals who have depression may also have difficulties with memory and those experiencing anxiety could have difficulties with maintaining attention. Therefore, the psychiatrists administered three affective tests to assess anxiety, depression, and hostility. A Distress Score was calculated from the sum of raw scores on the anxiety, hostility, and depression scales. The Distress Scores were not significantly different ($p=.05$) between those cancer patients who received chemotherapy and those cancer patients who did not receive chemotherapy. In addition, abnormal scores on affective tests did not influence abnormal scores on cognitive tests.

As psychiatrists, Silberfarb et al. (1980), acknowledged the potential relationship between emotional distress (identified as anxiety, hostility, and depression) and the accompanying subtle changes in cognition related to memory and attention. Although some of their patients were depressed and anxious, they stated that their symptoms of emotional distress were within normal limits. Therefore, they concluded that change in cognition following chemotherapy occurs even when measures of emotional distress are normal. This early study is important in two ways: first, it established the importance of the inclusion of objective measures of both cognitive ability and emotional distress in studying chemotherapy-related cognitive change; and second, it established that chemotherapy may be a possible source of cognitive change in cancer patients.

Research specifically related to cognitive impairment following standard chemotherapy treatment did not appear again until 1995. The emergence of the topic at this time may have been related to scientific advancements of the early 1990s which improved the ability to administer chemotherapy agents at higher doses than previously possible. In addition, during the same time period new chemotherapeutic agents had emerged with greater potential for causing neurological side effects. These side effects most commonly include sensory and peripheral neuropathies (Kannarkat, Lasher, & Schiff, 2007).

In 1995, Wieneke and Dienst set out to study the link between cognitive change and chemotherapy. They found that changes in cognitive function following chemotherapy were common but not well documented. Specifically, they studied the effects of chemotherapy drug regimens, length of treatment, and levels of depression on cognitive function in patients with stage I and stage II breast cancer who had completed treatment within the previous 12 months. Wieneke and Dienst (1995), both psychologists, administered a battery of tests with specificity to measure mild or subtle cognitive changes across nine cognitive domains. Depression was evaluated using the Beck Depression Inventory. Despite a small sample size ($n=28$), lack of a control group, and lack of pretreatment comparisons, this study drew attention because the results demonstrated cognitive impairment following treatment with chemotherapy in younger high functioning women with early stage disease.

In the same year, Cull et al. (1995) published an article comparing subjective reports of cognitive difficulty to objective measures (i.e., cognitive tests for memory concentration, and executive functioning). They studied individuals with lymphoma who

were disease free and had completed treatment at least six months earlier. Cull and colleagues (1995) focused their study on the complaints of memory and concentration, anecdotally reported at the time. This study limited its focus to measures of memory and concentration and did not include a broad range of cognitive domains. Cull et al. (1995) tested whether subjective complaints of memory and concentration difficulties matched the objective findings or instead reflected emotional distress and fatigue. They found that those who reported difficulties with concentration and memory and those who reported no difficulties scored similarly on objective measures. They therefore concluded that patients' self-reports of problems with concentration and memory cannot be measured using standard objective tests. In addition, they found that those who reported problems had significantly higher scores on measures of anxiety, depression, and fatigue. These early findings have been substantiated over time as research on the topic has progressed.

The next two studies can be described as landmark because they approached new questions about chemotherapy-related cognitive change. They were published by a team of researchers from the Netherlands. The first study compared the cognitive effects of high-dose to standard-dose chemotherapy (van Dam et al., 1998); and the second, examined the late effects of chemotherapy on neuropsychological testing (Schagen et al., 1999).

van Dam et al. (1998) assessed the prevalence of cognitive deficits in breast cancer patients receiving both high-dose chemotherapy and tamoxifen (n=34) or standard-dose chemotherapy plus tamoxifen (n=36) and a control group (n=34). Patients were tested, on the average, two years following completion of chemotherapy treatment. van Dam et al. (1998) used an extensive battery of neuropsychological tests. These

objective measures included 13 tests covering a broad range of functions and cognitive domains. Additional measures included an interview regarding problems in daily life checklist, a health-related quality of life questionnaire, and the Hopkins Symptoms Checklist to assess depression and anxiety.

This study substantiated the earlier claims that women receiving chemotherapy were at greater risk of developing cognitive impairment than those who did not receive chemotherapy (van Dam et al., 1998). Furthermore, the findings demonstrated that the risk of cognitive impairment was 8.2 times higher in those women receiving high-dose chemotherapy and 3.5 times greater for those receiving standard dose therapy compared to the control group who received radiotherapy following surgery with no systemic chemotherapy. This was the first study to document differences in cognitive change related to chemotherapy dose.

The van Dam et al. (1998) study has several limitations. As with many early studies, sample size was relatively small and the sample did not account for differences in hormonal status. In addition, the researchers note that test completion took two hours. This raises concerns regarding test fatigue. Lengthy testing is an important limitation particularly in this context where attention and concentration abilities may already be impaired.

In 1999, this same research team now headed by Schagen, examined the late effects of chemotherapy on neuropsychological functioning. In a retrospective study, they examined breast cancer patients approximately two years (median 1.9) following the completion of treatment. A similar battery of neuropsychological tests was used covering a broad range of functions. Measures for self-reported complaints, quality of life, and the

assessment of depression and anxiety were the same. Subjects included 39 women who had operable breast cancer with lymph node metastasis who received six courses of standard dose chemotherapy following surgery and a control group which included 34 women who had no axillary lymph node involvement and did not receive adjuvant chemotherapy. Those who received adjuvant chemotherapy were further divided into two groups: those who received chemotherapy alone (n=19) and those who also received tamoxifen for three years (n= 20).

Findings showed that breast cancer patients who received chemotherapy had significantly more problems than the control group with concentration (31% vs. 6%, $p=0.007$) and memory (21% vs. 3%, $p=0.022$). Consistent with previous findings, the risk of cognitive impairment in this group was not related to anxiety, depression, or fatigue. A new finding added by this study is that the risk of cognitive impairment was also not related to time since treatment. In this case, the patients studied two years following treatment exhibited changes in cognitive impairment demonstrating a higher risk of cognitive change than those not treated with chemotherapy. This finding raises further questions about the duration of cognitive change and whether the symptoms linger for undefined periods of time or might in some cases resolve over time. Additionally, hormonal therapy did not influence women's self reports of symptoms or test performance on cognitive measures. Due to the small sample size, it is difficult to draw conclusions concerning hormonal effect.

Poised for the New Millennium

To summarize this decade of discovery (1990s), three important events or influences will be discussed. First, was the recognition that psychological factors are

likely important variables that play several roles in the experience of cognitive change following cancer treatment. Second, was the consensus report of the President's Cancer Panel recognizing that the cognitive impact of cancer treatment is an important issue for further study; and third, the emergence of neuroscience as a new scientific discipline.

The earliest studies recognized the relevance of psychological factors to the phenomenon of chemotherapy-related cognitive change. Psychological factors commonly include problems of anxiety and depression often referred to as emotional distress. Distress is defined by the National Comprehensive Cancer Network (Distress Management Version 1.2011), the recognized standard for clinical policy in oncology, as

...a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional) social, and /or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness, and tears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. DIS-2)

Since distress can be an integral part of the cancer experience, most studies include measures to control for anxiety, depression, and fatigue. To date no studies have demonstrated that these variables (anxiety, depression or fatigue) cause the cognitive changes identified in the cancer population. In fact, when study designs control for symptoms of emotional distress, cognitive change still emerges as a separate identifiable problem. However, studies repeatedly demonstrate that individuals with high emotional distress self-report greater cognitive difficulties. Today, there is agreement that the experience of cognitive change following chemotherapy may be influenced by factors such as emotional distress or fatigue (Cohen & Armstrong, 2004; Jansen, Miaskowski,

Dodd, Dowling, & Kramer, 2005b; O'Shaughnessy, 2003; Staat & Segatore, 2005; Vardy, Rourke, & Tannock, 2007; Von Ah, Russell, Storniolo, & Carpenter, 2009).

The second important influence is an event that had a major impact on the generation of research in the new millennium. In 1998, the President's Cancer Panel completed their review of survivorship issues related to the long term effects of cancer treatment. The consensus report, *Cancer Care Issues in the United States: Quality of Care, Quality of Life* identified "Systemic chemotherapies are associated with cognitive deficits such as memory and concentration. Some of these deficits may be subtle, but may substantially affect survivors' ability to work in certain environments within their profession. Such changes may have a major impact on quality of life." (National Cancer Institute, 1999, p. 25). This consensus report provided the call for research and the funding sources to support it.

Lastly, important developments in neuroscience also occurred in the 1990s. While neuroscience already existed as a branch of biology, this decade witnessed the merging of several other scientific disciplines. The result was an interdisciplinary science consisting of biology, psychology, medicine, computer science, mathematics, physics, and philosophy. In addition, subgroup specialties within medicine came together to form Neuroscience Departments combining the expertise of neurosurgery, neurology, and psychiatry. This collaboration led to numerous advancements in neurobiology, neuropsychological testing, and neuro-imaging. The influence of these advancements likely had an important impact on the research related to chemotherapy-related cognitive change that followed in the next decade.

Meeting the Problem Head-On

In 2000, the scientific community was poised to move forward with investigations to better understand the phenomenon of cognitive changes related to chemotherapy. Early studies had identified changes in specific cognitive domains and patients complaints of “chemo brain” were gaining validity. In addition, research funding mechanisms were available to move forward. As a result, numerous studies were published. The majority of these focused on attempts to identify the causative mechanisms and describe the areas of cognition most affected. In some cases, the aim was to identify predictive variables such as types of chemotherapeutic agents, dosage differences, and time since treatment effects. Despite research efforts to better explain this phenomenon, much is still unknown.

Describing Cognitive Change

Chemotherapy-related cognitive change is not referred to consistently in the scientific literature. In fact, the concept has many different labels. Some of the following terms that have been used to describe the concept: cognitive impairment, cognitive decline, cognitive deficit, cognitive dysfunction, cognitive difficulty, cognitive effects, cognitive change, cognitive sequelae, cognitive reserves, neurobehavioral disorders, neurocognitive disturbance, neuropsychological effects, neuropsychological impact, and neuropsychological performance. In addition to these scientific terms, the phrases “chemo-brain” and “chemo-fog” (Jansen, 2006; Nelson & Roth, 2006) and “chemo malaise” and “memory lock” (Mitchell, 2007) have been used among cancer survivors.

Lack of consistent terminology to identify the concept of chemotherapy-related cognitive change leads to further confusion in identifying characteristics of the observed

side effects. In addition, the lack of a comprehensive language to identify cognitive change impedes communication among professionals. When patients report symptoms of cognitive change, they are commonly referring to their perceptions of mental slowness, decreased attention, lack of concentration, and difficulty with short term memory (Silverman et al., 2007). When health care professionals address the topic they often use terms that refer to a variety of cognitive abilities related to specific domains of cognition (Staat & Segatore, 2005).

Cognitive change following chemotherapy was described by Schagen et al. (1999) as “neuropsychological symptoms, in particular memory and concentration problems, frequently reported by cancer patients treated with chemotherapy, even years after completion of treatment” (p. 641). Ahles et al. (2003) described changes in cognitive function following chemotherapy as being “relatively subtle changes in memory, concentration, and executive function” (p. 612). Others have substantiated these claims describing cognitive change related to chemotherapy as involving difficulty with memory, as well as, some higher order processes that include psychomotor speed and executive functioning (Hess & Insel, 2007). Specifically, executive functioning includes such activities as planning, decision-making, judgment, and ability to shift between activities in a flexible way (Schagen et al., 2006).

In general, cognitive function refers to mental processes. Specifically it involves those higher order processes that include memory, psychomotor speed, and executive functioning which includes such activities such as planning, decision-making, and judgment (Hess & Insel, 2007). Describing the symptoms and specific cognitive difficulties is an important step in understanding the phenomena. However, until the

cause of cognitive change in cancer patients is better understood, survivors will be left to live without clearly defined interventions.

What cognitive domains are affected? Normal cognitive function is a multidimensional concept involving mental processes that span multiple domains of cognition (Bender, Paraska, Sereika, Ryan, & Berga, 2001; O'Shaughnessy, 2003; Phillips & Bernhard, 2003). Several researchers conclude that chemotherapy-related cognitive impairment may also be generalized across several cognitive domains such as, language, verbal and nonverbal memory, spatial ability, and motor function (Bower, 2008; Faletti, Sanfilippo, Maruff, Weih, & Phillips, 2005). In a meta-analysis of the sensitivity of neuropsychological tests used to detect chemotherapy-related cognitive change, Jansen, Miaskowski, Dodd, and Dowling (2007) concluded that the domains of cognition may be interdependent so that a change in one domain may affect another.

As previously noted, professionals often refer to cognitive function as mental processes that are typically assessed by one's performance on a battery of neuropsychological tests. These tests are specific to established cognitive domains. Currently, there is a lack of standard identification and description of the cognitive domains that should be tested in the cancer population. Some studies identify testing nine cognitive domains: verbal ability, spatial ability, verbal learning, verbal memory, visual memory, psychomotor function, motor function, attention accuracy, and attention reaction time (Ahles et al., 2002; Ahles et al., 2003). Other studies identify eight cognitive domains: verbal fluency, verbal learning, verbal memory, visual memory, visuospatial function, psychomotor speed, reaction time, and executive function (Castellon et al., 2004). In addition, each study identifies a specific group of tests used to

measure cognitive performance in a particular domain. While there are commonalities in the tests selected, the lack of uniformity makes it problematic to draw reliable conclusions. In addition, the battery of tests often described may take several hours to complete leading to fatigue and inaccurate results.

What comparisons can be drawn to other known cognitive impairments?

Related aspects of cognition have also been explored in the scientific literature in attempts to increase the understanding of the phenomenon. For example, the problem of attentional fatigue and its impact on one's ability to concentrate has been considered as an attribute of cognitive dysfunction. Cimprich (1993) studied patients following breast cancer surgery and reported that reduction in attentional fatigue is important to carry out everyday activities, maintain clarity of mind, take effective action, and regulate interpersonal behaviors. Furthermore, the capacity to direct attention is important to other cognitive functioning (Von Ah et al., 2009). These behaviors, also described as social functioning, require attentive listening, exercising patience, or delaying when responses are appropriate.

Comparisons have been made between the capacity to direct attention and the clinical features of Adult Attention Deficit Disorder (Staat & Segatore, 2005; Simmons, 2009). In a study of symptom experiences and symptom distress in women undergoing treatment for breast cancer, Boehmke and Dickerson (2005), reported similar descriptions of chemotherapy-related cognitive changes including difficulties with attention and concentration. Additional findings are consistent with reports of individuals appearing to be disoriented, inattentive, and having difficulty learning new tasks (Louiselle & Rockhill, 2009).

Searching for Potential Causes

Physiologic causes. Researchers have hypothesized about the possible causes of chemotherapy-related cognitive change. The first is that chemotherapy, which is known to act as an irritant to some tissues and cause tissue necrosis in others, may in fact cause direct toxic injury to the brain or to the blood brain barrier (Staat & Segatore, 2005). Another hypothesis described by Saykin, Ahles, and McDonald (2003) involves a potential mechanism related to injury to the microvasculature leading to brain ischemia or infarction. It is also hypothesized that the release of cytokines which are activated by chemotherapeutic treatment may enter the brain causing inflammatory changes that lead to decreases in cognitive function (Saykin et al., 2003).

Several researchers question whether cognitive changes commonly seen in cancer patients are really attributed to chemotherapy and hypothesize that sickness behavior may be the true cause. The inflammatory process described above is believed to also cause sickness behavior associated with the inflammatory processes and subsequent cytokine release that occur with the body's response to the cancer disease process. This includes a group of symptoms that appear in cluster: fever, fatigue, lethargy, muscles aches, anorexia, decreased ability to concentrate, and loss of pleasure (Barsevick, 2007; Myers et al., 2008; Myers, 2009). Scientific knowledge of these processes is still developing.

The role of chronic disease in general and its impact on cognitive function has also come into question. Raffa et al. (2006) draw a comparison of cognitive impairment among individuals with other chronic diseases such as heart failure, diabetes, chronic obstructive pulmonary disease, and depression where similar association of cognitive impairment has been reported. Since cancer patients may have pre-existing diseases in

addition to a cancer diagnosis, the importance of obtaining baseline information on cognitive functioning becomes increasingly important. To date, research has not fully explored this hypothesis.

Hormonal therapies. The effect of hormonal therapy used in the treatment of breast cancer is an issue of increasing importance to patients and health care providers. Hormonal therapy is often prescribed following surgery and chemotherapy for breast cancer patients whose tumors are hormone receptor positive to prevent disease recurrence and prolong survival. Hormonal therapies can consist of anti-estrogen therapy and a newer group of agents, aromatase inhibitors. Although the number of young breast cancer survivors requiring adjuvant hormonal therapy is increasing, little is currently known about the long term effects of these agents on cognitive function (Pandya & Morris, 2006, Bender et al., 2006). As a result, there are increased numbers of studies examining the cognitive effects of hormonal therapies in combination with adjuvant chemotherapy.

Castellon et al. (2004) found that women who received adjuvant chemotherapy performed significantly worse in several cognitive domains than those women who had surgery alone. In particular, the domains most affected were verbal learning, visual spatial function, and visual memory. The greatest cognitive effect was seen in those who received both chemotherapy and tamoxifen. These findings are consistent with findings by van Dam et al. (1998) described earlier. An important limitation of this and earlier studies is that the sample size is small (n=53) and did not include the group of breast cancer survivors who receive only adjuvant hormonal therapy without chemotherapy. Castellon et al. (2004) acknowledge that the study limitations make it difficult to come to any definitive conclusions about the neurocognitive functioning of breast cancer

survivors following chemotherapy treatment. Importantly, their findings do support the need for further investigation into the effects of hormonal therapies on cognitive functioning in breast cancer survivors.

In a more recent study, Collins, Mackenzie, Stewart, Bielajew, and Verma (2009) explored the effects of hormonal therapies on cognition comparing women with breast cancer taking either tamoxifen or anastrozole to a healthy control group. They found that those taking hormonal therapy were more likely to show cognitive decline when compared to controls. The cognitive domains most affected were memory and processing speed. An important limitation of the study is that most of the patients were also receiving radiation therapy which is known to cause considerable fatigue, a factor not controlled for in the study design. Nonetheless, the findings suggest that subtle symptoms may be clinically significant and should not be discounted.

Finding Accurate Measures

Subjective measures versus objective measures. As previously mentioned, a variety of instruments have been used in attempts to measure cognitive change related to chemotherapy. These instruments address specific domains that are typically used in assessing neuropsychological disorders (Jansen et al., 2007). It is unknown whether these tests are reliable measures of cognitive changes related to chemotherapy. In other words, it is not known if these standardized tests have the ability to detect the subtle cognitive changes reported following chemotherapy. A meta-analysis of the sensitivity of neuropsychological tests used to detect chemotherapy related cognitive change in patients with breast cancer revealed variation in the tests used and often little or no explanation of how the tests were chosen (Jansen et al., 2007).

Although studies have reported an association between chemotherapy and both early and delayed cognitive changes in breast cancer survivors, limitations related to methodologies in most of these studies makes it difficult to draw conclusions with certainty (Taillibert, Voillery, & Bernard-Marty, 2007). Several studies report that even when patients showed little or no change in cognitive ability on standard assessment instruments, the same patients often perceived cognitive changes to occur (Castellon et al., 2004; Galantino, Brown, Stricker, & Farrar, 2006; Hermelink et al., 2006; Paraska & Bender, 2003; Tannock et al., 2004; Vardy et al., 2006). The incongruence between objective measures of cognitive change and patient's self-report of cognitive difficulties is well documented yet little progress has been made.

The shortcomings of current neuropsychological tests employed in studies of chemotherapy-related cognitive change are recognized by researchers worldwide (Rugo & Ahles, 2003; Vardy et al., 2006; Wefel, Lenzi, Theriault, Davis, & Meyers, 2004a). In fact, experts from the scientific community have convened at international workshops to review current studies and to establish criteria for future research. Consensus was reached, concluding that a research priority include the identification of neuropsychological tests that are sensitive to subtle changes seen in chemotherapy-related cognitive change and the development and validation of self-reporting procedures (Tannock et al., 2004). In addition, Vardy et al. (2008) reported from the 2006 international workshop that "At present cognitive research in cancer is limited by methodological challenges and the lack of standardization in neuropsychological studies" (p. 623).

Due to the lack of suitable instruments for measuring cognitive changes over time in cancer patients, Galantino et al. (2006) set out to develop and test a Perception of Cognition Questionnaire (PCQ) to be used in the context of an outpatient breast cancer population. Items for the PCQ were identified by using a two step process. Two focus groups, each made up of 35 participants, convened for one hour to produce data and insights for the question items. They verified the items and were asked to rank them from most important to least important. The second step involved transforming the items to questions. The final set of items identified from the focus groups were worded as questions comparing aspects of cognition from the initiation of chemotherapy treatment to the present time. The final result was an eight item questionnaire using a seven-point Likert scale and requiring an average of five to ten minutes to complete.

Psychometric testing of the PCQ instrument was done by adding the new instrument to an ongoing longitudinal study of breast cancer patients receiving anthracycline-based chemotherapy for Stage I, II or III disease. The PCQ was administered along with a Symptom Experience Scale (SES) and a Functional Status-Cancer (IFS-C) that were part of the parent study. Factor analysis and construct validity testing demonstrated that the PCQ is an internally consistent, valid, and sensitive instrument to measure perceived change in cognitive function.

The strength of the PCQ is that it measures changes in perception of cognition over time (Galantino et al., 2006). Galantino and colleagues point out that the purpose of the PCQ is not to capture the complexity of the many components of cognition nor the domains affected. Instead, the PCQ offers the possibility of measuring the general problem of cognitive difficulties as they relate to quality of life. Further testing of the

instrument is needed to establish criterion validity and to draw additional conclusions.

To date little progress has been made toward the goal of instrument development that is sensitive to the cognitive changes in cancer patients.

Predicting Susceptibility

Do cognitive changes occur in all malignancies? Chemotherapy-related cognitive change has been largely studied in women with breast cancer. This population makes up the second largest group of cancer survivors (Wefel et al., 2004b). Although the majority of research related to cognitive change following chemotherapy has focused on individuals with breast cancer, some of the following cancer diagnoses have also been studied: multiple tumor types (Fitch, Armstrong, & Tsang, 2008); breast and lymphoma (Ahles et al., 2002); lymphoma (Cull et al., 1995); GI and hematologic (Eberhardt et al., 2006); solid tumors (Kohli et al., 2007); lymphoma, breast, lung, and testes (Myers et al., 2008); and multiple sites (Vardy et al., 2006). Findings from these studies are not adequate to determine whether cognitive change is manifested differently across cancer diagnoses. Therefore, the question about whether cancer diagnosis predicts the occurrence or degree of chemotherapy-related cognitive change remains unanswered.

Does the time since treatment predict the effect? Researchers have also explored the timing of cognitive changes following treatment with chemotherapy. Still, there is a lack of clarity about how time since treatment predicts cognitive changes. Findings suggest that cognitive changes may develop at different intervals from the time of treatment, and may even pre-exist in some patients. The intervals studied have included the period following surgery but before chemotherapy (Bender et al., 2006; Hurria et al., 2006), the period during chemotherapy treatment, and at various intervals

following treatment for the first year (Wefel, et al., 2004a). A few studies have also evaluated long term effects noticeable years beyond treatment (Ahles et al., 2002; Ahles et al., 2003; Ferguson et al., 2007). Two of these studies will be highlighted.

Bender et al. (2006) studied cognitive function changes over time in women with breast cancer who received adjuvant chemotherapy versus those who received no adjuvant chemotherapy. Three groups of women were included: Group 1 received chemotherapy alone, Group 2 received chemotherapy and tamoxifen, and group 3 consisted of women with ductal carcinoma in situ who did not require adjuvant therapy. Importantly, this study included a pretreatment evaluation of cognition and post treatment measures at set time intervals for all three groups. One of the study limitations, common to longitudinal design, is that the subject attrition rate increased over time. In this study, the sample size decreased at each timed interval; however, the attrition rate was not different across the three groups. In the final analysis, the researchers found that women with breast cancer experience subtle changes that may be limited to memory deficits. Evidence of memory impairment was found in both groups who received adjuvant chemotherapy. In addition, those who received chemotherapy plus tamoxifen were found to experience the broadest deterioration in memory through the first 18 months following treatment.

Wefel et al. (2004a) found that 61% of the study cohort treated with standard dose chemotherapy experienced cognitive decline at the completion of therapy, typically six months from diagnosis. Primarily they noted decline in attention, learning new information, and processing speed. Long term results showed that at one year following completion of therapy, 50% had improved and 50% had remained stable. These findings

are problematic in that the sample size is very small ($n=18$); however, it poses the question of whether there is a subgroup of patients whose cognitive difficulties may have lingering effects.

Do genetic factors increase susceptibility? Scientists question whether a genetic predisposition could increase susceptibility to cognitive changes in some following chemotherapy. Ahles and colleagues (2003) explored the possibility that individuals who are carriers of the $\epsilon 4$ allele of the apolipoprotein E (APOE) gene, an identifiable factor in individuals with Alzheimer's disease, might have increased vulnerability to experiencing cognitive impairment following chemotherapy. Ahles et al. (2003) studied 51 breast cancer survivors and 29 lymphoma survivors who had been on the average 8.8 years post treatment. A standard battery of neuropsychological tests was administered to identify function in nine cognitive domains. In addition, psychosocial assessment tests were administered to control for the effects of depression, anxiety, and fatigue. Genotyping was performed on blood samples to detect presence of the $\epsilon 4$ allele.

This preliminary study showed that survivors with at least one of the $\epsilon 4$ alleles scored significantly lower in visual memory ($p<0.03$), spatial ability ($p<0.05$) and psychomotor function ($p<0.08$) compared to those without the $\epsilon 4$ alleles. However, the interpretation is limited. In addition, there are several study limitations such as small sample size, objective measures that may not be sensitive enough to detect the type of cognitive changes self-reported, and the lack of pretreatment measures. It is too early in this work to draw conclusions; however, the findings of this study support the continued investigation of genetic markers as a potential factor influencing susceptibility in some groups.

Intervention Studies

There is a scarcity of studies focusing on intervention strategies and to date there is not definitive evidence that any one strategy is superior for improving cognition related to chemotherapy. This section will address three intervention studies used specifically with breast cancer patients. The first study focuses on women who had surgery alone for localized disease. The second study was conducted with women who had completed chemotherapy treatment. The third was conducted with women who had completed chemotherapy and were admitted to a rehabilitation setting.

The first study was a National Cancer Institute (NCI) funded project to design an intervention to minimize or prevent attentional fatigue in breast cancer patients with stage I or II localized disease following surgery. Thirty-two women participated in activities that “engage fascination and have other restorative properties” (Cimprich, 1993, p. 83). Participants were randomly assigned to two groups, intervention or no intervention, each with 16 subjects. Their capacity to direct attention was assessed with both objective and subjective measures at four time intervals of 3, 16, 60, and 90 days following surgery. The restorative intervention included assisting the women to identify and choose from a list of activities thought to be helpful in resting and restoring the ability to concentrate. Significant improvement was seen in subjects in the intervention group over the timed intervals. The non-intervention group, on the other hand, showed a pattern of inconsistent performance.

Study limitations were primarily related to demographic differences between the groups. Although they were randomly assigned, differences in age and type of surgery may have influenced the findings. Specifically, the intervention group was older and

consisted of women who had mastectomies. Cimprich (1993) offers that these differences may account for the intervention group demonstrating greater overall improvement at the first time point. Aside from other strengths of the study, Cimprich (1993) makes an interesting observation concerning the subjects' preferences in activity selection. It was noted that the most frequently selected activities were those that involved the natural environment, such as walking or sitting in the park, bird watching, or tending to flowers and plants (Cimprich,1993). These findings can help to guide attention-restoring interventions in a variety of patient populations. The potential benefit to breast cancer patients who have cognitive changes following chemotherapy is unclear.

A second project, also funded by the NCI, examined the effects of cognitive behavioral management of chemotherapy-related change. Ferguson et al. (2007) presented the results of a single arm of a pilot study testing a brief cognitive-behavioral treatment, the Memory and Attention Adaptation Training (MAAT). The sample consisted of 29 women with Stage I or II breast cancer who completed chemotherapy treatment an average of eight years prior to testing. Ferguson et al. (2007) explained that the MAAT consisted of a participant workbook and four individual monthly visits. In addition, phone contacts were made one time between visits to offer support and provide review of the training. The MAAT is a technique Ferguson adapted from a behavioral technique called self-instructional training. The technique involves talking through a set of instructions alternately reading the same passage aloud and then silently (Hede, 2008).

The monthly visits were 30 to 50 minutes in length and provided a review of current knowledge of chemotherapy-related cognitive problems, identifying situations that may place the individual at risk for situations of memory difficulty, and time to learn

and rehearse strategies to compensate for their unique difficulties. Participants were asked to apply these strategies between visits. Problems between visits were assessed through telephone contacts between visits. Neuropsychological tests, measures of anxiety and depression, breast cancer survivor quality of life, and self-reported cognitive function measures were used. No control group was used in this preliminary study, but participants were assessed at baseline, immediately after treatment, and at two and six month time periods.

