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The Relationship Between Cancer-Related Fatigue and Upper Extremity Function in Breast Cancer Survivors

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THE RELATIONSHIP BETWEEN CANCER-RELATED FATIGUE AND UPPER

EXTREMITY FUNCTION IN BREAST CANCER SURVIVORS

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Life is not about waiting for the storm to pass, it is about learning to dance in the rain.
~Anonymous

To John

Je t'adore plus qu'hier moins que demain.

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ABSTRACT

THE RELATIONSHIP BETWEEN CANCER-RELATED FATIGUE AND UPPER
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Background: Cancer-related fatigue (CRF) and arm morbidity constitute the two most common symptom complexes impacting breast cancer survivors (BCS) following surgery and adjuvant treatment, but these multifaceted entities have traditionally been researched as if they were separately occurring events in the survivor's recovery.

Objective: This study examined the relationship between breast cancer survivors' perceptions of CRF and upper extremity function one to six years post-diagnosis. The study further investigated the impact of multiple adjuvant therapies, node dissection procedures, caring for dependent children, and physical aspects of employment on CRF and upper extremity function.

Methods: One hundred fifty-eight BCS responded to an exploratory internet-based cross-sectional demographic survey, the FACIT-F and the DASH. Descriptive statistics, correlation and simple linear regression were used for data analysis.

Results: An analysis revealed a moderate statistically significant relationship between CRF and upper extremity function, $r = -.661$, $p < .001$, such that BCS with higher levels of fatigue also exhibited higher levels of arm morbidity. In addition, 22.3% reported persistent fatigue symptoms, consistent with the criteria for a diagnosis of CRF, with

45.5% of the fatigued subset also reporting significant limitations in upper body function. BCS demonstrated significantly higher levels of fatigue when compared to prior research on a nationally representative sample of adults (p = .037). Women who were caregivers of at least one dependent child demonstrated higher levels of fatigue than women without dependent children (p = 0.38). The BCS reported high levels of function overall indicating that many survivors are functioning well in the years that follow treatment, however a subset of women reported persistent problems that interfere with daily function and participation, and the overall sample was more fatigued than the general population.

Conclusions: The results from this exploratory study document preliminary evidence that a relationship exists between CRF and upper extremity morbidity. It also adds support for persistent fatigue in a subset of BCS long after surgery and adjuvant therapies conclude. Further research is indicated in order to meet the long term survivorship needs of this growing population.

CHAPTER I

Introduction

Survivorship

Increased longevity for many individuals diagnosed with cancer has served to refocus the research community and government agencies on the phase of the cancer trajectory that begins after acute medical interventions conclude. Survivorship, even when measured well beyond the calculated five-year survival rates, may be accompanied by a myriad of physical, psychosocial and economic consequences of living with the late effects of the disease process and treatment modalities (NCI, 2006; Hausman, Ganz, Sellers, & Rosenquist, 2011). A national panel, convened to study issues of survivorship, concluded that survivorship research and intervention is a priority for all cancer patients in order to enhance quality of life for this growing population (Centers for Disease Control [CDC], 2005). The results of this CDC study signify a paradigm shift in cancer care that envisions and defines the long-term post-intervention needs of cancer survivors as a chronic disease state that must be monitored longitudinally, rather than viewed as an acute medical condition (2005). Survivorship can thus be conceptualized as a distinct stage in the continuum of the life experience of the person living with cancer, one that requires an equivalent amount of attention as afforded the acute management experience (NCCN, 2006). Defining the breadth and scope of the problem, understanding key symptomatology, better identification and follow-up of at-risk individuals, and the development of targeted interventions are therefore indicated for this population.

Zebrack (2000) defined cancer survivorship as "the state or process of living after a diagnosis of cancer, regardless of how long the person lives" (p. 239). Family and friends of diagnosed individuals are also included within the definition of survivorship due to the impact of cancer on roles and socialization (National Cancer Institute [NCI], 2006). The term survivor is accepted by most national cancer organizations and governmental agencies, although some individuals with a cancer diagnosis object to the use of this label (Twombly, 2004; Jennings, 2010). A unified concept of survivorship has yet to be established rendering attempts to develop survivorship theories to support clinical practice and research agendas more difficult (Doyle, 2008). The term BCS (Breast Cancer Survivor) will be used throughout this document for consistency and readership ease to refer to women living with breast cancer, unless individuals living with other forms of cancer are discussed.

Definitions of Survivor and Survivorship

National Cancer Institute (n.d., para. 1)

> "In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience."

National Coalition for Cancer Survivorship (n.d., para. 2 – 3)

> "The term survivorship, as defined by the founders of NCCS, is the experience of living with, through and beyond a diagnosis of cancer. The founders of NCCS also extended the term survivor to apply to an individual's friends and caregivers."

American Cancer Society (2012)

"The American Cancer Society believes that each individual has the right to define his or her own experience with cancer and considers a cancer survivor to be anyone who defines himself or herself this way, from the time of diagnosis throughout the balance of his or her life."

In the United States, 2010 prevalence statistics for persons living with a history of cancer or a cancer diagnosis with treatment are estimated at 13.8 million persons (Centers for Disease Control, 2011; Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). If current trends prevail, the estimated population of cancer survivors will rise to 18.1 million by 2020 (Mariotto et al., 2011). Female breast cancer survivors comprise the largest segment of this growing population, estimated at 22% of all cancer diagnoses (NCI, 2011). According to the National Cancer Institute (2010) one in eight American women will be diagnosed with breast cancer during her lifetime. The prevalence estimate for breast cancer survivors in the United States is 2.6 million women with over 200,000 women diagnosed annually (NCI, 2010; Howlader et al., 2010). Further expansion of this population is anticipated as 5 and 10 year survival rates continue to improve (NCI, 2010). Earlier detection has resulted in more positive five-year survival outcomes for Caucasian BCS (91%); African-American BCS still have a disturbingly lower percentage of survival for the same time period than other ethnic or racial groups (79%) (NCI SEER Statfact, 2011).

Background of the Problem

A robust body of literature suggests that select cancer-related sequelae may not resolve after surgical and adjuvant therapy interventions conclude, subtly or overtly impeding functional capacity in everyday activities as well as negatively impacting

quality of life (Sadler et al., 2002; Portenoy & Itri, 1999; Vogelzang et al., 1997). A recent qualitative study exploring BCS survivorship needs found that there was not a clearly defined path or consistent quality of care to help women address post-treatment transitional needs, including residual symptoms (Roundtree, Giordano, Price, & Suarez-Almazor, 2010).

As the information that follows will clarify, the most common and noteworthy of these potentially prolonged symptom complexes for breast cancer survivors are cancer-related fatigue (CRF) and upper extremity morbidity.

Cancer-Related Fatigue

Cancer-related fatigue (CRF) has been long-recognized as a side effect during adjuvant cancer therapies or potentially due to the cancer disease process itself (Piper & Cella, 2010; Portenoy & Itri, 1999). There is evidence to indicate that fatigue symptoms resolve following intervention for many survivors, but studies repeatedly identify a subset of BCS for whom CRF will become a chronic fatigue condition creating difficulties completing daily tasks, employment responsibilities and socialization (Stone, Richardson, Ream, Smith, Kerr, & Kearney, 2000; Servaes, Verhagen, S., & Bleijenberg, 2002). CRF has also been identified as one of the most likely causes of decreases in perceived quality of life (CDC, 2005; National Institutes of Health State-of-the-Science Panel, 2003; Curt, Breitbart, Cella, Groopman, Horning, Itri et al., 2000; Andrykowski, Curan, & Lightner, 1998; Broeckel, Jacobson, Horton, Balducci, & Lyman, 1998). This fatigue complex can persist for years or decades after treatment concludes, despite achievement of remission or disease-free status (Bower et al., 2006; Servaes, Verhagen, S., & Bleijenberg, 2002; Andrykowski, Curan, & Lightner, 1998).

Estimates from NCI (2011) and the National Institutes of Health [NIH] State-of-the-Science Panel (2003) place the prevalence rate of fatigue in individuals with all forms of cancer at 14 – 96% of the total cancer population. Other research findings report prevalence rates from diagnosis through the varying phases of intervention as high as 100% (Ream & Richardson, 1999). Inconsistencies may be due to differences in study designs, fatigue measurement tool selection, defining cancer fatigue terminology, and the heterogeneous nature of the fatigue experience for each survivor. Despite these disparities in consensus, it is widely agreed that CRF is the most commonly experienced symptom of patients across the cancer trajectory which negatively impacts the lives of survivors.

CRF is a complex multi-dimensional symptom construct that comprises a distinct entity from acute complaints of fatigue or exhaustion experienced by busy adults due to high daily task demands, over-exertion, or stress-related daily events (Stasi, Abriani, Beccaglia, Terzoli, & Amadori, 2003; Wu & McSweeney, 2001). CRF is not resolvable by a temporary reduction in daily activities or rest and is more closely aligned with the quality of fatigue experienced by individuals with chronic fatigue syndrome (Young & White, 2006). The National Comprehensive Cancer Network [NCCN] defines CRF as a "distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (2012, p. FT-1).

Although the exact etiology is as yet unknown, contributing factors to CRF include experiences of pain, side effects of chemotherapy and radiation, anemia, metabolic disorders, immune function disturbances, sleep dysfunction, inactivity,

medication use, psychological distress and additional disease comorbidities (Mortimer, Barsevick, Bennett, Berger, Cleeland, DeVader, & Escalante et al., 2010; Portenoy & Itri, 1999; Yellen, Cella, Webster, Blendowski, & Kaplan, 1997). One recent study examining the role of several biomarkers suggested that elevated C-Reactive Protein levels, as one measurement of underlying inflammatory cell activity, may have a potential contributory role in CRF (Alexander, Minton, Andrews, & Stone, 2009). Depression, frequently correlated with fatigue symptoms in mental health diagnosis, has been implicated as a co-morbid factor in CRF, but there are conflicting research study results as to whether depression exists as a pre-existing psychiatric comorbidity or results from living with a chronic fatigue-based condition (Bower et al., 2006; Sadler et al., 2002; Broeckel et al., 1998). The sheer scope of these factors presents difficulties when designing and interpreting fatigue study outcomes. Mortimer et al. (2010) identified the conundrum faced by researchers since a clearly articulated conceptual framework and definition of CRF must currently be defined by each study's parameters, further limiting comparisons and generalizability.

Instrumentation design and choice to measure the variability and extent of the fatigue experience remains elusive owing to the multidimensional nature of this construct. CRF, as it is experienced during different stages of cancer treatment and its aftermath, cannot necessarily be measured by a single assessment tool or assumed to be a static state. Similar to accepted beliefs regarding the assessment of pain, the assessment of fatigue is acknowledged to be a subjective experience with the National Institutes of Health State of the Science Panel (2003) stating that reporting of fatigue symptoms are "best assessed by the patient" (p. 1111), identified as a self-perceived

state (NCI, 2011). Patient self-perception is increasingly recognized in research and medical outcomes studies as a viable indicator of quality of life. In one longitudinal study, self-ratings of fatigue by breast cancer patients were found to be predictive of risk of cancer recurrence (Groenvald, Peterson, Idlen, Bjoourner, Fayers et al., 2007).

Numerous fatigue questionnaires have been developed and researched to establish psychometric properties with multiple instruments receiving support from researchers and clinicians. However, there has been no consensus as to which of the fatigue assessment tools currently available constitutes the gold standard for fatigue assessment (National Institutes of Health State of the Science Panel, 2003). Brief, single-item CRF assessment tools have been found to be advantageous for use in clinical settings where time is often at a premium, but these tools are often limited to unidimensional aspects of fatigue, such as daily fatigue level or disturbance in daily routines (Butt, Wagner, Beaumond, Paice, Peterman, & Shevrin et al., 2008; Schwartz, Meek, Nail, Linquist, & Donofrio et al., 2002). Lengthier, more cumbersome multi-dimensional tools provide the breadth of knowledge of the extent of the fatigue experience, but can be time consuming for the respondent and therefore are often relegated to research studies and not in general use in clinical settings (Schwartz & Meek et al., 2002). More than 25 CRF tools were identified by an expert panel with no single tool emerging as the standard for this construct, although the NCCN committee recently charged with this task developed a consensus-based screening tool for clinical use (Mortimer et al., 2010). The new tool, focused on contributory influences, activity levels and exercise, does not include questions about the impact of fatigue on daily functional performance in the spheres of self-care, home and community activities or

employment, outcomes of significant importance to cancer survivors. It is derived from expert opinion and not from quantitative outcomes from randomized controlled trials.

Attempts to define the CRF construct in recent years resulted in a compilation of clinical findings by fatigue experts for a proposed diagnostic category for CRF in the International Classification of Disease, 10th edition, Clinical Modification (ICD-10 CM) (Sadler et al., 2002; Portenoy & Itri, 1999). The goal of the criteria was to provide clinicians with a defined symptom list to assist in identification of patients experiencing CRF. The proposed criteria have been used in research studies to validate the symptom list and determine prevalence rates (Young & White, 2006). Post-intervention cancer fatigue prevalence estimates are reduced to 17-25% of the survivor population when the proposed ICD-10 criteria for CRF are applied (Gerber et al., 2010; Young & White, 2006; Sadler et al., 2002; Cella, Davis, Breitbart & Curt, 2001). Conservative estimates, using the proposed ICD-10 CM criteria for inclusion, therefore approximates the severely fatigued BCS population at 391,000 – 483,000 women living in the United States. However, recent actions by the NCCN committee charged with developing national recommendations identified CRF as a "subjective changing experience not a diagnosis" (Mortimer, 2010, p.1132). Formal implementation of the ICD-10-CM is not expected until October 2013; however a code description, R530, Neoplastic (Malignant) Related Fatigue, has been identified (CDC, 2011).

Early studies on fatigue assessment and management primarily targeted individuals undergoing cancer treatment (Passik, Kirsh, Donaghy, Holtsclaw, & Theobald, et al., 2002; Curt et al., 2000). Late onset fatigue was less likely to be identified and addressed by health care professionals after cancer treatment concludes

(Curt et al., 2000; Carlson et al., 2004, Stone et al., 2003). Failure to identify and address CRF is a complex problem for patients who may be reluctant to request assistance with a symptom that appears to be an expected consequence of the cancer experience (Passik et al., 2002), one that patients believe has no solution (Vogelzang et al., 1997), or one that is identified as a commonly experienced symptom in the general adult population (Cella, Lai, Chang, Peterman, & Slavin, 2002). Physicians may fail to assess or document fatigue, underestimate the impact of it on daily function, provide limited advice on fatigue management, prescribe rest as a solution or offer no intervention advice at all (Gerber, Stout, McGarvey, Soballe, Shieh, & Diao et al., 2010; Vogelzang et al., 1997). While physical sequelae such as hematopoiesis during or following treatment is more easily identified and treated by oncology teams, prolonged variable fatigue symptoms with an unclear etiology may not be as clearly targeted. The result is that individuals living with CRF may not be referred for supportive care to other health professionals, such as occupational and physical therapists, who might be able to address residual symptoms and ameliorate the impact on function and role performance (Watson & Mock, 2004; Taylor & Currow, 2003; Galantino, Capito, Kane, Ottey, & Switzer et al., 2003).

Barriers to effective management of fatigue in patients with cancer "include a lack of awareness that fatigue is the most prevalent symptom, a lack of knowledge about the causes of fatigue among physicians and patients, and a lack of proven methods to treat fatigue" (National Institutes of Health State-of-the-Science Panel, 2003, p.1113). Other impediments to fatigue management include a dearth of evidence-informed interventions offered to patients experiencing CRF by health professionals, as well as

patients lacking the knowledge that possible solutions exist (Passik et al., 2002; Wu & McSweeney, 2001).

One population with a demonstrated need for ongoing CRF evaluation and intervention is women with breast cancer, BCS in remission or those who have achieved disease-free states, who still experience fatigue on a daily or weekly basis. The Agency for Healthcare Research and Quality (Carr et al., 2002) documented prevalence rates in post-treatment breast cancer survivors that ranged from 35 – 56%. Fatigue has a documented significant effect on reported quality of life and functional ability in women with breast cancer (Servaes, Verhagen, C., & Bleijenberg, 2002b; Curt et al, 2000; Stone, Richardson, Ream, Smith, Kerr, & Kearney, 2000). A subset of BCS experience ongoing fatigue that persists much later in the treatment process (Yates et al., 2005) and can continue for years or decades after treatment concludes (Andrykowski et al., 1998). BCS who are considered free from disease may also experience CRF symptoms that interfere with daily life tasks and employment (Stone et al., 2003; Curt et al., 2000; Andrykowski et al., 1998).

In one study, BCS reported fatigue frequency at one year post-diagnosis equivalent to that of newly diagnosed women (Vogelzang et al., 1997). A study of disease-free BCS found that women classified by fatigue measures as severely fatigued or non-severely fatigued experienced greater impairment in the ability to manage and complete daily activities than a control group without breast cancer (Servaes, Verhagen, C., & Bleijenberg, 2002b). Research on this topic has addressed population identification, prevalence, and assessment of CRF, but concerted efforts to develop and research interventions for prolonged fatigue in cancer survivors remain limited. This is a

critical area for continued study that acknowledges the persistent nature of the fatigue experience and the impact on BCS and their families.

Those studies with documented interventions for the management of treatment-related or prolonged post-treatment fatigue (Yates et al., 2005; Stanton et al., 2005; Barsevick, Dudley, Beck, Sweeney, Whitmer, & Nail, 2004; Holley & Borger, 2001; Grant, Golant, Rivera, Dean, & Benjamin, 2000; Mustian et al., 2004; Galantino, Capito, Kane, Ottey, Switzer, & Packel, 2003) have generally not incorporated an approach to assess the impact of fatigue on functional performance of daily life tasks, although many address quality of life. Only one study was identified that used an established measure of occupational performance for activities of daily living (ADLs) (Mallinson, Cella, Cashy, & Holzner, 2006). Less frequent follow-up visits for BCS once they enter the extended survivorship phase create barriers for women with prolonged CRF unless clinicians mount a concerted effort directed toward identification and monitoring of this symptom.

Upper Extremity Function

A separate body of research suggests that upper extremity deficits and altered sensory experiences following cancer surgery and treatment produce additional side effects that may also persist following the conclusion of surgical and adjuvant therapies for breast cancer. Differences in treatment options for type and stage of breast cancer, location of tumors, individual preferences regarding treatment and clinical expertise figure strongly into the physician-patient decision making process. Those decisions and the underlying disease processes and other patient factors can potentiate or alleviate development of upper extremity sequelae.

The literature offers insights into the impact of breast cancer surgery and adjuvant therapies on upper extremity physical function (Hayes, Battistutta, & Newman, 2005; Collins, Nash, Round, & Newman, 2004; Reitman, Dijkstra, Debreczeni, Geertzen, & Robinson, 2004). Upper extremities are the 'tools' that permit dynamic interaction with the environment, performing the majority of functions that promote participation and fulfillment of life roles. The consequences of reduced arm function can impair the ability of survivors to independently perform and complete desired activities including self-care tasks requiring reaching, household tasks necessitating increased demands for upper body strength, employment tasks and community activities (Reitman et al., 2003; Collins et al., 2004).

The unique contributions of factors instrumental to the development of extremity symptoms following breast cancer surgery or intervention are multifaceted. The majority of the research conducted has focused primarily on lymphedema prevalence, assessment and intervention rather than the functional implications of those physical factors. Lymphedema is defined as the "swelling that occurs when protein-rich lymph fluid accumulates in the interstitial tissue" (NCI, 2011). In BCS, lymphedema, identified as a potentially distressing side effect may limit arm function, diminish participation in life spheres and alter body image (Reinertsen et al., 2010; Hack et al., 2010; Hayes, Rye, Battistutta, DiSipio, & Newman, 2010). It is one of the most dreaded side effects of breast cancer, negatively impacting the ability of the survivor to fulfill life roles and maintain occupational performance (Collins et al., 2004), potentially altering or disfiguring physical appearance, and limiting full use of the affected extremity.

Generally accepted incidence figures for lymphedema indicate that 15 - 30% of BCS will develop lymphedema at some point following surgery and treatment (Hayes et al., 2008; Petrek & Heelan, 1998), with an estimated 120,000 – 600,000 BCS experiencing this complication (Soran et al., 2006). A recent cross-sectional national study in Denmark was conducted surveyed the entire BCS population (N = 3253, 85%), 13 – 41 months post surgery, in a country with standardized health care and defined adjuvant and surgical protocols (Gärtner, Jensen, Kronborg, Ewertz, Kehlet, & Kroman, 2010). Depending upon surgical and treatment modality, the authors reported a self-perceived lymphedema prevalence rate of 13 – 65% with 11 – 44% of BCS also reporting decreased occupational performance after treatment, particularly for employment (Gärtner et al., 2010, p. 511).

In a longitudinal multi-center study with complete data on 296 subjects, persistent edema was noted in 32% of BCS within 3 years following surgery with three times the risk for developing arm edema noted with every additional lymph node that was dissected (Paskett, Naughton, McCoy, Case & Abbot, 2007). Fifty percent of women reporting upper extremity edema identified diminished abilities to complete household chores (Reitman et al., 2003) with 69% of BCS reporting decreases in the ability to complete activities of daily living due to edema (Oliveri et al., 2008). Hayes, Battistutta, Parker, Hirst, & Newman (2005) reported the highest task burden was noted when "carrying a moderate weight, washing the upper part of the back, opening a tight jar, and doing up a bra" (p. 257). A subsequent study by Hayes et al. (2008) indicated that some women confuse typical short-term upper extremity and breast side effects of radiation with lymphedema, noting that self-perceived symptoms may overestimate the

population. It is also possible that women may perceive slight increases in limb swelling before mechanical measurements can detect this changes. Several validated measurement options are available to measure limb edema including circumferential tape measurements, volumetric water displacement, bioelectrical impedance analysis and self-report (Johannson & Branje, 2010; Norman, et al., 2009; Hayes, Janda, Cornish, Battistutta, & Newman, 2008).

The advent of sentinel node biopsy has overtaken axillary node biopsy as the prevailing standard of care and is the most commonly performed procedure for initial surgical node removal and staging (McGuire et al, 2009), altering the landscape for BCS and researchers. This trend developed following more than a decade of literature suggesting that a significant relationship exists between the number of lymph nodes removed during axillary node dissection and the development of subsequent arm morbidity and sequelae such as lymphedema (Hack et al., 2010). Breast conserving surgery with follow-up radiotherapy, chemotherapy, and hormonal therapy or combination therapies has accelerated the acceptance of this method of node removal (McGuire et al., 2009). However, women with positive sentinel nodes on biopsy may require additional axillary node removal to obtain an accurate diagnosis and differentiate treatment choices. Therefore node removal remains a great source of concern for women with breast cancer and for those involved in survivorship care.

Extensive axillary node dissection and radiation to the axilla and chest wall have been strongly implicated as causal agents resulting in the development of post-surgical extremity symptoms such as lymphedema (Rietman et al., 2006; Tsai et al., 2009). One study contradicted those findings implicating chemotherapy as causative (Paskett et al.,

2007). Mastectomies can produce more arm limitations and potential lymphedema than breast-conserving therapy, such as lumpectomies. A meta-analysis of 98 lymphedema studies found that women followed for three years or less who underwent mastectomy demonstrated the most significant correlations for lymphedema and women who underwent radiation therapy and axillary dissection were at the highest risk of the development of lymphedema (Tsai et al., 2009). Recent evidence suggests that mastectomy rates have risen at major cancer centers after several years of diminishing percentages of women who underwent this more extensive surgery (McGuire et al., 2009; Katipamula et al., 2009). Factors accounting for this unexpected rise include an increase in contralateral prophylactic mastectomies as genetic testing provides women with significant breast cancer risk factors options to prevent the development of breast cancer, decisions by some women to request more extensive surgery to avoid or decrease the use of radiation or chemotherapy, and younger women hoping to avoid recurrence (McGuire et al., 2009; Katipamula et al., 2009). The impact on the prevalence of lymphedema as a result of this trend is unknown.

While arguably the most serious and visually distressing problem, swelling from lymphedema is not the only extremity side effect that may result from breast cancer surgery or treatment (Fu & Rosedale, 2009). Surgical procedures, type of node biopsy and notably radiation therapy may also be accompanied by other upper extremity sequelae including muscle weakness, numbness, pain, paresthesias, loss of shoulder range of motion, strength, tightening of scar tissue, and decreased hand strength and function (Fu & Rosedale, 2009; Kärki, Simonen, Mälkiä, & Selfe, 2005; Stariano & Ragland, 1996). Pain in the upper extremity has been reported to negatively impact arm

function, decrease task performance, participation and quality of life (Oliveri et al., 2008; Dawes, Meterissian, Goldberg & Mayo, 2008). Pain has also been linked to higher levels of disability (Dawes et al., 2008).

As the magnitude of the survivor population increases in the United States, the imperative to clarify and address upper extremity functional deficits expands as well. Interest in assessing and promoting long-term quality of life for individuals across the cancer care continuum must include special attention to education and management of the prolonged or delayed onset of arm symptoms in survivors that interfere with daily life.

Purpose of the Study

This descriptive, exploratory cross-sectional study was designed to examine perceived upper extremity functional status and cancer-related fatigue in breast cancer survivors who have achieved remission or disease-free status one ($\geq$ 12 months) to six years ($\leq$ 72 months) after the conclusion of surgical and adjuvant therapies. Perceived upper extremity functional status and cancer-related fatigue were further explored by examining participant differences in node dissection status, adjuvant therapies received and dependent caregiver responsibilities.

Research Questions

Four questions were guided by the literature for this study.

1. Is there a relationship between self-reported cancer-related fatigue and perceived upper extremity functional deficits in breast cancer survivors?

2. Is there a difference in perceived upper extremity function and fatigue between survivors who underwent sentinel node dissection and those who underwent axillary node dissection?

3. Is there is a difference in perceived upper extremity function and fatigue between survivors who underwent differing types of adjuvant cancer therapies, including chemotherapy, radiation, or combination therapies?

4. Is there a difference in perceived upper extremity function and fatigue between survivors who have dependent caregiver responsibilities and those without dependent caregiver responsibilities?

Pilot Study

A pilot study (n = 42) was conducted in early 2011 to determine the feasibility of the snowball recruitment methodology and to assess the ease of completion of the researcher designed demographic survey and standardized questionnaires.

Conceptual and Theoretical Framework

The capacity to fulfill life roles and participate in the everyday activities that create meaning and identity in our lives is part of the experience of adulthood. Adults can be described as "occupational beings…a person who is fully engaged in the world of activity – work, play, leisure - who is productive and feels a sense of self-worth" (Clark, Ennevor, & Richardson, 1996, p.374). This ability to engage in desired occupations has been shown to have a positive impact on health and well-being (World Health Organization, 2001, Clark, Ennevor, & Richardson, 1996). Occupations are meaningful activities that individuals choose to engage in. The term 'occupation' is not restricted to activities tied to employment but is defined as "daily activities that reflect cultural values, provide structure to living, and meaning to individuals; these activities meet human needs for self-care, enjoyment, and participation in society" (Crepeau et al., 2003, p. 1031).

Adults form perceptions of their identities through participation in these meaningful activities, acquiring skills and achieving completion of desired and required

tasks that are woven throughout the life narrative. Furthermore, the ability to complete daily occupations and routines creates opportunities for goal attainment and add meaning to our daily existence. Christiansen (1999) described successful goal achievement as resulting in feelings of efficacy and influence over the environment. Any illness or disability that disrupts the continuity of performance of these common activities can threaten beliefs about competence and therefore impact identity (Christiansen, 1999).

Frank (1995) refers to this disruption as a loss of the "destination and map" that previously helped the person navigate through difficult periods in life. People who believe that they can successfully manage disruptive life challenges are better able to cope with the stressors that accompany life-threatening illness. Yet, Frank acknowledges that current health care practices do not sufficiently prepare the person to live in the world after biomedical intervention for the disease process has concluded (1995). Even occupational therapists, skilled in addressing compensatory and adaptive strategies for specific impairments in life skills, have not sufficiently "focused on assisting survivors of disability to handle the social environment with which they inevitably collide after hospitalization" (Clark, 1999, p. 388).

Theoretical models. Theories of cancer survivorship are not well established since basic conceptual models and definitions for shared terminology are still evolving (Doyle, 2008). Recent efforts have centered on clinical applications, such as the development of survivorship care plans to manage the period of time post-treatment when survivors lose consistent contact with the oncology team (Hausman, Ganz, Sellers, & Rosenquist, 2011). Planning in advance for the acute to post-treatment

progression may facilitate the survivor's transition to community-based resources (Hausman, et al., 2011). To adequately address survivorship needs posed by this burgeoning population requires a multipronged approach that includes attention and accessibility to medical, psychosocial, financial, employment and health care system resources.

The biopsychosocial model (BPS) and International Classification of Function (ICF) were chosen as the framework for this project since the implementation of best practice using this holistic model and international taxonomy includes person and environmental factors leading to enhanced participation in daily life. Conjointly, it is not possible to discuss the post-treatment experience without reference to the staged survivorship model, "Seasons of Survivorship", developed by Dr. Fitzhugh Mullan (1985), framing his own cancer experience as a physician and cancer patient. Mullan (1985) aptly described the inadequacies of available services:

> "It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and sputter on their own in the belief that we have done all that we can (p. 273)."

His model was later reframed by Miller, Merry, and Miller (2008) to better reflect a quarter of a century of survivorship research, including awareness of the heterogeneity and increasing diversity of the lives of cancer survivors, many of whom are living well beyond the five year longevity benchmark defined in governmental surveillance databases. It is increasingly clear that these stages or phases of the cancer experience can extend for decades beyond acute medical management, further

supporting the paradigm shift from a biomedical, reductionistic model to one in which quality of life and resumption and continuation of life activities move to the forefront. These underlying frameworks will be discussed more fully in this section.

Biopsychosocial Model (BPS) and the International Classification of Function (ICF). The biopsychosocial model (BPS) was conceptualized by George Engel in a seminal 1977 article arguing for the need to create a holistic framework that would account for the patients' perceptions of their illness experience, and psychological, social and biological factors encountered within the dynamics of the healthcare system. He hoped that an integrated model would provide guidance to practitioners and researchers and shift the paradigm away from the inherent mind-body dualism of the biomedical model (Engel, 1977). BPS was also conceptualized as an alternative holistic model to drive occupational therapy practice, focusing on the complex factors required to enhance participation in the community (Mosey, 1974). "Occupational therapy practitioners recognize that health is supported and maintained when clients are able to engage in occupations and activities that allow desired or needed participation in home, school, workplace, and community life (American Occupational Therapy Association [AOTA], 2008, p.629). A review of BPS model twenty-five years after Engel's publication reaffirmed the need to honor the subjective illness experience in clinical practice and research (Borrel-Carrió, Suchman, & Epstein, 2004).

The World Health Organization (WHO) used the BPS model as the foundational theory during construction of the ICF, stating that "In order to capture the integration of the various perspective of functioning, a 'biopsychosocial approach is used" (WHO,

2001, p.20). The use of this theory fostered an integrated perspective on the biological, psychological, social, environmental and individual perceptions of health-related quality of life (HRQOL) (WHO, 2001). These alterations represented a substantial shift from the early disablement model of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980-1993) to one that identified health, personal and contextual factors as integral to function and participation.

The ICF (WHO, 2001) is in actuality a taxonomy as opposed to a theory or practice model, providing an international language and systematic classification to facilitate communication about global health, participation and environment. The ICF domains describe body functions (e.g., underlying physiologic systems), structures (e.g., anatomical, cellular, neurochemical), activities (all daily tasks and occupations across the lifespan) and participation (e.g., engagement in occupation with attention to physical, social, and environmental factors, and economic barriers) (WHO, 2001). The structure identifies participation as involvement in a variety of life spheres, including learning and applying knowledge, general tasks and demands (handling responsibilities, stress and other psychological demands), communication, mobility, self-care, domestic life (acquisition of needed daily resources, household management, caring for personal and other household objects, and caregiving), interpersonal interactions and relationships, major life areas (work and school), and community, social, and civic life (recreation and leisure activities, spirituality and religious participation, and politics) (WHO, 2002). Research studies have documented "the positive influence on health and well-being" (Law, 2002, p.641) that participation in these desired and meaningful occupations provide.

Documenting the positive impact of the development of the ICF model on interventions, Üstün, Chatterji, Kostansjek, & Bickenbach (2003) opined that the biological view was only one facet of the ICF, demonstrating a more comprehensive view of the individual and environmental factors influencing health and disability. Recently Huber, Sillick and Skarakis-Doyle (2010) suggested that while the ICF clearly references the internalized subjective experience articulated in the BPS model, these concerns are subsumed under contextual factors and may not be easily identified when viewing the actual design. Seaburn (2005) countered, proposing that it is not the design or model that is problematic but the adoption and application of the biopsychosocial approach within the current health care system. Nevertheless, researchers are increasingly using the ICF framework and adding health-related quality of life (HRQOL) measures to studies (Allan, Campbell, Buptill, Stephenson, & Campbell, 2006; Dixon, Johnston, McQueen, & Court-Brown, 2008). There is enhanced recognition that the gestalt of the person's life experience is central to understanding the trajectory though the illness process. Assessment of life roles, psychoemotional responses and function in self-care, instrumental activities of daily living, productivity, and social interactions offer rich insights that enhance patient care (Ryff & Singer, 2000). Addressing these areas, particularly psychoemotional functioning, is helpful for individuals with chronic diseases where cure is not the clear objective (Ryff & Singer, 2000). van Dijk (2000) described quality of life "as degree of goodness of daily living" (p. 104), envisioned as the meaningfulness of the transaction between the person and life contexts in which activities take place. Well-being incorporates role performance, productivity and daily function (Ryff & Singer, 2000). Internalized perceptions of capacity and quality of

performance compose the individual's understanding of their HRQOL (Huber et al., 2010). The focus on the subjective lived experience of cancer is an essential component of HRQOL, and serves as the core of conceptual models of survivorship.

Stages of survivorship. Some survivors experience cure following completion of all medical interventions, others live with partial or complete remission, encounter recurrence, or will continue with ongoing treatment to address maintenance needs or secondary complications from the cancer. Additionally, psychological, cognitive, or physical sequelae may persist. Fears of recurrence may resurface across the survivor's lifespan at critical junctures for medical tests or follow-up visits. The lived experience of survivors, noted through personal identification of subjective well-being, focuses on completion of daily activities that are meaningful or desirable.