The researchers recognized several limitations to the study: lack of a control group, potential for practice with repeat testing, and lack of generalizability to other groups. The sample in this case was highly educated and read and learned the strategies quickly. Despite these limitations, this study adds to the science related to interventions for cognitive impairment in breast cancer survivors. Ferguson et al. (2007) found that in the sample studied, MAAT improves the self-reported cognitive function in daily life. Additionally, the participants rated this intervention helpful in terms of learning and using the strategies and high in terms of their overall satisfaction with the treatment.

The third study was conducted in Germany by Poppelreuter, Weis, and Bartsch (2009) and evaluated the efficacy of integrative cognitive therapy approaches early in the rehabilitation phase of breast cancer patients following adjuvant chemotherapy. The researchers note that, in Germany, rehabilitation services are routinely offered and do not imply a complicated recovery. Ninety-six women who were admitted to an inpatient oncology rehab unit were enrolled. The study intervention was led by an occupational therapist and team of eight specialists. The interventions were aimed at creating training situations that would best reflect activities of everyday life. The first intervention

involved face to face instruction and discussion and the second intervention involved a computer-based training activity. Potential participants were screened for cognitive deficits that were at least minor based on neuropsychological screening measures.

Poppelreuter et al. (2009) reported that the neuropsychological testing scores improved significantly in all three groups but could not claim a specific intervention effect since improvement also occurred in the control group. They speculated that the rehabilitation environment itself may provide beneficial cognitive stimulation. A problematic aspect of the study design was the inclusion of those with minor cognitive deficits. Recommendations for future studies would include stricter inclusion criteria to try to capture those with greater cognitive difficulties (Poppelreuter et al., 2009). This illuminates an important point for the development of inclusion criteria for studies related to chemotherapy-related cognitive change. The use of appropriate screening tools is needed to capture the desired population.

Impact of the Problem

As early as 1980, it was recognized that although the symptoms of cognitive impairment were often mild and went undetected, they were still capable of influencing one's ability to carry out routine daily activities (Oxman & Silberfarb, 1980). Ongoing research has further substantiated these early claims that the symptoms of cognitive change make it difficult to carry out normal daily activities in one's personal and professional life. Moreover, the emotional stress this may cause for the individual can result in additional physical and psychological consequences (Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000; Byar, Berger, Bakken, & Cetak, 2006).

The effect of cognitive dysfunction and its relationship to quality of life in breast cancer survivors was studied by Von Ah et al. (2009). The capacity to direct attention was selected as the cognitive measure because it is necessary for cognitive performance such as learning new information, planning, and making decisions. The final analysis of this descriptive, correlational study demonstrated that deficits in capacity to direct attention were related to poorer quality of life, including more depressive disorders, poorer well-being, poorer physical functioning, and greater fatigue (Von Ah, 2009). A major strength of this study is that the sample of 134 women included an almost equal number of African American and Caucasian women from a wide income range. The study was a secondary analysis which limited the variables and instruments to be selected. It would be helpful to know whether other cognitive processes impact quality of life to the same degree.

In a qualitative study to explore cancer patients' experiences with cognitive changes after chemotherapy, Fitch et al. (2008) found that cognitive changes could have significant personal impact. They conducted in-depth interviews with 32 individuals (25 female, 7 male) which focused on the persons' experiences with cognitive changes since treatment, the impact of those changes and strategies they used to manage them. Memory changes were the most commonly reported symptoms. The impact of the changes on daily life included difficulty completing activities related to daily living, work, and leisure activities. Several of those interviewed described the need to be organized in order to accomplish basic tasks and reported that tasks which demanded attention to detail were often seen as overwhelming.

Researchers from the University of California, Los Angeles, conducted focus groups and personal interviews to identify the impact of chemobrain on work, social networks, and health care response among breast cancer survivors (Boykoff et al., 2009). All 74 subjects participated in interviews and 20 subjects participated in both a focus group and interviews. All of the participants were all at least one year post radiation and/or chemotherapy treatment. Some were receiving hormonal treatment with tamoxifen. Findings revealed that cognitive change following chemotherapy can affect job performance related to varying levels of memory loss, decreased efficiency and speed, and increased stress. Participants in this study reported diminished quality of life and daily functioning. In some cases, the experience of treatment related cognitive impairment required changing employment to less demanding work and had significant financial ramifications. Although the sample consisted of equal numbers of white and African American women with breast cancer, the researchers recognize the benefit of future research to expand to other ethnic groups.

In a phenomenological study of the social and emotional toll of chemotherapy on individuals with cancer, Mitchell (2007) described eight major themes emerging from the data: striving for normality, the role of significant others, feeling up-feeling down, flagging, being sociable, anxiety, the chemotherapy process, and participating in research. An important finding of this study demonstrates that difficulties with concentration can lead to loss of confidence, which at times affects the individual's safety at home and compromises their ability to communicate effectively. Mitchell (2007) reported that many cancer survivors described feeling out of control, frustrated, and helpless. This study offers important insights into the treatment experience; however, the

study did not focus on cognitive changes alone and included a variety of individuals with different cancer diagnoses. A greater understanding of the impact of chemotherapy side effects, specifically focusing on cognitive changes, is needed to provide the necessary follow-up evaluation and support for cancer survivors.

Breast Cancer

To date, most studies of chemotherapy-related cognitive change have been conducted in women with breast cancer. This is most likely explained by the fact that women with breast cancer make up the largest number of cancer survivors (Ganz et al., 2004). In addition, treatment for a large number of women diagnosed with invasive breast cancer will consist of adjuvant chemotherapy and/or hormonal therapy. Consequently, minimizing the side effects of chemotherapy is an important goal in optimizing quality of life for breast cancer survivors (Phillips & Bernhard, 2003).

Breast cancer survivors, particularly those who are diagnosed at younger ages, may be faced with greater challenges than older women in managing the side effects of chemotherapy. In a study of adjustment to life following breast cancer diagnosis and treatment, Costanzo et al. (2007) concluded that the concept of “off time” events, particularly health-related events that occur during the prime of one’s life, may be the cause of distress in younger woman. In addition, this age group experiences greater demands in terms of parenting and work responsibilities. Importantly they found that younger women were more likely to experience depression, anxiety, and cancer related distress.

As described earlier, emotional distress may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment (NCCN, 2010).

Researchers found that the unexpected nature of lingering symptoms and the realization that certain symptoms were not improving was a source of increased distress and anxiety (Rosedale & Fu, 2010). Some women also experienced distress over thinking that nothing could be done to improve the symptoms and did not want to bother the physician with continual complaints. Further studies are needed to explore the relationship between emotional distress and the overall experience of symptom distress in breast cancer survivors.

In summary, quality of life in breast cancer survivors has been studied extensively (Byar et al., 2006; Ganz et al., 2004; Kessler, 2002). However, most studies have focused on symptom clusters consisting of pain, depression, and fatigue (So et al., 2009). Several studies have explored the sources of emotional distress and their impact on quality of life (Barez, Blasco, Fernandez-Castro, & Viladrich, 2009; Costanzo et al., 2007; Rosedale & Fu, 2010). Only a few studies have focused on the impact of cognitive change on quality of life in breast cancer survivors (Fitch et al., 2008; Von Ah et al., 2009). Further research is needed to understand the impact of cognitive change on quality of life in breast cancer survivors; specifically, how cognitive change affects one's ability to meet responsibilities and to fulfill personal and professional roles in this vulnerable population.

Summary

The science of cognitive change related to chemotherapy is in its early stages. As shown in this review of the literature, we are just beginning to understand the impact of cognitive changes on everyday function and productivity. Researchers and clinicians worldwide are interested in this phenomenon; however, they have not yet developed an

understanding of the subjective meaning of these symptoms. A gap currently exists in research relating to the lived experience of this phenomenon and objective measures alone do not provide the answers to describe how women cope with these changes. Giving voice to women's experiences of cognitive change following cancer treatment may help to identify the challenges they face on a day to day basis. Qualitative research methods offer a means to achieve a clearer understanding of the lived experience and to identify interventions that can be developed to improve quality of life for breast cancer survivors.

Chapter 3

Research Design and Methods

A phenomenological study was conducted to uncover the meaning of the lived experience of cognitive change following chemotherapy in breast cancer survivors. Problems best suited for a phenomenological approach are those in which it is important to understand several individuals' common or shared experiences of a phenomenon (Creswell, 2007). In addition, phenomenology is the method of choice when seeking to understand, make sense, and elicit meaning of a phenomenon (Morse & Field, 1995).

The specific aims of this research were to uncover the meaning of chemotherapy-related cognitive change in women with breast cancer, how symptoms are experienced and become evident, how the cognitive change impacts roles in personal and professional lives, and how women cope with these changes. Giving voice to women's experiences of cognitive change following chemotherapy treatment helps to identify the challenges they face on a day-to-day basis and how they manage to cope with these changes while attempting to fulfill various roles and responsibilities.

This chapter includes an overview of phenomenology including the description of phenomenology as both a philosophical movement and as a research method. The philosophical origins of phenomenology including intentionality, bracketing, and interpreting essence in phenomenology are described. The philosophical basis of phenomenology as described by van Manen (1990) is applied to the research question: What is the lived experience of cognitive change following chemotherapy? In addition, the study procedure is described in detail including setting, subjects, data collection, methods, and data management.

Phenomenology

Phenomenology is a qualitative research methodology commonly used in nursing and social sciences. From a post-positivist perspective, this method differs from traditional quantitative methods of scientific inquiry and offers new ways of knowing. The following section describes the development of nursing as a discipline, the shift in research paradigms, the role of qualitative methods in acquiring scientific knowledge, and the challenges for nursing in the use of phenomenological research methods.

Science and Philosophy

The phenomena of interest to nursing are people and the world they live in; specifically, how the world or environment impacts them. Nursing science is a discipline that focuses on the interaction of man, health, and environment (Newman, 2009). In fact, nurse scientists recognize that nursing knowledge is developed from multiple perspectives. While, empirical knowledge provides an important kind of evidence, it is recognized that plurality is needed to reflect the many aspects of nursing science and to illuminate complex phenomena present in patient care situations (Warms & Schroeder, 2009).

The structure of nursing knowledge has been described as a triad consisting of philosophy, science, and theory which are interrelated and are dynamic in nature (Silva, 2009). In addition, Silva (2009) asserts that “all nursing theory and research is derived from or leads to philosophy” (p. 16). Philosophy includes metaphysics, epistemology, ethics, and logic which are philosophical approaches that guide scientific endeavors and how we arrive at knowing (Silva, 2009). Although philosophers debate the meaning of metaphysics, for purposes here, metaphysics examines the causality of concepts of

importance within the discipline. Logic focuses on the validity of thoughts and correct reasoning. Ethics examines values and moral principles. Lastly, epistemology focuses on the theory of how knowledge is acquired, the nature of it, and how it is tested.

Inherent to knowledge are truth, secure belief, and evidence (Silva, 2009). Furthermore, knowledge is essential and foundational in science, theory, and research.

There are two important points inherent in Silva's view. One is that the advancement of nursing knowledge is dependent upon the openness of the discipline to all potential avenues of increasing knowledge within the discipline. Specifically, this means openness to accepting and incorporating knowledge from other disciplines. The second is the belief that the pursuit of nursing knowledge should not be confined to traditional scientific methods that emphasize rigor over outcomes of importance to nursing practice.

Paradigmatic Inquiry

Over time, nursing's acceptance of multiple paradigms has allowed the integration of knowledge from different perspectives (Giuliano, Tyer-Viola, & Lopez, 2009). The resultant increase in cumulative knowledge is needed for the development of the discipline and to provide research that is relevant to clinical practice (Weaver & Olson, 2009). Paradigms have been described as the "patterns of beliefs and practices that regulate inquiry within a discipline and provide lenses, frames, and processes through which investigation is accomplished" (Weaver & Olson, 2009, p. 250). The major inquiry paradigms that have influenced nursing science and social science in the last century are positivism, post-positivism, critical theory, constructivism, and

participatory-cooperative. From a truth perspective these paradigms range from foundationalism (positivism) to relativism (participatory-cooperative).

Traditional scientific inquiry is based on the positivist belief that there is one truth that transcends opinions and biases. Conversely, the post-positivist stance is that we may never truly know the “truth” but can arrive at an approximation of it or a high probability of reaching the truth. Positivism, in relation to how we come to know (epistemology), values objectivism which requires a dualism of investigator and investigated as separate entities that must be held apart (Gortner, 2009). Whereas, post-positivism values both objective and subjective means and incorporates both quantitative and qualitative methods of conducting scientific inquiry. Although post-positivists look to qualitative methods as valid ways of knowing, they still hold onto the importance of validity, reliability, and generalizability common to the positivist stance. This “holding on” to the remnants of positivist thought may contribute to the discussion that follows.

In the latter part of the twentieth century, trends in the philosophy of science moved from logical empiricism to historicism. Silva and Rothbart (2009) claim that historicism, which calls for a more holistic and human approach to science, has significantly impacted nursing theory development and theory testing. Importantly, they point to historicism as encouraging theory expansion through integrating components of different research traditions which will lead to better understanding of the phenomena of importance to nursing. Specifically, qualitative research with its broad range of methodologies provides an alternative research tradition for nursing inquiry (Sandelowski, 2008).

Qualitative Research and Phenomenology

Qualitative research varies from traditional quantitative methods in several ways. The setting of qualitative research is a naturalistic or field setting which takes in all the aspects of the setting and influencing variables as part of the whole (Creswell, 2007). Quantitative methods involve controlled situations, where the researcher limits the effect of extraneous variables in order to increase generalizability and context has a limited effect. In contrast, in qualitative designs, the context is important; but the research is not always context bound (Morse & Field, 1995; Creswell, 2009). The nature of the data in quantitative studies is referred to as “hard” data or numbers that represent data converted to codes for statistical manipulation. Conversely, qualitative methods incorporate “soft” data that is not transformed to numbers; rather, the data include interviews, transcripts, historical or personal documents, photographs, observation, videotapes and literature (Morse & Niehaus, 2007).

The dominant styles of reasoning are also different. While quantitative methods use deductive methods of reasoning; qualitative methods utilize inductive approaches that are reiterative and cyclic and analysis evolves through the process of the research rather than occurring as a final step (Morse & Niehaus, 2007). The design of quantitative studies is rule based, carefully planned and can be replicated; whereas, qualitative methods are principle based. The design of qualitative studies is characteristically flexible and responsive, and replication is not the goal (Morse & Niehaus, 2007). Polit and Beck (2006) describe qualitative findings as providing rich descriptions that enable readers to understand and make sense of clinical reality. The goal of qualitative research is to derive meaning or understanding from real life situations (Morse & Field, 1995).

Phenomenology is one qualitative method of inquiry that has been used within the fields of nursing and the social sciences. Giorgi (2005) describes the significance of phenomenology to human science research:

The introduction of phenomenology on the philosophical scene offered a very important promise. It is a shift of focus from physical nature, cause-effect analyses, impersonal forces and their manipulation and control to human subjectivity, intentionality, the meaning of actions, and the freedom and responsibility that intrinsically belong to them. (p. 77)

Phenomenology has its philosophical roots in the works of such philosophers as Husserl, Heidegger, and Merleau-Ponty (Patton, 2002). These twentieth century philosophers were part of a movement that is now referred to as continental philosophy which called for “A renewal of thinking not as an abstract endeavor but related to concrete situations where thinking occurs in action” (Lawlor, lecture, Sept 1, 2009).

Phenomenologists view human existence as meaningful and interesting, accepting experience as it exists in the individual’s consciousness. Phenomenological researchers ask: What is the essence of a phenomenon as experienced by a group and what does it mean? Morse and Field (1995) describe the goal of phenomenology in research “to describe accurately the experience of the phenomenon under study and not to generate theories or develop general explanations” (p. 23). In addition, they caution that many qualitative research approaches are incorrectly classified as “phenomenology” merely because the research focuses on “experience.” For this reason, the reader must carefully evaluate the writer’s descriptions. Consequently, the challenge before researchers planning to conduct phenomenological studies is to gain an understanding of philosophical thought and the origins of phenomenological practices to prevent misrepresentation of their work.

Challenges for Nursing

Although phenomenology addresses concepts of importance to nursing, there are controversial issues in relation to the methods employed. Paley (1997) asserts that phenomenology has been imported into nursing in ways that are problematic and states that “While Husserl is often referenced, he is seldom quoted” (p. 187). Although nurse researchers may take up phenomenology in their own work, many do not hold true to its philosophical traditions (Paley, 1997). The result is a scarcity of information within the nursing literature concerning phenomenological methods and ways to conduct this research.

Phenomenology as a research methodology in nursing has received criticism and concern from several within the discipline. Lawler (1998) identified tensions that arise from using phenomenology as a research methodology. One of these is the issue of “adapting a fundamentally philosophical means of understanding human beings” for use as a research method that is both robust and has pragmatic utility (p. 104). When nurse scientists became interested in qualitative research in the 1980’s, these methods were not accepted by other serious scholars of science. Subsequently, nurses and others using these methodologies resorted to methods of analysis that held true to traditional scientific scrutiny. They sought to incorporate a process that could be argued as scientifically rigorous. Although greater support and funding exists at the national level for qualitative research studies, nurses and social scientists still have the challenge of convincing colleagues of the merit of their work and so continue to incorporate quantitative methods of analysis in their projects.

Although the issues surrounding the use of phenomenological research are complex; three goals for phenomenological research emerge as imperative. These are principles for conducting phenomenological studies that offer balanced integration of philosophical thought. Described by de Witt and Ploeg (2006), they include: an “articulation of the general philosophical theme and its fit with the researcher and the research topic,” a clear description and “intertwining of the philosophical concepts within the study methods and findings;” and lastly, pursuing a “balance between the voice of the study participants and the philosophical explanation” (p. 224).

Intentionality and the Natural Attitude

In Husserl’s essay, *Transcendental Phenomenology and the Way through the Science of Phenomenological Psychology* (1927/1999), he states “The term ‘phenomenology’ means two things: a new kind of descriptive method which made a breakthrough in philosophy at the turn of the century, and a priori science derived from it...” (p. 322). Husserl (1927/1999) begins with a discussion of “psychological phenomenology” which is described as closer to our “natural thinking” and he guides us through a thoughtful process to the description of the “a priori pure or ‘phenomenological’ psychology” (p. 322). In this essay, he begins to disentangle pure psychology from pure science: “...necessary is a clarification of what is peculiar to experience, and especially to the pure experience of the psychical – and specifically the purely psychical that experience reveals...” (p. 323).

This is specifically what nurses and social scientists refer to when they describe the importance of qualitative research methods in revealing the meaning of certain experiences. Furthermore, to accept qualitative methods over traditional scientific

methods requires being open to new ways of thinking and thoughtful reflection on our current beliefs. Husserl (1927/1999) continues "...Focusing our experiencing gaze on our own psychic life necessarily takes place as reflection, as turning about a glance which had previously been directed elsewhere" (p. 323). Therefore, reversal of the gaze is to look at the experience itself. In addition, one may interpret that the world is relative to consciousness as it appears to me. The following quote from Husserl's same essay demonstrates this point:

Through reflection, instead of grasping simply the matter straight-out – the values, goals, and instrumentalities – we grasp the corresponding subjective experiences in which we become "conscious" of them, in which (in the broadest sense) they "appear." For this reason, they are called "phenomena," and their most general essential character is to exist as the "consciousness-of" the specific things, thoughts... (p. 323)

Husserl states "...the basic character of being as consciousness, as conscious of something, is *intentionality*. In unreflective holding of some object or other in consciousness, we are turned or directed toward it: our '*intentio*' goes out toward it" (p. 323). Intentionality is the foundation of all phenomenological psychology. Therefore, all of our thinking, feeling and acting are always about things in the world. The reality of an object is linked to one's consciousness of it. It is the fundamental concept for understanding conscious acts and experiences. In this thought one can see a clear refusal of the subject/object dichotomy. Husserl (1927/1999) explains:

Psychic life is accessible to us not only through self-experience but also through experience of others. This novel source of experience offers us not only what matches our self-experience but also what is new, inasmuch as, in terms of consciousness and indeed as experience, it establishes the differences between own and other, as well as the properties peculiar to the life of a community... (p. 324)

This rings true in the examples of the phenomena of interest to nursing. Consider the question of what the experience of miscarriage is for women in lower socioeconomic groups. The researcher may have some personal experience with miscarriage but through the experience of others, in this case a specific “community,” brings a new view, a new understanding of the phenomenon.

A challenge associated with Husserl’s conception of phenomenology is trying to escape from natural forms of thinking, so that we are open to new ways of knowing.

Husserl (1927/1999) explains further:

Ultimately, the great difficulty rests on the way that already the self-experience of the psychologist is everywhere intertwined with external experience, with that of extra-psychical real things. The experienced ‘exterior’ does not belong to one’s intentional interiority, although certainly the experience itself belongs to it as experience – of the exterior. Exactly this same thing is true of every kind of awareness directed at something out there in the world. (p. 325)

The relationship of the inside to the outside reflects the directing of one’s thinking to something other than consciousness. Therefore when things are led into our thinking, they are made questionable to us. It is through this process that nursing inquiry develops. The phenomenological approach is to suspend all judgment about what is real, the “natural attitude” or natural way of thinking. Husserl (1927/1999) refers to the suspension of our natural belief as the “epoche” in this excerpt:

The universal epoche as it becomes known in consciousness (the “putting it in brackets”) shuts out from the phenomenological field the world as it exists for the subject in simple absoluteness; its place, however, is taken by the world as given in consciousness (perceived, judged, thought, valued, etc.) the world as such, the “world in brackets. (p. 325)

The “epoche” is done in a consistent way and is universal, therefore, it leaves nothing out. This method of reduction or disentangling is done to reveal the true or genuine inner experience.

Interpreting “Essence”

The aim of phenomenological studies is to elucidate the lived experience and to uncover its hidden meaning. The meaning of the lived experience is revealed through descriptions of the nature of the phenomenon (Parse, Coyne, & Smith, 1985).

Uncovering the meaning requires revealing the essences of the phenomenon under investigation. In *The Idea of Phenomenology*, “The First Step in the Phenomenological Orientation,” Husserl (1907/1990) explains this about essences:

What I want is clarity. I want to understand the possibility of that reaching. But this if we examine it sense, signifies: I want to come face to face with the essence of the possibility of that reaching. I want to make it given to me in an act of “seeing.” (p. 4)

Therefore, as described in Husserl (1907/1990), of essence, “Their imminence is simply their givenness to ‘seeing’” (p. 3). In human science research, essences of a phenomenon may be the core meanings mutually understood through a phenomenon commonly experienced by different individuals (Patton, 2002). For example phenomena of interest to nursing may include the subjective experiences of pain, cancer, and miscarriage. The goal of the researcher is to “see” as Husserl describes the essence of the lived experience. The essence is revealed through the subjects rich descriptions of the experience.

As the phenomenological movement progressed in the early twentieth century, Heidegger posited a different way of conceptualizing phenomenology. Heidegger believed that knowledge of being in the world, one’s “lifeworld,” required movement

beyond description to that of interpretation (McConnell-Henry, Chapman, & Francis, 2009). Since, Husserl and Heidegger were once colleagues, some historians suggest that Heidegger's divergent views created tension and a parting of ways. What is certain is that the world in which they lived was in social, political, and economic turmoil. Subsequently, the thoughts of philosophers, such as Heidegger, began to change in response to their world. The philosophical views that resulted may represent a natural progression in man's understanding rather than the formation of oppositional camps.

Heidegger's views took a turn from Husserl's in that he claimed that it was not possible to separate oneself from one's being in the world and that one's experiences contribute to one's interpretation of phenomena. Important to Heidegger's view is the notion that time (temporality) creates the context in which phenomena are experienced and interpreted. In *The Basic Problems of Phenomenology*, Heidegger (1927/1982) posits that "...temporality makes possible the understanding of being" (p. 302). The concept of temporality suggests that one's experience of the world is a result of one's interconnectedness with other things and other human beings (Johnson, 2001). The notion of temporality and the significance of human relations in understanding human experience will be explored in the following section.

Phenomenology as a Research Methodology

When phenomenological methods are used in research, it is important for researchers to identify and to explain the philosophical stance of their approach to phenomenology. The philosophical foundation provides a context in which to understand the research process, its logic, criteria, and analytical methods. In addition, research findings and conclusions should demonstrate congruency with the identified method.

The following will explore the differences between descriptive and interpretive perspectives and explore van Manen's view of a blended approach.

Descriptive versus Interpretive Perspectives

Descriptive phenomenology is based on the assumption that the researcher can provide a pure description of the lived experience; whereas, interpretive phenomenology assumes that meaning is embedded in the experience. Spiegelberg's (1975) suggests that these approaches are not necessarily oppositional and argues that phenomenology occurs in stages as a progression of ideas. The descriptive stage stimulates our perceptiveness of the essences of experience through suspending judgment and making us aware of our subjective claims to knowledge. In the interpretive or hermeneutic stage, we are open to the concealed meanings in the phenomena. Hermeneutics "goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices" (Lopez & Willis, 2004, p. 728). This corresponds to Heidegger's concept of the "lifeworld" in which the interconnectedness of context and time influence the meaning of an experience. Polit & Beck (2006) describe interpretive phenomenological research as entering "another's world and to discover the practical wisdom, possibilities, and understandings found there" (p. 221).

Theoretical frameworks. Descriptive phenomenologists negate the idea of incorporating theoretical frameworks into the process of inquiry. In addition, some argue that a review of the literature is not needed prior to research as it might direct the nature of the inquiry. On the other hand, the interpretive approach differs from the descriptive approach in that it incorporates theoretical frameworks in a way to identify where research gaps may exist and to elucidate aspects of the concept under study including the

state of the science and identification of research questions (Thorne, Kirkham, & MacDonald-Emes, 1997). Furthermore, some suggest that a description of how the theoretical framework was used should be included in the interpretation of data and subsequent research findings (Lopez & Willis, 2004).

How findings are generated and used. Lopez and Willis (2004) offer a comparison of descriptive and interpretive phenomenological methods based on their philosophical values and knowledge claims. They identify two ways in which these approaches differ: how findings are generated and how findings are used within the professional context. Using the framework offered by Lopez and Willis (2004), a researcher using descriptive methods to study the phenomena of cognitive change following chemotherapy would ask “Tell me what it is like to have cognitive difficulties” and follow-up with questions to identify the essence of the experience common to a group of subjects. On the other hand, a researcher using an interpretive approach would ask “Describe a typical day in detail when you’ve experienced cognitive difficulties.” The follow-up questions would explore the interactions experienced throughout the day, work or professional responsibilities, relationships to others, and embodiment of the experience. Therefore, a purely descriptive approach is useful in uncovering essences of phenomena that have not been fully studied conceptually; whereas, an interpretive approach is useful in revealing hidden aspects of a phenomenon by examining the influence of contexts in which it is experienced (Smith, 2004; Wojnar & Swanson, 2007). Translated into nursing practice, descriptive methods lead to findings that improve our understanding of certain constructs that can help to refine current measures. Whereas,

interpretive approaches which include contextual features of a phenomenon may guide practice or lead to recommendations for new practice strategies.

Blended Approaches

Max van Manen (1990), an educator and scholar, posits that phenomenology has both descriptive and interpretive elements. First is the description of the lived experience; and second, is the description of the meaning of the expressions of the lived experience. The expression is interpretive when mediated by language, action, poetry, art, or narrative. Therefore, van Manen points out that “all description is ultimately interpretive” (p. 25) and that the more important issue is what makes a phenomenological description different from other kinds of descriptions.

van Manen has developed a framework for conducting phenomenological studies that has been used widely by nurses and social scientists. The philosophical ideas of twentieth century philosophers, Husserl, Heidegger, and Merleau-Ponty, are evident throughout van Manen’s writings. van Manen distinguishes human science research (qualitative methods) from natural science research (quantitative methods). The difference between the two begins with the types of research questions posed. Natural science studies things or natural events and the way that objects behave. Conversely, the human sciences study people, not things, and are concerned with “beings that have ‘consciousness’ and that act purposefully in the world by creating objects of ‘meaning’ that are ‘expressions’ of how human beings exist in the world” (van Manen, 1990, p.4). This is true of nursing which is interested in the meaning of human experience.

van Manen identifies eight important concepts related to phenomenological research. They are listed here with summative statements of van Manen’s descriptions:

- *Phenomenological research is the study of lived experience.* Phenomenological research begins in the lifeworld. This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, and pre-theoretical. The questions asked are: What is it like to have a certain experience? van Manen (1990) emphasizes that such a question often leads to theorizing in search of answers. Consider the question, “What is it like to live with cognitive changes such as difficulty concentrating and multi-tasking?” To answer these questions, we could look to knowledge based on theories about cognition and the pathophysiology of neurological pathways. But, they would not likely get us any closer to the answer. Instead, the knowledge of what it is like to live with cognitive changes is best made visible by returning to the lifeworld, to the lived experience.
- *Phenomenological research is the explication of phenomena as they present themselves to consciousness.* Consciousness is our only access to the real world, so for us to understand something it “must present itself to consciousness” (van Manen, 1990, p. 9). Since we “cannot reflect on lived experiences while living through the experience” (p. 10), van Manen (1990) concludes that phenomenological reflection is not introspective but retrospective. Individuals experiencing cognitive changes following cancer treatment may ask themselves “What just happened here?” It is through retrospection, that they may be able to describe the circumstances that led to the experience, how they became aware of cognitive difficulties, and how they compensated for the changes in cognitive ability.