Mullan (1985), additionally cited in a CDC document on cancer survivorship (2005), described a three-stage model of acute, extended and permanent events that support the identification of changes in daily occupations based on patient experiences of cancer. The acute stage encompasses the initial diagnostic process (Mullan, 1985; CDC, 2005, p.3). During the extended stage, described as a hypervigilant state which begins when treatment is completed or remission occurs; the individual begins to consider the potential for recurrence, and realizes that there are still residual daily symptoms that must be addressed (Mullan, 1985; CDC, 2005, p.3 - 4). The permanent stage occurs when the medical status of the cancer is deemed to be very stable, but the survivor is still facing sequelae of cancer treatment including persistent symptoms and socioeconomic concerns (Mullan, 1985; CDC, 2005, p.4).

This oft cited model was later reframed by Miller et al. (2008) to better reflect the increasing diversity of cancer survivors, many of whom are living well beyond the five year benchmark. The definition of the acute survivorship stage remained unchanged from Mullan's original conceptualization. Transitional survivorship was added to correspond to the time when either "watchful waiting" or maintenance therapies may be present, but the survivor and family are readjusting to the consequences of the cancer experience (Miller et al., 2008, p.372). Extended survivorship, described by Mullan (1985) and augmented by Miller et al. (2008), highlights the ambivalent psychoemotional responses and heterogeneity of the post-treatment experience, whereby some individuals may be in remission while others continue ongoing maintenance treatment with potential side effects. Life for those individuals vacillates between "'regular life' and 'the ups and downs' of living with cancer and its treatment" (Miller et al., 2008, p.372). Expansion of the permanent survivorship stage, also viewed as a heterogeneous experience, was divided into "individuals who are cancer free and free of cancer"; those who are "cancer free, but not free of cancer" (Miller et al., 2008, p. 372); those with "secondary cancers" resulting from adjuvant therapies; and those with new "second cancers" whose lives revert to the acute survivorship phase (p. 373). The expanded stages offer further direction to researchers seeking to explore the diverse and variable lived experiences of cancer survivors.

For the purpose of this study, individuals participating in the study were conceptualized as falling into the permanent survival stage – specifically "cancer-free and free of cancer" or "cancer free but not free of cancer" (Miller et al., 2008, p. 372),

focusing on women who had concluded all adjuvant therapies and surgery a minimum of one year prior to completing the survey.

Survivorship and Breast Cancer

Prolonged symptoms, such as cancer-related fatigue and upper extremity morbidity, resulting from the cancer experience are noteworthy due to the disruption they cause to typically predictable daily routines and occupations. These symptom complexes profoundly impact the ability of BCS to continue desired occupations, especially targeting instrumental activities of daily living (IADLs), work, leisure, and socialization. It is noteworthy that basic self-care or activities of daily living (ADLs) are not typically identified in the literature as problematic for BCS, except for those with significant lymphedema (Fu & Rosedale, 2009). IADLs are defined as "essential self-maintenance activities which are necessary for independent living that are not considered basic ADL, or self-care tasks" (Christiansen & Baum, 2004, p.598). These include activities such as home maintenance, shopping, meal preparation, caregiving, communication device use, financial management, health management and maintenance, and community mobility (Christiansen & Matuska, 2004). Difficulties in these more complex daily activities have been reported in cancer survivors with physical comorbidities, such as fatigue and pain, resulting from the cancer and subsequent interventions (Miller et al., 2008).

For the majority of BCS, symptoms resolve after treatment and adjuvant therapies such as surgery, cytotoxic chemotherapy, radiation, or a combination of modalities concludes. However, a proportion of this population will be impacted by prolonged, persistent symptoms that may continue for years or even decades after the

cessation of treatment, impairing participation in life-performance arenas for those individuals. Previously learned coping strategies may be ineffective when confronting a variable condition such as CRF or arm morbidity and may leave the survivor unable to resolve encountered occupational dilemmas.

The changeable nature of fatigue alters the ability to be an active participant in all of the life spheres described by the ICF, disrupting daily routines and life roles that functioning adults take for granted. A systematic review documenting qualitative comments gleaned from 26 cancer fatigue studies concluded that the severity of the impact of fatigue on daily task performance was far more damaging to survivors than the actual physical feelings of fatigue (Scott, Lasch, Barsevick, & Piault-Louis, 2011).

Therefore, CRF that interferes with daily performance constitutes a disability that negatively impacts participation in occupations. Law (2002) stated that the presence of such a disability potentially increases social isolation resulting in less diversified participation in activities in society. Past strategies that were developed for acute fatigue resulting from overexertion or stress are not responsive to the prolonged and daily variability of cancer-related fatigue. New strategies must be conceived and implemented to address management of this symptom. A WHO report (2002) on Innovative Care for Chronic Conditions (ICCC), designed to improve management and prevention of chronic conditions, cites the need to develop innovations in relaxation techniques, coping skills training, and problem solving to decrease cancer-related symptoms such as fatigue (p.95).

Summary

A national panel convened by the Centers for Disease Control (CDC) to study issues of survivorship concluded that survivorship research and intervention is a priority for all cancer patients, confirming the paradigm shift that envisions the long-term post-intervention needs of cancer survivors as a chronic disease state (Centers for Disease Control [CDC], 2009). Studies that explore the perceived functional impact of persistent symptoms resulting from cancer, surgery, or adjuvant therapies are needed. Framed within the ICF and BPS theory, this project examines body structures (upper extremity use), body functions (fatigue), and self-perceptions of activity execution, limitations and participation restrictions. The increasing emphasis on survivorship by federal agencies and healthcare organizations addressing the needs of this population affords us the opportunity to better understand the impact of perceived persistent symptoms on the lives of BCS.

The potentiality of a relationship between CRF and upper extremity morbidity, two entities that may continue to challenge breast cancer survivors after treatment concludes, is not well described in the literature. It is not known whether these two underreported and under-diagnosed symptom complexes (Paskett et al., 2007; Stone et al., 2003; Stone, Richardson, Ream, Smith, Kerr, & Kearney, N., 2000) indeed represent separate concerns, or if a subset of the larger BCS population experiences both sets of symptoms. Understanding these relationships may enable healthcare practitioners to determine which women require further screening, monitoring or referral for interventions to address CRF or upper extremity dysfunction.

No studies were located exploring whether there is a relationship between cancer-related fatigue and upper extremity morbidity, despite prevalence statistics that conservatively suggest that approximately 30% or more of breast cancer survivors may experience either syndrome (Lash & Silliman, 2002; Hayes et al., 2008). Current research remains compartmentalized, focused on upper extremity morbidity and lymphedema, or cancer-related fatigue. The profound negative impact on occupational performance of desired activities and tasks is well documented for both concerns. Additionally, these two symptom complexes may appear long after adjuvant therapies conclude or continue permanently, thus altering quality of life. The International Classification of Function (ICF) Core Sets for Breast Cancer categorize the activities and tasks deemed critical to this population, based on the ICF from the World Health Organization, and include specific reference to addressing hand and arm use, activities of daily living, instrumental activities of daily living, employment, leisure and socialization (Brach et al., 2004).

Statements from the National Comprehensive Cancer Network [NCCN] Practice Guidelines in Oncology, additionally confirm the "necessity to develop interventions that focus on fatigue as a primary endpoint for research" (NCCN, 2009, p. MS-10), further supporting the need for research on CRF. Without knowledge of how these two fundamental constructs may be linked, it will be difficult to fully address the needs of breast cancer survivors or develop targeted interventions. The extended lifespan estimates for this population support further examination and explication of prolonged symptoms that interfere with daily life. There is a pressing need to explore the potential relationship between CRF and upper extremity functional deficits in order to begin to

ascertain how best to monitor and address survivors' desires to remain full and active participants in desired and required life tasks. This exploratory study may offer an alternative vantage point from which to begin to view prolonged symptoms, assisting clinicians to design screening tools and educational models to address BCS concerns, as well as laying the groundwork for future studies to help determine which women are at highest risk for prolonged effects from breast cancer interventions.

CHAPTER II

REVIEW OF LITERATURE

This chapter provides a review of the relevant literature on cancer-related fatigue (CRF) and upper extremity function in breast cancer survivors (BCS), including the impact of symptoms on activities of daily living (ADLs), instrumental activities of daily living (IADLs), employment, and caregiver status. Biological and physical contributors to fatigue and upper extremity deficits resulting from surgical interventions to the breast or adjuvant cancer therapies that impact daily function will also be explored. Furthermore, identification of current research trends, knowledge gaps and study limitations in the literature that provided the basis for this study and formulation of the study hypotheses will be reported.

Cancer-Related Fatigue (CRF)

Fatigue has long been recognized as one of the most common and significant cancer symptoms resulting from the cancer disease process, surgical intervention, chemotherapy, radiation, combined treatment interventions, immunotherapy, or marrow transplantation (Portenoy & Itri, 1999; Cella, Davis, Breitbart, & Curt, 2001; Sadler et al., 2002). It is also one of the most frequently researched symptoms across the cancer trajectory. Fatigue can produce undesirable consequences that diminish concentration and attention to tasks, result in sleep dysfunction, psychological distress, depression or anxiety (Sadler et al., 2002) or bring about physical weakness and diminished energy (Portenoy & Itri, 1999; Cella et al., 2001). The subjective experience of CRF can be characterized by a multiplicity of attributes including fatigue severity, duration, intensity, and variability, and exacerbating and remitting factors that potentially contribute to a

negative impact on occupational performance, socialization, and participation in the community (Bower, Ganz, Desmond, Rowland, Meyerowitz, & Belin, 2000; Curt et al., 2000; Portenoy & Itri, 1999).

The following section describes and defines CRF, known etiologies, prevalence rates, and patient and practitioner awareness of the frequency of CRF and potential interventions. The section further explicates the physical and emotional symptoms associated with CRF.

Definitions, Etiology and Prevalence

Cancer-related fatigue [CRF] is a distinct phenomenon with differential presenting symptoms that distinguish it from the acute fatigue experience typified by activity overexertion, a single poor night's sleep or the presence of stressful events. Acute fatigue symptoms are characterized by a connection to particular activities or events, responding to rest or cessation of activities and resolving within a reasonable time period to permit resumption of typical functional capacity. Conversely, the individual with CRF experiences a more persistent chronic form of fatigue that does not resolve with periods of rest, and may interfere with the performance of life tasks including employment (Spelten et al., 2003). The National Comprehensive Cancer Network (NCCN) defines CRF as a "distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (2012, p. FT-1). Fatigue has been shown to negatively impact occupational performance in instrumental activities of daily living (Curt et al., 2000), and negatively impact the ability to return to work (Spelten et al., 2003).

Portenoy and Itri (1999) speculated that CRF may "represent a final common pathway to which many predisposing factors or etiological factors contribute" (p.2). Potential contributors to the etiology include anemia, decreased cytokine or antibody responses, underlying metastatic disease, abnormalities of energy metabolism, neurophysiologic changes of skeletal muscle, chronic stress response, hormonal changes, adjuvant therapies, comorbid systemic diseases, sleep disorders, immobility and lack of exercise, use of pain medications, and psychosocial variables such as depression and anxiety (Stasi et al., 2003; Portenoy & Itri, 1999). Identifiable disorder-based symptoms such as anemia, metabolic or hormonal dysfunction may be adequately addressed or alleviated through medical intervention, thus allowing those individuals to experience reduction or resolution of their CRF symptoms. For other patients, the frequency of the fatigue experience combined with an elusive defined etiology is commonplace, particularly in survivors who have already completed the acute phase of cancer treatment.

In a study by Stone et al. (2000), patients identified fatigue as the most poorly controlled symptom in their cancer experience (p < .0001). They suggested that the population of individuals with cancer-related fatigue might be under-represented in current prevalence statistics due to the failure of patients to report their CRF symptoms, and the failure of health professionals to request detailed information about fatigue experiences during patient visits (Stone et al., 2000). A cross-sectional, questionnaire-based survey was used to investigate perceptions of cancer-related fatigue and the impact on quality of life on 576 patients and 576 caregivers (Stone et al., 2000). Fatigue was identified as the most significant symptom (P < .0001) resulting from patient cancer

experiences with 82% experiencing it at least a few days over a month-long period, 56% experienced it on most days or every day, with only 7% not reporting any fatigue (Stone et al., 2000, p.972).

CRF and Adjuvant Therapies

Research on CRF over the past decade predominantly detailed the impact of fatigue on recently diagnosed oncology patients undergoing treatment with adjuvant therapies. Cancer treatment, particularly chemotherapy and radiation therapy, has been implicated as a potential cause for CRF. Reported results have been contradictory with CRF correlated with chemotherapy in some studies (Broeckel et al., 1998; Bower et al., 2000), with radiation therapy in others (Lee et al., 2007), and with combined adjuvant therapies in still others (Jacobsen, Donovan, Small, Jim, Munster, & Andrykowski, 2007; Bower et al., 2006). Patients who receive cyclic chemotherapy usually experience fatigue within a few days of treatment, which then declines until the next treatment cycle is initiated (Portenoy & Itri, 1999). For patients undergoing radiation therapy, fatigue appears to be cumulative, potentially increasing with time in treatment (Portenoy & Itri, 1999).

Prevalence rates vary dramatically in the research literature providing confusing estimates of the scope of this problematic symptom. In a 2002 review of 54 articles on cancer fatigue prevalence, Servaes, Verhagen, C., & Bleijenberg (2002a) identified a prevalence range of 25 – 99% in the literature. Some discrepancies appear to be population dependent, with expanded sampling along the continuum of the cancer experience trajectory accounting for some of the variation, and the operational definition of fatigue used in a particular study accounting for additional variance (Servaes et al.,

2002a). If patients were asked if they were fatigued and responded affirmatively without further delineation for a fatigue diagnosis, then the prevalence rates appeared to be higher and may be artificially inflated (Cella et al., 2001; Servaes et al., 2002a). Patients who are in the process of undergoing adjuvant therapies almost universally report fatigue at some point in time during treatment. These prevalence numbers are substantially reduced when only post-treatment survivors are examined. Overall prevalence rates in disease-free survivors are estimated at between 17 – 30% of the total cancer survivor population (Servaes et al., 2002a). These numbers are further reduced when the more stringent proposed ICD-10 neoplastic related fatigue diagnostic criteria are applied.

Broeckel et al. (1998) authored one of the original studies supporting the persistence of CRF after adjuvant therapies concluded. The investigators completed a cross-sectional questionnaire-based survey combined with a researcher-conducted phone survey in 61 BCS who were 3 – 36 months post chemotherapy treatment and compared them to peer-matched controls (Broeckel et al.). Univariate analysis revealed that patients treated with chemotherapy agents reported more severe fatigue (P < .05) at 1.5 times the level of the controls, and higher levels of current fatigue (P < .05) (Broeckel et al.). Other studies have not substantiated the impact of cancer treatment modality on the development of CRF in off-treatment populations (Reinertsen, 2010).

In a later study, Bower et al. (2000) surveyed two large independent samples of breast cancer survivors to examine fatigue in survivors of breast cancer. Two centers, one in Los Angles and one in Washington, D.C. (N = 1957) recruited women to examine health-related quality of life, depression, sleep and vasomotor symptoms. All survivors

were between 1 – 5 years post diagnosis and had completed all medical treatment for breast cancer. Data results were compared with two national sets of norms; one for general population scores on the Medical Outcomes Short-Form 36 (SF-36) as well as against baseline data from a large (N = 9,749) prevention trial for women at high risk for breast cancer (Bower et al., 2000).

Women with increased fatigue rated health-related quality of life as lower than women who had higher scores on the energy/fatigue scale (Bower et al., 2000). Fatigued women were younger, less likely to be married, less affluent (p < 0.05), and more likely to have received combination treatment (Bower et al., 2000). The results documented improvements in energy levels until the second year post-adjuvant therapies when gains stabilized; however, one-third of the women surveyed experienced persistent moderate to severe fatigue beyond the expected two years post-diagnosis (Bower et al., 2000).

Bower et al. (2006) continued the aforementioned research study, conducting a longitudinal assessment of 817 disease-free BCS to evaluate the persistence of CRF five to ten years post-diagnosis, finding persistent fatigue in sixty-three percent of the women who were classified as fatigued in the original study (p.754). Fatigue prevalence rates for in both studies was 21% with income as the only significant fatigue correlate in the second study (P = 0.05) (Bower et al., 2006).

Another longitudinal study examined predictors, prevalence and correlates of CRF in 317 long-term BCS at two time points: 2.5 – 7 years post-treatment, and 2.5 – 3 years following initial data collection (Reinertsen et al., 2010). Twenty-three percent of the sample documented CRF at both data collection points, a small sample

demonstrated resolution of initial fatigue (10%), and 16% exhibited new CRF at the second data collection point (Reinertsen et al., 2010). This study was of interest not only for the length of time the participants were followed, but because the authors provided support for the development of new cases of CRF long after diagnosis and treatment conclude.

The ICD-10 diagnostic criteria was applied to a nationally representative sample of 379 cancer patients living in the United States, the majority of whom were between 1 – 5 years post-diagnosis (Cella et al., 2001). Seventy-nine percent reported significant fatigue as the most common symptom, versus 21% who reported no fatigue during the continuum of pre- to post-treatment (Cella et al., 2001). When the CRF criteria were applied, only 17% of the sample satisfied the diagnostic criteria (Cella et al., 2001). This is particularly significant because the ICD-10 criteria, as opposed to some other measures of cancer fatigue, specifically requests confirmation that the patient experiences dysfunction in areas of occupational performance for daily tasks as a result of CRF. The authors note that the prevalence rate obtained would appear to be more accurate for off-treatment survivors, but cautioned that these figures may still underestimate the population (Cella et al., 2001). Persistence of the prevalence figures was demonstrated when 1 year off-treatment survivors were compared to 5-year off-treatment survivors (Cella et al., 2001) indicating that fatigue symptoms in the subset of individuals meeting the ICD-10 criteria do not easily resolve over time and may leave the survivor with persistent functional deficits.

Prevalence rates in off-treatment survivors are sufficiently high to warrant continued research into the potential factors that underlie this common symptom. The

need for practitioners and survivors to attend to the potential serious ramifications of

fatigue symptoms was underscored in a study by Groenvald et al. (2007). The authors

conducted a longitudinal study (median follow-up 12.9 years) of 1,588 patients with

breast-cancer in Denmark examining how self-perceived fatigue and other quality of life

health measures might impact long-term survival and recurrence rates (Groenvald et al.,

2007). The reported results indicated that fatigue was the only significant predictor of

breast cancer recurrence (risk ratio 1.45, confidence interval 1.04 – 2.04, p = 0.030),

whereas emotional function emerged as the only predictor of overall survival (Groenvald

et al., 2007). Using psychoneuroimmunologic theory linking emotional distress and

immune function, they concluded that mind-body interventions should be designed to

decrease fatigue in order to exert an influence on recurrence, but could not conclude

that potential interventions would ultimately alter survival rates (Groenvald et al., 2007).

Patient and Practitioner Awareness of CRF

Awareness of cancer-related fatigue has increased as published research

studies with an emphasis on quality of life in cancer patients become known, but

practitioner and patient awareness of the pervasiveness of CRF remains a significant

problem in clinical practice. As recently as 2010, Escalante, Kallen, Valdres, Morrow,

and Manzullo noted that CRF remains an enigma to patients and providers alike,

acknowledging that persistent CRF that develops into a chronic condition for a subset of

survivors requires the focused attention of a dedicated multidisciplinary team of

providers.

An early study by Stone et al. (2000) demonstrated that patients experiencing

fatigue attempted to discuss fatigue with their physician during most appointments

(25%) or at least once (43%) in a cross-sectional randomized survey. A startling 52% of the overall sample in the study had never discussed CRF with their physician (Stone et al., 2000). The authors posited a potential explanation for this lack of identification as stemming from patient values and beliefs about their cancer experience. Forty-three percent of respondents surveyed felt that fatigue was an inevitable side effect of cancer treatment or the actual disease process, 34% thought it was unimportant, and 27% thought it was untreatable (Stone et al., 2000). Only 22% believed that the fatigue symptoms could be controlled by some kind of intervention (Stone et al., 2000). The authors concluded that patients did not discuss what they felt could not be ameliorated. Prevalence rates may therefore not be reflective of the total population of individuals with CRF, since patients who fail to report symptoms might not be included in data surveys that rely on health providers for identification of this population.

In a nationally randomized study that assessed perceptions about CRF and prevalence rates in 419 patients, 200 patient-nominated caregivers, and 205 oncologists, Vogelzang et al. (1997) reported that 78% of patients reported the experience of fatigue during the cancer treatment experience. The mean prevalence of daily fatigue for all groups was 32%, with younger adult patients experiencing more fatigue (45%), women experiencing more daily fatigue (36%) and one-year post-diagnosis rates similar to those recently diagnosed (Vogelzang et al., 1997, p.6). One third of patients reported that fatigue significantly impacted daily activities and routines, limited their ability to work, engage in social activities (57%), and participate in community mobility (48%) (Vogelzang et al., 1997). Fatigue resulted in slowed task completion (69%), reduced task completion (49%), or rendered them unable to care for

their families (Vogelzang et al., 1997). Sixty-one percent reported that fatigue was the

primary symptom affecting daily life with younger patients and working patients

reporting that fatigue impacted life functions more than pain (Vogelzang et al., 1997,

p.6). Patients did not view fatigue as manageable with only 50% of patients in this study

reported ever bringing this concern to the attention of their treating physician

(Vogelzang et al., 1997). Seventy-three percent of respondents who vocalized about

the fatigue symptoms to their oncologist reported that they were told this was "a

symptom to be endured" (Vogelzang et al., 1997, p.8). Primary recommendations from

the surveyed oncologists identified rest as the potential solution to these symptoms

(Vogelzang et al., 1997). Patients and oncologists reported few prescriptions or ideas

for treating fatigue, with oncologist most often advising rest (68%), medication (42%),

diet or nutrition (30%) and infrequently, exercise (7%) (Vogelzang et al., p.9). Dimeo,

Stieglitz, Novelli-Fischer, Fetscher, & Keul (1999) suggested that during adjuvant

therapies, patients altered activity choices in an attempt to self-modulate fatigue and

"down-regulate their level of activity" secondary to deconditioning, thus furthering a self-

perpetuating cycle that led to the need for increased rest (p.2274). Vogelzang et al.

concluded that patients who received specific treatment for CRF felt that it was a

controllable symptom and provided some relief (66%); however surveyed oncologists

only believed that attempted treatment successfully impacted 17% of patients with CRF

(1997, p.9).

Mortimer et al. (2010) documented an exploratory study to examine patient

descriptions of the functional impact of fatigue on function utilizing 26 articles from a

literature search of previously published research. The patients documented functional

limitations in activities of daily living, instrumental activities of daily living and

socialization and indicated that survivors begin to self-limit daily tasks and decrease

expectations of task accomplishment (p. E197-199).

Fatigue and Other Symptomatology

Additional cancer-related or treatment-related symptoms have been correlated

with CRF in numerous research studies. Of specific concern is the ongoing controversy

in the literature surrounding the meaning or presence of depressive symptoms in

individuals experiencing CRF. Twenty-five percent of patients with a cancer diagnosis

are also diagnosed with a major depressive episode at some time during the course of

their illness, with highest risk for depression in those with advanced disease,

uncontrolled cancer-related symptoms such as pain, or a prior history of a mood

disorder (Bower et al., 2000; Portenoy & Itri, 1999). The importance of understanding

the presence of depression is highlighted when reviewing the anticipated ICD-10 CRF

diagnostic criteria which denote the need to rule out major affective disorders or other

comorbid psychiatric disorders in order to assign a diagnosis of CRF (CDC, 2007; Cella

et al., 2001).

In a previously referenced study by Broeckel et al. (1998), the presence of a prior

psychiatric disorder was not statistically significant in determining CRF; only a current

disorder accompanying the breast cancer emerged as significant lending credence to

the idea that CRF contributes to depression and not vice versa. Spelten et al. (2003)

found statistically significant results demonstrating decreases in fatigue, physical

complaints and psychological distress from the first to last data collection in a

prospective inception cohort study with 12 months follow-up of 195 previously employed

patients with a primary recent (4-6 months) cancer diagnosis (Spelten et al., 2003). Upon baseline assessment, fatigue and depression were correlated (r = 0.54), as were fatigue and physical complaints (r = 0.61), sleep problems (r = 0.33), and emotional distress (r = 0.32) (Spelten et al., 2003). Physical complaints were related to depression and sleep (r = 0.50) and depression was related to psychological distress (r > 0.50) (Spelten et al., 2003).

Fatigued women also reported greater frequency and number of menopausal symptoms than non-fatigued women, and identified more depressive symptoms (Bower et al., 2000). The predictive model described by the latter was significant (P = 0.0001) with depression (p = 0.001) and pain (p = 0.001) emerging as the strongest predictors of CRF (Bower et al., 2000). Bower et al. (2000) concluded that even though their results demonstrated that depression was the strongest predictor of fatigue, there was no causal relationship citing the reciprocal nature of fatigue symptoms such as diminished occupational functioning preceding depressive mood or depressive mood causing fatigue. In a 2006 study, Bower, Ganz, & Desmond et al. affirmed their previous findings. Fatigued women were more depressed, had increased comorbid pain, higher fear of cancer recurrence, and were more likely to have undergone both chemotherapy and radiation than non-fatigued women (Bower et al., 2006).

Sadler et al. (2002) found that increased reporting of depressive symptoms were higher in individuals meeting the ICD-10 criteria (P = 0.02). Since decreased energy is a significant symptom in individuals meeting the DSV-IV-TR criteria for a depressive mood disorder, this might argue in favor of CRF as a manifestation of an underlying mood disorder. However, Sadler et al. concluded that the ICD-10 CRF criteria are

designed to specifically eliminate those individuals with an underlying mood disorder before the criteria can be accurately applied (2002).

Researchers have also explored the potential for CRF existing as part of a defined symptom cluster. Dodd, Miaskowski, & Paul (2001) investigated linkages between fatigue, pain, and sleep dysfunction in a longitudinal study with 93 participants who had recently completed chemotherapy. The Karnofsky Performance Scale (KPS), a clinical assessment tool used to classify patients based on the extent of medical intervention needed, patient disease prognosis, and a measure of functional performance, revealed the emergence of fatigue as the highest rated predictor for changes in KPS scoring, with pain emerging as a secondary predictor (Dodd et al., 2001). The study's findings refuted their hypothesis that fatigue, pain, and sleep constituted a cluster, and lends credence to the view of cancer-related fatigue as a multi-faceted single entity (Dodd et al., 2001).

Cancer-Related Fatigue Instrumentation

A gold-standard measurement tool for CRF has yet to be identified. Over 25 self-perception tools assessing CRF, ranging from single item to complex multifaceted scales, are available for use with varying psychometric reliability and validity (Mortimer et al., 2010). Previous research studies have validated instruments capable of defining aspects of CRF, but none have emerged in either research or clinical settings as the outcome measure of choice. Difficulties in measurement are directly attributable to the problem of defining the parameters of this multidimensional construct. For example, instruments that are capable of measuring the physical attributes of fatigue, may not record the undesirable consequences that interfere with daily life. Attempts to refine the

CRF construct and discriminate it from other forms of fatigue have resulted in the development of ICD-10 diagnostic criteria.

The development of the proposed diagnostic category for CRF for the next publication of the International Classification of Disease, 10th edition, Clinical Modification (ICD-10 CM) (Sadler et al., 2002; Portenoy, & Itri, 1999), should assist clinicians in the identification of patients experiencing CRF. The proposed criteria have been studied to validate the symptom list and determine prevalence rates (Young & White, 2006). For researchers, a formal diagnosis of neoplastic related fatigue offers the potential to identify and target interventions meeting the needs of severely fatigued patients living with cancer; however the criteria poses the risk of excluding individuals with fairly significant fatigue who may fall short of the required six symptoms for diagnosis.

Young and White (2006) utilized the ICD-10 criteria to estimate prevalence rates of CRF in 69 disease-free BCS in Scotland and to further validate the draft criteria due to concerns regarding discrepancies in the literature between higher reported prevalence rates when self-perceived fatigue questionnaires were used with cancer survivors versus prevalence when the new criteria was applied. Twenty-three percent of participants met symptoms criteria, while 18.8% met the determination of interference with daily function (Young & White, 2006, p.33). Those meeting the criteria reported daily fatigue patterns that worsened as the day progressed, had received more types of adjuvant therapy, and experienced higher psychological distress (Young & White, 2006). They also reported a broader fatigue experience that impacted daily life tasks,

experiencing fatigue an average of 2.7 more days per week and reported increased anxiety, depression, and psychological distress (Young & White, 2006, p.35)

Sadler et al. (2002) evaluated off-treatment fatigue in 51 individuals who had previously undergone autologous or allogenic blood or marrow transplantation to establish validity for a structured CRF interview based on the P-ICD-10 CM. Results indicated that the interview discriminated between fatigued and non-fatigued populations, identifying 43% of the sample (n = 22) experiencing fatigue daily or nearly every day during at least two weeks within the past month (p. 409), 77% of those who were fatigued perceived the need to struggle to overcome activity, and 36% reporting that they had difficulty completing daily tasks due to fatigue (Sadler et al., 2002, p.410). Twenty-one percent of the sample (n = 11) met at least 6 of the 11 symptoms in the criteria, defined as the cut-off for a diagnosis of CRF (Sadler et al., 2002, p. 410).

A Belgian study of 834 cancer patients established cut-off scores for the ICD-10 for the purposes of diagnosis (Van Belle et al., 2005). Descriptive statistics revealed that 79% of fatigue-positive patients documented "difficulty completing daily tasks attributed to feeling fatigued" versus 24% of non-fatigued patients, and 65% of fatigue-positive patients reported "decreased motivation or interest in engaging in usual activities" versus 24% of non-fatigued patients (Van Belle et al., 2005, p.249).

In a randomized representative sample of U.S. households with individuals with cancer (Cella et al., 2001) the prevalence of CRF was found in 17% of 379 individuals evaluated using the guidelines for symptoms and functional impact of the ICD-10 criteria. Committees of researchers working to refine the definition of CRF have suggested that the ICD-10 diagnosis for CRF include four criteria: "the presence of CRF

for 2 or more weeks, significant distress or impairment, consequence of cancer or its treatment, and absence of comorbid psychiatric disturbance (Mortimer et al., 2010, p. 1332)."

The FACIT-fatigue scale was used to assess a population of cancer patients with and without anemia compared to a general U.S. sample population (Cella, Lai, et al., 2002). The general population, as expected, reported lower levels of fatigue than cancer survivors regardless of anemia status (p < .0001). Using a cut-off score of 43, the FACIT-fatigue was capable of distinguishing between the general population and cancer survivor with and without anemia (sensitivity 0.92; specificity 0.68).

Functional Assessment of Cancer Therapy - Fatigue Subscale (FACT-F). Based on prior studies and psychometric stability, the Functional Assessment of Cancer Therapies (FACT) was chosen as the fatigue scale for this study. FACT is a system of well-researched self-report questionnaires designed to evaluate various QOL impact of cancer therapies on individuals living with cancer (Yellen et al., 1997). The FACT is a subset of the larger Functional Assessment of Chronic Illness Therapy (FACIT) system, a vast test bank of questions designed for a variety of health-based conditions and translated into 43 languages (Stasi et al., 2003). Subsumed, as part of the FACT system, is a tool that was designed to assess anemia (FACT-An) in individuals undergoing treatment for cancer. Contained within the FACT-An is a 13-item subscale designed to assess cancer-related fatigue since fatigue is foremost among symptoms of anemia. Subsequent research validated the FACT-F as a separate assessment instrument from the FACT-An questionnaire that can be used across the cancer

spectrum to assess fatigue-based symptoms (Van Belle et al., 2005; Hwang, Chang, Rue, & Kasimis, 2003; Passik et al., 2002; Yellen et al., 1997).

The FACT-F is composed of the same 13-item fatigue subscale described in the FACT-An, as well as questions from the FACT-G on information related to the impact of fatigue on quality of life concerns such as physical, social, emotional, and functional status (Cella, Eton, Jin-Shei, Peterman, & Merkel, 2002; Yellen et al., 1997). Each item retrospectively assesses the experience of fatigue over the past seven days and is rated on a 5-point Likert scale, from 0 "not at all" to 4 "very much so" (Cella, Lai et al., 2002; Van Belle et al., 2005). Higher scores are indicative of better functioning (Yellen et al., 1997). Estimated completion time for the complete FACT-F is 10 minutes; the 13-item subscale would therefore take less than 10 minutes to complete. The FACT system has a reading level of 6.0, making it suitable for a range of populations and can be administered via verbal interview or questionnaire (Yellen et al., 1997). The FACT-F has been documented as a suitable measure of self-perceived fatigue in populations with cancer (Mustian et al., 2004; Bennett, Goldstein, Lloyd, Davenport, & Hickie, 2004; Stasi et al., 2003; Yellen et al., 1997). Van Belle et al. confirmed the validity in the FACT-F subscale and unidimensional measure of fatigue for systematized assessment of fatigue in individuals with cancer (2005).

Another study delineated a cut-off score of 37 out of the 52 possible points on the FACT-F subscale as constituting moderate to significant fatigue in a population of women with breast cancer undergoing and following radiation therapy (Wratten et al., 2004), but the sample size of 52 was small. In this study, baseline fatigue subscale scores, along with neutrophil and red blood count, were found to be predictive of

membership in fatigued versus non-fatigued groups at 6-week post-treatment (Wratten et al., 2004). The cut-off score was chosen based on an earlier study which extrapolated this test score from high correlation scores between the FACT-F and Brief Fatigue Inventory (BFI). The relationship between the FACT-F and BFI was supported by the work of Hwang et al. (2003) who found that a factor analysis yielded 91% of the variance through loading on one factor between the FACT-F and BFI. Van Belle et al. (2005) established that a cut-off score of 34 allowed for prediction of ICD-10 status in 93% of 470 patients (sensitivity 0.91, specificity 0.75) (p.251). For this proposed study, the Van Belle cut-off score of 34 will be considered to define significant fatigue on the FACT-F.

CRF Summary

The exigent circumstances that surround the imperative to develop interventions for CRF are noted as the BCS population grows in response to early detection with increasing survival statistics. These women remain at risk for the development of secondary morbidities such as fatigue and upper extremity deficits after adjuvant therapies conclude directly impacting occupational performance in all spheres of life. The majority of the research literature has focused on defining the parameters of the construct and determining prevalence rates. There is still a paucity of intervention research addressing CRF and functional status. The potential for long-standing health deficits and functional limitations that spiral from the persistent experience of CRF, including the potential for cancer recurrence, supports concerted efforts directed toward furthering our understanding of CRF and its impact on daily life.