- *Phenomenological research is the study of essences.* Phenomenological research asks what is the very nature of a phenomenon, what “makes a some ‘thing’ what it is...” (p. 10). The very nature of the phenomenon of chemotherapy-related cognitive change may be discovered in the essence of these cognitive changes that are different and unique from other instances of cognitive change in other populations. According to van Manen (1990), this is a “systematic attempt to uncover and describe the structures, the internal meaning structures or the lived experience” (p. 10). For example, a researcher might ask: What is the nature or essence of the experience of cognitive change in breast cancer survivors so that I can better understand what it is like for these women? According to van Manen, the essence is “adequately described in language if it reawakens” (p. 10) or brings to light the lived experience of cognitive change in breast cancer survivors in a fuller or deeper manner.
- *Phenomenological research is the description of the experiential meanings we live as we live them.* van Manen (1990) describes phenomenological research as “the study of lived or existential meanings” described and interpreted to “a certain depth and richness” (p. 11). Quantitative methods of scientific inquiry seek to explain relationships among variables related to human behavior through statistical manipulation; whereas, phenomenology looks for meanings “as we live them in our everyday ... lifeworld” (p. 11). The impact of chemotherapy-related cognitive change could be studied quantitatively using measures of emotional and psychosocial variables and quality of life measures. Specific quantitative design questions might include: What is the relationship between cognitive impairment

and emotional distress? How does cognitive change following chemotherapy impact quality of life in breast cancer survivors? Consequently, quantitative research methods fall short of exploring the meaning of the lived experience beyond “what” is experienced and does explain how it is experienced and the meaning of the experience.

- *Phenomenological research is the human scientific study of phenomena.* This research is described by van Manen as systematic and including approaches that consists of questioning, reflecting, focusing, and intuiting. The content and form of phenomena are explicitly described in rich detail and depth. van Manen (1990) contrasts this to poetry and other forms of literature which have implicit meaning. van Manen describes phenomenological research as “self-critical” and “intersubjective” (p. 11). According to this description, phenomenological research is “self-critical” in that the researcher is continually reexamining the goals and evaluating the strengths and weaknesses of its methods. van Manen describes phenomenological research as “intersubjective” in that the researcher needs the reader for validation of the phenomenon described. This validation of the interpretation is important to many qualitative research methods.
- *Phenomenological research is the attentive practice of thoughtfulness.* As an educator, van Manen’s (1990) writings are based on pedagogical everyday relationships of teachers and their students. For nurses, phenomenological interests present themselves in our everyday activities. Similarities can be drawn to the nurse-patient relationship and the responsibility of the nurse to the individual person or family. Cognitive change following chemotherapy is a

concept that needs to be discussed with individuals prior to treatment, during treatment, and during follow-up visits. Validation of the symptoms of cognitive change, as well as, potential methods for managing anticipated difficulties are important conversations between the patient and health care provider.

- *Phenomenological research is a search for what it means to be human.* van Manen (1990) explains that as we research the lived experience and its meaning, we expose the sociocultural and historical traditions that give meaning to our existence and we come closer to understanding what it means to be in the world. For example, a nursing study of the experience of living with a cognitive change might reveal the social and cultural aspects found in the disruption of traditional family roles and relationships. Importantly, van Manen (1990) claims that “phenomenological research description carries a moral force” (p. 12) because it discloses how to be in such situations. This is of particular importance for breast cancer survivors who may struggle with changing family roles. Some of these roles may include common daily activities such as who transports the children to after-school activities or who helps the children with homework assignments. These roles and responsibilities may be what one ties to their moral view of how to be a “good” mother.
- *Phenomenological research is a poetizing activity.* van Manen (1990) reflects on Merleau-Ponty in drawing comparisons to poetry. “Poetry does not ask for a conclusion. The poem is the result. The poem is the thing” (p. 13). Similarly, the participants in a phenomenological study express themselves with language that is used as a genuine, valid description of the world. In other words, the results are

the experience. It is important to develop an understanding of the experience of chemotherapy-related cognitive change in women's words to better identify the impact of the symptoms of the phenomenon and how women cope with these changes in relation to their daily roles and responsibilities.

Summary

In general, qualitative researchers emphasize that a good phenomenological description is one that “resonates with our sense of a lived life” (van Manen, 1990, p. 27) and one that rings true for others who have had the similar experience. van Manen's work integrates the philosophical thoughts of several twentieth century philosophers: Husserl, Heidegger, and Merleau-Ponty. He draws strict comparisons between research methods, procedures, and techniques; and describes “methodology” as a philosophical framework that follows a certain tradition in pursuit of knowledge. van Manen (1990) believes that “the method of phenomenology is that there is no method” and he strongly emphasizes the importance of philosophical tradition and scholarship (p. 28). In what van Manen (1990) refers to as “the validation circle of inquiry” he states “...a good phenomenological description is collected by the lived experience and recollects the lived experience - is validated by lived experience and it validates lived experience” (p. 27). Therefore, the goal of phenomenological descriptions is to reveal the hidden meaning of the lived experience.

Phenomenological Analysis

Phenomenological research begins with the researcher's recognition of preexisting assumptions and pre-established interpretations of the phenomena of interest. In addition, continued reflection on these preconceptions is an important part of all

phases of phenomenological analysis. Husserl (1927/1999) described the recognition of pre-existing perceptions as a critical first step in reflection and recommended purposefully suspending all judgment about what is real, the “natural attitude” or natural way of thinking. The “epoche” or refraining from judgment is important in reinforcing rigor as the researcher “looks inside to become aware of personal bias” (Patton, 2002, p. 485). Self-reflection and awareness enables the researcher to bracket preexisting ideas and biases. As a result, bracketing assists the researcher in uncovering an accurate description of the reality of the phenomenon as it is lived. In addition, bracketing may help the researcher to separate their own experience or beliefs of the phenomenon studied from the reality of others (Swanson-Kauffman & Schonwald, 1988). Ultimately, the researcher’s awareness of their own presuppositions and knowledge of a phenomenon may help to guide the inquiry in a more meaningful way (Dowling, 2007; Walters, 1995).

The literature includes several interpretations of bracketing. The broadest of these describes bracketing as suspending one’s understanding or beliefs in a reflective way that promotes curiosity about a phenomenon of interest (Creswell, 2007). In contrast, bracketing is sometimes described as a structured activity that takes place at a defined period of time and aimed primarily at establishing rigor and objectivity (Hamill & Sinclair, 2010). Criticism of the latter description is that it focuses on bracketing as an activity rather than as a thoughtful consciousness process (Dowling, 2007).

Bracketing Typologies in Qualitative Research

Gearing (2004) recognized that the application and operationalization of bracketing in qualitative research is often vague. Using a historical approach he offers a typology of bracketing in qualitative research based on the dominant philosophical

stance. The construction of this typology includes the identification of how bracketing is accomplished at three distinct stages of the research process. The first of these stages is the abstract formulation which is dependent upon the researcher's philosophical orientation and theoretical framework. The second phase of bracketing is research praxis which includes the detailed steps of the process, the description of what is to be bracketed, how this is to be achieved, and when it is to be done. Lastly, Gearing (2004) offers the idea of reintegration as an often overlooked phase of bracketing. Reintegration requires analysis of bracketed information and its integration back into the data and its interpretation.

The typology of bracketing includes six types of bracketing in the order of their historical development. These include: ideal (philosophical), descriptive (eidetic), existential (interpretative), analytical, reflexive (cultural, hermeneutics), and pragmatic (range of qualitative theories). Ideal bracketing is the purest form of descriptive phenomenology where all suppositions are held in abeyance. The descriptive form of bracketing "represents the refinement and maturation of this ideal into a more practical application" (Gearing, 2004, p. 1439). Although, it is closely rooted in Husserl's views, it acknowledges that it may not be possible to bracket all of the influences that may exist and impact the research process. Existential bracketing incorporates the philosophical views of Heidegger. The researcher sets aside presuppositions when possible but does not establish explicit boundaries. Rather, the bracketing is described as "porous" allowing some bracketed elements to flow through and reintegrate in the data. The analytical form of bracketing can be found in other types of qualitative research such as ethnography and grounded theory. This form recognizes the impact of social life, the

larger world, and environment. Bracketing in this form is a process that lacks structure and is one in which the researcher enters and exists to reintegrate data. In reflexive bracketing the focus is to make the process transparent. The researcher's values, presuppositions, and background are made explicit prior to the research. However, the external presuppositions are not bracketed out because they are recognized as essential to study of the phenomenon. The final form of bracketing presented by Gearing (2004) is the pragmatic. This form of bracketing allows the least structure and enables the researcher to construct the bracketing to fit their particular research question, study design, and analytical methods.

Perspectives on Bracketing in Phenomenological Research

As demonstrated in the above discussion, the type of qualitative research method employed determines the type of bracketing that is applied. Likewise descriptive and interpretive approaches to phenomenological research maintain different perspectives on bracketing. The following discussion compares and contrasts two dominant views of bracketing in phenomenological research. The perspectives of Giorgi and van Manen are used to illustrate the differences in bracketing related to the distinction between descriptive and interpretive phenomenological approaches.

In terms of bracketing, van Manen (1990) maintains that suspending one's beliefs is an important process even in interpretive approaches because doing so brings to one's consciousness the awareness of their potential impact on interpretation of the phenomenon. Simply stated he suggests that we often know too much about a phenomenon of interest and he refers to our "'common sense' pre-understandings" (p. 46) and preconceptions, and assumptions as an important problem in phenomenological

research (van Manen, 1990). van Manen agrees with the concept of bracketing as important in recognizing one's beliefs but questions how it is possible to totally separate oneself from them. Instead, he recommends making one's presuppositions, beliefs, assumptions, and theories explicit and visible so that they are continually exposed to the researcher. This approach aligns with the reflexive type of bracketing described by Gearing (2004).

In contrast, Giorgi (2009) posits that bracketing is not forgetting past knowledge but rather that "we should not let our past knowledge be engaged while we are determining the mode and content of the present experience" (Giorgi, 2009, p. 92). Giorgi's background as a psychologist is evident in his writings about phenomenological reduction and description. From a philosophical perspective, his writings strongly reflect the ideas of Husserl specifically related to the concepts of consciousness and experience. The question of importance to Giorgi is one of interpretation. He asks "How does one analyze a description of a concrete experience in a psychologically meaningful way and achieve at least some degree of objectivity?" (Giorgi, 2009, p. 121). The answer he suggests is in trying to understand the meaning of the description based solely on what is presented in the data. At this point, he deviates from van Manen. Giorgi's method provides an analysis of the data that is purely descriptive and aligns with the descriptive type of bracketing described by Gearing (2004). Giorgi's approach may be problematic in research which aims to not only reveal the essences of a phenomenon but also seeks to understand the phenomenon within a larger context.

Approaches to Thematic Analysis

Phenomenology as a research method involves identifying themes from the participant's descriptions of the meaning of a phenomenon of interest. The goal of this method is to understand the common or shared experiences of the phenomenon (Creswell, 2007). Yegdich (2000) asserts that what is essential or universal to an experience may not necessarily be what is subjectively experienced by the individual. Contrary to this view, van Manen (1990) claims that "Phenomenology is neither mere particularity, nor sheer universality" (p. 23). He also describes that in phenomenology one mediates that which is different and unique and that which is universal. Moreover, one can assert that the consciousness of the individual subject reveals to the researcher the differences of the lived experience preserving what is unique while seeing what Husserl (1927/1999) described as "properties peculiar to the life of a community..." (p. 324).

Approaches to thematic analysis in phenomenology are based on the dominant philosophical stance. To demonstrate this point the following discussion contrasts the approaches taken by Giorgi (2009) and van Manen (1990). Giorgi's descriptive approach to phenomenology includes the following steps of analysis: reading the whole and suspending beliefs (bracketing), analysis to determine the meaning units, identification of central themes, and descriptive statement of the essential themes. The final product is a descriptive statement of the essential structures of the phenomenon that rings true to anyone who has had the experience.

In contrast, the method described by van Manen (1990) incorporates elements of both description and interpretation into the following steps: uncovering thematic aspects,

isolating thematic statements, composing linguistic transformations, deriving thematic descriptions from artistic sources, interpreting through conversation, exploring lifeworld existentials as guides to reflection, and determining incidental and essential themes. For van Manen, writing is the focus of phenomenological analysis. Writing thematically, analytically, exemplificatively (identifying essential structures), exegetically (conversational scripts), and existentially is done to develop a text that provides an interpretive description of some aspect of the lifeworld (van Manen, 1990).

van Manen and Lifeworld Existentials

van Manen (1990) describes common existential themes that are present in all human experience and belong to the fundamental structure of the lifeworld. These lifeworld existentials include: lived space, lived body, lived time, and lived human relation. van Manen posits that for any experience of interest, one “can always ask the fundamental questions that correspond to these four lifeworld existentials” (p. 102).

Lived space (spatiality) refers to a felt space rather than a physical space. This can best be described by the way that certain space makes one feel. Exploring the qualities and aspects of this lived space will help one to understand it. For example, a space that makes one feel safe or nurtured will have certain qualities that ring true in the description. *Lived body*, or corporeality, refers to the fact that one exists in a physical sense. One’s physical presence reveals certain aspects about them that are openly revealed but also includes that which may be consciously hidden. Furthermore, one’s behavior may change in response to perceived responses of others. *Lived time* (temporality) is the subjective sense of time that appears to either speed up or slow down depending on the nature of the experience. Enjoyable activities seem to pass too quickly;

whereas, unpleasant situations seem to last forever. Lived time also refers to the effect of collective experiences (one's past) on one's present situation and future plans or visions. Important to temporality is the notion that the present can change how one interprets the past as they reinterpret who they are and how they got to their current place. Finally, *lived human relation* (relationality) refers to the relationships one has with others. For example, one comes to learn about another from different types of interactions. First impressions or preconceived ideas of someone may lead one to conjure up a certain image of an individual's personal appearance, how they behave, or what they believe; whereas, a personal meeting may lead to a whole new understanding of the person.

Summary

Phenomenology is an appropriate method to employ when the researcher seeks to understand the meaning of a phenomenon through giving voice to those who experience the phenomenon. Nursing is an inter-subjective, interpersonal, relationship-based activity that focuses on the experience of the person in relation to their health and the environment in which they exist (Rapport & Wainwright, 2006). Phenomenological methodologies are useful for studying many of the phenomena important to the promotion of well-being and the nature of interpersonal relationships. Descriptive methods improve our understanding of certain constructs that can help to refine current practice. In contrast, interpretive approaches may guide practice or lead to recommendations for new practice strategies. Therefore, interpretive phenomenology is the method best suited to answer the questions: What is the lived experience of chemotherapy-related cognitive change? What is the impact of cognitive change

following chemotherapy? And, what strategies do women use to cope with these changes in everyday life?

Procedure

The study procedure is described in the following section beginning with the setting for subject accrual. Next, sampling method and eligibility criteria are described. Methods for data collection and data sources are delineated. Finally, the procedure for data collection and data management are explained.

Setting

At the start of this study, the Penn State Hershey Cancer Institute and Breast Cancer Support Group were the primary settings for targeted recruitment. As the study progressed, one additional institution and three additional support groups were added. The Penn State Hershey Cancer Institute is a comprehensive cancer center designed to provide cancer care to residents of the central Pennsylvania region and beyond. The goal of the Cancer Institute is to provide a multidisciplinary, comprehensive, and integrated approach to cancer prevention, education, diagnosis, treatment, and follow-up care and to conduct research into its causes, treatments, and side effect management. The environment at the Penn State Hershey Cancer Institute is supportive of research from all disciplines and there are close working relationships among clinical staff, researchers, and medical and nursing faculty from multiple departments.

Separate from my role as researcher in this study, I also serve as a member of the Penn State Hershey Cancer Institute's clinical team serving in the role of Oncology Nurse Educator. The Breast Care Team welcomed me to the weekly Breast Care Conference where diagnostic concerns and treatment plans are discussed. The team consists of

surgeons, pathologists, radiologists, radiation oncologist, medical oncologist, geneticist, and nurse coordinators for surgery and medical oncology. Participation in this group of breast care professionals provided me with a strong knowledge base of the natural history of breast cancer and variations in treatment trajectories.

Approximately 100 women with breast cancer visit the outpatient facility for some phase of treatment or follow-up care each month. In addition, the Breast Cancer Support Group membership numbers over 100 women. The Breast Cancer Support Group consists primarily of those women who have completed therapy and often are dealing with long term effects of treatment and other survivorship issues. Women receiving treatment at the Cancer Institute are invited to attend the support group. In addition, all breast cancer survivors from the South Central Pennsylvania region are invited to attend through advertisements in local newspapers and web site information. This group meets monthly on the campus of the Penn State Hershey Medical Center. Approximately 10-30 women who are breast cancer survivors participate in the Support Group each month. Participation fluctuates each month partially dependent upon the degree of interest in the planned topics or presenters.

Permission to conduct the study was received from the Breast Cancer Team and underwent full review of The Penn State Hershey Cancer Institute's Scientific Review Committee prior to full review of the Penn State Hershey Medical Center's Institutional Review Board (IRB). Written permission to distribute materials concerning the study was obtained from the IRB. In addition, the Mount Nittany Medical Center in State College, Pennsylvania, also provided permission and posted study announcements in their patient waiting room. The following support groups shared study announcements

with their members: THRIVE Cancer Support Group located in Lower Paxton Township, Pennsylvania; All Breast Cancer Survivors (ABC'S) Breast Cancer Support Group in Carlisle, Pennsylvania; and, Celebrating Hope in Cancer Survivors (CHICS) support group in Lower Allen Township, Pennsylvania. In addition to providing study announcements, I was an invited guest at three of the four breast cancer support groups and provided a brief overview of the study purpose and criteria for participation.

One subject was accrued at a support group meeting. Following the formal meeting, I met with the potential subject and obtained limited information based upon inclusion and exclusion criteria. A date, time, and location for the first interview was then determined. Another subject contacted me directly after seeing the study announcement posted in the outpatient clinic. I discussed the study and eligibility criteria with the potential subject by phone and arranged for a date, time, and location of the first interview.

The remaining subjects were accrued through physician and nurse contacts in the outpatient clinic setting. Announcements for the study were placed in the Penn State Hershey Cancer Institute Outpatient Clinics (Appendix A). I worked collaboratively with the Nurse Coordinators of the Breast Cancer Team and the Attending Physicians in Medical Oncology to identify those women completing their last chemotherapy treatment. Women who had completed chemotherapy treatment were identified by the team during follow-up clinic visits. The Medical Assistants then provided a "Research Information Sheet" to those who had completed chemotherapy. The "Research Information Sheet" allowed the individual to include their name and contact information if they were interested in learning more about the study (Appendix B). I collected the

forms from the outpatient clinic locations weekly and contacted interested individuals. Several subjects met with me in the outpatient clinic on the same day that they inquired about the study. Others were contacted by phone, I provided an explanation of the study, determined subject eligibility, and set a date, time, and location for the first interview.

Subjects

Purposive sampling was employed to recruit study participants with a breast cancer diagnosis who had completed standard chemotherapy treatment within the past 12 months. Because breast cancer treatment varies widely based on pathology of the tumor and the clinical staging of the disease, a description of breast cancer treatment will be provided.

The treatment of breast cancer follows tissue biopsy and a detailed analysis of several biological, hormonal, and genetic factors (Carey, 2010). Standard treatment for all stages of breast cancer includes surgical removal of the tumor (Chapman, 2007). The surgical procedure, however, may vary from simple lumpectomy to total mastectomy dependent on tumor size and the extent of the tumor's invasiveness into surrounding tissue (Chapman, 2007; Yackzan, 2007a). The degree of tumor invasiveness along with tumor pathology guide decisions related to the potential benefit of radiation therapy and chemotherapy (Saurel, Patel, & Perez, 2010). The tumor's specific hormone receptors determine the benefit of hormonal therapy alone or hormonal therapy following chemotherapy (Yackzan, 2007a). Additional genetic markers located on the tumor determine risk scores that aid in predicting prognosis and guide physicians in prescribing chemotherapy regimens (Yackzan, 2007b).

The purposive sampling technique sought to include women with breast cancer, between the ages of 21-60, who had completed standard chemotherapy treatment within the past 12 months. Standard treatment in this case often includes chemotherapy alone or chemotherapy treatment followed with endocrine therapy often referred to as hormonal therapy. The women in this sample had all completed standard chemotherapy treatment but may have been receiving continued monthly treatment with either endocrine therapy or biotherapy. The selected age group (21-60) is based on findings by Costanzo et al. (2007) that adjustment to life following breast cancer diagnosis and treatment is influenced by “off time” events, particularly health-related events that occur during the prime of one’s life. In addition, the parenting and work responsibilities experienced by this age group may make the experience of cognitive changes following chemotherapy more recognizable and challenging.

Other inclusion criteria consisted of the following: 1) fluent in English; 2) willing to describe their experience; and 3) report being concerned about cognitive changes such as difficulties with memory, concentration, thinking clearly, or making decisions. Exclusion criteria include: chemotherapy prior to current regimen, a new breast cancer recurrence, documented evidence of distant metastasis, and history of any neurological disease.

It was anticipated that eight subjects would be adequate to obtain a full description of cognitive change following chemotherapy. Explanatory power for understanding the phenomenon of chemotherapy-related cognitive change is based on the principle of having a sufficiently strong database upon which to make confident claims (Morse & Field, 1995). Patton (2002) recommends that qualitative sampling designs

identify minimum sample size based on “expected reasonable coverage of the phenomenon given the purpose of the study and stakeholders interests” (p.246). In this study, data saturation was achieved with seven subjects as determined by the emergence of redundancy in data related to the identification of the major themes. As described by Lincoln and Guba (1985) redundancy is the point when no new information emerges from new subjects. Discussion of the limitations of this sample size related to adequate descriptions of subthemes is discussed in Chapter 5.

Data Collection

Data collection methods included semi-structured in-depth interviews and personal journal entries. Creswell (2007) describes four basic types of data collection: observations, interviews, documents (journals or diaries), and audiovisual materials (audio recording). In addition, journals and diaries are described as a useful source of data in providing an intimate, descriptive account of an individual’s everyday life (Morse & Field, 1995). The primary data collection method was semi-structured individual interviews approximately 60 minutes in length. The semi-structured interview approach is described by Morse and Field (1995) as an ideal approach because short questions serve as a prompt that can provide an opportunity for the participant to explain a situation in his or her own words

van Manen (1990) explains that thematic descriptions of phenomena can be found in various artistic expressions that recreate experiences by transcending them.

Incorporating the journal as a data collection method provided an additional semi-structured method of acquiring specific information in relation to the experience of cognitive change. Journal entries did not need to occur daily but the journal was

available as needed to capture events and feelings that the subjects experienced when they experienced them.

Data Sources and Procedure

Each subject was interviewed two times with interviews taking place one month apart. Since cognitive changes do not occur as a single event but rather occur over a continuous period of time, subjects often have new experiences to describe over time. The location of the interview was one that was mutually acceptable to the subject and the researcher and offered sufficient privacy for an uninterrupted conversation. One interview took place in the subject's home. The other interviews took place in a private meeting room in the Cancer Institute or Breast Center.

The first meeting with each subject included in order the completion of the following: 1. Written informed consent; 2. Demographic Questions Form; and 3. Audio-recorded Interview. The "Informed Consent" form is presented in Appendix C and "Demographic Questions" form is presented in Appendix D. I reviewed the written informed consent in its entirety with each participant. We both signed and dated the form and a copy was given to the participant. Demographic information obtained at the beginning of the first interview was based upon factors presented in the review of the literature related to breast cancer treatment and cognitive changes following chemotherapy. Specific questions included: age, marital status, members of household, highest level of education achieved, occupation, employment status (hours worked outside of home), first cancer diagnosis, first time receiving chemotherapy, chemotherapy agents received, number of cycles of chemotherapy, length of treatment, and past and present use of hormonal therapy.

I conducted each of the interviews in person and all of them were audio recorded. The interview questions were structured according to the framework employed by Penrod (2003). A broad open-ended question was used to begin the interview by focusing the participant on her experience of living with breast cancer treatment side effects: “Tell me about what you’ve lived with since your breast cancer treatment began.” The participants were not interrupted as they told their stories. After the participants exhausted their response to this opening question, they were prompted by questions related to difficulty with memory, concentration, thinking clearly, and decision-making.

The questions used as prompts were based on the following domains of cognitive function: executive function, attention, concentration, memory and recall, and processing. Hess and Insel (2007) provide descriptions of these cognitive domains. Executive function includes activities such as planning, sustained attention, and ability to problem solve. Attention is defined as the ability to concentrate on one thing while ignoring other things. Concentration is the process of focusing one’s efforts on a particular task. Memory and recall include the ability to retain information and reconstruct past experiences. Lastly, processing refers to the time needed to complete cognitive tasks. The interview guide with preliminary questions is included in Appendix E. The following is an example:

Tell me about a time when you had difficulty with memory.

- How would you describe this experience?
- How did you know what was happening?
- How did you feel?

At the conclusion of the first interview, the subjects were given a pocket size journal from a selection of four basic styles and colors. They were encouraged to make

entries in the journal concerning any experiences related to cognitive difficulties during the month between interviews. All methods of expression, such as narratives, poetry, drawings, or other artistic expressions of their choice, were encouraged. The second interview was scheduled four weeks from the first interview. Selection of specific date, time, and location for the second interview were decided at the end of the first interview. A thank you note following the first interview included a reminder to bring the journal with its entries to the second session.

The audio recorded interviews were transcribed verbatim by a professional transcriptionist. I verified each of the transcripts prior to the second interview. The second interview included questions based on emerging themes. Referring to the first interview transcript, I asked subjects for clarification of statements and further description of emerging themes. Because the analysis of data was concurrent with data collection, interview questions changed as the study progressed.

Journals were returned by all but two subjects. The journal entries were used at the opening of the second interview to introduce recent experiences. Questions and statements at the second interview included some of the following:

- Tell me about your journal entries.
- What difficulties have you experienced in cognitive abilities since we last spoke?
- When we last spoke you mentioned ... Tell me more about that.
- When we last spoke you mentioned ... Tell me how you coped with ...

Importantly, the journal served as a means for the subjects to express their reflections on the experience of cognitive change in different contexts within their lifeworlds.

Following the second interview, all journal entries were photocopied and returned to the

subjects. In addition, a note of appreciation for participation in the study was sent along with a \$10 gift card.

Field notes including specific behaviors and observations were also recorded by the PI immediately following each interview and following any phone calls between interview dates. Field notes supplement other forms of data and provide a written description of what the researcher sees, hears, experiences, and thinks (Morse & Field, 1995). Field notes also included any pertinent discussion that took place following the tape recorded interview. For example, one participant described difficulty that she had in remembering the names of plants in her garden. Following the interview, we walked through the garden and she proudly identified the plants by their names. It was a triumphant moment for this woman.

Interpretation and Hermeneutic Circle

Through the interpretive process, or hermeneutics, we use language to find the intended or expressed meaning of a phenomenon that is revealed to us. Beginning with the first interview, the study participants entered into the hermeneutic circle of interpretation with me. This culminated with the second interview which also included their experience of journaling about the experience. The conversation during each interview was part of a hermeneutic circle of inquiry. van Manen describes interviews used in this way as having a “hermeneutic thrust” (p. 98). The next two paragraphs describe how this occurred and how questions were posed.

The first interview was semi-structured and allowed each participant to tell her story of being diagnosed with breast cancer and the subsequent treatment path. Specific questions related to cognitive change revealed the phenomenon within the context of the

total breast cancer experience. As the researcher, I entered into the hermeneutic circle of interpretation with the participant by focusing on expanding the descriptions and insights that emerged. Questions that were posed included: “How is that which you’re describing different from the cognitive difficulties that others may experience with middle-age or menopause?” And, “You mentioned feeling “overwhelmed.” What does that mean to you?” As the interviews revealed new themes, these were added to subsequent subject interviews.

As described earlier, the transcripts of the first interview were reviewed prior to each second interview. This first analysis revealed questions about the meaning of certain words and phrases and the emergence of themes that had not yet been identified. The second interview centered on these emerging themes and a discussion of their journal entries. All but two completed the journal. Those who completed the journal felt it was helpful to reflect on the day-to-day challenges they confront. Some developed new insights by thinking about how they experienced cognitive changes every day. This provided an effective way to co-create the essential components of the experience. Questions directed at understanding the meaning of certain phrases were often used. This is demonstrated in the following example:

Interviewer: *“You mentioned mental noise. That’s an interesting description. I’m interested to know more about what that’s like for you.”*

Subject: *“Mental noise – getting sidetracked. You know you’ll be thinking really hard about something and something else will pop in your head. Then you’ll start thinking about that and then you’ll worry...”*

van Manen (1990) describes this method as the “hermeneutic interview” (p. 98). The art of the interview is to continue to listen and to ask questions that reveal the essence of the phenomenon. In this example, the interviewee becomes a co-investigator who is equally interested in the research. In this study, the participants were actively engaged in interpreting their experience of cognitive change following chemotherapy.