Upper Extremity Function

The range of deficits and impairments found in the upper extremity secondary to breast cancer diagnosis, surgery, or adjuvant therapies is broad, thus defining the impact of these symptoms depends upon the research variables of interest, definitions of function, instrumentation choices and when data is obtained. There is a sizable body of literature describing the impact of breast cancer surgery and adjuvant therapies on upper extremity physical function (Hayes et al., 2005; Collins et al., 2004; Rietman et al., 2004), but less is known about the impact of residual symptoms on function in BCS. Incidence rates for all problems vary from 7 – 80%, with pain and sensory deficit estimates ranging from 9 – 68%, lymphedema from 2 – 17%, and decreases in range of motion from 3 – 73% (Hack et al., 2010). Lymphedema of the ipsilateral extremity is a potential complication of breast cancer surgery and treatment, with differing incidence and prevalence numbers reported due to variations in research study parameters, impacting 15 - 20% of BCS (Petrek & Heelan, 1998). Hack and colleagues documented that multiple treatment and demographic factors, often in combination, influence persistent symptoms including pain, lymphedema, and ROM on the results of a Canadian multi-center assessment of persistent arm dysfunction in 316 BCS (2010).

A focal point for recent literature has compared the significance on upper extremity function resulting from axillary lymph node dissection [ALND] or sentinel lymph node biopsy [SLNB] during the diagnostic process (Rietman et al., 2006). Node biopsy and particularly radiation therapy may be accompanied by upper extremity sequelae including muscle weakness, numbness, pain, paresthesias, loss of shoulder range of motion, tightening of scar tissue, and risk for or exacerbation of lymphedema

(Kärki et al., 2005). These resulting deficits can further complicate hand function in the affected extremity (Kärki et al., 2005). The consequences of reduced physical function in the upper extremity and hand directly impact occupational performance in all areas of occupation (Collins et al., 2004). The upper extremities typically provide the means through which performance of most activities of daily living and instrumental activities of daily living take place. Therefore, marked impairment in upper extremity function will likely also impact life role fulfillment and quality of life.

Surprisingly, research on CRF has not explored the interrelationships between upper extremity deficits resulting from surgery or adjuvant therapies on energy usage and the experience of fatigue. Linkages within the CRF body of literature clearly identify occupational performance deficits resulting from the fatigue experience (Ashbury, Findlay, Reynolds, & McKerracher, 1998). It is also acknowledged that both CRF and upper extremity limitations are commonly experienced by many BCS and diminish quality of life. These two distinctive impediments place an undue burden on survivors' abilities to perform IADLs, work-related tasks, leisure and socialization, and in turn impact family relationships (Hayes et al., 2005; Taylor & Currow, 2003).

In light of the emphasis on engagement and participation in all life spheres emphasized by the World Health Organization (2001), this section stresses the importance of the impact of upper extremity function on occupational performance in life tasks and roles. Definitions for terminology related to functional performance and study variables are located in Appendix A. It concludes with a description of the research literature supporting the use of the Disability of the Shoulder, Arm, and Hand (DASH) as an outcome measurement tool for this proposed study.

Impact of Breast Cancer on Upper Extremity Physical Parameters

Hladiuk, Huchcroft, Temple, & Schnurr (1992) reported results from a pilot study to examine objective measures of upper extremity function when compared with the contralateral extremity in a sample of 57 BCS who underwent ALND alone or in combination with surgical tumor resection, describing follow-up from 6 – 15 months post-surgery. The most improvement in range of motion occurred by month 6 and roughly stabilized thereafter, with external rotation demonstrating the highest level of residual limitations in 12% of the participants (Hladiuk et al., 1992). Of particular interest in this study was the finding that 42% of the women experienced ongoing, measurable, diminished function after one year post-surgery (Hladiuk et al., 1992). Diminished grip strength was documented in 16% of the participants, with a reduction of 12 – 18% when compared to grip strength of the non-surgical arm, although arm dominance was not related to recovery of physical function (Hladiuk et al., 1992, p.49). Women who continued to follow the typical health professional BCS guidelines for post-surgical upper extremity exercise a year following surgery documented a trend toward less impaired grip strength, but the small population size and the decision of the authors to alter the alpha level to 0.25 brings the results into question (Hladiuk et al., 1992).

The impact of dominance and treatment side is a critical issue when examining functional performance resulting from upper extremity deficits after adjuvant treatment concludes and is another area of breast cancer morbidity that has been underreported. Hayes et al. (2005) examined the relationships between objective upper body function and subjective questionnaires on quality of life measures in Australian BCS under the age of 75 using the Disability of Arm, Shoulder, and Hand (DASH) questionnaire, the

Functional Assessment of Cancer Therapy, Breast (FACT-B), and upper body strength, range of motion, and grip strength as objective measures. Radiation therapy emerged as the only adjuvant treatment associated with decreased flexibility, but only when the non-dominant side was treated (Hayes et al., 2005). When the dominant side was treated, participants consistently demonstrated greater objective upper body function for strength, endurance, and grip strength ($p < .001$), but simultaneously reported lower quality of life (Hayes et al., 2005). Similar findings were observed for the IADL task of childcare which was positively correlated with hand grip strength, but negatively associated to self-perceived function (Hayes et al., 2005, p.3-4). Income, extensive axillary node dissection, and lymphedema were all associated with factor with decreased upper body function (Hayes et al., 2005, p.4). This unexpected finding that the dominant treatment side demonstrated increased function was first identified in an earlier study by Swedborg and Wallgren (1981). The authors reported higher grip strength scores and more degrees of external rotation on the dominant affected side, with 34 – 44% of BCS demonstrating better grip strength and 40 – 48% with improved range of motion (Swedborg & Wallgren, 1981). The authors conjectured that women whose dominant side was affected still needed to use the arm functionally resulting in increased objective measures, but greater recognition of subtle losses in function resulted in less satisfaction in performance (Hayes et al., 2005).

Node Dissection and Adjuvant Therapy Impact to the Upper Extremity

It was previously mentioned that the methodology used for the staging of breast cancer frequently involves dissection of the lymphatic nodes in the axilla. Historically, ALND was the standard of care for decades with multiple nodes removed for biopsy

often at the same time as surgical resection of solid breast tumors. This procedure is identified as "the most prognostic variable in patients with breast cancer "(Rietman et al., 2003, p.229). However, ALND has been associated with the development of upper limb dysfunction in BCS (Rietman et al., 2006; Rietman et al., 2003). Nodal staging during the last decade has been supplanted by SLNB (McGuire et al., 2009, p. 2682). Breast conserving surgery with follow-up radiotherapy, chemotherapy, hormonal or combination therapies further accelerated the acceptance of this method of node removal. However, many women with positive sentinel nodes on biopsy will require further axillary node removal to obtain an accurate diagnosis and differentiate treatment choices. Therefore node removal remains a great source of concern for women with breast cancer.

The advent of SLNB, as opposed to ALND, as the prevailing standard of care for initial surgical node removal and diagnosis has altered the landscape for BCS and researchers. The National Cancer Institute describes sentinel node biopsy as the process of locating and systematically examining the most likely lymph nodes to be affected by cancer cells from the primary tumor (2005). Radioactive dye is used via lymphoscintigraphy, followed by the use of a gamma probe to identify the sentinel nodes for surgical biopsy (Rietman et al., 2006). Typical ALND regional clearance of many or most nodes may not be necessary if the sentinel nodes, once examined by pathologists, are clear of metastasized cancer cells (NCI, 2005). SLNB is usually performed as a separate procedure from breast tumor resection; therefore women may need to undergo more than one invasive procedure. Removing fewer lymph nodes for

staging and diagnostic purposes has the potential to cause less arm morbidity; however current research has not fully established this link (NCI, 2005).

A decade of literature suggests that a significant relationship exists between the number of lymph nodes removed and the development of subsequent arm morbidity and sequelae such as lymphedema (Hack et al., 2010). While SLNB has become an alternative diagnostic procedure resulting in lower numbers of removed nodes, research has not yet established this techniques' accuracy in enhancing survival rates or identifying cancer recurrence (NCI, 2005).

There is also recent evidence that mastectomy rates are increasing again after years of diminishing percentages of women undergoing this more extensive surgery (McGuire et al., 2009; Katipamula et al., 2009). Identified factors accounting for this unexpected rise include an increase in contralateral prophylactic mastectomies followed by reconstruction as genetic testing provides women with increased information that may alter collaborative decision-making with the oncology team, as well as decisions of women to request more extensive surgery in order to try to avoid or decrease radiation or chemotherapy (McGuire et al., 2009).

The impact of SLNB on upper extremity function and self-perceived occupational performance and quality of life was the focus of a study of 181 BCS in the Netherlands in a pretest-posttest design examining upper limb, function-based, and quality of life assessments from the day before surgery to a second time period two years post-surgery (Rietman et al., 2006). ALND was predictive of negative adverse effects two years after treatment concluded in objective physical measures including decreased grip strength, decreased shoulder abduction and some diminished aspects of ADL

status and quality of life (Rietman et al., 2006). Individuals who had undergone radiation therapy further demonstrated diminished range of motion and increased arm swelling (Rietman et al., 2006). Women who underwent SLNB experienced less adverse effects in all areas measured (Rietman et al., 2006).

Radiation therapy was also implicated as a contributing factor in upper extremity morbidity in a much earlier study of 475 BCS who underwent modified radical mastectomies in Stockholm, and were randomized to pre-surgical radiation therapy, post-surgical radiation, or no radiation therapy (Swedborg & Wallgren, 1981). One hundred sixty of the original cohort underwent further physical evaluation for volumetric lymphedema measurement, shoulder range of motion, and grip strength (Swedborg & Wallgren, 1981). Following surgery and/or radiation, it was noted that BCS who did not undergo radiation therapy experienced less edema, had increased mobility, and a trend toward increased grip strength in the affected upper extremity, but with no significant differences for the two radiation therapy groups (Swedborg & Wallgren, 1981).

Conflicting results on the role of chemotherapy in the development of lymphedema and functional impairments have been reported. Rietman et al. (2004) found that radiotherapy was the most significant predictor of loss of range of motion, with chemotherapy contributing only minor predictive interest. Paskett et al. (2007) focused on the prevalence of lymphedema and resulting impact to quality of life in a sample of 627 women recruited from four nationally recognized cancer centers. Lymph node removal was the most significant factor in the development of lymphedema ($P = 0.003$) with hazard equations demonstrating an increasing risk of 2.2% for every additional node removed (Paskett et al., 2007, p.779). The unexpected finding was the

high risk of lymphedema in those receiving chemotherapy (76%), as well as increased risk in married women. Paskett et al. conjectured that increased lymphedema risk for married women might be related to more frequent engagement in IADL tasks (2007).

ADL and Upper Extremity Instrumentation

The predicament of how to measure fatigue outcomes is echoed by the same difficulties when comparing studies that measure occupational performance or upper extremity function. Rietman et al. (2003) conducted a literature search yielding 15 studies that met their criteria to explore the effects of late morbidity on function and quality of life. They documented the lack of uniformity, documented criteria, and psychometrically sound assessment tools to measure ADL and IADL function, as well as in tools those chosen to measure upper extremity dysfunction. For the proposed study, one measure has been chosen to assess self-perceived ADL/IADL function and upper body symptoms. The Disabilities of the Arm, Shoulder, and Hand (DASH) was chosen due to its reliable and validated psychometric properties with a variety of patients with upper extremity dysfunction (Jester, Harth, Wind, Germann, & Sauerbeir, 2005; Beaton, Katz, Fossell, Wright, & Tarasuk, 2001; SooHoo, McDonald, Seiler, & McGillivary, 2002; Hudak, Amadio, Bombardier, & Upper Extremity Collaborative Group [UECG], 1996).

Disabilities of the Arm, Shoulder, and Hand (DASH). Developed by the Institute for Work and Health in Toronto, Canada, and the American Academy of Orthopedic Surgeons in 1996, the Disabilities of the Arm, Shoulder, and Hand questionnaire (www.dash.iwh.on.ca/index.htm) is a standardized quality of life outcomes measure designed to assess patient perceptions of upper extremity musculoskeletal

disability causing limitations in ADL and IADL tasks, as well as perceived extremity-related symptoms such as pain or weakness (Hudak et al., 1996; Kennedy, Beaton, Solway, McConnell, & Bombardier, 2011). It consists of a 30-item questionnaire asking patients to assess their ability to perform common ADL and IADL tasks within the prior week using a 5-point Likert scale with answers ranging from "not at all" to "extremely." The instrument has been translated into 17 different languages resulting in an increasing body of international literature on upper extremity musculoskeletal disorders to support the use of this instrument in assessing perceived disability, as well as health burden (Gummesson, Atroshi, & Ekdahl, 2003).

Normative data in the DASH from a United States random population sample using the National Family Opinion's household panel database matched to the U.S. census has been documented (Hunsaker, Cioffi, Amadio, Wright, & Caughlin, 2002). In this nationally representative sample, the DASH exhibited Cronbach's alpha ranging from 0.94 to 0.98, Pearson correlations of 0.49 to 0.87, and item internal consistency of 100 (Hunsaker et al., 2002, p.213). Mean scale scores for global function on the DASH (n = 1706) was 10.10 (SD 14.68); Sports optional scale (n = 1113) 9.75 (SD 22.72); and Work optional scale (n = 1610) 8.81 (SD 18.37) (Hunsaker et al., p.211, 2002). Reliability of the DASH was demonstrated in this population with a Cronbach's alpha coefficient above 0.9 (Gummesson, 2003, p.4).

Construct validity of the DASH as an extremity specific quality of life outcome measure was supported by data from SooHoo, McDonald, Seiler, and McGillivary (2002) in a study examining correlations of the DASH to the Medical Outcomes Study Short-Form 36 (SF-36), a well established quality of life outcome measure with available

standardized normative scores for the U.S. population. The hypotheses were confirmed

with moderate correlations observed ranging from 0.36 for the general health subscale

to .62 for the role emotional subscale (SooHoo et al., 2002).

Beaton et al. (2001) also assessed the psychometric properties of the DASH,

examining within-subject responsiveness, reliability and validity in a study sample of 172

patients from major hospital centers in Toronto (n = 109) and Boston (n = 91) engaged

in treatment for a variety of upper extremity disorders. Working patients demonstrated

lower DASH disability scores than those who were unable to work due to upper

extremity dysfunction, demonstrating statistically significant discriminative validity (26.8

vs. 50.7, t = -7.51, p < .0001) between these groups, as well as between those

diagnosed with shoulder vs. hand conditions (Beaton, 2001, p.135). Reliability of the

DASH as measured by Cronbach's alpha was reported as 0.97 (Beaton et al., p.140)

during baseline data collection and is further supported by data from Gummesson et al.

(2003), documenting Cronbach's alpha levels above 0.90.

Convergent construct validity was also found in Pearson correlations exceeding

0.70 between the DASH and joint-specific measures, the Shoulder Pain and Disability

Index (SPADI) and the Brigham questionnaire for hand and wrist dysfunction (Beaton,

2001, p.135). Pearson correlation using data over the course of 3 – 5 days from 56

subjects, indicating that they had no change in deficits during that time period, was 0.96

and Spearman ranked correlation was 0.96 at the 95% CI (Beaton et al., 2001)

indicating high test-retest reliability. The ICC was 0.96 (95% CI) and the SEM of 4.6

points provided a minimally detectable change (MIDC) of 12.75 on the 100-point scale

or 10.7 of 100-points using a 90% MIDC (Beaton, 2001, p.135). This is also consistent

with the 10 point MIDC described by Gummesson et al. (2003) and Hunsaker et al. (2002). Results indicate that the DASH is a valid, reliable, and responsive tool for single or multiple disorders in the upper extremities.

One dissenting study from Australia questioned the discriminative validity of the instrument. Dowrick, Gabbe, Williamson and Cameron (2006) evaluated the use of the Short Musculoskeletal Functional Assessment (SMFA) and the DASH comparing three groups of individuals with upper extremity injuries, lower extremity injuries, and a control group. Reported data supported previous DASH validation studies to identify upper extremity dysfunction, but noted that the lower extremity group demonstrated higher scores on the DASH than the control group ($z = -7.1$, $p < .001$) (Dowrick et al., 2006, p.526). While this finding was not supported by other research, identification of some lower limb disability using the DASH provides support for the complexities inherent in ADL and IADL tasks. If certain ADL and IADL tasks delineated on the DASH were subjected to an activity analysis, they might not solely be comprised of upper quadrant requirements as these tasks are typically performed by adults in daily life. The authors cautioned that investigators should attempt to insure that only upper extremity disorders exist when choosing the DASH as an upper quadrant outcome measure (Dowrick et al., 2006). In that study, the Dowrick et al. altered the instructions to request information about lower extremity function. The standardized instructions developed by the DASH developers will be used since all subjects in this study have experienced some type of medical intervention in one breast that has the potential to impact upper quadrant function.

One study was located describing the use of the DASH as a measure of perceived upper extremity function for research on recovery advice given to women with breast cancer (Round et al., 2006). All of the research studies previously described (Beaton et al., 2001; SooHoo et al., 2002; Gummesson et al., 2003) support the use of the DASH as an outcomes measurement with established psychometric properties that can be used to assess upper quadrant dysfunction, including upper extremity function in women with breast cancer.