Data Management

As described earlier, phenomenological analysis requires that the researcher recognize preexisting assumptions and pre-established interpretations of the phenomena of interest. Husserl (1927/1999) recommended purposely suspending all judgment about what is real, the “natural attitude” or natural way of thinking. Suspending one’s beliefs so that they are brought to one’s consciousness enables the awareness of their potential impact on interpretation of the phenomenon (van Manen, 1990). Bracketing, or suspending one’s beliefs and biases, is an iterative process that is intentionally performed (Polit & Beck, 2006). In this study, the intentional suspension was achieved at each step of the research process beginning with the statement of the research question and development of the research proposal. Bracketing also occurred prior to interviewing each subject interview, analyzing subject transcripts, interpreting the data, and summarizing the study findings.

The process of self-reflection and self-awareness, along with field notes, were described in a reflective journal. It is important to recognize that I approached this study with a significant amount of knowledge about this phenomenon. As an oncology nurse educator, I have taught many courses about chemotherapy and its side effects. However, my interest in this phenomenon and these methods came from a sincere interest in

exploring what was not known and could only be answered by hearing the voice of those who had the experience. Therefore, as the researcher, I made every attempt to focus on staying true to the purpose of this phenomenological study and to ensure trustworthiness of the study findings. The following steps describe how bracketing was achieved:

- I consciously performed self-reflection prior to each interview bringing to consciousness my own potential biases. This was a purposeful activity to identify what I knew about the concept and what I thought I knew to be true about cognitive difficulties and the breast cancer experience. This mental activity was especially helpful in reviewing the transcripts. I was able to identify more effective ways to ask questions and I challenged myself to ask if my interview style was leading the participant toward a specific response.
- I consciously reminded myself to focus on the question: What is it like living with cognitive changes following chemotherapy? The kinds of cognitive changes that occur following chemotherapy have been identified, but we don't know enough about the nature of living with these changes. This reinforces the notion that phenomenology seeks to reveal "a mystery in need of evocative comprehension" (van Manen, 1990, p. 50). The "mystery" was revealed to me several times when participants explained aspects of the phenomenon that I never had imagined.
- I maintained reflective field notes to capture my thoughts and reflections of self-awareness following each interview. This exercise was also helpful between interviews with the same subject so that specific follow-up questions could be developed for the second interview.

In summary, successful self-reflection ensured that the study participant's reality was not obscured by my personal assumptions.

All interviews and journal entries were transcribed verbatim. All personal identifiers were removed and a subject code assigned to protect confidentiality. The typed transcript was checked for accuracy against the original audio recording and corrections made to both the electronic and hard copies of the transcript. Field notes including specific behaviors and observations were also transcribed. I began to analyze the data following each interview and reflected on findings in subsequent interviews by asking questions such as: In our first interview you mentioned having difficulty paying attention. Can you describe a specific situation when this happened?

The transcripts were read and reread to allow repeated immersion in the data prior to beginning coding, classifying, or creating linkages (Thorne, Kirkham, & MacDonald-Emes, 1997). The typed transcript documents were labeled with subject and interview number and date. Document line numbers were added for ease of locating exact words and phrases within the narrative. The transcripts were read, line by line, and key words and concepts were located and coded. The process of coding is done to uncover underlying meanings and is achieved by identifying persistent words, phrases and themes within the data (Morse & Field, 1995). During this open-coding step, words were extracted verbatim and comment boxes added within the document so that the original text could be easily retrieved. Once the individual transcripts were open-coded, these words and phrases were sorted to highlight words, sentences and sentence clusters that stood out as themes of the breast cancer survivor's lived experience of cognitive change. A table was then created with seven columns, one for each subject. The coded words and

phrases were then placed in the table. This provided a visual image of the data that allowed for groupings of words and phrases that were similar in structure. This visual representation of the data also enabled me to make comparisons among subjects.

Thematic analysis was then conducted using van Manen's approach (1990) which includes: uncovering thematic aspects, isolating thematic statements, composing linguistic transformations, interpreting through conversation, and exploring life-world existentials as guides to reflection. The emerging themes were written and rewritten until major themes and subthemes emerged from the data. During the final stages of analysis as the interpretive process continued, themes were again written and rewritten. At this juncture, I returned to the interview transcripts and was once again immersed in the data. In addition, three faculty members with expertise in qualitative analysis reviewed interview transcripts and through group discussion provided assistance with the final thematic analysis. As a result, new insights were gained which led to several subthemes being collapsed and others being relabeled to capture the true essence of the experience of cognitive change following chemotherapy. Lastly, existential analysis was conducted for each of the major essential themes. This approach to analysis required a total immersion in the interpretive process and provided a deeper understanding of the essential themes.

Human Subjects Protection

Approval for the use of human subjects was obtained through the Institutional Review Board (IRB) of The Penn State Hershey Medical Center (Appendix F). The first steps consisted of approval of the Breast Care Team and a full scientific review by the Penn State Hershey Cancer Institute Scientific Review Committee. The second step

consisted of full review of the IRB. All study participants provided signed informed consent under principles of full disclosure and were given a copy of the consent form. A copy of the consent form is presented in Appendix C. All participants were informed of their right to refuse, withdraw, or stop the interview or stop further participation at any time.

Confidentiality

Upon the first contact initiated by the subject, I explained the study criteria to assure appropriate selection of participants. Privacy and confidentiality practices were described in detail. To maintain privacy, I made all calls from a private office at an agreed upon time. To minimize the risk of loss of confidentiality, I labeled all digital audio recordings and transcripts with code numbers. Participant identifiers that were collected include: Name, address, telephone number, and date of last chemotherapy treatment. One list exists that links the coded numbers to electronic audio recordings, typed transcripts and journal entries. Taped interviews, typed transcripts, and scanned copies of journal entries were coded and stored in an electronic file.

Risk to the Subjects

While it was believed that the risk to subjects was minimal, it was recognized that there is the possibility of psychological distress as participants discuss experiences of living with breast cancer and specifically with their experiences of cognitive difficulties. As an experienced oncology nurse, I am skilled in talking to and counseling patients at various stages on the cancer trajectory. If a subject found the discussion to be distressing, I was equipped with emergency contact phone numbers for the participant to access for counseling services. In addition, if the participant discussed any healthcare related issues,

I would encourage them to contact their primary care provider or oncologist. All but one of the interviews took place at the Penn State Hershey Cancer Institute or Breast Center where other professional staff were present to offer additional assistance if needed. None of the study participants experienced any distress during the interview.

Protection against privacy risks. All interviews took place in a private setting that was mutually acceptable. A private room in the subject's home and a private room in the Hershey Medical Center were the locations found to be acceptable. Coded subject identifiers were used on all retained typed transcripts. Electronic copies of all transcripts and copies of journal submission are stored in a file in a password secure computer which is stored in my locked office at the Penn State Hershey Medical Center. In addition, printed copies of the coded typed transcripts and coded journal entries were used in data analysis. Hard copies of the transcripts, the demographic data forms, and the code record are stored in a locked file cabinet in my locked office. Original audio recordings and electronic files will be stored for three years following the study as defined by federal regulation and IRB then destroyed.

Potential benefits of this research to the subjects and others. The expression of one's experience may have a beneficial psychological effect. It was anticipated that the very nature of the study might validate for the study participants the realities of living with cognitive difficulties. In fact, the participants reported that they felt comforted in talking about their experiences with cognitive difficulties and expressed their hope that this side effect of therapy would be openly discussed more frequently. They also described comfort in learning that they were not alone in this experience and that others report similar cognitive changes. In addition, they expressed hope in knowing that the

problem of cognitive change following chemotherapy treatment is being studied so that they and others may benefit from subsequent research findings.

Summary

Phenomenology, as a research method, has been used when the research question seeks to understand the meaning of a phenomenon through giving voice to those who experience it. This phenomenological study incorporates interpretive methodology to phenomenological research seeking to uncover the meaning of the lived experience of cognitive change following chemotherapy in breast cancer survivors, how symptoms are experienced and become evident, how it impacts roles in personal and professional lives, and how women cope with these changes. van Manen's approach to phenomenological research was employed in this study and described in detail. The philosophical threads of this interpretive phenomenological approach are consistent throughout the descriptions of the research design and procedures. Reflective journaling and total immersion in the data through reading, writing, and rewriting provided rigor. Lastly, the analytical processes and credibility of the findings were enhanced by a transparent audit trail. The thematic analysis of the data is described fully in Chapter 4.

Chapter 4

Results

This chapter presents a description of the study participants, analysis of qualitative data, and interpretation of results. van Manen's framework for interpretive phenomenology is employed throughout the interpretive process. Essential themes are identified which are unique to the experience of cognitive change following chemotherapy in women with breast cancer. Incidental themes are also described as the text is further analyzed. Phenomenological interpretation is achieved both exemplificatively, by providing specific examples of the essential structures of the phenomenon, and existentially by describing how the lifeworld existentials are woven through the textual examples. Through this interpretive process, the experience of chemotherapy-related cognitive change in women with breast cancer is revealed.

The Study Participants

As established earlier, breast cancer is a complex disease that can have several treatment paths that are dependent upon tumor pathology and stage of the disease. Chemotherapy is currently recommended for some forms of stage I and stage II disease. In addition, the timing of chemotherapy administration, based on the disease specifics, may be administered neoadjuvantly (before surgery) or adjuvantly (following surgery). Since the women in this study were diagnosed with either stage I or stage II breast cancer, the treatments also varied. Several of the subjects received chemotherapy following biopsy and diagnosis confirmation but received the treatment before the primary surgical procedure. In addition, three of the participants had breast reconstructive surgery which includes two phases, the first involving insertion of tissue

expanders followed several months later by the final reconstruction. At the time of the study, one of the participants had completed phase I of reconstruction and two of the participants had completed the final phase. Some participants also had completed radiation therapy following chemotherapy.

In addition to their unique treatment paths, each participant in this study has a unique personal story. Seven women with a diagnosis of breast cancer who had completed chemotherapy treatments within the past twelve months agreed to participate in this study. Each of these women had self-reported cognitive changes during chemotherapy treatment that had persisted for at least one month beyond final treatment and were present at the time of the study. The ages of the women ranged from 42 to 59 with the median age of 52. Names have been replaced with a pseudonym and their specific occupations have been excluded to protect their anonymity. Table 1 summarizes the participant demographics.

Participant 1: Cheryl

Cheryl is a 52 year old who had localized breast cancer diagnosed nearly a decade ago. The disease had recurred in December 2010. Although her disease is believed to be early stage, the size of the tumor was questionable. This time it was advised that she receive chemotherapy. She was treated with the following chemotherapy agents: Adriamycin, Cytosan, and Taxol. Cheryl experienced several physical side effects following treatment including a drug reaction that required an Emergency Department visit for prompt treatment. Cheryl has a master's degree and is employed in a professional role in a supervisory position. She is divorced and in a supportive relationship. She has one grown daughter.

Table 1. Participant demographics.

Assigned Pseudonym	Chemotherapy Drugs	Age	Highest Education Level Completed	Relationship Status	Employment Status
Cheryl	Adriamycin Cytosin Taxol	52	Master's degree	Divorced with one adult child. Current new relationship.	Full time professional position. Supervisor
Holly	Taxotere Carboplatin Herceptin Tamoxifen	42	Bachelor's degree	Married with 2 school age children.	Part time professional position.
Erica	Taxotere Carboplatin Herceptin Tamoxifen	54	Master's degree	Divorced with two adult children. Lives alone.	Full time professional position.
Mary	Taxotere Carboplatin Herceptin	52	Doctoral degree	Married with two children child (high school and college).	Full time professional position.
Barbara	Taxotere Carboplatin Herceptin Tamoxifen	45	Bachelor's degree	Married with 3 children (elementary, high school, college).	Full time homemaker
Ruth	Docetaxol Carboplatin Herceptin	59	High School	Widowed. No children Lives alone.	Full time professional position.
Nancy	Adriamycin Cytosin Taxol	56	High School with some college courses	Married with two adult children.	Currently on disability from her last position.

Participant 2: Holly

Holly is a 42 year old who was diagnosed with breast cancer in August 2010.

Holly had two surgeries including breast reconstructive surgery. She was treated with the following chemotherapy agents: Taxotere, Carboplatin, and Herceptin. She continues to take Zoladex for ovarian suppression and Tamoxifen. She experienced several physical

side effects following treatment including hemorrhagic cystitis, gastrointestinal side effects, nail and skin changes, and fatigue. Holly has a bachelor's degree in neuroscience and is employed part-time in the health care industry. She is married and has two school age children.

Participant 3: Erica

Erica is a 54 year old who was diagnosed with breast cancer in January 2011. Erica has had three surgeries one of which included breast reconstructive surgery. She was treated with the following chemotherapy agents: Taxotere and Carboplatin followed by Herceptin. She was then prescribed Tamoxifen for several months but due to side effects has stopped treatment. She experienced several physical side effects following treatment including mucositis, neutropenia, and fatigue. Erica has a master's degree and is employed fulltime in healthcare. She is divorced and has two adult children and a network of supportive friends.

Participant 4: Mary

Mary is a 52 year old who was diagnosed with breast cancer in January 2011. Mary received chemotherapy prior to surgery and is now completing treatment with radiation therapy. She was treated with the following chemotherapy agents: Taxotere and Carboplatin followed by Herceptin. She experienced some physical side effects following treatment the most notable being fatigue. Mary has a doctoral degree and is employed full-time in healthcare. She is married and has two children, one in high school and one in college. She also has an extended family that is supportive; however, they live out of state and only get to visit on occasion.

Participant 5: Barbara

Barbara is a 45 year old who was diagnosed with breast cancer in September 2011. Her treatment plan consisted of surgery followed by chemotherapy and radiation therapy. She received Taxotere and Carboplatin followed by Herceptin. She is currently taking Tamoxifen and has experienced fatigue during treatment. Barbara has a bachelor's degree and is a self-proclaimed "stay at home mom." She is married and has three children: one in college, one in high school, and one in elementary school. She has supportive family and friends.

Participant 6: Ruth

Ruth is a 59 year old who was diagnosed in February 2012. Following surgery she received treatment with Docetaxol and Carboplatin followed by Herceptin. Ruth is self-employed as an in-home sales representative and district manager of sales. She works approximately 30 hours per week from a home office. Ruth has experienced several physical side effects following treatment including fatigue and skin and nail changes that still persist. Ruth is widowed for more than 10 years and has no children. She has a supportive network of friends and is active in her church community.

Participant 7: Nancy

Nancy is a 56 year old who was diagnosed with breast cancer in February 2012. Following the initial surgery, Nancy received the following chemotherapy agents: Adriamycin, Cytosan, and Taxol. She experienced neuropathies during treatment that have since subsided. She was receiving radiation therapy treatment weekly during her participation in the study. Nancy was scheduled to complete the final phase of breast reconstructive surgery within a few months of her second interview. She was previously

employed by a governmental regulatory agency in an administrative assistant role and worked during treatments to maintain healthcare insurance. She was counseled on having a poor job performance while still receiving treatment with chemotherapy. She has since qualified for disability benefits for up to three years related to the physical side effects of treatment and future reconstructive surgery. Nancy is married and has two adult daughters who live at home.

Language and Meaning

The following section describes the data obtained through the method of semi-structured interviews. The language of the participants is described as it was presented to the researcher. Language is an expression of human thoughts as they come into one's consciousness. Likewise, language, in the form of the spoken or written word, is the open expression of those thoughts. In his famous essay, "Poetry, Language, Thought," Heidegger (1971) challenges us to consider language as more than an expression of some internal thoughts. He posits that language itself speaks. van Manen (1990) describes the phenomenological method as consisting of the art of being "sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak" (p. 111). Words, phrases, and the meanings assigned to them provide a glimpse into the individual's experience. Each woman in this study has a unique story of the experience of cognitive change following chemotherapy for the treatment of breast cancer. The following paragraphs will provide examples of the language of this experience as expressed in the language of feelings and the language of coping.

The language of feelings associated with memory and word retrieval difficulties varied as greatly as the women's personalities. Participants in this study used several

phrases that gave meaning to the experience. Participants commonly described how the experience made them feel: “*stupid,*” “*like a ditz,*” “*bubblehead,*” or a “*scatter brain.*” These phrases suggest feelings of negative characteristics, inadequacy, incompetence, and mental dullness. In addition, the degree of distress is reflected in the language of feelings associated with the experience as emphasized through repetition of the spoken word by Holly: “*I could not, could not, could not remember.*”

The language of coping revealed the women’s adjustment to the diagnosis of cancer and the relative importance placed on certain life events. Erica explained:

“Well I know I am different so I get overwhelmed and then I think okay I need to take this more slowly. And sometimes I’m startled by being overwhelmed. I’m not someone who gets angry quickly. I think I’m the type that gets more startled.”

Erica’s careful and purposeful selection of words provides a glimpse into the importance of her maintaining some control in being able to cope with cognitive change in her life.

Personality differences and the experience of other life stressors may strongly influence the expression of the lived experience from the frustrating to the comical.

Cheryl described the frustration in terms of annoyance: “*It annoys me because I was usually very organized and it frustrates me that I’m not as much now.*” Ruth described frustration with cognitive changes which have created in her someone she didn’t know. “*It’s just right out of my mind and for me that’s frustrating because you know that’s just not me.*”

Barbara described in detail how it feels upsetting but she is able to see the humor in the situation.

“It’s pretty immediate and it feels like somebody has it on a string and they just yank it right out of my brain and that was upsetting at first and now it’s not. It’s kind of funny. It’s like oh there it just went... when I can’t think of a word and what my kids do now is they let me struggle for it and then they start giving me weird words that have nothing to do with what we’re talking about. So they know it’s over so they throw in weird ones and then it’s funny.”

The use of metaphors both in the spoken and the written word are sometimes used as a way to describe the experience of cognitive change. Cheryl explained: *“It was like I hit a wall.”* Mary described it this way: *“I felt like my mind was like a bowl. When it’s full it’s done for the day.”* Finally, Barbara shared this revealing analogy:

“If I could draw a picture of it, it would be like the game where...all the balls are at the top and they fall through according to size it feels like the word has fallen out of where like the top level is where everything is and it falls below, I know I know it but it’s nowhere where I’m searching for it. Like how can it be completely gone?”

Identification of Themes

Interpretive phenomenology is a process of reading text, rereading text, writing, and rewriting as the essential structures or themes emerge. This approach described by van Manen (1990) reveals the essential themes that make an experience what it is. In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is (p. 107).

Analysis of the transcribed interviews revealed five essential themes: Noticing the difference, experiencing cognitive changes, interacting socially, coping, and looking forward. In addition, subthemes were identified many of which are essential to the experience and a few which are incidental but noteworthy in revealing the phenomenon. Table 1 includes the themes and subthemes.

Table 2. Themes and subthemes

Essential Themes	Subthemes	
Noticing the difference	Discovering that it is real	Essential
	Explaining to others	Essential
Experiencing cognitive changes	Finding the words	Essential
	Problems with memory	Essential
	Paying attention	Essential
	Concentration difficulties	Essential
	Organizing and prioritizing	Essential
Interacting socially	Fatigue	Essential
	Being a full participant	Essential
	Turning inward	Incidental
	Overcoming one's fears	Essential
Coping	Changing priorities	Incidental
	Facing the challenges	Essential
	Finding support	Essential
Looking forward	Strategies to compensate	Essential
	Fear of sustaining symptoms	Essential
	Employment concerns	Essential

Analysis of Themes

The data are analyzed thematically, exemplificatively, and existentially. Thematic analysis isolates themes and subthemes to describe the essential aspects of the experience of chemotherapy-related cognitive change in women with breast cancer. Exemplificative analysis provides specific examples of the essential structures of the phenomenon.

Lastly, the existential analysis weaves the description of the phenomenon against the lifeworld existentials described by van Manen (1990): lived space, lived body, lived time, and lived human relation. As described earlier, lifeworld existentials are common themes that are present in all human experience. They belong to the fundamental structure of the human existence and human reality; therefore, the lifeworld existentials can serve as a guide for phenomenological reflection. Although van Manen asserts that these lifeworld existentials cannot be separated he suggests that they can be temporarily differentiated for purposes of research. The guiding principle is that the lifeworld existentials are so closely interwoven into the human experience that the examination of one creates linkages to another.

Noticing the Difference

All of the women interviewed described how they first became aware of their cognitive difficulties and their reaction to the experience. For some, the first changes began during chemotherapy and have continued post treatment. Some noticed the changes immediately following chemotherapy and others were not as aware of changes until months after their last chemotherapy treatment.

Erica described gradually coming to the realization that she had cognitive difficulty this way:

“I know I had a little bit of that before but this is different because I know I’ve forgotten faces sometimes too. I know there’s things that have happened but I just, it’s like I wasn’t completely present for that experience whatever was going on with me and so I am not able to totally recall it. So I just try and be honest about it...I’m not sure exactly when it started during my chemo but I realized if there

was a really complex conversation going on with very new information that if I wanted to learn it I was going to have to take a few notes and then go back (to them)...”

For Ruth the changes were subtle:

“I think at first I didn’t really realize I just thought I don’t know I just didn’t pay attention to it. But then after I began to think about it and really pay attention to different things that were going on then I realized that you know I would forget someone’s phone number ... Or I would as normal go into my office and look around and wonder what did I come in here for and I don’t remember. So then I would go back to the other room and try to re-trace my steps...So I think those are probably, things like that that just little, sometimes at first seemed insignificant but then you realize that the chemo brain really is true that you really do experience. For me it was mostly forgetting little things, usually not anything really, really important but little things that I do on a daily basis that I was forgetting to do.”

For those who experienced significant physical side effects during treatment, cognitive changes were not immediately evident because the focus was on the physical symptoms. Once healing and physical side effects subsided and life routines returned to a relatively normal state of activity, the cognitive changes became more evident. Holly described it this way:

“If I was having cognitive issues during my treatment I did not pay attention to them. It was more like I said the, you know the GI issues or I didn’t have neurotoxicity’s but I did get headaches after some of my treatments and it’s just

those kinds of things the taste changes and the recovery from the surgery. Those were the things that were kind of at my forefront of thought at that time as opposed to now, where you're in follow up and you have time to concentrate on those kinds of things more where you say wait a minute this is different. I can't remember being like this. So it really wasn't a thought in the beginning...And like I said it could have been during treatment that it was starting but I just didn't notice as much. When things kind of fall back into routine, that's when you start to notice."

For most, the awareness came with an event or several events in which the loss of memory or specific words were sudden and unexpected. Barbara described

"It's sudden. When I'm having the conversation you know it's not like oh I'm going to say this and I know I can't think of the word."

Ruth said

"I didn't really have any problem with remembering anything or people's names. I didn't have any problem like that before. That's really when I started to realize all these little things. That's when I realized that the chemo brain was really true."

A common perception was the loss of sharpness in thinking and concentration. Cheryl offered: *"I've always been pretty attuned to everything and now I'm all over the place."*

Mary shared: *"I recognize the lack of sharpness and you know I realize that those skills that I usually draw on are not there."*

Holly compared her experience of recognizing cognitive change to that of the character, in the book *Still Alice*.

“But I don’t feel like I’m losing my mind or anything you know. Have you ever read that book “Still Alice”? When you’re reading through that and I think it’s actually one of the saddest books I’ve ever read in my entire life...it’s not like that, it’s not like that at all you know. But it’s that same feeling of recognizing something different in yourself... I think about that book. Yeah I don’t feel I have dementia you know.”

Recognition of cognitive change along with uncertainty about what was happening was common to the experience for all of the participants.

Discovering that it is real. Most of the participants had not received specific information about cognitive changes following chemotherapy from their healthcare providers. Several women in the study described how cognitive changes following chemotherapy were not typically discussed and how the general public has little knowledge of the problem. Cheryl explained:

“I think it isn’t discussed much and it catches you off guard. So people always want to discuss your physical side effects. But mental is sort of like oh just deal with it or do counseling, which isn’t actually mental it’s emotional. That isn’t like mental processing or memory.”

Nancy recounts first noticing the cognitive changes during the treatment phase. When faced with difficulty in performing her job responsibilities, she sought information on the Internet.

“You know just little disconnects but enough of them that I noticed. I think probably when my boss gave me the speech was when I started looking up and I didn’t even know there was something called chemo brain...I started looking up

the side effects of chemotherapy and then some Google flashed up chemo brain and then I looked at it.”

Those who did receive information from their healthcare provider did not worry much about it because they were not yet aware of cognitive changes. Having the information was helpful when they first noticed cognitive difficulties. One woman did receive written information that first alerted her to the possible side effect. Nancy remembers receiving information at a clinic visit.

“I just remembered that actually the first day of chemotherapy they gave me a paper on it, but I didn’t know. I read it, but I didn’t understand it and I don’t remember identifying with it before then. Only maybe two or three weeks later I said oh they gave me something. When I started looking up chemo and then I read chemo brain and then I thought oh they gave me a handout about that. So I made those connections.”

Some did not worry about cognitive change during treatment because they were experiencing many physical side effects as well. As time passed, it became more apparent that the cognitive changes were not subsiding. Erica describes learning that the cognitive changes could persist beyond treatment.

“I went to the American Cancer Society you know I went to all proven websites. I did not just google chemo. So I tried going through the approved channels. Somewhere along the way I had heard about chemo brain but I thought it just had to do with this feeling I was getting after my infusions. I didn’t realize it was this thing that really could last.”

Explaining to others. Most women described concern when cognitive changes surfaced while interacting with others. Some worried about what others might think of them, especially how it would influence their first impressions. Holly described

“Well I mean you know you find somebody whose fumbling over words, not sure what they’re trying to say and you know your first thought is wow they’re not real clear. And you know for the people who know me, if I’m having trouble, I say sorry it’s chemo brain give me a minute whatever. But for someone you don’t know and doesn’t know you I think it would be kind of an uncomfortable situation for me to say oh pardon my, you know lack of concentration but—or just a casual mention of chemo brain and people will be like oh you know. So it kind of leaves you with the thought that they might think that you’re just not too wise ... it is kind of interesting and makes me think you know what are people thinking when I’m saying ‘why did I come here?’ ‘What else did I need?’”

Others handled these situations in a straightforward manner but worried about their abilities and the impact of these changes over time. In the following example, Erica moves quickly from admitting the problem exists to recognizing her feelings and thinking about possible remedial interventions.

“Sometimes I’ll say you know part of my memory went with my hair or I’ll just say I really need to write things down but I just want to be honest because I want to make sure that they’re getting the right thing...So it’s kind of like oh, oh alright. I don’t know if humbled is the right word but just—and I will tell people sometimes I am not 100% reliable. Like you just you know I just don’t remember everything. If I have a conversation with someone and they tell me no we talked

about doing this I'll say okay I'm not 100% reliable. So I just tried to flow with it. Sometimes it does really get me down and I think: when do I need to do some kind of memory work? Should I read a book about memory? Would some kind of memory exercises help me? Should I take up playing bridge again? Or, is this just going to come back."

Ruth describes receiving written information about chemo brain from the clinic nurse and she recounts how she tells friends and acquaintances about cognitive change:

"I tell them that they'll have to excuse me that's my chemo brain and they're like what? I'm like it's a real thing it's chemo brain. Then I'll tell them about that paper that I got you know when I first started my chemo and I thought that the nurse was just joking with me but it's not a joke. Yeah it really does happen. They're like really? I'm like yeah it really does affect your thinking process and your memory and just all kind of things that you wouldn't think you know."

Many women described feeling embarrassed by situations when cognitive change emerged in social interactions. Ruth described an embarrassing situation that occurred at a family reunion:

"...I got out of the car to my sister in law's, this is on my late husband's family's side, two of my sister in laws came up to the car and they gave me hugs and the one I knew it was Anna and you know I gave her a hug and how are you and then the other one gave me a hug and I acted just like I knew her and I couldn't think of her name and I knew I knew her from somewhere... So David came up and I gave him a hug and I was so excited to see him and I said where's your better half at? He goes she's sitting right there. I'm like awwhh. I was so embarrassed... I

said that's my chemo brain kicking in. I said you know when you walked up I knew I knew you, but I could not think of how I knew you or what your name was. I said that's awful and I felt really bad about that."

Barbara was able to confront and seemingly accept the new reality of her cognitive difficulties. She describes simply telling her husband: "... *I'm going to forget words or I'm going to come up with the wrong word and I know it's wrong but I can't come up with anything else. So you have to get used to it.*"

Existential themes when noticing the difference. The theme of *noticing the difference* was a central component of the existential of women's lived space. For most women, the first realization that they were experiencing some cognitive changes was startling. Whether the cognitive change included having difficulty remembering a word or a name, forgetting to do something important, or feeling a little fuzzy, they all described feeling caught off guard and unsettled. Suddenly, they didn't feel that they were in a safe place. A world that had already placed them in a fragile position with the diagnosis of breast cancer, surgery, chemotherapy, and for some, radiation therapy, had now become even more tenuous. As one woman stated, "*I didn't feel completely present.*"

The existential of lived body was evident in the women's descriptions of how their focus had been on the physical changes that had endured since diagnosis. Breast cancer begins as a physical disorder that requires surgical intervention and treatments that may cause many different physical side effects that alter everyday life activities. In addition, the treatments may cause severe physical fatigue. The entire focus early in the treatment phase is on the body and survival. Then suddenly women notice that

something is different. They are not thinking clearly. They cannot remember or cannot mentally process certain information. This may be manifested in behaviors such as fumbling over words or becoming exasperated when trying to remember a name or knowing what action to take next.

Lived time is the existential that refers to the subjective sense of time. In the experience of noticing the difference, lived time, stood still. Time was suddenly suspended. This was apparent in women's descriptions of asking: What just happened here? What did I come here to do? The perception of time shifted for some who began to question: Am I getting worse? Will this get better over time? Should I be doing something to make this better? In other situations, it was time that revealed the cognitive change. When active treatment was near completion, the presence of cognitive change surfaced and was recognizable.

The subtheme, explaining to others, is dependent upon lived human relationships. When women first noticed the difference in cognitive abilities, they were alarmed. When they had to explain to others, they were embarrassed. Discussing this with others meant first admitting to self and then to others that they were having cognitive difficulties. Most women described apologizing to others for their loss of words or not remembering a name. It was especially difficult to explain to a stranger. One woman thought it easier to let someone think they were "just not too wise" than to attempt to explain. They were concerned about the first impression that one might develop. For all the women, it was embarrassing to some degree. In addition, the relationship that existed between the woman and the other person was critical to the type of interaction that followed. They could be open with friends and family and feel safe in explaining their difficulty. Some

said “*part of my memory went with my hair*” and “*I’m so sorry...that’s my chemo brain kicking in.*” Interactions in professional relationships created a greater sense of uncertainty and stress as they acknowledged not remembering something and attempted to move on. These situations helped them to anticipate future difficulties and prepare steps to prevent problems in the future. This was especially true in employment situations where several women developed processes in their work flow that would keep them on track.

Experiencing Cognitive Changes

Experiencing cognitive changes creates many day-to-day struggles. This major theme emerged with several subthemes that elucidate the specific cognitive changes along with their consequences. Finding the words, problems with memory, difficulty paying attention, concentration difficulties, organizing and prioritizing difficulties, and physical and mental fatigue are all examples supporting the theme of experiencing cognitive changes.

Finding the words. All of the women in this study revealed some level of difficulty with word retrieval. This difficulty includes not being able to find the words to explain something, not being able to remember names, or feeling like one’s mind is completely blank and the words cannot be found. The women described this difficulty in interactions with family and friends and in work situations. When “finding the words” occurred in interactions with friends, the participants could sometimes laugh about the experience and move on. Erica describes:

“So sometimes I’ll think this is what I want to say and it doesn’t quite come out or I won’t think of the word. Like I was trying to explain to someone this morning

what we did last night and we were trying –that it was just funny at one point because there were like I said we were split up into groups and there were these four good cooks and we were trying to put things together and I kept going like this and work it and just kept waving my hand. What I wanted to say was assembly line. And so I got it later but like I didn't get it at the time. I mean I've had that before when I've had a migraine sometimes I'll have a problem with word retrieval you know but it's not like I'm trying to remember you know quagmire or you know I'm trying to remember something like simple things. It's just different.”

At other times, not finding the words created feelings of frustration. Holly describes her frustration in the following situation:

“Just the other day my husband and I were talking about someone with my son's baseball and I just couldn't remember their name. Could not, could not, could not. He didn't know who I was talking about so it was very frustrating to me because I'm trying to explain all the things about this person and he wasn't getting it but I couldn't come up with their name...Whether it's really true or just memory loss or just I don't know. I don't feel that it's just memories necessarily. It almost seems to me like it's more of a retrieval, storage and retrieval problem.”

Even though loss of words or remembering names is common among some middle aged adults, women in this study described how “not finding the words” is different from anything they've ever experienced before chemotherapy. Cheryl describes this difference:

“At work I sometimes draw blanks. Blanks and it wasn’t just temporary blank and then later on it comes or like it comes immediate. It was just not there. So I’d look it up or I would ask someone about it or I would just realize that I couldn’t recall it. It’s a total blank. I’ll see...a visual but have no words to put.”

Barbara describes her post-chemotherapy experience of not being able to find the words:

“The worst, well the one that annoys me the most, is when somebody asks me a question and I know the answer and then it disappears, you know it’s on the tip of your tongue. It doesn’t go to the tip of my tongue it goes away completely and I can’t. I feel like I’m searching for it and I can’t find it. It’s nowhere and that is really weird.”

Barbara further describes the loss of names and certain words:

“It’s just the names of anything. Or I was trying to describe something to my daughter and there was a certain word I knew was fine for the situation but I couldn’t think of it. I gave her the definition of it and then she gave me the word.”

Not finding the words is generally frustrating to most women in the study. Many women described the words being somewhere in the brain but unreachable. They speak of not being able to “find it” or “bring it back out.” This is demonstrated in Holly’s story:

“Losing the car twice was frustrating. I just felt like a bumbling idiot... The other time it was very frustrating was just this past weekend ... I have two aunts that I’m pretty close to and we all like to garden and some of the plants they gave me...[I sat] down with my aunt Janice to show her the pictures and I could not remember the names of half of these plants. It was so frustrating because I know every single name of every single plant. I could probably tell you where I got

it...That was so frustrating because I know the names... I'm out there weeding and caring for these things and that was really frustrating. But it was noisy. It was a wedding I had a drink, not much but one. So I don't know if that just, all those things I was just having trouble kind of again retrieving the information, the words. I knew what they were but I just couldn't bring them back out."

Although not finding the words is generally frustrating most of the time, there is a greater sense of discomfort when this occurs when attempting to communicate to a stranger. Barbara's experience describes the difficulty that not finding the words can bring to normal daily activities:

"It's frustrating if I'm talking to someone I know then it doesn't bother me, I'm like oh well. But I was on the phone the other day and I needed to order a new remote for our dish satellite and I couldn't remember the word for remote and I just sat there on the phone going—and I said let me start over...In my head I have it all straight. I know what I want to say and then all of a sudden the word I want is gone. Completely gone. It is the weirdest feeling."

This difficulty can also create feelings of anxiety and distress in common social interactions. In some cases, women felt inadequate and felt the need to apologize for this short coming. This created anxiety for Erica:

"I found you know with my word retrieval it's still a challenge but I try and I think I have less anxiety about this now than when it initially started happening to me because I just felt like I can't worry about it, because when I found that you know I would go into this mini self-loathing in my head but it just made me more anxious, it didn't do me any good. So I would just tell people you know I can't

find the word or I'm really sorry I know I know you but I have had some medicine that has affected my memory and I can't remember your name but I really enjoyed meeting you. So I would try and put it in this positive light but I would just tell people you know I don't remember."

Problems with memory. Problems with memory were common to all of the women in this study. Often this consisted of short term memory problems. Sometimes problems with memory involved difficulties remembering certain conversations or the details of a conversation; while at other times, it consisted of difficulty in remembering steps in a familiar activity.

In the following example, the difficulty came with remembering a short sequence of numbers. Barbara described her difficulty with memorizing a phone number:

"The other day and this was a new thing, I was trying to call a phone number that had texted me and it wasn't someone who was in my phone and I could not remember the phone number. I would look at it and say it and then I would try and dial it and I couldn't do it. My daughter finally took the phone; you don't even have to do that, you can go right here. But that was, that was very frustrating for me and it got to the point where I was like no I am going to memorize this and I couldn't do it. There were too many 5's and 8's and it threw me off."

In other situations, a name heard just moments earlier was gone. Barbara's example reveals this experience and her acceptance of this new normal:

"Just if I'm talking to someone and oh my husband said what is Toby's last name and as soon as he said it, it left my brain. I couldn't think of it. Instead of trying to

think about it I said it's gone and that was it. I had to ask my daughter what his last name was. So that seems to be normal now."

In both cases, hearing a name or a number seemed to be within grasp but the participants in this study could not mentally hold onto it. Cheryl described a situation at work when she forgot both seeing and signing some documents in her possession:

"Sometimes they say "Don't you remember that?" I'll say, "No I don't." They try to help me remember that and I'll say "sort of, yeah," and sometimes I'll just say I do or I don't. Also my co-workers are very kind. Whenever I just say I don't remember looking at that. Then they'll show me my signature on it and I'll say okay I guess I did see it. Sorry and I just don't remember it."

Difficulty in remembering the detail of conversations was described by several of the participants. One woman analyzed her situation concluding that the conversations that create the greatest difficulty in remembering are those that go back and forth before a decision is made. The longer the discussion, the more difficulty she experienced. Holly described:

"Sometimes things that I'll forget about like conversations I've had with my kids. Not little things. When I drop them off in the morning on the ride to school it's a big discussion as to whether they're taking the bus home or I'm picking them up. If the discussion lasts too long and there are too many back and forth moments with what we're going to do, by the time I get to work, I sit there and go was I picking them up or were they taking the bus? Things like that. I think for me the more things that go on the harder it is for me to pull out the memory if that makes sense."

Some participants described difficulty in remembering the steps in familiar activities. Cheryl described how she noticed this when cooking. She was preparing a common dish for Thanksgiving dinner and could not remember the ingredients.

“You know the green bean casserole dish that everybody makes and I have made it just 100 times. I couldn’t remember what to put in it. I knew that it was beans and mushroom soup and those onions. Then I put in sour cream because I believed that was a part of it. Then it was terrible and I thought oh my gosh what did I do wrong. I thought it out and I thought there’s no sour cream in it. It was really sort of upsetting.”

Nancy recalled the difficulty she had in working on her doll restoration hobby. She describes her difficulty with this familiar activity:

“I restore old dolls and ... we kind of leave our mark with the kind of restoration we do as far as taking it back to as much original looking as they can. I couldn’t remember all the steps at once and I would have to go back and re-do some of the restoration because I missed one of the middle steps so it really wasn’t perfect from my point of view. It’s what made my restorations...So that I make them look like as close to Mattel factory as I can. But it could be a silly little thing like I’m supposed to pull that up into the rubber band but if you don’t do that in the middle you have to start all over.

Problems with memory sometimes created a sense of panic. In the following example, Erica describes the mounting panic while searching for her keys:

“It’s kind of like I can’t find my keys. I always because you know it’s not like I’ve had a fantastic memory my whole life and this is a change. Like you say you know

I was having a few things related to age or I can get distracted. So I try and always put my keys in the same place in my purse, but sometimes I just throw them in because I'm carrying too many things or whatever. So it's like oh okay they're somewhere else. So I'm digging and digging. I keep digging and digging – no they're not there. I'm shaking my purse and then I am there huh they're really not in my purse. Then I'll pat my pockets you know. Whereas in the beginning I would reach in my purse and pat my pockets at the same time thinking oh okay maybe I just stuck them in my pocket. So it's kind of like oh, oh alright.”

Paying attention. The participants acknowledged that their ability to pay attention had changed. This involved recognition of fragmented thoughts, difficulty refocusing when interrupted, difficulty sitting still, and experiencing wondering thoughts moving from one topic to another. Erica describes it this way:

“I think if I had a longer attention span, that being fragmented and being interrupted and having all of these lists all over the place, I wouldn't be [so fatigued]—because that takes a lot of energy. That's what I've noticed. When I get home from work I'm really tired. I don't want to have an intense conversation I want to sit down. I want to take the dog for a walk, stand barefoot in the grass, and whereas before I would change gears pretty quickly.”

Erica further described using techniques taught to her by her son who was diagnosed with attention deficit disorder.

“Sometimes fidgeting is a way that I'll pay attention, because I find—and my son actually gave this to me he said if he wiggles a little bit his brain doesn't jiggle as much. So sometimes I find if I do something that's not annoying to other people

and I will tap my foot in the air or I'll rub my fingers or just do something that's unobtrusive but just helps me focus on what's going on."

Cheryl described having difficulty paying attention while at a job related training session:

"I recently had a full day of leadership training. And it was a full day. I could listen but I couldn't be still. So I was always like doing something. I was always like doing this or picking my fingers or doing this and I could not be just sitting. I wasn't disruptive. I could stop at times, but then I would be like looking at other people and looking at stuff on the floor and it was just really hard to just sit there and look. I was always moving and looking and I did take notes for a while but then after I didn't do that anymore I was really just antsy."

Some participants believed that they were able to stay on task more effectively at their jobs where they have specific tasks to perform that are carried out in standard or methodical manner. Holly contrasted the difficulty staying on task at work and at home:

"I'm better at work. I don't know if you're more accountable... At home yeah I do think that my scatterbrain ways of not staying on task can be an issue you know in regard to just getting things done. I'll start a project and then I'll get oh let me go do that. So then project A doesn't get done because I'm off to project B."

Especially problematic are activities that are not physically engaging such as conversations that are long, church services that require listening with little interaction, and reading. Ruth's story reveals this:

"I might find myself wandering again you know out to that field somewhere. I don't know where I am, but on the phone it's probably you know if the conversation goes too long I might tend to start to think of other things, but as far

as face to face or just having a short conversation or the television that's all fine but reading is the big one."

Although paying attention in these situations might already be difficult for some people, the women in this study state that it is now clearly more problematic and intense compared to the pretreatment period.

Concentration difficulties. Difficulty concentrating was described by all of the participants. Sometimes physical noise was identified as a causative factor. Other times, concentration was difficult when conversations consisted of too much detail or when multiple conversations occurred at the same time. Erica explains it this way:

"It's difficult to concentrate. I forget, like it's hard for me to follow the conversation and so then I will hear something and this is so strange for me, like I'll hear something but I can't repeat the topic back right away. So then I'll listen and you know but there are people there who know me both well and just acquaintances. So the person I was sitting next to knows me very well and she looked at me at one point and said did you get that? You know just like very quietly. I'm like yeah, this is loud I'm having a hard time. So she noticed it, but nobody else did."

Difficulty controlling the flow of thoughts seemed to be a problem for many. Women in this study commonly described being engaged in an activity when multiple ideas entered their thoughts. These thoughts usually took them in a different direction. Once there, they were conscious of the diversion and asked how that happened. Holly revealed:

“I’ll start something and then something else will pop into my head and depending on how much I’m concentrating on something if I’m not all that concentrated then I’ll be off in that direction as well...more so than I used to be... I definitely think that I have recognized that if I am not completely putting my 100% concentration into something it isn’t going to stick ... I have to really put forth an effort for certain things.... If I meet somebody I need to really make an effort to somehow remember the name or within a couple minutes I’m like what the heck was their name again. Which I know and that would happen to me to some degree before you know. If you’re visiting and you meet someone and you go about talking and you forgot the name but I think more so now I need to make an effort to really concentrate on just about everything.”

Ruth also expressed similar difficulty in concentrating:

“That’s a big problem. Yeah I think the concentration part for me is worse than the memory because I like to every day you know do some type of devotion reading or read from the bible or whatever and I’m a big avid reader I love to read books, magazines, I’m a big book reader and I find myself, I’ll be reading the book and all of a sudden my mind is wandering about what I might have to do out in the yard. I have to mow the grass tomorrow and I’m like I’m trying to read this book so I have to go back and it’s been difficult to concentrate and read. I like to read and I really haven’t been able to do that even to read, I like to read Joe Lowestein and sometimes I find myself reading the whole chapter over because I’ll read it and I couldn’t even tell you – I think to myself if you offered

me a million dollars I couldn't tell you what I just read. It's just right out of my mind and for me that's frustrating because you know that's just not me."

All of the participants in this study described difficulty concentrating when they were presented with too much detail. When the conversations were lengthy and detailed, the subjects described them as both tiring and overwhelming. Erica provides a vivid description of how her brain felt during this experience:

"The type of things that you have to keep track of lots of details, but details really bothered me and made me very tired and really gave me a feeling of pins and needles at the base of my skull. I'm not sure if that was—that was kind of my signal that this was getting to be too much."

Cheryl described her once felt passion for discussions about social issues and political debates. She now explains that what was once interesting and exciting to her is now too tiring to even think about or to discuss.

"It's too much work. I need to save my mental energy. I just am more centrally focused than I am widely focused."

Several participants described "background noise" or "mental noise" as types of distractions that made concentration more difficult. Erica explains:

"I'm finding I could rely on my memory more and also like I realized last night in certain situations and it happens at work sometimes you know, I just I have to be careful to pay attention to what I'm supposed to be paying attention to. There's just a noise is louder to me, kind of the background noise."

When asked to explain this "noise" further, Nancy described:

“Mental noise – getting sidetracked. You know you’ll be thinking really hard about something and something else will pop in your head. Then you’ll start thinking about that and then you’ll worry. Oh but I was working on something else before I started and that can happen at night when you’re trying to sleep. It used to happen more to me in the first 3 or 4 months when I was also dealing with fear and stress. I’m petrified when I start something new. I made it through the surgery okay. I was scared to death to start chemo. But I took chemo you know and I was scared all over again with radiation...That’s like physical noise but I think it causes mental noise. Mental noise is just when you get distracted by other life events. I’m not talking about huge life events but I’m talking about the dog barking.”

The impact of mental noise on concentration abilities in work and social environments is demonstrated in Nancy’s story:

“When I was at work I would just want everybody to shut up around me. I could not – they would distract me terribly. They added physical noise to the mental noise. It was overwhelming to me. I actually have not eaten out at a restaurant since before the diagnosis. I will always go to restaurants, I’ll go to any restaurant that you can snap off your fingers, but I will take it home. I’m a real car side to go person now.”

A consequence of having difficulty concentrating is that it often takes longer to complete tasks. When one is lost in their thoughts, they pause to determine what has been done, what needs to be done, and sometimes need to start over at the beginning.

Erica describes this difficulty in ordinary daily activities:

“The other thing I do I noticed is because my memory is not great, it takes me longer to complete tasks and so I’ll be in the yard gardening and kind of like if you walk into a room you know and you’re like what did I come in here for, I’ll stand in my yard and say okay—it’s almost like I’m dirty and I’m outside so I’m not going to make a list, but it would be good if I could say you know plant these perennials here, do this now, go water that you know because I would think okay what do I need to do next.”

Nancy, whose hobby is doll restoration, described how the difficulty in remembering all of the steps in the process would take so much more time to complete. In this case, a task that would typically take hours to complete can now stretch into days.

“...So that was the kind of thing that I would forget and I would get frustrated and it’s something that I would normally be able to do in a couple of hours because hair drying all over again has to happen. It would stretch it into days.”

Organizing and prioritizing. Six of the women in this study worked outside of the home. In addition, the one woman who was not employed was a college graduate and a busy mother of three children. For all of them, organizing and prioritizing activities, a component of executive functioning, was suddenly very challenging. Erica describes the problem and how she manages the deficit:

“I find that I have a harder time organizing and prioritizing my lists. So I tend to just keep checking and checking you know. Sometimes I feel like I know what someone with OCD[Obsessive Compulsive Disorder] feels like because I’ll say okay you know did you do that? Then I won’t remember so I’ll look. So it’s kind of like I just feel like I need to check up after myself and I’m constantly working. I

don't feel like I have the perfect system to do that now. I carry the pad and paper so I write things down. I have a number of lists around the house and at work but if I get interrupted I might not have the right list. I might have a new ipad and I'm going to try keeping some electronic list and see if it helps me."

Difficulty in completing household chores and projects was described by all of the participants. The women in this study experienced this difficulty from initiation of the activity to its completion. This was especially true when more than one task had to be done at the same time. Cheryl provided this example:

"I don't take on big projects at home anymore because I can't sort of like organize it in my mind. So I just, sort of say I can't do that and put it off and it just isn't as easy anymore. But on Saturday we cleaned out the garage and I could do my task but to answer questions and do my task it was—I was very disoriented and I couldn't do that. I would just have to like stop and then re-orient and it was awful. I couldn't do two things at the same time."

Most of the women in this study described difficulty in tracing their steps mentally in order to problem solve. This added an unexpected dimension to an already difficult situation. Cheryl explains it this way:

"But usually I could really like back track mentally and like I could say oh okay it's either here or else I did this okay. So I got to like you know check these things. But as it is I no clue. I cannot back track mentally. Just absent in my mind. I don't know like what I did exactly. I'd have to really focus to remember ...to do like a sequence of events. It seems like it goes away."

Barbara needed to take care of some financial issues at the college that her son was attending. She described knowing exactly what steps needed to happen concerning the school loan. However, she was worried about her ability to convey her thoughts into words over the telephone.

“I knew the steps...I felt that it was this big scattered plot and I needed to hone it down into one cohesive thing. I couldn’t get straight where I needed to start and where I needed to go ...”

She also described her fear in volunteering at her child’s school. Although many would pass up this opportunity, for her the concern was in placing herself in a situation where she could become “frazzled.” This sense of vulnerability is evident in her description.

“Like I haven’t shut down or anything but with the chemo that was you know physically hard to do. So if I felt like something was overwhelming or would be hard, I just wouldn’t do it. So I think I still have some remnants of that. Like they’re looking for somebody to organize the snack stand for my daughter’s volleyball games and I’m like oh I don’t think I’m going to do that. I don’t know what it is. I just don’t want to push it too much yet. It might also be like the thought of organizing all of that like do I really want to do that right now. No. So when I think normally I would have been oh yeah I’ll do it. So that it is holding me back just a little bit. I don’t want to get frazzled.”

The avoidance of certain situations, exhibited in Barbara’s examples, was common for most of the participants. This included avoiding situations and places that could place them in uncomfortable predicaments.

Fatigue. Fatigue has both physical and mental components that together contribute to the overall experience. Several of the women in this study had complex surgical procedures to remove their tumors or to complete breast reconstruction. Still others received radiation therapy which can also contribute to fatigue. In addition to these physical causes for fatigue, the women in this study clearly identified what they referred to as “mental fatigue.” Cheryl described the fatigue:

“I am hoping it will get better. That’s the thing. Because I realize I get tired and that I’m changing priorities and maybe just not as quick... I still hit a wall. Suddenly you’re exhausted mentally.”

Several women described mental fatigue related to work routines and achievements. Mary described her struggles at work this way:

“I said I’m done. You can’t ask anything more from me today. I went home and went right to bed that night and for the rest of the week I could barely function...I just was like I need to go to bed before I can even think about how to make that list. I could not make another decision. I describe to the people like the brain only has so much room and it was filled to the brim. It was done for the day.”

Ruth described the change in energy and ability to do what she normally could accomplish:

“...when you get that tired then I think it affects your mind because it’s so overwhelming and it’s so much to do and I just can’t do any of it so I’m not going to do anything. That for me, was very hard because that’s not how I am. I’m like real—as far as work, aggressive, overachiever, I want to win every contest and get the A on everything and I want to do it all...”

Several women described difficulty sleeping and questioned the relationship of insomnia and lack of sleep to their cognitive functioning. Mary's experience was described this way:

“The other thing that’s really been different since the fifth cycle is much more sleep disturbance... You go to bed and you can’t fall asleep and waking up at 4:00 in the morning and just I think that plays a role...and I’m not sure exactly what causes that sleep disturbance you know but like I said I’m really tired today because I did not sleep well last night. I could not go more than 2 hours. Now I didn’t take any Benadryl before I went to bed so tonight I’ll probably try that. If I can get 6 to 8 hours sleep a night I would feel much better you know. But that’s been the big problem is the sleep disruption this time.”

Existential themes when experiencing cognitive changes. Experiencing cognitive changes gives meaning structure to the existential of lived space. All of the women in this study described situations when the experience of not finding the words, not being able to pay attention or to concentrate, or not remembering steps in a common activity left them feeling unsafe in their space. Feeling lost in terms of mental processing was a powerful component of the experience. When trying to find the words, the participants questioned, where did it go? *“In my head I have it all straight. I know what I want to say and then all of a sudden the word I want is gone. Completely gone.”* Most had experiences of suddenly feeling lost in an activity and not being able to make the necessary mental connections to find their way back. *“...I cannot back track mentally. Just absent in my mind.”* This aspect of the experience of cognitive change following chemotherapy caused most to be alarmed at first and eventually led to a high degree of

frustration. The unpredictable nature of these difficulties made it difficult to engage in certain activities. These dreaded experiences became predictably unpredictable.

Lived body refers to the physical sense of an experience and the physical way that the body responds to the subconscious parts of an experience. Several participants described a sense of disconnect between their body and mind. Many described knowing what they wanted to say but not being able to articulate their thoughts. One woman described having an out of body feeling: *“I just had like an out of body feeling. It was really hard for me to process things in that present moment.”* In addition, the existential theme of lived body is interwoven into the experience of fatigue which has both physical and mental components. All of the participants in this study described the mental fatigue mounting to a point that the body needed to mentally shut down. All of these women could identify the point at which they had reached the maximum amount of cognitive stimulation. They described the personal demands to respond to requests from family or co-workers as reaching a precipice. Beyond that point, they would mentally shut down and decision-making was impossible. This was especially true when conversations were lengthy and too much detail needed to be processed.

Lived time is woven into the theme of experiencing cognitive changes in several ways. Taking more time to complete even the most common tasks created new challenges for all of the participants. Taking more time is a consequence of some of the cognitive changes but it is notable in itself because it leads to another cause of frustration and concern among the women in this study. Difficulty remembering the steps in common activities or trying to find the words were described by all of the participants. When these difficulties occurred, time seemed to be suspended. One woman described:

“I was very disoriented and I couldn’t do that. I would just have to like stop and then re-orient and it was awful. I couldn’t do two things at the same time.”

Lived human relations is an existential that illuminates the theme of experiencing cognitive changes. The difficulties with forgetting the details of conversations or not remembering names of individuals can directly affect relationships with family, friends, and co-workers. The potential consequence of the experience on interpersonal relationships was always a feared possibility. Some women were able to confide in family and friends about their cognitive difficulties: *“I said I’m done. You can’t ask anything more from me today.”* Some women related turning to others for help with the day-to-day struggles: *“I was trying to describe something to my daughter and there was a certain word I knew was fine for the situation but I couldn’t think of it. I gave her the definition of it and then she gave me the word.”* Even though they were able to get through the immediate struggles, the women in this study viewed these difficulties as personal shortcomings and nearly always felt the need to apologize.

Interacting Socially

The significance of interacting socially differed for the women in this study. Some identified the need to maintain social contacts as very important to their perceived well-being; while others turned inward to find healing. Several women described how some social interactions were more challenging due to difficulties in managing the mental noise and keeping up with the conversation. Many described changes in their participation in certain social interactions due to changing priorities in their personal life.

Being a full participant. Cognitive changes created challenges for many women in certain social situations. Most of the participants described times when it was difficult to participate fully in a conversation. Holly described:

“...being able to pull things out from our conversation 15 or 20 minutes ago I don’t do that as well anymore and I don’t think it’s because I’m not paying attention. I still feel like I’m paying attention to what someone is telling me, but sometimes I can’t pull those things back out anymore.”

Being a full participant was especially difficult when there was a great deal of conversation to follow or when situations required participation in an activity. Erica describes the importance she places on maintaining social contacts and the challenges this presents:

“... Sometimes I get tired sooner with conversations and social outings. So I think that worries me just because I want to keep my friends and my relationships. Yeah I find social things more challenging because it’s that little bit of delay sometimes. Like I went to a wine pairing and I don’t know a lot about wine, I know a little bit...but there were some people there who really knew a lot about wine. So usually I would really be trying to learn everything right there. So this representative came to the table and they were talking about all these different wines and all these different regions and I just thought I’m not going to get this whole thing so...I was pleasant and smiling. I had a very good friend there with me and no one knew that I was really struggling because I was engaged enough in the conversation. But I wasn’t really learning everything about all these

details like I usually would. It's almost—I would best describe it as it's this delay and this being overwhelmed with lots of new information at once."

Turning inward. Turning inward for some women meant isolation, and for others, it meant being more introspective. Some topics of conversation seemed to require too much mental energy. Cheryl described: *"It's too much work. I need to save my mental energy for more practical tasks."* Barbara explained difficulty fully engaging in social activities because of the overall experience of a new cancer diagnosis:

"...when I look back on it, I probably was just there with a blank stare... I just didn't feel like myself. So, I just kind of sat there and you know maybe participated a little bit in the conversation but not like I normally would. Just because I got other things going on. No it was just too much going on. Too much cancer going on."

For Nancy, social interaction was not as important to her well-being at present. She describes this as a relative change from how she viewed her personality prior to her breast cancer diagnosis and cognitive difficulties:

"My life isn't very social right now. It's mostly my two daughters... I don't have a big social network right now at all...I used to even consider myself much more extraverted and now I'm very much an introvert. I don't know if that's depression. I think I'm just going to be—I'm just going to float through these different stages. I'm doing better. I think I'm pretty gregarious when I'm here."

In terms of quiet and alone time Nancy added:

"I need more of it than I used to. I think somebody once explained—so I do remember some stuff that you can still seem very extroverted but to get to re-

energize you have to be alone ...I definitely to re-energize I have to be alone. Before it wasn't quite like that. At one point, even I thought I was an extrovert, but not anymore. I did the Meyers Briggs and all that stuff. I know how it works. See I can remember that, but I can't remember if I took my vitamin that day you know."

For these women, turning inward provided the necessary energy to meet their daily challenges.

Overcoming one's fears. Placing oneself in certain social situations was often avoided. Barbara describes her fear with accompanying a friend to the seashore for a short vacation. Although extending herself required urging from her friend, the result was rewarding in that she was able to overcome one of her significant fears.

"My friend wanted me to go to the beach with her for four days and that was overwhelming, but I did it anyway because it was the beach and it turned out to not be overwhelming. It was great...I was afraid that we were staying in a hotel we went to Rehoboth and we had to drive to the beach. Her daughter was going to visit her boyfriend's family, he was in Lewes and we were going to Rehoboth and all of that, it was just more of the same to me you know driving around, getting her where she needed to go. Then we were going to go to the beach and it was going to be for the whole day and I didn't know if I would make it... So that was good because I thought—I thought I'm not going to be able to do it and I did. So then they said we need somebody to do this snack stand and I thought that was more mentally I'm going to have to think about it all day. Because that was another thing during chemo I couldn't plan ahead."