Impact of Fatigue and Upper Extremity Dysfunction on Occupational Performance

The consequences of cancer-related fatigue are disturbing, but the negative impact of fatigue on occupational performance highlights the need to further define the functional implications. Occupational performance of IADLs suffered most from the impact of CRF in the daily lives of survivors, however ADLs that involve lifting, pushing, carrying, or tasks that demand increased shoulder range of motion can be affected as well (Hayes et al., 2005; Stariano & Ragland, 1996). Patients with advanced stage cancer reported more significant ADL deficits that increased as the disease process progressed (Taylor & Currow, 2003). In 1998, Ashbury et al. surveyed 913 Canadian cancer survivors to assess the perceived relationship between fatigue and function. Seventy-eight percent of the respondents reported moderate to severe interference with occupational performance ($P < .0001$) with work, socialization, family relationships, and personal finances highlighted as the most affected activities. In the 2000 study by Stone et al., the authors also documented specific areas of occupational performance that were most frequently impacted. These included work-related functions, the ability to enjoy life, and sexual relations (Stone et al., 2000). Broeckel et al. (1998) documented

the negative impact on employment by fatigue symptoms (P < .05). Aside from the emotional factors that accompany the ability to work, the economic impact of loss of work is large with 75% of survivors and 40% of caregivers noting changes in the status of their employment attributable to fatigue (Spelten et al., 2003).

Servaes, Verhagen, S., & Bleijenberg (2002) compared a sample of 150 younger disease-free pre-menopausal BCS in the Netherlands (6 – 70 months post-adjuvant therapies) with 78 peer-nominated controls to assess various dimensions of the fatigue construct. Results indicated that 38% of the BCS met the criteria for severe fatigue on self-perceived fatigue measurement tools and 16% met the criteria for non-severely fatigued status, whereas only 11% of the control group met the same criteria. Severely fatigued BCS reported more functional impairments than controls, although the authors found no difference in task demands or hours spent in daily tasks between the groups using a prospective recording form for ADL and IADL activity that was completed four times daily over 12 days; their findings indicated that BCS performed the same tasks as disease-free counterparts, but performance was more difficult due to fatigue (Servaes, Verghagen, S., & Bleijenberg, 2002). BCS were also employed for fewer hours per day than the control counterparts and fatigued BCS also reported less physical activity and less social functioning than controls or less-severely fatigued BCS (Servaes, Verghagen, S., & Bleijenberg et al., 2002).

Not all studies have examined CRF as a correlate to occupational performance deficits, yet many have clearly identified the loss of functional status in BCS from specific upper extremity deficits. Hayes et al. (2005) identified specific ADL and IADL tasks that caused difficulty for BCS, stratifying difficult tasks into those that were usually

performed more frequently to calculate which daily tasks created the greatest overall

burden. The tasks most frequently cited were "carrying a moderate weight, washing the

upper part of the back, opening a tight jar, and doing up a bra" (p.257). BCS also

identified other difficulties in IADLs that included carrying, pushing or pulling tasks such

as laundry and grocery shopping; repetitive tasks such as vacuuming, raking, or

sweeping; and tasks that involved reaching overhead (Hayes et al., 2005). The

presence of lymphedema increased task burden by 15 – 21% (Hayes et al., 2005).

Taylor and Currow (2003) conducted a cross-sectional prevalence survey in 104

outpatients and 13 inpatients to identify unmet ADL and IADL needs in a mixed cancer

population in Australia. Thirty-percent of patients identified unmet ADL and IADL needs

that might benefit from assistance to develop alternative techniques or the use of

adaptive equipment, with women identifying more unmet needs than men. Work,

leisure, and driving were the most frequently cited concerns (Taylor & Currow, 2003).

A qualitative study of twenty-four BCS in Australia confirmed previous literature

results documented the impact of upper extremity impairments on occupational

performance and continued complaints of upper extremity dysfunction in 50% of the

participants six months post-surgery (Collins et al., 2004). IADL task performance was

impacted most once BCS had completed all surgery and adjuvant therapies, but were

further complicated by perceived fatigue and emotional distress (Collins et al., 2004).

Task deficits reported in this study included "sleeping on the affected side, putting

washing on the line, putting curtains up, washing the windows, gardening, writing,

cutting vegetables, ironing, computer work, carrying a handbag, doing up a bra, wearing

a bra and buying a comfortable one, and driving in a car (seatbelt wearing, putting

hands on the wheel and driving over bumps) (Collins et al., 2004, p.109). Women expressed uncertainty, confusion, or denial about the need to include exercise as a component of breast cancer recovery, but women who attended a gentle exercise group described the benefits of the exercises and increased realization of the extent of their upper quadrant deficits (Collins et al., 2004). This study was important in providing a detailed description of specific activities that resulted in deficits in occupational performance, despite the small sample size and participants who once again composed an educated cohort within a higher socioeconomic class.

The heterogeneity of breast cancer survivors has been described throughout the literature. Individual variability in fatigue throughout the day was explored by Dhruva et al. (2010), in a repeated-measures study of 73 BC patients examining patterns of fatigue throughout and following radiation therapy. This study confirmed the variability of idiosyncratic fatigue experiences and identified differences in predictive factors for morning and evening fatigue. Two occupational performance variables, specifically caregiving for children and employment, emerged as predictive for evening fatigue (Dhruva et al., 2010).

Fatigue and Arm Function Symptoms

No studies have specifically examined the relationship between cancer-related fatigue and physical symptoms in the ipsilateral extremity, but a few have documented findings that suggest that factors related to limb function and CRF may interact. In a large study (n =1,933) conducted in Korea that examined prevalence rates and relationships between CRF, depression and QOL in BCS, Kim et al. (2008) documented five risk factors for developing CRF and depression: dyspnea, sleep disturbance,

appetite loss, constipation, arm symptoms, and lower monthly income. Further details about arm symptoms, which were assessed as part of a larger quality of life measure, were not explored. A recent study by Gerber et al. (2010) reported significant correlates of biological and behavioral factors to persistent fatigue in 44 BCS nine months post-diagnosis, identifying higher levels of fatigue in women with increased body mass index (BMI), WBC counts > 8,000, increased ipsilateral limb size, and decreased levels of physical activity. Their findings indicated the presence of a predictive relationship between defined symptoms of upper body morbidity, lifestyle factors, and cancer fatigue in breast cancer survivors (Gerber et al., 2010). Significant fatigue was found in 25% of the study sample using a single item 0 – 10 point numeric rating scale (Gerber et al., 2010). Several studies have also identified pain, although not always specified as related to upper limb function, as a contributing factor in CRF. Reinertsen et al. (2010) noted this relationship in a longitudinal study of off-treatment long-term BCS described earlier in this section, reporting statistically significant pain and discomfort on the side of the body treated for cancer (p < .001).

Impact of CRF and Arm Function on Employment

Women spend a great deal of their daily life at work when usual economic conditions prevail, and additional time performing household maintenance tasks and childcare. The United States unemployment rate for 2011, the time period during which data was collected for this study, was 7.9% for adult women (U.S. Bureau of Labor Statistics, 2012). Time use studies on the U.S. population documented that employed and non-working women between ages 20 - 64 spent a mean of 20.9 – 27.3 hours per week in work related tasks, a mean of 10 – 18.3 hours on household tasks and a mean

of 27.4 – 36.2 on leisure activities (U.S. Bureau of Labor Statistics, 2010). Women with more education devoted more weekly hours to employment, whereas women with less education spent more hours on household tasks (U.S. Bureau of Labor Statistics, 2010).

For BCS under retirement age, employment during or following treatment for breast cancer is often a desirable outcome and some may view the return to work as a hallmark of successful management of the disease process (Spelten et al., 2003). Persistent symptoms resulting from the cancer or subsequent surgical or adjuvant therapy interventions may alter the trajectory of employment for BCS, particularly since nearly half of all cancer survivors are under retirement age (de Boer et al., 2009). However persistent symptom burden resulting from the disease process or treatment may negatively impact employment status (Hansen, Feurerstein, Calvio, & Olsen, 2008). Employment was a secondary area of interest for this exploratory study; several questions were formulated in the demographic survey to survey potential changes in employment resulting from the breast cancer itself or current United States economic conditions, as well as to understand the current employment profile for the study sample. In addition, data from the Disability of the Arm Shoulder Hand (DASH) Optional Work Module was collected to try to ascertain perceived interference from upper extremity symptoms on physical work-related tasks.

A review of the cancer survivor literature revealed that the majority of studies on employment were conducted on individuals who were still receiving cancer treatment during data collection. de Boer et al. (2009) conducted a meta-analysis and meta-regression analysis of 26 articles compiling results from 26 studies to ascertain key factors that may predispose survivors to employment risk. Breast cancer survivors were

found to be 1.28 times more likely to be unemployed than comparable healthy controls (35.6% vs. 31.7%) (de Boer, 2009, p. 757). Limitations in physical status or persistent residual cancer symptomatology were identified as key factors contributing to unemployment in all cancer survivors, although not inclusive to BCS (de Boer, 2009). A longitudinal study examined physical and cognitive task requirements for job performance in 447 BCS and 267 prostate cancer survivors at 12 and 18 months post-diagnosis demonstrated that there was a subset of survivors that continue to experience work-related problems secondary to physical limitations even though many survivors do well following the conclusion of treatment (Obserst, Bradley, Gardiner, Schenk, & Given, 2010). At one year post-diagnosis, they found that 71% of the BCS reported the need to perform physical job task demands and almost universal agreement on the requirement for cognitive task demands at work (Obserst et al., 2010). More women reported physical disability at one year that limited work performance (60%) with improvement at 18 months (36%; $p < .01$), but employment decreased for women with disabling residual physical limitations at both time points compared with BCS without these limitations (Obserst et al., 2010, p. 326).

Hansen et al. (2008) captured information regarding residual symptom burden in a study of 100 working BCS who were an average of four years post-treatment and a healthy comparison group responding to an online survey. The authors found that fatigue was significantly higher in BCS than the comparison group ($p < .001$), as were symptoms of depression, anxiety and cognitive limitations, with fatigue accounting for 71% of the total symptom burden (p. 781). The study did not examine the impact of residual arm symptoms in the BCS, although pain was noted to be a non-significant

contributor as was tumor stage and cancer treatment. It is difficult to compare these studies since Obserst et al. (2010) examined actual task demands and Hansen et al. (2008) reported on a range of symptoms, but did not address the actual work tasks performed by the respondents. The impact of going to work every day with persistent symptoms should not be underestimated. Studies researching the economic burden of survivorship indicate that when time post-treatment is included as a variable, working survivors still experience more functional limitations and variability in employment status than individuals without cancer (Yabroff, Lund, Kepka, & Mariotto, 2011).

Literature Summary

The imperative to address the needs of breast cancer survivors is repeatedly affirmed in the literature and throughout government agencies focused on cancer survivorship. Cancer-related fatigue [CRF] has been shown to contribute to decreased quality of life and reductions in occupational performance in BCS and persists as a long-standing symptom in a subset of women after adjuvant therapies conclude. In addition, upper extremity deficits resulting from the cancer disease process, surgical excision of tumors and single or combination adjuvant therapies also negatively affect occupational performance and quality of life. The loss of functional status in specific tasks related to IADLs, work, and social participation are oft cited for the physical parameters associated with upper extremity dysfunction, as well as those resulting from fatigue sequelae.

CRF is regarded as a complex multi-dimensional construct measured most accurately by self-report and by noticeable effects on occupational performance of life tasks. Research is necessary to contribute to the growing body of evidence that

supports acknowledgement and interventions for these disruptive symptoms and

prevention of secondary morbidities resulting from surgical intervention and adjuvant

therapies. A desirable goal must be to assist BCS to return to full participation in all daily

occupations, including the performance of ADLs, IADLs, work, leisure, and socialization

activities.

CHAPTER III

METHODS

Introduction

This study describes the relationship between perceived cancer-related fatigue and upper extremity functional status in breast cancer survivors a minimum of one year (> 12 months) to a maximum of 6 years (< 72 months) following the conclusion of surgical and adjuvant therapies. Perceptions of cancer-related fatigue and upper extremity functional abilities were additionally explored by examining participant differences in node dissection status, adjuvant therapies received and caregiving responsibilities. This chapter details the methodology for the study including design, subject criteria and sampling methodology, an overview of the psychometrics related to the outcome variables of interest, and administrative procedures.

Design

The study is an exploratory, cross-sectional descriptive design. A correlational study was chosen since the relationship between the two main constructs of interest, cancer-related fatigue and upper extremity function, have not been explored in the literature. This type of study can be used to generate other research hypotheses and further describe the variables of interest (Polit & Hungler, 1995; Portnoy & Watkins, 1993). A series of self-report instruments were provided to obtain demographic and health data, and to assess perceived cancer-related fatigue and upper extremity function. On-line convenience-sample survey methodology was employed to recruit the sample and collect data.

Research Questions and Hypotheses

There were four research questions for this study.

RQ1. Is there a relationship between self-reported cancer-related fatigue and perceived upper extremity functional deficits in breast cancer survivors (BCS)?

Ha.1. There is a relationship between self-reported cancer-related fatigue and perceived upper extremity functional deficits in BCS

RQ2. Is there a difference in perceived upper extremity function and fatigue between breast cancer survivors (BCS) who underwent sentinel node dissection and those who underwent axillary node dissection?

Ha.2.1: There is a difference in perceived upper extremity function between BCS who underwent various node dissection procedures, including axillary node dissection, sentinel node dissection and both axillary and sentinel node dissection.

Ha.2.2: There is a difference in perceived cancer-related fatigue between BCS who underwent various node dissection procedures, including axillary node dissection, sentinel node dissection and both axillary and sentinel node dissection.

RQ3. Is there is a difference in perceived upper extremity function and fatigue between breast cancer survivors (BCS) who underwent differing types of adjuvant cancer therapies, including chemotherapy, radiation, or combination therapies?

Ha3.1: There is a difference in perceived upper extremity function between BCS who underwent chemotherapy, radiation, immunotherapy, hormone therapy or combination therapies.

Ha3.2: There is a difference in perceived cancer-related fatigue between BCS who underwent chemotherapy, radiation, immunotherapy, hormone therapy or combination therapies.

RQ4. Is there a difference in perceived upper extremity function and fatigue between breast cancer survivors (BCS) who have dependent caregiver responsibilities and those without dependent caregiver responsibilities?

Ha4.1: There is a difference in perceived upper extremity function between BCS who have dependent caregiver responsibilities and those without dependent caregiver responsibilities.

Ha4.2: There is a difference in perceived cancer-related fatigue between BCS who have dependent caregiver responsibilities and those without dependent caregiver responsibilities.

Description of Participants

Women were eligible to participate in the study if they (1) were between 21 - 65 years of age (2) could read English; (3) had a confirmed diagnosis of breast cancer, Stage 0 to III (Andrykowski, Curran, & Lightner, 1998); (4) had received and completed required surgical intervention, adjuvant chemotherapy and/or radiotherapy treatment for breast cancer a minimum of 1 year (>12 months) and a maximum of 6 years (<72 months) prior to participation in the study (Curran, Beacham, & Andrykowski, 2004;

Young & White, 2006), (5) were currently in remission or considered to be disease-free, (6) had access to the internet; (7) were willing to complete on-line questionnaires and a demographic survey and (8) resided in the United States. Women who were not in remission or considered to be disease-free, were in Stage IV (metastasis), were still undergoing active cancer treatment or surgical intervention, did not have internet access, resided outside the United States, or whose diagnostic and treatment completion parameters did not fall within the designated time parameters, were excluded. No compensation or incentives were offered to participants who volunteered to complete the study.

Pilot data was obtained from February 2011 through April 2011. Active recruitment for the final data sample occurred from October 2011 through January 2012.

Sample Size Estimate. An a priori sample size of 268 participants was estimated using G*Power, version 3.1, based on a medium effect size of 0.30, an alpha level of 0.05 (two-tailed) and 0.80 power (Faul, Erdfelder, Lang, & Buchner, 2007).

Sampling Method

An internet snowball sampling strategy was chosen due to the exploratory nature of the study. Locating an adequate sampling frame for participants within the narrowly defined inclusionary criteria was anticipated to be difficult without a broader recruitment effort. Snowball recruitment has been found to be less expensive than mail recruitment methods, time efficient for respondents and uses increasingly available informal and social networking to bolster recruitment efforts (Ritter, Lorig, Laurent, & Matthews, 2004). This methodology has been used to recruit populations that are difficult to access

by other means, including for studies that must request sensitive health or personal information (Sadler, Lee, Lim, & Fullerton, 2010). This sampling schema originated in "'contact tracing' in public health in which one individual names all other individuals who were associated with a specific event" (Sadler et al., 2010, p. 370), or as one researcher euphemistically described, using the social equivalent of "six degrees of separation" between contact groups (Gruppetta, 2005, p.8).

Research is limited on internet use patterns for women with breast cancer. Fogel, Albert, Schnabel, Ditkoff, and Neugut (2002) conducted a cross-sectional study, using a mailed questionnaire, to examine the use of the internet for breast cancer-related concerns by 188 BCS in New York City who were under the age of 65 and within three years of diagnosis. They found that 41.5% of the sample reported utilizing the web for information, finding that users were more educated, had higher socioeconomic status, were more likely to be Caucasian, and trended toward younger ages (Fogel et al., 2002). They further noted that minority participants demonstrated a trend toward less use of the internet for health-related concerns (Fogel et al., 2002). This is consistent with other studies that continue to report the existence of a digital divide in computer and internet access.

A 2011 survey by the Pew Research Center's Internet and American Life Project documented the use of the internet by 78% of adults residing in the United States, with 59% of all adult users researching health-related information (Fox, 2011, p.5). The largest percentage of health information seekers, 66%, searched for specific medical conditions with women seeking health information (83%) more often than men (73%) (Fox, 2011, p.9). White users (70%; N = 1267) comprised the largest group of

individuals who sought information on health problems regardless of gender, followed by Latino users (58%; N = 285) and Black users (54%; N = 356) (Fox, 2011, p.23), although the Pew Foundation noted that increasing access to mobile devices, such as cell phones, may continue to positively alter user percentages in minority populations over time (Fox, 2011, p.3). Limitations in the sampling and recruitment method are discussed in Chapter V.

Breast cancer survivors constitute the largest percentage of cancer survivors in the United States, but are a heterogeneous group. Women may not participate in virtual or in-person support group networks or return to clinical sites for follow-up on a time table that permits cost-effective and timely recruitment efforts for research. The parameters for this study were further limited to a narrow sector of the overall population of breast cancer survivors living in the United States. Since community-dwelling BCS who had completed all initial treatment were the target population, it was felt that a general snowball recruitment effort would result in sufficient subject self-selection to meet the a priori population estimate. Additionally, recruitment efforts for the final sample were initiated at the beginning of October during Breast Cancer Awareness Month, typically a time of focused attention on this population in popular media and NGO educational and fundraising directives. Unlike snowball recruitment using mail surveys, participant anonymity was maintained and researcher blinding was not required since it was not necessary for the investigator to contact an identified potential respondent in order to forward the survey. This type of recruitment is, however, considered to be non-probability sampling and typically does not produce a random sample or reduce all recruitment bias (Sadler et al., 2010; Etter & Perneger, 2000).

Study Sample Recruitment. Faculty, Staff, and Students in the School of Health and Medical Sciences (SHMS) as well as professional and personal contacts received the pilot e-mail snowball recruitment announcement requesting voluntary participation in the study for eligible BCS, or asked the recipient to forward the e-mail to other individuals who might be eligible. Distinct collectors, for example, 'Faculty and Staff' were identified by the investigator using the collector function in Survey Monkey prior to deployment of the survey. Each collector was automatically assigned a unique URL address by the software package that was individually pasted into the e-mail request for participation in order to assess the responsiveness of selected groups to recruitment efforts. Anonymity was maintained since collectors only covered broad categories of potential respondent pools. Pilot sample snowball recruitment invitations were sent to 7 administrators, 8 staff, 41 faculty (N. Blaszka, personal communication, February 23, 2012), and 428 students in the School of Health and Medical Sciences at Seton Hall University (D. Verderosa, personal communication, February 23, 2012), along with 7 personal contacts, an oncology nurse specializing in breast cancer and two oncology social workers.

Final sample recruitment included 506 administrators, 341 staff, and 455 faculty on the South Orange Campus, and 43 administrators, 42 staff, and 81 faculty at the Newark Law School Campus (M.J. Hudson, personal communication, February 23, 2012). Additionally, 5300 undergraduate students and 4400 graduate students on the Seton Hall University South Orange Campus (SHU.edu, 2011) received the e-mail invitation to participate or forward the study information. An additional 21,495 Seton Hall University alumni also served as initial contact sources (D.P. Nugent, personal

communication, February 16, 2012), along with 300 personal and professional contacts, solicitation of cancer support organizations serving breast cancer survivors, and three physician practices willing to forward the survey information or place IRB approved recruitment fliers in their offices. In December 2011, a second request for participation was forwarded to the South Orange Campus only through the Seton Hall University Campus Digest, a university news and event e-newsletter that replaced the Broadcast e-mail system for non-administrative contact with faculty, staff and students. The e-mail and paper recruitment letters included an e-mail address and phone number in the event that contact with the investigator was desired, as well as IRB contact information.

Procedures

Institutional Review Board approval was obtained for the pilot study and for clarification in the wording for selected items on the demographic survey questions prior to final data collection to facilitate ease of completion by respondents. Moreover, a sentence was added to the recruitment invitation asking BCS who completed the pilot survey to refrain from responding to the survey a second time. Modifications in demographic survey questions included the following alterations:

Question 1 was changed from "What is your date of birth?" to "What is your age?" since the exact date of birth was not required for data analysis. An additional response option, "Asian" was added to Question 3, "How do you identify yourself?", as this variable was inadvertently omitted from the pilot study demographic questionnaire. An open-ended response option permitted respondents to self-identify in whatever manner they deemed appropriate and was available for pilot and final data collection surveys; no individuals in the pilot survey self-identified as Asian. Question 13, "Have you had more than one episode (recurrence) of breast cancer (yes, no)? Right or Left

side?" was added to the final data collection after two respondents in the pilot study indicated that they developed recurrence of breast cancer during the inclusionary time period of 12 to 72 months post-treatment. The exclusionary criteria eliminated BCS diagnosed with metastasis, but did not request incidence information about recurrence. It was felt that recurrence data should be captured for accuracy in data analysis and reporting of results.

Question 14 was amended from "What type of surgery did you have? (Choice of none, lumpectomy, *partial mastectomy, total mastectomy*, reconstruction – can select more than one response)" to "What type of surgery did you have? (Choice of none, lumpectomy, mastectomy, reconstruction – can select more than one response). Pilot data collection indicated that participants may have had difficulty understanding the medical terminology used to describe mastectomy procedures. Definitions were not provided during the pilot study, therefore simplifying the terminology to a single category of 'lumpectomy' for breast conserving surgery and 'mastectomy' was deemed to be less confusing to respondents. The research hypotheses for this study did not require further delineation of the specific type of lumpectomy, mastectomy or reconstructive surgery procedure.

Two optional open-ended questions, "Are there any other daily activities that have been impacted by having fatigue (list)?" and "Are there any other daily activities that have been impacted by problems with arm function (list)?" were added to the survey following pilot data collection. Functional activities identified in the FACIT-F or DASH surveys might not capture the full range of performance deficits in tasks that BCS encounter on a daily basis. Questions 33 and 34 permitted the respondent to describe

other activities impacted by fatigue or problems with arm function, unimpeded by the assumptions of the validated instruments or investigator-generated questions.

Broadcast e-mails through Seton Hall University, e-mails to cancer support groups, selected community organizations, professional and personal contacts were used to recruit participants. Snowball recruitment methodology was utilized. All individuals who received the initial recruitment request were asked to forward, "snowball", the e-mail to women they knew who might be interested in participating in the study or individuals who might be willing to forward the request to others. Women interested in participating were directed to click on a link to a unique URL address on Survey Monkey, allowing them to view and complete the self-administered survey. Seven unique URLs were assigned to the final survey during data collection to identify collector sources, e.g., professional contacts, in order to assess the snowball recruitment methodology during data analysis. A brief summary of the research study, inclusionary and exclusionary criteria and informed consent information was posted on the initial e-mail. In addition, a paper version of the recruitment e-mail solicitation was approved by the Institutional Review Board for distribution, but survey completion was only available through the Survey Monkey internet-based site.

The survey was conducted via Survey Monkey, an internet-based survey company providing server and encryption security to ensure data protection. According to company information, Survey Monkey is one of the most frequently used web survey platform tools available on the internet (surveymonkey.com, 2009). Prospective participants or individuals who might know potential respondents received an e-mail invitation to participate and were then provided with a URL address specific to this

survey if they are eligible and willing to participate. Confidentiality of participants was maintained by the automatic assigning of unique numeric codes to each participant during data downloads into SPSS from the survey site.

Survey Monkey parameters were set to cue participants, through highlighted text, to complete any unanswered questions on the demographic survey or assessment tools prior to allowing respondents to submit that section of the survey or questionnaire in an attempt to obtain complete information and reduce missing data points. Data obtained from participants was secured in a locked file cabinet in the School of Health and Medical Education on the Seton Hall University South Orange campus.

Assessments were administered in the same order to all participants: demographic information and health history, Functional Assessment of Cancer Therapy Fatigue Scale (FACT-F), Disabilities of the Arm, Shoulder, and Hand (DASH), Optional Work Module of the DASH, and two optional open-ended questions, Q32 and Q33, inquiring about other daily activities that have been impacted by having fatigue or problems with arm function respectively.

Instrumentation

Demographic Survey. Demographic information collected included ICF Personal Factors (age, state of residence, race, marital status, number of dependent children, and highest level of education achieved (WHO, 2001), ICF Work and Employment Factors (current occupation collected as part of the Disability of the Arm Shoulder Hand [DASH] Optional Work Module) and employment status) and ICF Environmental Factors ascertaining whether employment status was impacted by the breast cancer or the current state of the U.S. economy respectively (WHO, 2001).

Participant-reported health history included ICF Body Functions and Structures (hand

dominance, side of tumor location, year and stage at diagnosis, type of surgery

including reconstruction, adjuvant therapies received, and lymphedema diagnosis,

treatment or management, including the preventative wearing of compression sleeves)

(WHO, 2001).

Respondents also answered an investigator developed set of questions for

cancer-related fatigue that corresponded to the major ICF Activities and Participation

categories of self-care [Self-care], care of others [Assisting Others], household tasks

[Domestic Life], shopping or errands [Domestic Life], work [Work and Employment],

leisure or relaxation [Community, Social and Civic Life], and socialization [Interpersonal

Interactions and Relationships] (World Health Organization [WHO], 2001). Perceptions

of the impact of fatigue on these functional activities were not addressed in items on the

Functional Assessment of Cancer Therapy Fatigue Scale (FACT-F). The questions also

corresponded to the Occupational Therapy Practice Framework, 2nd edition, delineating

the domains of practice for the profession of occupational therapy (AOTA, 2008). They

were added to the survey to provide a better descriptive understanding of the impact of

fatigue on daily function.

Disabilities of the Arm, Shoulder, and Hand (DASH). Developed by the

Institute for Work and Health in Toronto, Canada, and the American Academy of

Orthopedic Surgeons in 1996, the Disabilities of the Arm, Shoulder, and Hand

questionnaire [DASH] (Kennedy et al., 2011) is a standardized health-related quality of

life (HRQOL) outcomes measure designed to assess patient perceptions of upper

extremity function resulting in limitations in ADL and IADL tasks, as well as perceived

extremity-related symptoms such as pain or weakness. It consists of a 30-item questionnaire asking patients to assess their ability to perform common ADL and IADL tasks, noting the level of disruption to function and musculoskeletal symptoms within the prior week using a 5-point Likert scale with answers ranging from "not at all" to "extremely" (Kennedy et al., Beaton, Solway, McConnell, & Bombardier, 2011). The questionnaire is designed to be self-administered. It requests responses to several different facets of upper quadrant function. The composition of the questionnaire details 21 questions about the respondent's ability to complete specific activities of daily living such as washing one's back or cutting food, and instrumental activities of daily living, including items asking for ability to complete heavy housework, meal preparation or changing a light bulb (Kennedy et al., 2011). Five questions assess physical symptoms such as pain, tingling and weakness, and four questions request information on socialization, global ability to complete tasks, sleep, and feelings of overall confidence in the ability to complete daily tasks (Kennedy et al., 2011).

The DASH was chosen due to its reliable and validated psychometric properties with a variety of patients with upper extremity dysfunction, including employed and disabled workers (Kennedy et al., 2011; Jester et al., 2005; Bot et al., 2004; SooHoo, McDonald, Seiler, & McGillivary, 2002; Beaton et al., 2001; Hudak et al., 1996). The instrument has also been used to research perceived upper body function in breast cancer survivors, with and without lymphedema (Smoot et al., 2010; Koh & Morrison, 2009; Dawes et al., 2008; Hayes et al., 2005). It is also one of the few measurement tools for the upper extremity that focuses on the functional activity outcomes resulting from whole arm movement patterns, rather than attending to single joints. It has been

also been studied relative to its fit with the ICF structure (Dixon et al., 2008),

demonstrating the ability to measure ICF outcomes at the impairment, activity, and

participation level and is thus consistent with the theoretical framework that supports

this study.

In 2002, the scoring for the DASH was revised, now calculated by adding the

sums of the item responses divided by the number of completed items, subtracting 1,

and multiplying by 25 (Kennedy et al., 2011). This produces a transformed value

ranging from "0" or no perceived disability, to "100", a greater level of perceived

disability. Greater than three missing item responses results in an inability to score the

questionnaire (Kennedy et al., 2011). Up to three missing items can be addressed by

replacing those values with "the mean value of the responses to the other items before

summing" (Beaton et al., 2001, p.129). The DASH takes an estimated 6 minutes to

complete and 3 minutes to score (Michener & Leggin, 2001).

There are also two optional DASH modules recording the self-perceived impact

of upper extremity dysfunction on work and on sports/performing arts. Either or both

modules may be used to obtain additional information. Each optional module consists of

4 questions rated on a 5-point Likert scale ranging from "no difficulty" to "unable"

(Kennedy et al., 2011). Each module is scored separately by adding the values for each

response, dividing by 4, subtracting 1 and multiplying by 25 (Kennedy et al., 2011). All

four questions on each module must be answered in order to obtain the summary score.

For the purpose of this study, only the optional work module was used since

employment is a key concern of cancer survivors and is often the benchmark by which

survivors measure their return to prior life activities (Maunsell et al., 2004). The DASH

Work Module has only four items and is designed to assess the level of physical difficulty the person has performing employment activities, including performing tasks in a similar manner as before illness and performing at usual levels (Kennedy et al., 2011). It does not assess or question other aspects of work performance, but does have an open response question asking the respondent to list their current job. Chronbach's alpha for this optional module is 0.89 (Tang, Pitts, Solway, & Beaton, 2009). It has been shown to discriminate differences in some diagnostic groups as well as by the number of upper quadrant regions impacted, resulting in increased levels of disability (Fan, 2008). There was only one study located that specifically cited the use of the optional work module with a sample of 18 individuals who had undergone latissimus dorsi flap reconstruction, including 4 BCS who underwent reconstruction following mastectomy (Koh & Morrison, 2009).

In a nationally representative sample in the United States, the DASH exhibited Cronbach's alpha ranging from 0.94 to 0.98, Pearson correlations of 0.49 to 0.87, and item internal consistency of 100 (Hunsaker et al., 2002, p.213). Mean scale scores for global function on the DASH (n = 1706) was 10.10 (SD 14.68) and 8.81 (SD 18.37) on the Work Optional Scale (n = 1610) (Hunsaker et al., p.211). The Institute for Work & Health 3rd edition of the DASH user's guide enumerates normative values for women in the general U.S. population (N = 1008), with a mean of 11.96 for the DASH and 9.44 for the DASH Optional Work Module (Kennedy et al., 2011, p.143). These values, rather than those delineated in the earlier publication by Hunsaker et al., were chosen for comparison with the study sample due to the ability to isolate gender-based scores.

Construct validity of the DASH as an extremity specific quality of life outcome measure was supported by data from SooHoo et al., (2002) in a study examining correlations of the DASH to the Medical Outcomes Study Short-Form 36 (SF-36), a well established quality of life outcome measure with available standardized normative scores for the U.S. population. The hypotheses were confirmed with moderate correlations observed ranging from 0.36 for the general health subscale to .62 for the role emotional subscale (SooHoo et al., 2002). Beaton, et al. (2001) also assessed the psychometric properties of the DASH, examining within-subject responsiveness, reliability and validity in a study sample of 172 patients from major hospital centers in Toronto (n = 109) and Boston (n = 91) engaged in treatment for a variety of upper extremity disorders. Discriminative validity was established between employed patients and those on disability, as well as between individuals diagnosed with shoulder versus hand conditions (26.8 vs. 50.7, t = -7.51, p < .0001) (Beaton, 2001, p. 135). Reliability of the DASH as measured by Cronbach's alpha was reported as 0.97 (Beaton, p.140) during baseline data collection and is further supported by data from Gummesson et al. (2003) documenting Cronbach's alpha levels above 0.90.

Convergent construct validity was also found in Pearson correlations exceeding 0.70 between the DASH and joint-specific measures, the Shoulder Pain and Disability Index (SPADI) and the Brigham questionnaire for hand and wrist dysfunction (Beaton, 2001, p.135). Pearson correlation using data over the course of 3 – 5 days from 56 subjects reporting that they had no change in deficits during that time period was 0.96 and Spearman ranked correlation was 0.96 at the 95% CI (Beaton et al., 2001) indicating high test-retest reliability.

Prior research supports the use of the DASH as a valid, reliable, and responsive HRQOL tool for single or multiple musculoskeletal disorders in the upper extremities. A review of the literature did not reveal any articles documenting computer-based self-administration of this instrument. Permission was granted from the Institute for Work and Health in Toronto, Canada, to use the DASH and to place the instrument in an on-line environment in Survey Monkey for participants (G. Palloo, personal communication, January 10, 2010).

Functional Assessment of Cancer Therapy Fatigue Scale (FACT-F): Fatigue Subscale. The Functional Assessment of Cancer Therapy (FACT) is a system of self-report questionnaires designed to evaluate various QOL impact of cancer therapies on individuals living with cancer (Yellen et al., 1997). The FACT is a subset of the larger Functional Assessment of Chronic Illness Therapy (FACIT) system, a vast test bank of validated questionnaires designed for a variety of health-based conditions and translated into 43 languages (Stasi et al., 2003). Subsumed as part of the FACIT system, is a tool that was designed to assess anemia (FACT-An) in individuals undergoing treatment for cancer. Contained within the FACT-An is a 13-item subscale designed to assess cancer-related fatigue since fatigue is a foremost distinguishing symptom of anemia. Subsequent research validated the FACT-F as a separate assessment instrument from the FACT-An questionnaire that can be used across the cancer spectrum to assess fatigue-based symptoms (Van Belle et al., 2005; Hwang et al., 2003; Passik et al., 2002; Yellen et al., 1997). The 4th version of the 13-item scale, titled the FACIT-Fatigue on the publisher's site is also referred to as the FACT-F in research studies (Santana et al., 2009). For the purpose of consistency within this

project, the tool will be referred to as the FACIT-F, except when describing other research studies that utilized the original FACT-F label.