Changing priorities. Changing priorities while undergoing cancer treatment and in the months of healing that followed was apparent in many of the participants' stories. Consequently, changing priorities could also place some social interactions in a new light. For some, changing priorities meant not participating in certain social interactions. Mary provided this example:

"I was invited to a party and after a couple of hours I was ready to go home... You know it's hard to say exactly what it was just lack of stamina or probably it was just the frivolous things people talk about I just had trouble you know—I can only care about that for so long."

As demonstrated in the example above, sometimes changing priorities occurred because the social interaction itself was no longer attractive. In contrast, at other times the lack of desire to participate was related to lack of stamina and the inability to participate. Cheryl described how interactions with a friend would often involve conversation about complex social issues that now she had no desire to discuss.

"I'll just say no, I won't—I don't want to talk about that. I'm not interested in that... there was an issue, legalizing marijuana. It came on the news and everything and he goes now what do you think about that? I said you know what I just really don't care. They can legalize it or not legalize it, I'm just not—I don't care."

Existential themes when interacting socially. The existential of lived space is evident in the feelings described about the challenges and rewards of social interactions. Lived space can be described as the space in which one feels safe or nurtured. The participants in this study identified this space differently but all recognized what they needed to feel

safe. For some, maintaining friendships was important to their overall well-being. This was especially true for one divorced participant who explained, “*Sometimes I get tired sooner with conversations and social outings. So I think that worries me just because I want to keep my friends and my relationships.*” In contrast, several women described the safe space that quiet and introspection provided. This space was welcomed because “... *it was just too much going on. Too much cancer going on.*”

For some women, choosing to be alone was an outward behavior change that was part of the lived body experience. Removing oneself bodily from certain situations openly reveals aspects of social interactions that can be uncomfortable for some. The challenges brought on by trying to manage the mental noise and to keep up with conversations could be remedied by limiting the number of social interactions. In addition, turning inward was important to some in order to reenergize. This is exhibited in the following description: “*It’s too much work. I need to save my mental energy for more practical tasks.*”

Lived time in social interactions slowed down and sometimes stood still as the women struggled to keep up with conversations or to connect the ideas discussed. As a result of this experience, they often shifted their priorities focusing more on their personal needs and health. This gave some a newfound time to reflect on the past few months since diagnosis and treatment. The women in this study spoke confidently of what they needed to do in order to be well.

Lived human relation is an integral part of the theme of interacting socially. Sometimes these interactions brought a sense of safety and belonging. This was evident in wanting to maintain the support of friendships. Sometimes these social interactions

were draining of one's mental energy. This was best seen in the descriptions of managing the mental noise by sometimes being alone. Lastly, sometimes these social interactions helped women to triumph over their fears. This was best described by this example: *“So that was good because I thought—I thought I’m not going to be able to do it and I did.”*

Coping

Coping with cognitive changes consisted of confronting the challenges, finding support, and identifying strategies to cope. Finding ways to cope started with first facing the challenges of living with cognitive change and coming to grips with feelings of being overwhelmed by the experience. Acknowledgement of the cognitive difficulty and the recognition of its effect on their lives led to a variety of strategies to cope with the cognitive changes.

Facing the challenges. As already described, women acknowledged feeling overwhelmed in certain situations that required decision making, planning and thinking about several things at one time. This new reality concerning struggles with common everyday activities created new challenges. Mary describes the challenge of carrying out normal daily tasks in the following example:

“Going to the grocery store just overwhelms me you know. Even if my lists have not been as good at you know...you know there’s a lot of multi-tasks that goes into a full thing of thinking about what you want for dinner. So you have to think of the meals and planning them and there’s just so much planning and I’m like—and it’s just – and I couldn’t see myself having the energy to even cook when I thought of the plan.”

Mary also discussed the difficulty in solving simple problems. For Mary, this was sometimes overwhelming.

“I feel like it would just overwhelm me...I just am not in the mode of solving a problem. It’s like yesterday I was supposed to go to the planning meeting...I went to the one two months ago and I was very sharp and I just like, I just can’t—I don’t want to use my mind and energy on that.”

The complexity of certain chores or tasks led to difficulties focusing and executing action. Subsequently, this led to feelings of being overwhelmed. Ruth’s experience led to delaying certain activities which further compounded the situation.

“Sometimes you just look at everything and it just looks like so overwhelming that there are so many things that you look at that you have to do and concentrate on and pay attention to that you just sort of like toss your hands up and say it’s just too much. I’ll do it tomorrow. Then when you put something off like that then it just compounds itself and makes it a bigger chore or job on the next day. I think it all comes down to just being able to you know having that concentration, the feeling that you can actually sit down and concentrate on this and you know do this and get it done and sometimes you know I just don’t feel like that.”

Several of the women in this study mentioned that cognitive difficulties were worse when stressed. Nancy described: *“I noticed I feel more foggy when I am stressed.”* Ruth expressed her feelings this way:

“One more thing! Annoying, frustrating, aggravating. Worry about cancer, it’s enough to deal with physical changes... to have your mental you know capabilities diminish a little bit makes it a little bit harder.”

Another challenge for many of the women in this study was the experience of physical side effects of treatment and complications from therapy. Some of these included gastrointestinal problems, peripheral neuropathies, skin and nail changes, neutropenia, cardiac changes, pain, and port infections. The women's optimistic responses to these physical challenges seemed to further encourage a positive attitude in their approach to dealing with their cognitive difficulties. They all had a "can do" attitude in terms of being able to manage the cognitive changes. Holly explained:

"I still find myself to be very fortunate....I mean I made it through the treatment and the surgery just fine...I'm just the kind of person I just truck through. Whatever is in front of me I deal with it. That's the way my dad is and that's the way I am."

The following demonstrates Erica's adaptability to physical changes:

"When I went to my surgical follow up appointment and I found out that...my pathology report was not what we had expected and that my margins weren't clear, that was really hard. That was really hard. I was really anxious about that. So for now when I think the things that I get anxious about more my aches and pains and when are they going to go away. I try and be kinder to myself. I have a really hard time—it's getting better now but for the longest time up until now I've had a really hard time opening jars and I've had to you know adapt and think like an occupational therapist and think okay what have I seen people use in the past you know and thinking okay I can use a rubber glove. You know I bought myself a jar opener."

Several participants spoke of feeling unhealthy at present but trying very hard to be normal. Mary's story demonstrates this point:

"I don't feel I have dementia you know... No it's never been a problem that's why I think it's different. The other thing that's different too is when you first start on treatment for breast cancer, you know I didn't go in with a symptom, I didn't ever go in with fear. Mine was a screening mammogram and I did not feel unhealthy until probably May you know. The first two chemo's it's like I'm watching and it's like somebody else is getting the drip you know... It didn't make me feel any different. I felt perfectly healthy. I had a few side effects. I definitely had a little nausea ... but I didn't feel unhealthy. Right now I feel unhealthy now. I feel kind of weird. This is the first time in my life I haven't felt healthy. You know I'm still optimistic that it's temporary."

Erica described feeling as though she lost a thread of her life. Confidence, control, and being highly effective in all that she did were important character traits. *"I feel like I've lost a thread of my life you know. Like I'm having a hard time putting together tasks and that is the thing that really frustrates me."* Wanting to be normal and whole again was expressed by several women. For Mary, this was especially important: *"I want to feel alive again...I miss that whole you know and I don't believe that people understand that toll that this has taken on me ...I mean to really feel things that make you feel alive."*

Cheryl described her struggle this way: *"I'm really try hard to be normal. I don't really like you know hating myself. I still have low energy days."*

Finding support. Finding support did not come in all of the usual places. Only one of the participants attended a breast cancer support group. In fact, several described how participation for them in support groups was not a good fit. Nancy explained:

“I don’t like them. I don’t... I think maybe even a good example is that I wouldn’t mind actually supporting one other person going through what I’m going through but I don’t feel like going near a support group. I just feel like—I don’t know if that’s mental noise but right now I’m just not ready for something big like that.”

Ruth described the challenges of being a widow and trying to cope with the physical and cognitive changes alone.

“It’s a huge mental drain and that probably also compounds you being able to concentrate on something because you have so many thoughts rolling around in your head you know. I think too because I live by myself I’m a widow so I think because I live by myself then you sort of carry that burden all by yourself. So you really—I mean I have a friend and I have other friends that come and visit and help me out and things but yet there’s not a husband there that helps carry the burden of being ill and you know trying to keep everything done and pay your bills and pay your mortgage. So all of that gets up in your head. So I guess it’s no wonder that you forget things. I don’t know...I’m usually a pretty strong person but you know when you go through something like cancer and not having my husband here, even though he’s been gone 25 years so it’s been a long time, but it still different when you don’t have that partner, that significant other that’s there to help carry you and the load.”

Both family and co-workers' expectations of their capabilities seemed to be based on the fact that they physically looked well. This was problematic because they didn't necessarily feel well. This was especially problematic for Mary who explained:

"... part of it is people keep saying 'you look so good', but I'm not good you know. You get the same thing at home...When my husband comes home from work he's tired and it's like you know he doesn't think I look more tired than him and why can't I go to the store...It's funny my 17 year old son now he's kind of picked up the slack."

In addition, Nancy described the problems she encountered when returning to work:

"I actually started to not put so much makeup on and to not look like my normal self just to get people to stop expecting the normal me. But it's true. When you go back just because the doctor said you could go back it doesn't mean you are recovered. It means you're okay to work."

Some women found that focusing on themselves above other people and things was therapeutic and essential to their recovery and well-being. Cheryl describes it this way: *"It's too much work. I need to save my mental energy. I just am more centrally focused than I am widely focused."* Erica speaks of focusing on self as she reflects on the total experience of having breast cancer, undergoing treatments, and returning to work:

"I just really needed to focus on myself which was another part of embracing this journey because I really tried to flow rather than roll you know. Before I was always thinking about having my game face on and I was thinking no this is more I have to find my flow and right now I need to focus more on myself cause I kept worrying about work."

Nancy described deriving support from understanding the science behind her specific breast cancer diagnosis and treatments: *“I find support in—I’ve always dealt with fear by learning about something instead of letting it overwhelm me. Because if I would let it, I could let what I don’t know cripple me.”* Nancy’s need to understand the science and the comfort she derives from it is most evident here:

“...there’s something called cancer map... I did have some muscles, it touched on the muscles and that’s where like the radiation is going to be. But one of them said if its only on the what is the pec muscles it’s not a big of deal...So of course I had my surgical reports and I read. But one of them I remember them saying it’s only if it’s in the pecs it’s no big deal. As it got further... that cancer map expects me to live until I’m 82 once I’ve done everything I’m supposed to do. So those things actually calm me down. Because it’s what they say grade 1, it is a good thing.”

Several women spoke of finding support in the spiritual realm. Nancy describes the meaning of spirituality and the comfort it brings this way:

“... I remember being at the chapel here once and I saw that they had this research posted that showed that some people actually—their prayer seemed to do something. It didn’t matter who you prayed to, it didn’t matter what your religion was, none of that mattered but prayer mattered. That’s when I started getting into okay so what’s the – there’s got to be some science to—well what makes prayer work and it has nothing to do with what you think about a God or something but what is that like a magic of believing you know.”

Spirituality brought great comfort to Ruth as demonstrated in the following:

“So God has a reason for everything and you know we find these things out but I don’t really know it’s just—you know I guess it’s better to be happy and have a good attitude and no matter what happens you know God is in control of it, the plan is already made. I might as well choose to be happy and have a good attitude than just face it with a strong positive attitude and I don’t want people to feel sorry for me or I don’t want to feel sad about it and I don’t want to look at it as a death sentence or that it’s—I don’t want it to change my life any more than it has to. So if I stay positive and just be happy about things then I think it will go better. I hope—it has so far.”

Strategies to compensate. As a result of their experiences, all of the study participants identified strategies to improve, prevent, manage, or eliminate the stressful situations brought on by their cognitive difficulties. Most identified the necessity and usefulness of writing lists and memory prompts. Erica explained this technique and her hope that that her cognitive difficulties will get better over time:

“I am trying to be kind with myself and just make my lists and realize what I need to do because I don’t feel like it’s—I don’t know how long it’s going to take to change and I’m just hopeful that it’s not going to stay this way forever and that there’s something I can do to help.”

Ruth described her techniques for remembering names:

“I definitely think that I have recognized that if I am not completely putting my 100% concentration into something it isn’t going to stick as likely as if you know I’m being more casual I guess. I have to really put forth an effort for certain things If I meet somebody I need to really make an effort to somehow

remember the name or within a couple minutes I'm like what the heck was their name again. Which I know and that would happen to me to some degree before you know. If you're visiting and you meet someone and you go about talking and you forgot the name but I think more so now I need to make an effort to really concentrate on just about everything."

Holly described her strategies for managing the cognitive change this way:

"I write myself a lot of notes, calendar keeping all of our activities straight which I've been doing. I think probably the biggest now is just recognizing that when something is going on I need to remember something or something is being stressful anytime there's a lot of activity or stress or things like that it seems to be worse. So if there's ever a time like that I need to just stop and take a break and take a breath and regroup and be able to really think about what I'm doing if that makes sense. I think that helps. It does seem like the crazier things get the harder it is. I feel more scatter brained when things are hectic and crazy and that's when I start to feel that I can't, I feel like I'm not accomplishing anything. I start one thing, then I'd start something else, then I'd start something else, then I'd go back to the first thing. But I need to just stop and regroup."

Ruth explained her nightly ritual:

"I try to write everything down. So I keep a note tablet in my kitchen and I started to keep one by my bedside so like sometimes at night I would sit there and go back over the day and then I would remember something or I would think tomorrow I need to do this. So then I thought I better get up, so I put a tablet beside my bed so then I would just get up and scribble those things down on the

tablet. So in the morning I would have it. Because before I wrote it down in the morning I couldn't remember what I was thinking about the night before."

For many of the women in this study, anticipating problems ahead of time led to planned interventions. In the following example, Holly described how to avert potential problems:

"The things that kind of made me laugh was two days in a row we went out shopping and both days I forgot where the heck I put the car... The kids were with me both times and they found it quite entertaining that mom couldn't remember where the car was. My grandfather always used to park by a lamp pole in the mall parking lot and he used to say it's more secure here because it's lit. But quite frankly I'm going to start parking next to a pole instead of taking the closest spot so I can remember where the heck I put the car. So that kind of gave me a laugh to think that here I am doing what my grandfather used to do".

Cheryl described how communicating with friends on *Facebook* was helpful to her in connecting with friends. This activity removed the usual stress that she sometimes experienced in face-to-face interactions.

"I make lists and I get a lot of sleep. I don't know. I like music. I like music a lot. It calms me. And I also like to post on Facebook...I don't feel any...deficit when I write. I can concentrate and I can spell things okay. It is casual and is not structured."

As the women in this study became better at compensating for their cognitive deficits, they talked about how they could now conceal these difficulties from others.

Ruth explains it this way:

“No. I don’t think anybody has picked up on it yet because I guess I’m getting good at trying to cover up that I didn’t remember where I met you or why I met you or what we have in common.”

Most women demonstrated a positive attitude about recovering from their current difficulties. They also expressed the belief that having a positive attitude toward their cognitive difficulties was an important approach. Barbara explained:

I’m feeling so much better as things go on and as time goes on. Yeah. So hopefully this memory thing will go away or I’ll just get used to it.

Ruth explained:

“I might as well choose to be happy and have a good attitude [rather] than just face it with a strong positive attitude and I don’t want people to feel sorry for me or I don’t want to feel sad about it and I don’t want to look at it as a death sentence or that it’s—I don’t want it to change my life any more than it has to. So if I stay positive and just be happy about things then I think it will go better. I hope—it has so far.”

Erica stated it simply:

“Now I’m just thinking, how am I going to adapt? You know it’s okay... you know you’re still here. You’re just not back to the way you were before.”

Existential themes when coping. The existential theme of lived space was present in two distinct ways when coping. First was the stage of confronting the feeling of being overwhelmed by activities that required mental processes. The second stage was being able to identify strategies for coping. For most of the women in this study, this was an unsettling experience that led them to a place of emotional vulnerability. Once the

vulnerability was before them to view openly and honestly, they were able to discuss a path to coping. Most of the women spoke of a spiritual path to assist them in the journey to healing physically and emotionally. This lived space was a warmer and safer space. At this juncture, it was not possible to isolate cognitive change following chemotherapy from the larger picture of surviving breast cancer. The conversations took a circular path of returning to the diagnosis and the impact of breast cancer on their being.

The existential theme of lived body is woven into dealing with physical healing and fighting for survival. Coping with the physical side effects of disease and treatment preceded any ability to think about the cognitive domains. All of the study participants experienced some physical side effects and some of those were chronic changes for which they had to adapt. Stress was identified as a factor for increasing one's awareness of cognitive difficulty. *"...just recognizing that when something is going on I need to remember something or something is being stressful anytime there's a lot of activity or stress or things like that it seems to be worse."* Women explained that their physical appearance often improved before their physical stamina improved. This created tensions between the women and their family and co-workers whose expectations were not congruent. One relayed, *"I actually started to not put so much makeup on and to not look like my normal self just to get people to stop expecting the normal me..."* In contrast, as women were further along in recovery, they often longed to be normal. As described by one, *"I want to feel alive again."* In addition, lived body includes those behaviors that may change in response to others. This was exhibited by some who described concealing their cognitive difficulties by planning ahead and developing

strategies to integrate into their work flow or social interactions. *“No, I don’t think anybody has picked up on it yet because I guess I’m getting good at trying to cover up.”*

Lived time is evident in several ways in the participants’ descriptions of coping strategies. These include more time for self and more time spent in planning activities to compensate for the cognitive difficulties. Keeping notepads in various locations and writing reminders is the most common strategy for carrying the day-to-day activities. When it came to job related strategies, women had a variety of strategies to manage their work flow and organization. One woman described her coping strategies this way:

“So it’s kind of like I just feel like I need to check up after myself and I’m constantly working. I don’t feel like I have the perfect system to do that now. I carry the pad and paper so I write things down. I have a number of lists around the house and at work but if I get interrupted I might not have the right list. I might have a new iPad and I’m going to try keeping some electronic list and see if it helps me...So now I am really focusing on that kind of documentation. So I’m feeling a little bit better about it because I can trust myself that for the things that I’ve done over and over and over in my career I’m still pretty good at what I was trained to do and then I have a good sense...”

While one is getting better, there is often the question of whether one will remain in this state.

“... am trying to be kind with myself and just make my lists and realize what I need to do because I don’t feel like it’s—I don’t know how long it’s going to take to change and I’m just hopeful that it’s not going to stay this way forever and that there’s something I can do to help.”

The participants in this study were able to approach this question directly. Although they did not dwell on it, they all recognized the possibility that these changes might be permanent and that they might need strategies to adapt to these changes over time.

Lived human relation is integral to the subtheme of finding support. As earlier described, support did not include belonging to a breast cancer support group; rather, it was directed toward other forms of support. Focusing on oneself and one's needs above others was a commonly described behavior. For those who were widowed or single, living alone was identified as an element that made their journey more challenging.

“... I also was thinking my situation you know because I am single and have a home, I don't have a partner at home who like to share the financial responsibilities with and other chores and things like that. So I don't know if it's different for single people. But I mean there's some things certainly that some people respond to therapy in this way so I was thinking you know it would be nice like if there were like someone living with cancer like some place to go, resources for living with cancer...in my opinion a lot of the information that's out there for cancer patients I find to be too generic and vanilla... I think we really need to problem solve with people.”

Several identified that increasing their knowledge of their disease stage and specific treatment plan became an important supportive strategy. The power of knowledge was in itself supportive. Knowledge validated for some the likelihood of long term survival. For others, it affirmed that they were on the best path and doing what they could do to contribute to the best possible outcome.

Looking Forward

Looking forward includes consideration of what the future may hold. Central to the theme of looking forward is reflection on the total experience of cognitive change and the realization of the challenges still to come. Looking forward consisted of the fear of sustaining symptoms or possible progressive symptoms, and concerns about both current and projected employment challenges.

Fear of sustaining symptoms. Looking forward begins with the realization that cognitive change could be a long term side effect. This is described by Erica: “... *I hadn't really thought that there would be lasting cognitive effects of the chemo and then I started reading more about chemo brain...*” Holly wondered if a coping mechanism could become so automatic that one wouldn't be able to discern if they had gotten better or if they were just better at compensating.

“...just becomes so automatic that you don't think about it... You know 5 years from now if I'm still writing down notes and I've just gotten used to really paying attention when I meet somebody new and that's just my norm. Is it still there or do I really have a change in cognition? I don't know.”

Most participants questioned the possibility of having early signs of dementia or Alzheimer's disease. This was particularly true of women who were over the age of fifty and were possibly more concerned about that possibility. They considered their age and began to wonder if the cognitive changes they were experiencing could be indicative of future cognitive difficulties. Once they learned that cognitive changes were a possible side effect of their chemotherapy treatments they readily discounted the possibility.

Their talk would often include statements of self-assessment. This is evident in Ruth's description:

"... they gave me that paper and they told me you know so it's not like dementia, or old age or Alzheimers or you know whatever it could be. So I don't really worry about it".

This issue had deeper meaning for one 44 year old participant. Vivid memories of Holly's grandmother's struggles with Alzheimer's triggered thoughts of behaviors that were similar to some of the cognitive changes she was experiencing:

"I look back at my grandmother who had Alzheimer's disease and looking you know she had it for years before we really truly knew what was going on...Having to go through and clear things out how many notes that she had written to herself to remember things. I sit there and I think, 'Holy cow! Am I headed that way?' ...She learned to cope with what she had at the time. Obviously it got to the point where it was more than she was not safe to live on her own. I do remember to turn the stove off and things. Things like that she would start to do."

Employment concerns. Working outside of the home created additional stressors for the study participants. All of the women, except for one, were employed and all of them spoke about the challenges that they experienced related to employment.

Erica described her concerns in the following:

"I would think 'What's going to happen to my career? I need my job.' Before when I wasn't as sure I wasn't going to forget things with patients and babies and maybe affect how I was taking care of patients. I was much more anxious about it. But now I've reassured myself through months of looking over my notes and

going back in kind of that OCD way and I'll know okay you did it and you did a good job..."

Women in this study were concerned about their job performance and the quality of their work. These women were employed in occupations that required some interaction with the public. Three were healthcare providers and one was a supervisor of a small department. Erica described her job performance concerns in the following:

"I had my evaluation and I am in the excellent category. You know like I followed through on my quality improvement. I followed through on all my initiatives... I think it's good that I was a high performer in the past because I'm still a high performer but I think you know I still don't have that edge. I'm hoping that I'll get it back."

Most of the women in this study described the pressure of returning to full workloads while continuing to receive treatments with radiation. Some were still recovering physically from the initial surgical procedure or were between surgical procedures for breast reconstruction. Mary's struggle is especially notable:

"That's been a stressor. Like okay are people going to expect me to hit the ground running because ... I think that was part of the stress in July was people saying to me oh chemo's done you should feel normal again. I'm like I didn't feel anything. I didn't feel normal in July at all. I feel good right now but I'm not working."

Although returning to work was initially distressing, most women were very astute in recognizing their limitations. This is evident in Ruth's story:

"Before where it was easy for me to keep up with my business and I have a team of girls to keep up with them it was easier, but now it takes more conversation to

keep up with them and it takes more energy from me to you know just to sit and do the e-mails and sit and do the work. So it's harder to concentrate and keep all those balls in the air."

In addition, Mary explained:

"But the big difference is after that week of June 4th, last week I just told people I can't do those kind of clinics. I just need to focus on getting better with my therapy. I can't do those anymore you know until I feel like my mind clears...It was just more than I could handle. I feel like I'm pretty good at recognizing what I can handle and what I can't. I cannot focus on trying to be superwoman."

Difficulty in learning new information is a characteristic of cognitive change that all of the women in this study experienced. This was especially problematic when trying to learn a new process in the work environment. Erica described ways that she manages new information:

"So going to conferences again I'm just taking notes and going back over my notes. Those are the areas that give me anxiety. Like okay you know am I going to be able to assimilate new information in the right way."

Nancy described the challenge in downloading computer antivirus software by following online instructions:

"To learn something new right now – no I can't. I'm not good at that at all. Instructions. I had like a Norton Antivirus software ... in my computer a week or two ago, I had to print out stuff to do whereas before I would be able to just fluff it off and okay hit save or whatever. But now I print out the instructions..."

Nancy was also enrolled in undergraduate classes prior to her breast cancer diagnosis.

She emphasized her belief that she could not return to college studies now:

“Like I said I couldn’t go back to school right now. I cannot imagine. I took a logic course last fall and I’d have a really hard time with a logic course now...I think I’d get lost. And new material I don’t know if I could absorb it now.”

Mary discussed her expectations and goals in planning to attend an upcoming professional conference:

“I’m realistic and I know that I’m not going to be able to sit there for eight hours a day listening to stuff that will definitely probably overwhelm me. So I just kind of set you know these are my goals and if I can get these couple things done.”

Employment concerns led some to consider new career options. Two participants explained that they had definite plans to explore new career options. Specifically, they believed that their current jobs required too many structured, cognitive activities. Cheryl woman explained it this way:

“I don’t feel the rewards cognitively...I just am not as capable or something in that way. So I want to be more like you know touching, seeing...I think I’m just tired of it. It’s sort of the same stuff, the same people, the same customers...I mean it’s good, it’s good, it isn’t just...charging me anymore.”

Existential themes when looking forward. The existential of lived space as one is looking forward is perceived as a safe place at present but is uncertain. Women often have a lingering fear that breast cancer will recur. The following description captures the essence of this fear:

“You know it’s not over yet. Well my story I don’t think, I’m always going to have to, I know there’s the magic 5 year thing and even on like with cancer math I know that there’s this sliding scale and at some point as long as everything goes like it has my life expectancy will be as high as if it never happened. It doesn’t mean I’m going to live forever but you know it’s as though it never happened, but I’m not there yet.”

Another explained the hope of full recovery but the lingering fear is evident: *“I hope I go back to normal. I know I feel I can go back and like being afraid of cancer is not always on my mind anymore you know.”*

The lived body existential is woven into the theme of looking forward as one experiences latent physical and cognitive side effects of chemotherapy. In addition, some fear the possibility of having lingering cognitive deficits or of developing dementia at an early age. The example discussed earlier demonstrates the depth of this concern when one’s cognitive difficulties resemble common behaviors exhibited with other cognitive disorders. In addition, all of the participants identified the fear of not being able to learn new things. This was true regardless of whether the activities to be learned were work related or recreational in nature. Several began to consider pursuit of new careers which would require a different set of cognitive skills.

Lived time, the subjective sense of time, slows down as one looks forward and reevaluates priorities and options. In addition, lived time in a broader sense includes how the present can influence our future plans. This component of lived time is seen in the participants’ plans to cope with anticipated employment concerns not only for tomorrow but also in the upcoming weeks and months. One woman left her job and was eligible for

social security disability for three years. She describes her most recent job and future plans:

“Plus because you know it’s one thing if ... your job is data entry and that’s all you do. It’s not going to do the same thing if you actually have to think about regulations and apply them. You know jobs are different... Yeah I just don’t ever want to do anything like I’ve done. I want to do something else if the time comes.”

Another woman who was employed in the same career for over twenty years and currently is in a supervisory position explained:

“Actually the cancer experience makes...me want to change jobs...I’d like to do something more visual and creative. Retail or something like that. I like more visual creative experiences and I like less complex. Just less like...intellectual. Like I did some research publishing in the past and everything and I just totally do not want to do that anymore. It isn’t interesting, but...maybe getting into a hobby or something is interesting like something artsy...I don’t feel the rewards cognitively...I just am not as...not as capable or something in that way. So I want to be more like you know touching, seeing.”

Lived human relation is evident as one looks forward in sustaining relationships with co-workers and supervisors. Sometimes these relationships were strained as the women struggled with their own recoveries while trying to meet the needs of a busy work environment. Achieving balance between the two was at times very stressful. In addition, the relationships that women developed with their healthcare providers became important for ongoing support and guidance. One woman described the relationship with a member of the healthcare team:

“Mark tuned in...he knew right away that what I had to hear was there was no evidence of more disease. He reminded me of that until I calmed down. Then I would be okay. He would help me through...”

Another woman described the overall importance of these relationships:

“I think part of your cure is that you have to have faith in your doctors and your medical center that you’re going to ... because your mental outlook on all of this is so important to you recovering well...It was too important to me to be sure that I was going to get well.”

In summary, for the women in this study looking forward first meant examining where they had been and how they made it to the current place. Although they were in different stages of physical and emotional recovery, all of the participants were taking measures to control their current and future health state. As described by one woman:

“You know...right now I mean I look good to people but I can’t lift my arm above my head and I have a lot of pain and tightness here and you know...I’m the only one that’s looking at my big picture.”

This type of reflection enabled women to face their challenges and fears head on. All of the women in this study had a positive attitude and looking forward meant taking charge of their own futures.

Summary

The participants in this study spoke openly about their experiences with cognitive changes following chemotherapy. They brought to life the key aspects of cognitive change that are not revealed in other descriptions. The method of conducting two interviews with each participant was effective in providing time for reflection by the

subject and the researcher. It also provided an opportunity for the participants to develop trust during the first interview that was carried over to the second session. Journaling between interviews created a new level of awareness for the participants. Most of the participants in this study eagerly began the second interview by explaining their journal entries. Only two of the participants did not submit a written journal. The women in this study were self-motivated to develop strategies for coping. All of the women in this study were taking control of important aspects of their lives including family and employment relationships.

The findings presented in this chapter resulted from an interpretive phenomenological approach which incorporated thematic, exemplificative, and existential analysis. Through this phenomenological analysis, five major essential themes of the experience of cognitive change following chemotherapy were revealed: Noticing the difference, experiencing cognitive change, interacting socially, coping, and looking forward. Subthemes, both essential and incidental, were identified within each major theme.

In this study, the experience of cognitive change following chemotherapy occurred within the context of the breast cancer experience. As the analysis progressed, the experience of cognitive change could not be isolated nor studied separately from the greater context of the women's reality of having breast cancer. Every interview began with each woman's story of her breast cancer experience and came full circle as they established their identity as a breast cancer survivor. The next chapter will describe these findings in relation to the literature on the experience of cognitive changes following chemotherapy and the breast cancer experience.

Chapter 5

Discussion

The purpose of this phenomenological study was to understand the lived experience of cognitive change following chemotherapy in women with breast cancer. Semi-structured interviews and journaling sought to uncover the meaning of cognitive change in women with breast cancer, how symptoms are experienced and become evident, how these cognitive changes impact roles in personal and professional lives, and how women cope with these changes. Phenomenological analysis revealed the following essential themes: Noticing the difference, experiencing cognitive changes, interacting socially, coping, and looking forward. In this chapter, the discussion of the study findings will center on these themes and their relationship to the current scientific literature. A discussion of the application of the study findings to the Theory of Unpleasant Symptoms (described in Chapter 1) will be offered. The implications for nursing practice and education, along with the strengths and limitations of the study will be also addressed. Lastly, recommendations for future research will be proposed.

Application of Findings to the Scientific Literature

Some scientists and clinicians still ask: Are cognitive changes following chemotherapy directly related to the chemotherapeutic agents or are they a result of other factors? This study does not focus on cause; but rather it aims to unveil the experience so that we can better understand the day-to-day challenges of living with cognitive change following chemotherapy in women with breast cancer. The findings of this research are consistent with several earlier studies which identified specific cognitive deficits following chemotherapy; however, this study offers a more in-depth description of these

cognitive changes and elucidates the day-to-day challenges of living with these difficulties in cognitive functioning.

Noticing the Difference

The participants in this study first noticed the difference in cognitive abilities in similar ways. For most, the awareness came with an event or several events where the loss of memory or words was sudden and unexpected. In addition, a common perception of the women in this study was the loss of sharpness in thinking and concentration. These specific cognitive difficulties have also been documented by other researchers. The literature demonstrates that the most frequently reported findings include evidence of changes in memory, concentration, and executive functioning (Ahles et al., 2003). In addition, it is reported that the cognitive symptoms experienced are often subtle, but that individuals are acutely aware of the differences in their thinking (Boehmke & Dickerson, 2005). This finding is also supported by Fitch et al. (2008) who reported that individuals could pinpoint the exact time in their treatment trajectory when cognitive changes became evident.

The participants in the current study were not evaluated with objective cognitive testing methods for existence of cognitive deficits. Rather, the women in this study self-reported cognitive changes, some to their healthcare providers and some to the study PI alone. As described in Chapter 2, reliance on neurocognitive testing is problematic due to lack of standardization in the cancer population. Objective neurocognitive tests have been employed in several studies in an attempt to identify cognitive deficits following chemotherapy in women with breast cancer (Ahles et al., 2002; Ahles et al., 2003; Castellon et al., 2004). However, it is reported that even when patients showed little or

no change in cognitive ability on standard assessment instruments, the same patients often perceived cognitive changes (Galantino et al., 2006; Hermelink et al., 2006; Paraska & Bender, 2003; Tannock et al., 2004; Vardy et al., 2006). While these studies identified the cognitive domains affected by chemotherapy and labeled the specific problems, the results of the current phenomenological study have elucidated how the symptoms of cognitive change are experienced. Giving voice to the women experiencing cognitive changes following chemotherapy has provided rich and detailed descriptions that can inform further scientific exploration of the exact physiological mechanisms of chemotherapy-related cognitive impairment.

Some of the participants noticed cognitive changes immediately following chemotherapy and others were not as aware of changes until months after their last chemotherapy treatment. This finding is consistent with other reports of variation in time from treatment of cognitive symptoms. Myers (2012) found that first recognition occurred for some after one to two treatments and for others did not appear until four or five months after completing chemotherapy. In the current study, these differences seemed to exist even when women received the same chemotherapy regimens. The women in this study who reported not noticing cognitive changes until months after therapy were also those who experienced significant physical side effects of chemotherapy. A possible explanation is that the physical symptoms were severe enough to require the full focus of attention. As one woman explained: “...*It could have been during treatment that it was starting but I just didn't notice as much. When things kind of fall back into routine, that's when you start to notice.*”

In general, the participants in this study revealed that the problem of cognitive change is not often discussed by healthcare providers. In addition, questions of cognitive change are not a standard part of the ongoing assessment in the treatment and post-treatment phases. This finding is supported by other researchers who report that many individuals have no warning of the possibility of cognitive change because it is not generally discussed by the health care providers (Boykoff et al., 2009; Fitch et al., 2008; Myers, 2012; Thielen, 2008). Three of the participants in this study did receive specific written information about cognitive changes following chemotherapy from their healthcare providers. Two of the women were aware of the potential problem from prior knowledge and two were taken off guard by the symptoms. Those who received information during treatment did not place much emphasis on it at the time but found the information helpful when they began to notice symptoms.

Once they understood that their cognitive difficulties were very likely related to their chemotherapy treatment, the women in this study felt a sense of relief. They were also reassured when discovering that the experience of cognitive change is recognized by many scientists and physicians as having a scientific basis. This was a pivotal point for some because prior to that realization, they did not know how to account for their experience. As one woman stated: *“I didn’t have any problem like that before. That’s really when I started to realize all these little things. That’s when I realized that the chemo brain was really true.”*

Although relieved in learning it was real, the participants in this study were distressed when cognitive deficits became apparent in interactions with others. In general, most of the women in the study described how cognitive changes following

chemotherapy were not typically discussed and how the general public has little knowledge of the problem. This was especially problematic as they needed to explain to others the reason for their cognitive difficulties. These situations were described by most as very embarrassing and led to some feelings of inadequacy. Most women were concerned about how their cognitive changes would be interpreted by others. Some worried about what others might think of them, especially how it would influence their first impressions. This finding is not described elsewhere in the literature.

It is important to note that several participants in this study never mentioned their cognitive symptoms to their physicians or nurses. One woman described: *“I never did [report it] because you know I don’t even know what to say about it...I kind of felt it would be minimized. Or there isn’t any treatment for it. So I just didn’t bring it up.”*

Rosedale and Fu (2010) also found that women did not want to bother the physician with continual complaints even though they experienced distress over thinking that nothing could be done to improve their symptoms.

Experiencing Cognitive Changes

The experience of living with cognitive change created many day-to-day struggles. This major theme emerged with several subthemes: Finding the words, problems with memory, paying attention, concentration difficulties, organizing and prioritizing, and fatigue. The literature supports these findings and describes the most frequently reported cognitive changes following chemotherapy as changes in memory, concentration, and executive functioning (Ahles et al., 2003).

Findings of this study add clarity concerning the issue of memory deficits. These findings provide important detailed descriptions of problems with memory following

chemotherapy that differentiate it from memory problems commonly associated with middle-age. One woman explained that this change was new and different from any earlier experience. She explained: *“I know the answer and then it disappears, you know it’s on the tip of your tongue. It doesn’t go to the tip of my tongue it goes away completely and I can’t [find it]. I feel like I’m searching for it and I can’t find it. It’s nowhere...”* All of the women in this study revealed some level of difficulty with word retrieval. This difficulty ranged from not being able to find the words to explain something, not being able to remember names, or feeling like one’s mind is completely blank and the words cannot be found. One woman revealed: *“Whether it’s really true just memory loss...I don’t know. I don’t feel that it’s just memories necessarily. It almost seems to me like it’s more of a retrieval, storage and retrieval problem.”* These findings of difficulty with word retrieval are supported by other qualitative researchers. Myers (2012) found in a study of 18 breast cancer survivors that “word finding” is a common problem even in women with extensive vocabularies (Myers, 2012). In the current study, participants’ descriptions of “finding the words” or “remembering the steps in a familiar activity” shed important light on the unique characteristics of the lived experience. The women in this study were well-educated; consequently, these difficulties were very discouraging to them and led to additional stress.

Difficulties with concentration and the ability to pay attention were reported by all of the participants in this study. Concentration deficits have been widely reported in the literature; however, most of these descriptions resulted from measurements derived from neurocognitive testing (Ahles et al., 2002; Ahles et al., 2003; Castellon et al., 2004). As described earlier, the results of objective measures of cognitive abilities do not often

match the subjective claims of symptoms. Although several qualitative studies have reported concentration difficulties, none have provided the depth of description as the current study. Participants in this study have revealed important detail that may assist in the differentiation of the ability to pay attention versus ability to concentrate.

Women in this study reported difficulty in paying attention and described feelings of mental fatigue. They also reported that paying attention was especially more difficult when there was too much detail presented or if the conversation was too lengthy. The capacity to direct attention has been observed and reported in other studies (Von Ah et al., 2009). Cimprich (1993) explained that directing attention behaviors are also social functioning behaviors that require attentive listening, exercising patience, or delaying when responses are appropriate. This was evident in the current study through women's descriptions of difficulty paying attention and following the conversation in certain social interactions. Additionally, this may have important clinical implications and perhaps contribute to why the majority of the women in this study did not seek to participate in support groups.

For the participants in this study, difficulty in paying attention involved recognition of fragmented thoughts, difficulty refocusing when interrupted, difficulty sitting still, and experiencing wondering thoughts moving from one topic to another. Several women in this study described moments or situations of feeling lost and disoriented during a conversation. One woman described: *"I was very disoriented and I couldn't do that. I would just have to like stop and then re-orient and it was awful. I couldn't do two things at the same time."* These findings are consistent with findings of other investigators who reported individuals appearing to be disoriented, inattentive, and

having difficulty learning new tasks (Louiselle & Rockhill, 2009; Wefel et al., 2004a). One woman described her difficulties in paying attention to the problem of Attention Deficit Disorder. *“Sometimes fidgeting is a way that I’ll pay attention, because (my) brain doesn’t jiggle as much. So sometimes...I will tap my foot in the air or I’ll rub my fingers or just do something that’s unobtrusive but just helps me focus on what’s going on.”* This finding is congruent with reports by other researchers who described similarities between the capacity to direct attention in individuals with chemotherapy related cognitive changes and the clinical features of Adult Attention Deficit Disorder (Simmons, 2009; Staat & Segatore, 2005).

The capacity to direct attention is necessary for cognitive performance such as learning new information, planning, and making decisions. Some researchers reported that deficits in capacity to direct attention were related to poorer quality of life, including more depressive disorders, poorer well-being, poorer physical functioning, and greater fatigue (Von Ah, 2009). Although the participants in the current study reported difficulty in learning new information, and in planning and making decisions, they did not express signs of physical or psychological distress. However, they all experienced fatigue and questioned its influence on their experience of cognitive difficulties. Some described it as mental fatigue that increased to a point in which the body needed to mentally shut down. Others described a change in energy that led to the inability to complete certain activities: *“...when you get that tired then I think it affects your mind because it’s so overwhelming.”* This finding is congruent with reports from other studies that cite fatigue as a possible contributing factor to cognitive impairment following chemotherapy

(Downie et al., 2006; Hess & Insel, 2007). Much is still unknown about how the degree of fatigue relates to the subsequent degree of cognitive impairment (Faletti et al., 2005).

Several women in this study described difficulty sleeping and questioned the relationship of insomnia and lack of sleep to their cognitive difficulties. One participant described: *“You go to bed and you can’t fall asleep and waking up at 4:00 in the morning ... I think that plays a role...and I’m not sure exactly what causes that sleep disturbance...”* The problem of insomnia and subsequent problems of fatigue in relation to cognitive difficulties following chemotherapy have been suggested by others but has not been well studied. Mitchell (2006) found that sleeplessness was a frequently reported side effect of chemotherapy; however, differentiated sleeplessness from fatigue. Mitchell posited that fatigue is different from feeling tired from being overworked in that fatigue could not be relieved by rest or sleep. The current study does not adequately inform this issue but does provide important detail that can frame the questions for future inquiry.

The ability to organize, prioritize, plan, and coordinate activities are components of executive function. In particular, this study revealed that difficulties in organizing and prioritizing were a significant problem associated with cognitive change following chemotherapy. In addition, the sequencing of steps in an activity when combined with changes in memory and concentration, led to tasks taking longer to complete. This finding is supported by Fitch et al. (2008) who reported that the need to be organized in order to accomplish basic tasks which demanded attention to detail were often seen as overwhelming. They concluded that cognitive changes could have significant impact on completing activities related to daily living, work, and leisure.

Interacting Socially

The importance of social interactions varied for the participants in this study. In addition, cognitive difficulties influenced their participation in social activities. For some, cognitive difficulties created fear and lack of confidence in social situations. This was especially problematic for those whose ability to participate in social activities was important for their perceived well-being: “... *Sometimes I get tired sooner with conversations and social outings. So I think that worries me just because I want to keep my friends and my relationships.*” Fitch et al. (2008) reported that social situations were a challenge for some cancer survivors related to their capacity to concentrate on what others were saying. The current study further substantiates this claim. As one woman described: “*I find social things more challenging because it’s that little bit of delay sometimes... I would best describe it as it’s this delay and this being overwhelmed with lots of new information at once.*” This finding is also supported by Myers (2012) who found that breast cancer survivors who reported increased difficulties in processing and learning new information subsequently feared engaging in social interactions and in trying new things. The current study reveals that the difficulty in engaging in social activities is related to what participants described as “*managing the mental noise*” in order to “*follow the conversation.*” As described in the previous section, these directing attention behaviors are essential for social interaction and are described by Cimprich (1993) as part of social functioning behaviors.

The current study found that women sometimes avoided social situations where they would need to draw upon their cognitive abilities. For some this was related to the fear and lack of confidence described above. For others, turning inward was helpful in

their overall emotional healing: *“I don’t have a big social network right now at all...I used to even consider myself much more extraverted and now I’m very much an introvert...to re-energize I have to be alone.”* Boykoff et al. (2009) investigated the impact of cognitive change on social networks and reported similar findings: individuals with chemotherapy-related cognitive changes often did not place themselves in situations where cognition was challenged.

Some participants explained that participation in certain social interactions had changed because of changes in their personal priorities. Changing priorities while undergoing cancer treatment and in the months of healing that followed was apparent: *“... I was invited to a party and after a couple of hours I was ready to go home...You know it’s hard to say exactly what it was just lack of stamina or probably it was just the frivolous things people talk about I just had trouble you know—I can only care about that for so long.”* This example demonstrates the interplay of anticipated cognitive difficulties in certain social situations with fatigue and the overall impact of the cancer experience. Similar concepts are documented in the literature in relation to cancer survivorship in general (Mitchell, 2006; Ness et al., 2013). However, research that specifically addresses this finding in relationship to cognitive change could not be found.

Some of the women in this study experienced reluctance and hesitation to engage in leisure or social activities that were once enjoyable. These findings are supported by earlier research which identified that the experience of cognitive change following chemotherapy in cancer survivors also changed their enjoyment of leisure activities (Fitch et al., 2008). These investigators cited the influence of loss of self-esteem as an important factor in this finding. Although the women in this study did not specifically

speak of their self-esteem, the notion of a perceived decrease in self esteem is evident in the current study by the subjects' selection of words in describing themselves. Some of these include terms such as *bubblehead*, *ditz*, and *scatterbrain*.

Coping

For the participants in this study, finding ways to cope began first with coming to grips with the diagnosis of breast cancer followed by feelings of being emotionally overwhelmed by the experience. The acknowledgement of having cognitive difficulties and the recognition of the effect on their lives led to a variety of strategies to cope with the cognitive changes. This essential theme was closely woven into the broader breast cancer experience. Other subthemes that emerged to explain this experience included facing the challenges, finding support, and strategies to compensate.

Confronting the feeling of being overwhelmed by activities that required mental processes was an unsettling experience for most of the women in this study. For some this led to a sense of emotional vulnerability. Cognitive changes following chemotherapy were predictably unpredictable for the women in this study. This perceived lack of control was unsettling for some. In a study of breast cancer survivors, Barez et al. (2009) investigated how perceived control predicts changes in psychological distress during the first year of cancer diagnosis. These investigators found that psychological distress improved over time as perception of control improved with the strongest predictor being the rate of change in symptoms (Barez et al., 2009). The question of whether cognitive change leads to perceived loss of control has not yet been studied quantitatively and the limited number of qualitative studies published have yet to reveal a clear understanding of this phenomenon.

Several studies of cognitive change following chemotherapy report increased anxiety and depression among individuals with cognitive impairment (Mitchell, 2006; Von Ah et al., 2009). Although the women in this study found that cognitive changes were at times distressing, they all had positive attitudes. None of them currently exhibited signs of anxiety or depression. In fact, several verbalized their efforts in maintaining control of their emotional well-being. When asked whether cognitive difficulties caused anxiety, one woman described: *“I try and change it to being startled because...there’s not much I can do about it. I know for myself that if I get anxious then this feeling of paralysis comes where I don’t know what to do next. So if I try and become more of an observer of the situation...”*

All of the women in this study experienced some physical side effects of treatment or complications from therapy. The physical healing that they endured and their overall fight for survival became an integral part of their stories about coping with cognitive changes. At the time of the interviews, three of the women in this study were still dealing with physical side effects of treatment. They appeared most vulnerable emotionally and were hyper-vigilant and attuned to physical and cognitive changes.

Once the vulnerability was before them to view openly, they were able to carve out a path to coping. Most of the women spoke of a spiritual path to assist them in the journey to healing physically and emotionally. One woman explained: *“So God has a reason for everything...you know I guess it’s better to be happy and have a good attitude and no matter what happens you know God is in control of it, the plan is already made. I might as well choose to be happy and have a good attitude.”* This finding is supported by Schreiber (2011) who found that women who viewed God as highly engaged in their

life situation experienced significantly greater increase in psychological well-being, decreased psychological distress, and decreased concern about disease recurrence.

All of the study participants identified strategies to improve, prevent, manage, or eliminate the stressful situations brought on by their cognitive difficulties. Most identified the necessity and usefulness of writing lists and memory prompts. They described the importance of maintaining detailed calendars and obtaining adequate sleep. Similar examples of specific coping strategies have been described by other researchers (Boykoff et al., 2009; Fitch et al., 2008; Myers, 2012; Thielen, 2008). This study revealed several novel interventions for easing the problems of cognitive deficits that were not previously seen in the current literature. One participant in the current study described using *Facebook* as a comfortable way to socialize. She described that this type of communication was rewarding because “*I don’t feel deficits when I write.*” Another participant discussed exploring a cell phone application with prompts to help her remember appointments.

Looking Forward

Looking forward to what the future may hold begins with the realization that cognitive change could be a long term side effect. Some continued to work through and beyond the treatment phase and to focus on managing the demands of current employment situations; while others began to entertain thoughts of new career options. For the participants in this study, looking forward meant facing challenges and fears head on. Although they were in different stages of physical and emotional recovery, all of the participants were in control of their current health state and faced their futures with positive attitudes.

The women in this study reported concerns about their job performance and the quality of their work. They described strategies to assure that their work was complete and thorough but identified difficulty in doing so. This finding is supported by Boykoff et al. (2009) who reported that cognitive change following chemotherapy can affect job performance related to varying levels of memory loss, decreased efficiency and speed, and increased stress. In the current study, the women who worked full time outside of the home reported greater fatigue and perceived greater overall stress. This is not described in other research findings. However, in a study of breast cancer survivors, Calvio et al. (2010) reported that stress and fatigue were more closely related to work output than cognitive limitations. The Theory of Unpleasant Symptoms presented in Chapter 1 describes the experience of symptom multiplicity and the consequences of symptoms experience on performance. Although the relationships between cognitive changes, stress, and fatigue require further investigation, the current study offers new insights into understanding how adaptation to cognitive changes in the employment setting is achieved.

Two women in the current study reported considering the exploration of new career options in the future. Specifically, they believed that their current jobs required too many structured, cognitive activities. Employment change was also reported in a study by Boykoff et al. (2009). They reported that the change in employment to less demanding work was required due to the experience of treatment related cognitive impairment. In contrast, the participants in this study were motivated to consider new careers due to changes in personal satisfaction.

One participant in the current study did need to terminate her employment due to current inability to fulfill the job functions. Her financial status was stable because she was able to qualify for temporary disability from her former employment. Boykoff et al. (2009) reported that employment change in those with cognitive changes following chemotherapy often led to financial losses. Other reported findings also support the notion that cognitive difficulties may lead to work absences and declines in productivity, job performance, and personal economic concerns (Fitch et al., 2008; Mitchell, 2007).

Most of the women in this study were hopeful that they would get better and several stated that they already perceived some improvement over time. This finding is consistent with other qualitative studies (Boykoff et al., 2009; Myers, 2012; Thielen, 2008). One woman whose deceased grandmother had been diagnosed with Alzheimer's disease had occasional thoughts about the similarities in the cognitive difficulties. She described looking back on her grandmother's behavior: "*... she had it for years before we really truly knew what was going on...Having to go through and clear things out how many notes that she had written to herself to remember things. I sit there and I think, 'Holy cow! Am I headed that way?'*" As described in Chapter 2, some researchers have explored the possibility that individuals who are genetically predisposed to developing Alzheimer's disease might have increased vulnerability of experiencing cognitive impairment following chemotherapy (Ahles et al. 2003). Research to date has not supported this hypothesis; however, the fear among cancer survivors who have also experienced cognitive changes is warranted and requires further investigation.

The Theory of Unpleasant Symptoms

The Theory of Unpleasant Symptoms (TUS) described in Chapter 1 provides a useful framework for understanding the complexity of cognitive change following chemotherapy (Lenz et al., 1997). The TUS conceptualizes symptoms as a subjective experience that can occur in relationship to certain activities or situations. As identified in the literature, cognitive changes following chemotherapy are often reported as a subjective experience despite the findings of objective measures. In addition, the findings of this study elucidate the situations in which cognitive changes following chemotherapy are especially problematic. These included situations in recalling names or remembering the steps in a process or participation in certain social interactions.

The TUS incorporates the important concept of symptom multiplicity which recognizes that symptoms often occur together producing a multiplicative response instead of an additive response. In addition, Lenz et al. (1997) state that experiencing multiple symptoms makes it difficult to differentiate one symptom from another. In some instances, there may be overlapping sensations resulting from multiple symptoms occurring simultaneously. While this generally refers to physical sensations, the current study demonstrates how cognitive changes and fatigue are closely interrelated.

The concept of symptom multiplicity is further demonstrated in this study by the participants' descriptions of mental fatigue and the subsequent perceived worsening of their cognitive difficulties. In addition, a multiplicative effect may be seen in some women who also experience physical side effects following therapy. Furthermore, women in this study who described increased physical fatigue also perceived increased

stress. In one case, the presence of physical symptoms may have delayed the recognition of cognitive changes.

The “quality” of a symptom generally refers to its intensity. In this study, the quality of the symptoms was expressed through the words used to describe the symptom experience. This varied among subjects but as the intensity increased they used similar words and phrases such as “scatterbrain,” “bubblehead,” or “ditz” to describe themselves. In addition, as the intensity of the symptoms increased, women’s overall level of distress also increased. According to the TUS, the level of distress is described as how bothered one is by the symptom and may determine whether one seeks treatment (Lenz et al. 1997). The current study reflected this concept in women’s descriptions of whether or not they reported their cognitive changes to their physicians. This study revealed that even when women were “bothered” by a symptom of cognitive difficulty, their decision to discuss cognitive change with the physician was influenced by their perception of whether that action would be of any benefit to them. Several verbalized that they felt that nothing could be done, so why mention it.

The TUS conceptualizes “influencing factors” as those physiologic or psychological changes that either lead to or affect the experience. As described earlier, the occurrence of physical side effects related to therapy or surgical healing from breast reconstructive surgery influenced the overall experience of chemotherapy-related cognitive changes. In addition, the psychological challenges of having a breast cancer diagnosis and the subsequent treatment challenges that ensued created increased stress and in some cases anxiety. A useful feature of the TUS is the recognition that this is not a linear process but rather consists of a feedback system where influencing factors may

contribute to the occurrence of the symptom but also may be a consequence of the symptom.

Social interaction, employment, marital and family support are described in the TUS as “situational factors” that influence the symptom experience. The findings of this study demonstrate the important interaction of these factors in one’s ability to cope effectively with cognitive changes following chemotherapy. An interesting finding is that employment which is often viewed as a positive supportive circumstance can also create additional stress. This is especially true when performance is below one’s previous standard or when additional energy is needed to maintain the same standard of performance.

The TUS conceptualizes cognitive ability as a “performance” outcome of the symptom experience rather than a symptom in and of itself. However, the theory has practical application if one isolates each specific cognitive deficit as a separate symptom rather than looking at cognitive change as a whole. In other words, the “symptoms” of cognitive change may include the following: memory loss, difficulty concentrating and directing attention, and difficulty with the elements of executive functioning such as organizing and prioritizing activities; whereas, cognitive ability is the output or consequence of the total experience.

In summary, the current study demonstrates that the TUS offers a logical framework in which to understand the experience of cognitive change following chemotherapy. The TUS helps to explain the dynamic nature of this experience including how cognitive change is impacted by the presence of other symptoms and how cognitive change is influenced by situational factors. Through the description of a nonlinear

feedback system, the TUS helps to explain how cognitive changes influence the performance of daily activities and impact the fulfillment of family, employment, and professional responsibilities.

Strengths of the Research Study

The hermeneutic phenomenological method employed in this study provides a unique analysis of the lived experience of cognitive change following chemotherapy not yet revealed. Thielen (2008) conducted a phenomenological study of the neurocognitive changes in women following chemotherapy for breast cancer using descriptive methods. Myers (2012) conducted a study of chemotherapy-related cognitive impairment in women with breast cancer using a qualitative, descriptive design. The interpretive phenomenological methods used in this study provided identification of essential themes and analyzed those findings against the lifeworld existentials common to all of life experiences. Using the lifeworld existentials as a means for reflection on the essential themes provides a richer and deeper understanding of the phenomenon in practical terms.

The purposive sample ensured that all of the participants in the study had cognitive changes following treatment with chemotherapy. Meeting with several staff members in the Penn State Cancer Center was helpful in assisting to recruitment women for this study. The staff included physicians, registered nurses, and medical assistants. Two oncologists provided patients with the study flyer during an office visit. Registered nurses in the Breast Center provided information to women and obtained their permission for me to contact them to discuss the study. In addition, the study protocol was revised to include a "Research Information" form (Appendix B) that the medical assistants handed

to patients during follow-up visits. This was an effective way to provide information in-hand that women could complete if interested in hearing more about the study.

Rigor in the phenomenological methods employed added strength to this study. This method incorporated two in-depth interviews done one month apart. The interview was semi-structured and allowed for a conversational tone. At the completion of the first interview, the subjects selected a pocket size journal from several styles and colors. They used these journals to capture ideas, thoughts, and examples of their experiences with cognitive difficulties. Also, between interviews a thank you note and a gift card were sent to the participants. By the second interview, the participants and I had developed a trusting relationship. The second interview began with a conversational tone and discussion of the journal and the situations that occurred in the last month. There were two participants who did not complete the journal. They did not explain why and I did not pursue the issue. In these two cases, I moved the conversation beyond the journal expectation to stating: "Well, tell me about what has happened during the past month." This interview style allowed the participants to freely express their feelings in a truthful manner. Of interest was the ability of the subjects to self-correct the narrative. When I provided a reflective statement, the women in this study would self-correct by explaining their situation in a different and often deeper description.

Conducting two interviews with each subject was very effective in this study and provided deeper and richer descriptions. Unlike other phenomena, cognitive change was not a past problem; rather, it was a continuing and evolving experience. Therefore, the time between interviews, along with journaling, enabled the participants to reflect on their experiences and to interpret those experiences. The second interview became a

hermeneutic conversation between the subject and researcher that included describing and interpreting the phenomenon.

The process of transcript analysis was rigorous. This process included open coding, collapsed coding, reading, re-reading, writing and re-writing until the essential and incidental themes emerged. In addition, three faculty members with expertise in qualitative analysis reviewed interview transcripts and through group discussion provided insights that led to renaming major themes and collapsing subthemes. van Manen (1990) described collaborative discussions and hermeneutic conversations as providing “deeper insights and understandings (p. 100).

Implications for Nursing Practice and Education

It is important for nurses to understand that cognitive change following chemotherapy is experienced by some individuals who receive chemotherapy. Knowledge of the common symptoms of cognitive change is critical in order to provide patient and family counseling and education. As revealed in this study, when patients are not aware of this possible side effect the symptoms can catch them off guard and lead to significant anxiety and fear. Efforts to increase nurses’ awareness and understanding of chemotherapy-related cognitive change are evident in recent publications and educational activities of the Oncology Nursing Society (ONS). The third edition of the ONS “Chemotherapy and Biotherapy Guidelines and Recommendations for Practice,” used as the standard curriculum for teaching nurses internationally, includes a detailed section on cancer treatment-related cognitive changes (Skinner, 2009). The majority of this information includes a summary of studies that focus on understanding the exact mechanisms that lead to cognitive changes. There is no information on how individuals

experience these changes and little on interventions for coping with these changes. Findings of this study will contribute to this body of information. It is necessary for nurses to understand these findings so that they can effectively prepare patients for this possible side effect of chemotherapy.

In a descriptive pilot study, Myers and Teel (2009) found oncology nurses were generally aware that cognitive impairment can be associated with chemotherapy. Yet only 38 percent of participants assessed patients for cognitive changes and 44 percent provided education to patients and families on the topic. The nurses in the same study did perceive changes in cognition could cause distress in patients and may result in a negative impact on activities of daily living (Myers & Teel, 2009). This finding suggests that some nurses do understand the impact of the problem of cognitive change. Therefore, next steps should include the implementation of standardized assessments and consistent methods of teaching patients about cognitive changes following chemotherapy.

There are several critical times in the treatment phase when assessment and education are important. At the first treatment appointment, all individuals would benefit from receiving written materials about chemotherapy side effects. Although the physical side effects of chemotherapy are most likely to occur in the immediate post-treatment phase, patients should be made aware of possible changes in memory and concentration. At each subsequent treatment visit, usually three to four weeks apart, each patient should be assessed for cognitive changes and provided written information. Finally, since cognitive changes may persist for 12 months and beyond, assessment for perceived cognitive changes should be a part of every follow-up visit.

The women in this study revealed that receiving the information in person was important. This was also described by Myers (2012) who found that breast cancer survivors described wanting someone who could spend time with them in an unrushed atmosphere. In the same study, one page hand-outs that did not use medical jargon were the most desired type of written material requested. As revealed in the current study, receiving information in writing was important. A few of the women in this study described reading the printed information initially and then coming back to it after noticing some cognitive changes. Educational materials should also contain examples of interventions that may be helpful for coping with the everyday challenges of cognitive changes.

Limitations of the Research Study

It would be helpful to understand how cognitive change following chemotherapy is experienced by women from different cultural and socio-economic backgrounds. The participants in this phenomenological study were recruited from two locations in central Pennsylvania. All were Caucasian American and had some post-secondary education. Three of the women held advanced degrees. In addition, the sample did not include any women from the ages of 21 to 40. It would be helpful to know how younger women experience and cope with cognitive changes following chemotherapy. Some younger women may experience an early menopause related to treatment but it would be interesting to know if their experience is different from that of women who are already peri-menopausal at the time of treatment.

Although it is not a limitation, it is important to note that phenomenology differs from other methods of research in that phenomenology does not seek to generalize

findings. Rather, phenomenology seeks to reveal the shared essences of an experience. However, of major importance to the strength of a phenomenological text is the achievement of data saturation. In this study, saturation was achieved in that there was redundancy in the descriptions of cognitive changes and in the descriptions of basic strategies used to compensate for the cognitive deficits. However, redundancy was not achieved for all of the subthemes that were identified. Additional subjects are needed in order to understand the following: (a) where younger women find support, (b) the impact of spirituality on coping, and (c) how cognitive changes impact career decisions.

A procedural challenge presented itself early in the study. The original plan was to recruit potential subjects from breast cancer support groups. The first subject was recruited from a support group; however, future contacts did not yield potential participants. With IRB approval, I contacted coordinators of several breast cancer support groups in central Pennsylvania and attended two additional support group meetings to discuss the study and to provide written study information. Expanding the number of support groups did not yield anymore participants for the study. The most effective method for recruiting subjects came from maintaining a continual presence in the outpatient Cancer Institute. When I made daily visits to the outpatient clinic, my presence served as a continual reminder to the nurses and physicians about the study.

Recommendations for Future Research

Ongoing research related to cognitive changes following chemotherapy is needed. The “Oncology Nursing Society 2009-2013 Research Agenda” calls for studies in cognitive function as a research priority. Specifically, it is recommended that future research related to changes in cognitive function should focus on the description of long

term effects, identification of sensitive measures, physiologic mechanisms underlying cognitive changes, and the development and testing of interventions.

Longitudinal studies to determine the long term effects of cognitive abilities is mentioned above but as this study reveals there is question among the participants of whether cognitive difficulties improve over time or if individuals become better at adapting to them. Longitudinal studies that explore the concept of improvement versus adaptation would be helpful in understanding the long term effects.

Most of what has been studied about cognitive change following chemotherapy has focused on middle-aged and older adults. Research on the experience of cognitive changes following chemotherapy in younger adults is needed. This group of individuals is typically active in all aspects of their personal and professional lives. Therefore, studies of this age group are needed to identify gaps in the availability of appropriate interventions and useful support services. Additionally, studies of younger women are needed to reveal whether the experience of cognitive change is different when treatment with chemotherapy occurs at different ages: young adult (21-39), middle aged (40-60), and older adults (60 and older).

To date, we do not yet have adequate instruments for assessing chemotherapy-related cognitive change. The Perception of Cognition Questionnaire (PCQ) developed by Galantino (2006) to measure the perception of cognition is described in Chapter 2. Further research utilizing the PCQ would be useful in measuring changes of perception of cognitive difficulties overtime as they relate to quality of life. In addition, studies that explore the impact of fatigue on the perception of cognitive difficulties and subsequent coping abilities would also be useful.

The development and testing of interventions should focus on tailored interventions that include cognitive training to improve targeted cognitive domains such as memory and attention (Von Ah, Jansen, Allen, Schiavone, & Wulff, 2011). In addition, interventions that focus on complementary methods are important. Avisar et al. (2012) described the potential benefits of complementary interventions to improve chemotherapy-related cognitive change. Modalities that have not been tested include mind-body techniques, acupuncture, nutrition, and herbal therapies.

Cimprich and Ronis (2003) tested the natural environment intervention aimed at restoring attention in a larger sample that included 157 women with a breast cancer diagnosis in the pre and postoperative period prior to any further cancer treatment. The study demonstrated that the natural restorative environment improves attentional problems in women with breast cancer. These findings may help to guide attention-restoring interventions in a variety of patient populations. The potential benefit to breast cancer patients experiencing cognitive difficulties following chemotherapy is unclear but worth further exploration.

Further research related to employment challenges among cancer survivors who experience cognitive changes following chemotherapy is warranted. Studies are needed to better understand the relationship between cognitive change, job performance, and stress. In addition, studies that identify predictors of job performance difficulties in individuals with cognitive changes may facilitate appropriate supportive action such as application for temporary employment disability compensation.

Cognitive changes have been studied mostly in women with breast cancer; therefore, studying other cancer populations could provide important information.

Cognitive complaints and impairment in men with testicular cancer have been studied by Schagen et al. (2008). In addition, chemotherapy-induced cognitive impairment in men and women with colorectal cancer has been studied by Galica et al. (2012). Further research in both of these groups plus those with lymphomas would also be helpful. All of these malignancies can occur in young and middle age adults where the impact on family and professional roles may lead to psychological distress and financial losses.

Conclusions

Cognitive change is a significant side effect of chemotherapy reported in a subset of patients. In general, cognitive change following chemotherapy is a multidimensional phenomenon that begins with the patient's perception of change in cognitive abilities (Kanaskie, 2012). For some these changes occur early in treatment, for others the changes do not become evident until after treatment has been completed. The purpose of this study was to uncover the meaning of cognitive change in women with breast cancer, how symptoms are experienced and become evident, how it impacts roles in personal and professional lives, and how women cope with these changes.

Most of the studies of cognitive change following chemotherapy have explored causal relationships related to physiologic responses to drug, dose, and time since treatment. Among these studies, breast cancer survivors are the group most frequently studied. Unfortunately, research is limited that has explored the lived experience of chemotherapy-related cognitive change in breast cancer survivors. A few qualitative studies of cognitive change following chemotherapy have been conducted using descriptive analytical methods. In contrast, this study incorporated an interpretive phenomenological approach. This method incorporates the analysis of the lifeworld

existentials which provided data to answer the question of the impact of cognitive change on all aspects of the participants' lives. Through this analytical approach, detailed information emerged about the experience that may inform the development of appropriate assessment tools and patient education. In addition, the hermeneutic interviewing approach used in this study revealed the unique aspects of cognitive change as experienced by the individuals which illuminates the importance of exploring tailored interventions in the cancer population.

The findings of this study provide clarity related to how cognitive changes are experienced, the impact of these changes on social interactions, and how women cope with these changes in relation to everyday activities. This research study also sheds new light on the impact of cognitive change on professional roles and responsibilities. In particular, this study reveals the struggles and stressors that women endure in attempting to adapt to employment demands. This study also contributes new knowledge to inform the development of interventions to help women adapt to living with cognitive changes.

As this study progressed, it became evident that the experience of cognitive change following chemotherapy cannot be understood as an isolated phenomenon. Rather, it is best understood in the context of the total cancer experience. As survival increases with new cancer therapies, oncology healthcare providers need to become more knowledgeable about the potential for cognitive changes in some individuals following chemotherapy. In addition, the development of sensitive assessment tools and tailored interventions will be important for identifying those at greatest risk and for providing adequate support to improve the quality of life for all cancer survivors.

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APPENDIX A

Study Announcement

CANCER RESEARCH

Breast cancer patients...

.. have you received chemotherapy to treat your cancer?

A Penn State School of Nursing doctoral student is interested in the experience of cognitive changes following chemotherapy in women. These may include memory loss, decreased ability to concentrate, or difficulty multitasking. Volunteers are needed for this study.

Who may participate?

- Women with breast cancer between the ages 21-60 who have completed chemotherapy within the past 12 months and are concerned about changes in memory and difficulties with concentrating or paying attention.

What do volunteers do?

- Two 60-minute interviews
- Keep a journal

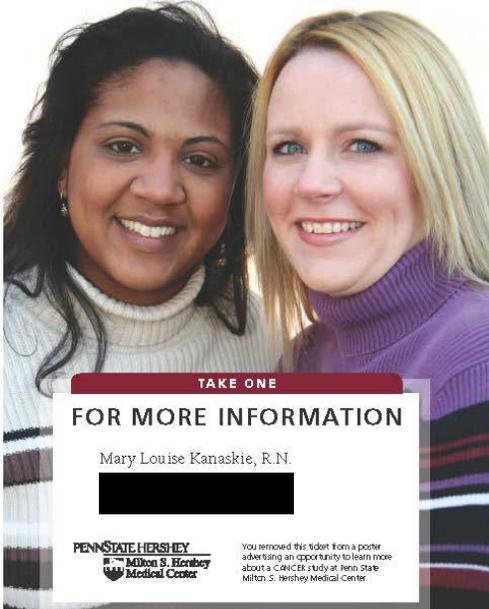
Compensation is provided in the form of a Sheetz gift card.

Call: [REDACTED]
Study director: Mary Louise Kanaskie, R.N.

PENNSTATE HERSCHEY
Milton S. Hershey
Medical Center

Good People. Great Medicine.™
PennStateHershey.org

This research study has been approved by the Institutional Review Board, under federal regulations at Penn State Hershey Medical Center, Penn State College of Medicine.



TAKE ONE

FOR MORE INFORMATION

Mary Louise Kanaskie, R.N.
[REDACTED]

PENNSTATE HERSCHEY
Milton S. Hershey
Medical Center

You removed this ticket from a poster advertising an opportunity to learn more about a CANCER study at Penn State Milton S. Hershey Medical Center.

U.S. MED 12-4791 RES | IRB 375/07 (02/12/11)

Pull by 01/01/2012

APPENDIX B

Research Information Sheet

Penn State College of Medicine
The Milton S. Hershey Medical Center

This information sheet is about a research study currently being conducted that includes women who have completed chemotherapy treatment for breast cancer and are experiencing trouble with memory, concentration, focusing attention and multitasking. The research is being done to find out what it is like to live with these changes on a daily basis.

Title of Project:

The Experience of Cognitive Change in Women with Breast Cancer following Chemotherapy

Principal Investigator: Mary Louise Kanaskie, PhD(c), RN

This research involves participation in 2 audio-taped interviews each lasting about 1 hour. It also includes writing your thoughts in a personal journal that is provided to you. The interviews will be in-person in a location that is quiet and private. Your home is an acceptable location. A private room in the Medical Center would also be an acceptable location. The second interview will take place one month from the first interview. It is during that time that you will be asked to record in the personal journal.

If you would like to know more about this study, please provide your contact information below and the researcher will call you directly.

COMPLETE THIS SECTION ONLY IF YOU WOULD LIKE THE RESEARCHER TO CONTACT YOU TO DISCUSS THE RESEARCH STUDY.

Name: _____

Address: _____

Phone Number: _____

Best times to call: _____

APPENDIX C Informed Consent Form

IRB Protocol No. 37567EP
Version Date: October 17, 2011

CONSENT FOR RESEARCH
Penn State College of Medicine
The Milton S. Hershey Medical Center

<small>HSPO USE ONLY DO NOT REMOVE OR MODIFY This form is not valid unless this box includes an expiration date.</small>
IRB Approval Expires After 09-30-2012
Penn State College of Medicine Institutional Review Board

Title of Project: The experience of cognitive change in women with breast cancer following chemotherapy

Principal Investigator: Mary Louise Kanaskie, PhD(c), RN

Other Investigators: Susan J. Loeb, PhD, RN

Telephone Numbers: Weekdays: 8:00 a.m. to 5:00 p.m. [REDACTED]

Participant's Printed Name: _____

We are asking you to be in a research study.

You do not have to be in the research study. If you agree to be in the research study, you can quit at any time.

This form gives you information about this research study. Please ask questions about anything that is unclear to you.

Please take your time to make your choice.

1. Why is this research study being done?

We are asking you to be in this research because you have completed chemotherapy treatment for breast cancer within the past 12 months and have reported having cognitive difficulties. Cognitive difficulties sometimes include trouble with memory, concentration, focusing attention, and multitasking.

This research is being done to find out what it is like to live with these changes on a daily basis. Approximately 10 women will take part in this research study from the Hershey area.

2. What will happen in this research study?

This research involves participation in 2 audio-taped interviews each lasting about 1 hour. It also includes writing your thoughts in a personal journal. The interviews will be in-person

in a location that is quiet and private. Your home is an acceptable location. A private room in the Medical Center would also be an acceptable location.

The research procedures include:

Month 1

1. Completing a short form on demographics (your age, sex, occupation, etc...). This will be completed at the first interview visit.
2. Interview 1 – A 1 hour audio-taped, in-person.
3. Writing or drawing in a personal journal over the next month between interviews. The journal (notebook) will be provided for you at the first interview.
4. Phone call – two weeks following the first interview, a phone call will be made to ask you if the journal entries have been helpful and to schedule the date and location for the second interview.

Month 2

1. Interview 2 – A 1 hour audio-taped, in-person.
2. Bring your journal to second interview to present to the interviewer. The journal can be returned to you following the study.

Month 4 - 6 – follow-up

1. The researcher will send you a brief summary of the study findings.
2. The researcher will phone you and ask for your opinion on how well the summary describes the experience and what, if anything, is missing.

3. What are the risks and possible discomforts from being in this research study?

The risks of participating in this research are low. However, it is possible that you may feel sad and emotionally upset in discussing your experiences. There is a risk of loss of confidentiality if medical information or your identity are obtained by someone other than the investigators, but precautions will be taken to prevent this from happening.

4. What are the possible benefits from being in this research study?

4a. What are the possible benefits to me?

There is no guarantee that you will benefit from this research. However, the opportunity to talk with someone about these difficulties may be comforting to some people.

4b. What are the possible benefits to others?

This research will add to knowledge about cognitive changes following chemotherapy that can help nurses and physicians to learn about the kinds of questions we should ask on patient visits. The results of this study may guide future treatment by helping in the development of patient education materials and interventions that will help women to cope with these changes.

5. What other options are available instead of being in this research study?

You may choose not to be in this research study.

6. How long will I take part in this research study?

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If you agree, you will be in the research study for 2 months. About 4 to 6 months later you will be sent the study findings to read, followed by 1 phone call to give your opinion on whether the findings fully describe the experience.

7. How will you protect my privacy and confidentiality if I decide to take part in this research study?

7a. What are the measures taken to protect my privacy and confidentiality?

In our research files at The Penn State School of Nursing we will include these identifiers: your name, address, phone number, age, email address and a code number.

- A list that matches your name with your code number will be kept in a locked file in Mary Lou Kanaskie's office at the Hershey Medical Center.
- All recordings will be stored in Mary Lou Kanaskie's password-protected computer in her locked office at the Hershey Medical Center.
- Audio-recordings will identify you by code number only.
- The recordings will be labeled by date and a numeric code. Coded subject identifiers will be used on all typed transcripts.
- The recordings will be erased by Mary Lou Kanaskie three years following the completion of the study.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

7b. How will my identifiable health information be used?

This section is about health information that can be traced to you.

- If you give your consent, health information that can be traced to you will be collected for this research study. If you do not want us to use your health information, you should not be in this research.
- Health information is protected by law as explained in the HMC Privacy Notice. If you have not received this notice, please request a copy from the researcher.
- At HMC/PSU your information will only be used or shared as explained in this consent form or when required by law.

Your permission for the use, storage, and sharing of your health information will continue for the period of time necessary for the preparation of a related follow-up research study activities. At that time information identifying you will be removed from such research results at HMC.

If you say yes at this time but change your mind later you can tell us to stop using and sharing health information that can be traced to you. You must do this in writing. Write to inform Mary Louise Kanaskie that you are withdrawing from the research study. Her mailing address is [REDACTED] Hershey, PA [REDACTED]

If you change your mind and tell us to stop using your information:

- We will stop the use of any health information about you for this research study.
- We cannot take back anything we have already done or any information we have already shared.

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- We may continue using and sharing your information that we already have if it is necessary for safety and scientific soundness of the research study.

The following people/groups within HMC/PSU may use your health information and share it with these groups for this research study.

- The principal investigator, Mary Louise Kanaskie
- The HMC/PSU Institutional Review Board
- The HMC/PSU Human Subjects Protection Office
- The HMC/PSU Research Quality Assurance Office
- PSU Faculty research advisors on dissertation committee.

The above people/groups may share your health information with the following people/groups outside HMC/PSU for this research study.

- The Office for Human Research Protections in the U. S. Department of Health and Human Services
- Interview transcriptionist appointed to this study.

These groups may also review and/or copy your original PSU/HMC records while looking at the results of the research study. It is possible that some of the other people/groups who receive your health information may not be required by Federal privacy laws to protect your information.

8. What are the costs of taking part in this research study?

8a. What will I have to pay for if I take part in this research study?

There are no costs to you for participating in this research other than possible travel to an agreeable location for the interviews. Meeting at your home is a possible location. The personal journal (notebook) will be provided at no cost to you.

9. Will I be paid to take part in this research study?

You will receive a \$10 gift card for your participation in this research study following each interview.

10. Who is paying for this research study?

The investigator is receiving a grant from The Nursing Foundation of Pennsylvania to support this research.

11. What are my rights if I take part in this research study?

Taking part in this research study is voluntary.

- If you choose to take part in this research, your major responsibilities will include 2 interviews, keeping a personal journal for 1 month between interviews, and a follow-up review of the study findings and 1 follow-up phone call.
- You do not have to be in this research.
- If you choose to be in this research, you have the right to stop at any time.

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- If you decide not to be in this research or if you decide to stop at a later date, there will be no penalty or loss of benefits to which you are entitled.

12. If I have questions or concerns about this research study, whom should I call?

Please call the head of the research study (principal investigator), Mary Louise Kanaskie at [REDACTED] if you:

- Have questions, complaints or concerns about the research.
- Believe you may have been harmed by being in the research study.

You may also contact the research protection advocate in the HMC Human Subjects Protection Office (HSPO) at [REDACTED] if you:

- Have questions regarding your rights as a person in a research study.
- Have concerns or general questions about the research.
- You may also call this number if you cannot reach the research team or wish to talk to someone else about any concerns related to the research.

You may visit the HSPO's web site at <http://pennstatehershey.org/irb> under participant information for:

- Information about your rights when you are in a research study;
- Information about the Institutional Review Board (IRB), a group of people who review the research to protect your rights; and
- Links to the federal regulations and information about the protection of people who are in research studies. If you do not have access to the internet, copies of these federal regulations are available by calling the HSPO at [REDACTED]

Signature and Consent/Permission to be in the Research

Before making the decision about being in this research you should have:

- Discussed this research study with an investigator,
- Read the information in this form, and
- Had the opportunity to ask any questions you may have.

Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.

Participant: By signing this consent form, you indicate that you voluntarily choose to be in this research.

Signature of Participant Date Time Printed Name

IRB Protocol No. 37567EP
Version Date: October 17, 2011

Person Explaining the Research: Your signature below means that you have explained the research to the participant and have answered any questions she has about the research.

Signature of person who
Explained the research

Date

Time

Printed Name

APPENDIX D
Demographic Questions

The Experience of Cognitive Change in Women with Breast Cancer
following Chemotherapy

The following demographic questions will be asked at the beginning of the first interview session:

Age _____

Marital status: _____ (single, married, divorced, separated)

Highest level of education achieved: _____ (HS, AD, BS, other advanced degree, other)

Number of members in household: _____

Occupation: _____

Are you currently employed outside the home? _____

Number of hours worked per week _____

Chemotherapy:

of cycles of chemotherapy completed _____ # of months of treatment _____

Chemotherapy drugs (if known):

Do you take any hormonal agents as part of your treatment?

Appendix E

Interview Guide

Opening Question

This broad open-ended question will be used to open the interview by focusing the participant on her experience of living with breast cancer and treatment side effects. The participant will not be interrupted as she tells her story.

Tell me about what you've lived with since your breast cancer treatment began.

Prompts

After the participant exhausts her response to this opening question, she will be prompted by the following questions:

Tell me about a time when you had difficulty with memory?

- How would you describe this experience?
- How did you know what was happening?
- How did you feel?

Tell me about a time when you had difficulty with concentration?

- How would you describe this experience?
- How did you know what was happening?
- How did you feel?

Tell me about a time when you had difficulty with thinking clearly?

- How would you describe this experience?
- How did you know what was happening?
- How did you feel?

Tell me about a time when you had difficulty with making decisions?

- How would you describe this experience?
- How did you know what was happening?
- How did you feel?

What has been the impact on your personal life (with family or friends)?

What has been the impact on your job (professional commitments and responsibilities)?

To what extent do you worry about these changes?

How have you coped with these changes?

APPENDIX F
IRB APPROVAL LETTERS

Scientific Review Committee – Penn State Cancer Institute
Penn State Hershey Medical Center IRB Approval Letter
Penn State Hershey Medical Center IRB Study Modification Approval Letter



Scientific Review Committee
Penn State Hershey Cancer Institute
Mail Code CH56



Scientific Review Committee Notice of Review

Memo Date: October 
Elliot M Epner, MD, PhD Chair

Protocol ID: PSHCI 11-091 The Experience of Cognitive Change in Women
with Breast Cancer Following Chemotherapy (IIT)

Principal Investigator: Mary Louise Kanaskie (HMC)

The above referenced study recently underwent review at a convened meeting of the Scientific Review Committee and is **APPROVED** to proceed to IRB submission, if applicable.

NOTE: Monitoring not required
Meeting Date September 27, 2011
Accrual Target: 10 participants over 6 months



Date: October 20, 2011

To: Mary Louise Kanaskie, Ph.D., RN, Nursing

From: Patricia L. Gordon, M.D., Executive Chair
Institutional Review Board

Subject: IRB Protocol No. 37567EP - The Experience of Cognitive Change in Women with Breast Cancer following Chemotherapy

Thank you for your application to the Institutional Review Board (IRB). The above IRB protocol number was assigned for the research and should be included on all future correspondence and documentation. In accordance with Federal guidelines and institutional policy, the proposed research was determined to qualify for expedited review and was reviewed accordingly.

Official approval: Official approval was granted for this research effective October 19, 2011 through September 30, 2012, at which time IRB reconsideration will be required. This approval includes the following:

- Research Protocol - Protocol summary (dated 10/18/2011)
- Total entry - 20 subjects. This research may not involve prisoners. If an individual becomes incarcerated after enrollment contact the IRB to address specific regulatory requirements in order to continue participation.
- Informed Consent - Consent form (version date 10/17/2011). **Use of IRB stamped consent forms is required.**
- Authorization to use protected health information (PHI) - Included in consent form.
- Advertisement – Recruitment Flyer (dated 9/12/2011); Letter to Professionals (PRAMS received date 10/05/2011)
- Questionnaires – Demographic Questions (version date 10/06/2011); Screening Questions (version date 10/06/2011); Interview Guide (version date 10/06/2011)
- Other – Phone Screen Script) version date 10/07/2011)
- IRB member exclusions from this review: No investigators for this research serve on the IRB.

Informed consent and Authorization: Only approved investigators may solicit consent for research participation. Subjects or their representatives must receive a copy of the consent form.

- Medical record - For clinical treatment protocols, include a copy of the consent form and the protocol summary in the patient's HMC medical record to inform other medical caregivers about this research.
- Originals – Original signed consent forms/authorizations should be filed in a secure place and retained after the research terminates for a period of 6 years if the research



October 20, 2011
IRB Protocol No. 37567EP

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accesses protected health information (PHI), or 3 years if no PHI is accessed. Longer retention periods and other requirements may apply for FDA or sponsored research.

Clinical Trials Registration: Not required

Required Reports and Modification Requests: See instructions on the IRB web site, <http://pennstatehershey.org/web/irb>, under Investigator Resources, to submit reports for this research or requests for modifications.

- **Problem Reporting:** Investigators are required to promptly report any events that may represent unanticipated problems involving risks to subjects or others. See the web for the IRB policy "Reporting of Unanticipated Problems Involving Risk to Participants or Others" and the applicable report form and tracking log.
- **Proposing Changes:** Federal regulations require prompt reporting to the IRB of any proposed changes in a research activity and prior approval before changes are initiated, except where necessary to eliminate apparent immediate hazards to the subject. Submit a request for a 'Modification' if changes are needed in the existing investigation.
- **Continuing Review:** A progress report will be required for reapproval of this research. You will receive an e-mail notice and instructions 8 weeks before the current approval expires.

The Institutional Review Board appreciates your efforts to conduct research in compliance with the institutional policies and federal regulations that have been established to ensure the protection of human subjects. Please feel free to communicate any future questions or concerns regarding this research to the IRB via its administrative arm, the Human Subjects Protection Office.

PG\kl



Date: Monday, July 2, 2012
To: Mary Louise Kanaskie, R.N.
From: Daniel J. McBride, Ph.D. [REDACTED]
Human Subjects Protection Office
Subject: Protocol: 37567EP: The Experience of Cognitive Change in Women with Breast Cancer following Chemotherapy

The Human Subjects Protection Office (HSPO) received your June 19, 2012 correspondence with the accompanying documentation regarding the above investigation.

In accordance with Federal guidelines and institutional policy, this issue qualified for review by a designated Institutional Review Board member.

The request to use the submitted Research Information Sheet (version date June 13, 2012) as part of your recruitment plan and a revised Protocol Summary Abstract (version date June 19, 2012) received expedited review and approval was granted on July 02, 2012.

If you have any questions, please contact me by telephone (ext. [REDACTED]) or email [REDACTED]

DJM



VITA
Mary Louise Kanaskie, PhD, RN, AOCN®

EDUCATION

The Pennsylvania State University
1977 Bachelor of Science in Nursing
1990 Master of Science in Nursing – Adult Health
2013 PhD – Nursing

PROFESSIONAL LICENSURE AND CERTIFICATION

Registered Nurse, Pennsylvania RN222491L, March 21, 1978 to present
Advanced Oncology Nursing Certified – Oncology Nursing Certification Corporation

PROFESSIONAL NURSING EXPERIENCE

Hershey Medical Center, Hershey, PA
Clinical Nurse Educator – April 1991-present
Staff Development Instructor – April 1980-April 1991
Staff Nurse – January 1978 to April 1980
The Pennsylvania State University, Hershey, PA
Instructor of Nursing (part time) – 1992-1994

AWARDS and HONORS

The Janet A. Williamson Graduate Award in Nursing, The Pennsylvania State University, 2011-2012
The Pauline Thompson Clinical Nursing Research Award, Nursing Foundation of Pennsylvania, 2011
Oncology Nursing Foundation - Doctoral Scholarship, 2011
Oncology Nursing Society - Excellence in Cancer Nursing Education Award, 2007.
Pennsylvania Nightingale Award Finalist in Nursing Education, 2003.

PUBLICATIONS

Kanaskie, M. L., & Tringali, C. (2008). Promoting quality of life for geriatric oncology patients in acute care and critical care settings. *Critical Care Nursing Quarterly* 31 (1), 2-11.
Kanaskie, M. L. (2011). Incorporating cafe design principles with end-of-life discussions: An innovative method for continuing education. *The Journal of Continuing Education in Nursing*, 42, 166-171.
Tringali, C., & **Kanaskie, M. L.** (2012). Measuring the impact of an educational program to teach nurses an evidence-based approach to oral mucositis. *Journal for Nurses in Staff Development*, 28, E1-4.
Kanaskie, M. L. (2012). Chemotherapy-related cognitive change: A principle based concept analysis. *Oncology Nursing Forum*. 39, E263-E26.