The FACIT-F is composed of the same 13-item fatigue subscale described in the FACT-An, as well as in questions from the FACT-G on information related to the impact of fatigue on quality of life concerns such as physical, social, emotional, and functional status (Cella, Eton, et al., 2002; Yellen et al., 1997). Each item retrospectively assesses the experience of fatigue over the past seven days and is rated on a 5-point Likert scale, from 0 "not at all" to 4 "very much so" (Cella, Eton et al., 2002; Van Belle et al., 2005). Scores range from 0 to 52; during data analysis items are reverse coded, therefore higher scores are indicative of better health and less fatigue, and lower scores indicate more fatigue and lower HRQOL (Yellen et al., 1997; FACIT.org, 2012). Estimated completion time for the FACIT-F is 2-3 minutes (FACIT.org, 2012). It has a reading level of 4.0, making it suitable for a range of populations and can be self-administered using computer-based testing (Yellen et al.; FACIT.org, 2012). The FACIT-F has been documented as a suitable measure of self-perceived fatigue in populations with cancer, including cancer survivors (Mustian et al., 2004; Bennett et al., 2004; Stasi et al., 2003; Yellen et al., 1997). Permission was granted by the FACIT organization to use this tool and place the questionnaire on a Survey Monkey web-based platform. The organization noted that the FACIT-F has been utilized in previous studies in virtual environments for linguistic validation and research (J. Bredle, personal communication, January 9, 2009)

Yellen et al., found that the FACT-F fatigue subscale demonstrates validity as an independent measure of cancer fatigue, construct validity, good test-retest reliability

over a 7-day period (r = 0.90) and internal consistency (alphas = 0.93 and 0.95) (p.68), with discriminative validity for hemoglobin levels and better functional performance (1997, p.71). Higher scores in the FACT-F, which indicate higher functioning, were correlated with higher quality of life scores (Yellen et al., 1997). Bennett et al. (2004) found internal consistency for the FACT-F, demonstrated a Cronbach's alpha coefficient of 0.94.

Cella and Eton et al. (2002) evaluated the reliability of the FACT-F, finding that scores demonstrated high internal consistency in three different population samples (> 0.85), good test-retest stability in Sample 1 (n = 50) over a 7-day time period (r > 0.80) and good stability for intraclass correlation coefficients (ICC) of at least 0.85 in all samples (Cella, Eton et al., 2002, p.553). The likely MICD, based on the mean differences for the three populations when retested on the fatigue scale, was 2.7 points (Cella, Eton et al., 2002, p.557). This is the scoring difference that would need to be achieved in order to estimate whether an intervention demonstrated a clinically relevant score change. It was further recommended that a conservative estimate of MICD for the FACT-F be rounded to the nearest whole number, or 3 points (Cella, Eton et al., 2002, p.559).

Van Belle et al. (2005) established that a cut-off score of 34 allowed for prediction of P-ICD-10 status in 93% of 470 patients (sensitivity 0.91, specificity 0.75) to define significant fatigue on the FACT-F (2011, p.251). This score meets the criteria for the diagnostic classification of neoplastic related fatigue in the ICD-10 (Van Belle et al., 2005). Normative values were also established for the FACIT-F for the general United States population using randomized digital dialing sampling methods and compared to

FACIT-F responses from anemic and non-anemic patients with cancer (Cella, Lai et al., 2002). The mean score for the general population (n = 1010) was 43.6 +/- 9.4; 40.0 +/- 9.8 for the non-anemic patients with cancer, and 23.9 +/- 12.6 for the anemic patients with cancer (Cella, Lai et al., 2002, p. 533). Using the findings from this study, a cut-off score of 43 was used to compare the study sample to the general U.S. population, as this provides "sensitivity of 0.92 and a specificity of 0.69", accurately predicting 84% of group assignment (Cella, Lai et al., 2002, p. 537). Both these values, 43 (Cella, Lai et al., 2002) and 34 (Van Belle et al., 2005), were used to compare the study sample to the normative values in order to assess the relationship of the sample to normative and diagnostic criteria. Webster, Cella, and Yost (2003) also reported that the FACIT-F could be self-administered via computer.

Data Analysis

Data analysis was conducted using SPSS version 18.0 software for Windows. Data was downloaded from Survey Monkey into SPSS software, coded and analyzed. Examination and analysis of the pilot and final data sample populations indicated that the pilot data for women meeting the inclusionary criteria could be safely aggregated with the larger sample of eligible respondents and is described in Chapter IV. All statistical tests were two-sided and a P value of < .05 was deemed to be statistically significant, unless otherwise stated. Confidence intervals of 95% were also computed by SPSS where appropriate.

Descriptive statistics, including frequencies, percentages, means and standard deviations were computed to describe the study population characteristics and assess variability in demographic and self-reported health data. Categorical demographic data

(race, marital status, education, employment status, impact of the economy), health factors (hand dominance, breast tumor location, surgical intervention, node dissection status, cancer treatment received, lymphedema diagnosis and treatment, use of compression sleeves), and activity and participation factors (perceived impact of fatigue on daily function and participation, and caregiver status for dependent children) were analyzed using frequencies and percentages. Participant age, tumor stage at diagnosis, year of treatment completion, and ages of dependent children were analyzed using frequencies, percentages, means, and standard deviations.

An evaluation of the relationship between perceived fatigue and perceived upper extremity function was measured using Pearson's correlation. Pearson's was chosen since normative data on the United States population was available for the FACIT-fatigue and the DASH, as well as cut-points to examine the relationship between the study sample and the population norms, as well as normative data for cancer survivors with and without anemia. One sample Student's t-tests were performed to test the hypotheses that the means of the normative scores for the FACIT-fatigue and the DASH respectively were not significantly different from the study sample means.

A Kruskal-Wallis was used to test the hypothesis that there were no differences on average in perceived CRF and perceived upper extremity function respectively between BCS who underwent sentinel node biopsy, axillary node biopsy or both types of node biopsy. Relationships between the FACT-fatigue, DASH, and continuous demographic data were explored using Pearson's product-moment correlation coefficient for normally distributed data. Statistically significant results from the correlational analysis were analyzed using regression analysis to determine the

presence of any predictive models. Categorical demographic data was analyzed using chi-square analysis. Ordinal non-normally distributed data was analyzed using Mann-Whitney U tests, and ratio level demographic data was analyzed using t-tests. An analysis was conducted using a Kruskal-Wallis to assess the difference in perceived upper extremity function and fatigue between survivors who underwent radiation, chemotherapy or combination adjuvant cancer therapies. An analysis was also conducted using an independent sample t-test was used to assess the difference in perceived upper extremity function and fatigue between survivors with dependents living at home and those without dependents living at home. Independent sample t-tests were also used to compare the results on the DASH and FACIT-F scores with the U.S. population or cancer-specific normative values.

Additional Questions

The Optional Work Module of the DASH was used in the survey as a brief measure of perceived physical function in the workplace. Independent sample t-tests were used to compare the results of the DASH Optional Work Module with the U.S. population normative values. Employment information was collected in the demographic survey. In addition, two questions on the demographic survey questioned participants about whether their employment situation had changed as a result of the breast cancer, and whether their employment status had changed as a result of the U.S. economy. Primary work roles described by participants as part of the DASH Work module were coded and stratified using the Standard Occupational Classification (SOC) system, a U.S. Department of Labor categorization system designed for the compilation and dissemination of employment-based data (U.S. Department of Labor, 2010). Descriptive

statistics for categorical variables including frequencies and percentages were used for

analysis of demographic data.

Chapter IV

RESULTS

Sample and Participant Selection

For the pilot study, 494 initial e-mail requests to participate were forwarded, asking individuals who received the e-mail to forward the study invitation to potential respondents if they were not eligible. Additional information directed specifically toward BCS was included in the same e-mail. Invitations were sent to 7 Seton Hall University administrators, 8 staff, 41 faculty (N. Blazka, personal communication, February 23, 2012), and 428 students through department secretaries. An additional 7 personal contacts, an oncology nurse specializing in breast cancer and two oncology social workers were also contacted. Fifty-two BCS responded to the invitation and completed the on-line survey for a response rate of 10.5%. Forty-two BCS met the inclusionary criteria and completed sufficient data points for data analysis.

For the second data collection, 32,663 initial e-mail requests were sent asking individuals to forward the survey information to other personal and professional contacts, resulting in 133 respondents for a .4% response rate. Snowball recruitment invitations were sent to 506 administrators, 341 staff, and 455 faculty on the Seton Hall University South Orange Campus, and 43 administrators, 42 staff, and 81 faculty at the Newark Law School Campus (M.J. Hudson, personal communication, February 23, 2012). Additionally, 5300 undergraduate students and 4400 graduate students on the South Orange Campus received the e-mail invitation to forward study information or participate if eligible. An additional 21,495 Seton Hall University alumni also served as

initial contact sources (D.P. Nugent, personal communication, February 16, 2012),

along with 300 personal and professional contacts, solicitation of cancer support

organizations serving breast cancer survivors, and three physician practices willing to

forward the survey information or place the IRB approved paper recruitment flyers in

their offices. In December 2011, a second request for participation was forwarded to the

South Orange Campus only through the Seton Hall University Campus Digest, a

university news and event e-newsletter that replaced the Broadcast e-mail system for

non-administrative contact with faculty, staff and students. The e-mail and paper

recruitment letters included an e-mail address and phone number in the event that

contact with the PI or IRB was desired.

In order to protect the anonymity of the participants as approved by the Seton

Hall University Institutional Review Board (IRB), no contact data was collected from

individuals who forwarded the e-mail invitation to other contacts or from survey

respondents, therefore it was not possible to contact participants who did not complete

the entire survey in order to request clarification of responses. The mean time for survey

completion time was 15.29 (N = 185) minutes.

Data from eligible respondents in the pilot study was compared to data from

eligible respondents from the final data collection sample. No statistically significant

differences were found between the two groups on general demographic or health-

related variables. Due to the lack of significance on any of these variables, the decision

was made to aggregate the data from the pilot study and the final data collection sample

since it was believed that both samples were drawn from the same larger population of

BCS meeting the inclusionary criteria. Data from the aggregated sample population of

185 BCS from the aggregated sample was then reviewed for eligibility. Twenty-one participants with completed surveys were ineligible based on number of years since diagnosis; 6 were diagnosed in 2011 and 21 were diagnosed before 2004. Final data analysis was conducted on 158 eligible respondents.

Changes that were made in the demographic and health-related variables following the pilot study, as described in Chapter III, were designed to ease respondent burden but the information obtained was unchanged between the two data collection periods. Only one additional question added to the demographic survey following pilot data collection, asking about breast cancer recurrence within the eligible time period. Only 6 respondents from the second data collection point (n = 113) indicated that they had recurrence; 5 (3.2%) on the ipsilateral side and 1 (.6%) on the contralateral side of the original BC (n = 113). The question was eliminated from further data analysis due to the lack of data for the entire sample. The two open-ended questions inquiring about the impact on other daily activities on fatigue and upper extremity function were not asked during the pilot data collection. This question was optional for respondents in the second data collection. Data analysis from those responses is detailed later in this chapter.

Demographics

The average age of the participants was 52 (N = 158, SD 8.08), ranging in age from 32 to 65. Eleven respondents were between ages 32 – 39 (7.1%), 45 respondents were between 40 – 49 years of age (28.4%), 72 were between 50 – 59 (45.5%), and 30 were between 60 – 65 (36.1%). Respondents were more likely to be highly educated with 71 respondents holding a graduate degree (44.9%), married (n = 112, 70.9%),

employed full-time ≥ 35 hours per week (n = 98, 62.0%), and Caucasian (n = 147, 93%).

Table 1 presents the demographic characteristics of the BCS.

Table 1
Participant Characteristics (N = 158)

	n	Percent
Race		
White/Caucasian	147	93.0
Black/African American	5	3.2
Hispanic/Latino	5	3.2
Asian	1	0.6
Education		
Graduate degree or higher	71	44.9
College degree	52	32.9
Associate's degree/some college	21	13.3
High school degree	14	8.9
Marital Status		
Married	112	70.9
Never married/single	15	9.5
Widowed	13	8.2
Divorced	11	7.0
Living with a significant other	4	2.5
Separated	3	1.9
Employment Status		
Full-time employed (≥ 35 hours)	98	62.0
Part-time employed (< 35 hours)	21	13.3
Full-time homemaker	16	10.1
Retired	11	7.0
Unemployed	6	3.8
Leave of absence	2	1.3
On disability	2	1.3
Full-time student	1	0.6
Part-time student	1	0.6

Table 2
Region and State [a] (N = 158)

	n	Percent
Middle Atlantic (NJ, NY, PA)	104	66.2
South Atlantic (DC, FL, GA, MD, NC, VA)	23	14.7
New England (CN, MA, NH, VT)	10	6.3
Pacific (CA, OR, WA)	11	6.9
East North Central (IL, OH)	4	2.5
West North Central (MN)	2	1.3
Mountain (AZ, NV)	2	1.2
East South Central (MS)	1	0.6
Unknown	1	0.6

[a] Respondents by U.S. Census Bureau Regions (n.d.)

Respondents identified 21 states of residency plus the District of Columbia, with the majority living on the East coast of the United States (n = 127, 80.9%) in the Middle and South Atlantic regions (U.S. Census, n.d.). The largest number of respondents lived in NJ (n = 74, 47.1%), NY (n = 24, 15.3%), and CA (n = 9, 5.7%) (Table 2).

Health and treatment demographics. The majority of respondents were right-dominant (n = 146, 92.4%). As data collection took place over the course of 13 months, year of diagnosis ranged from 2004 – 2010 (Table 3). Tumor stage at diagnosis was most likely to be Stage I (n = 60, 38.0%) or Stage II (n = 49, 31.0%). There were equal numbers of BCS identifying the original tumor location as right versus left sided with 6 BCS identifying bilateral tumor identification at diagnosis (3.8%). Eighty-six participants (54.4%, N = 158) listed the number of nodes removed during diagnostic procedures for tumor staging. The average number of nodes removed was 8.87 (S.D. 8.122, range 1 –

33) (Table 4). Sentinel node dissection was the most frequent staging procedure

identified by a ratio of 4.5:1.

Table 3
Year of Diagnosis (N = 158)

	n	Percent
2004	7	4.4
2005	18	11.4
2006	20	12.7
2007	20	12.7
2008	39	24.7
2009	35	22.2
2010	19	12.0

Table 4
Type of Node Dissection (N = 158)

	n	Percent
None	19	12.0
Axillary Node	18	11.4
Sentinel Node	81	51.3
Both	30	19.0
Do not know	10	6.3

Additional health and treatment characteristics are presented in Table 5. Of the

69 BCS who underwent lumpectomies (43.7%), none had reconstructive surgery. Of the

68 respondents who underwent mastectomies (36.7%), 45 had undergone

reconstructive surgery (66.1%). Twenty BCS had lumpectomies and mastectomies

(12.6%). Of those BCS who underwent both procedures, 15 had reconstruction (75%).

Twenty-five women identified a diagnosis of lymphedema (15.8%); 7 (39%) BCS

with axillary node dissection, 12 (15%) BCS with sentinel node biopsy, 4 (13%) BCS

who underwent both types of node biopsies and 2 (20%) BCS who did not know the

type of node biopsies they received. Ten (6.4%) were receiving treatment for the

lymphedema from an occupational or physical therapist at the time of survey completion; 4 (40%) with axillary node dissection, 4 (40%) with sentinel node biopsy and 2 (20%) with both types of node biopsies. Eleven (7.2%) BCS used compression wrapping to treat the lymphedema.

Additional questions were asked about the use of compression garments (sleeve) during daily tasks to manage or prevent lymphedema. Compression sleeves were worn by 33 BCS during air travel (n = 98, 33.7%), by 12 participants (n = 82, 14.6%) while exercising, by 14 (n = 86, 16.3%) when performing heavy housework, and 4 wore the compression garment at all times (n = 76, 5.3%). Of the 25 BCS reporting diagnosed lymphedema, 86% wore their garment during air travel, 75% during exercise, 71% during heavy housework, and 40% at all times.

Table 5

Health and Treatment Characteristics (N = 158)

	n	Percent
Hand dominance (n = 158)		
Right	146	92.4
Left	12	7.6
Tumor location (n = 158)		
Right	75	47.5
Left	75	47.5
Both sides	6	3.8
Tumor stage at diagnosis (n = 158)		
0	25	15.8
I	60	38.0
II	49	31.0
III	22	13.9
Do not know	2	1.3
Type of surgery (n = 158)		
Lumpectomy	69	43.7
Mastectomy	68	36.7
Both	20	12.7
Breast reconstruction	65	41.4
None	1	0.6
Diagnosed with Lymphedema (n = 157)		
Yes	25	15.8
No	132	83.5
Receiving treatment for lymphedema (n = 157)		
Yes	10	6.4
No	147	93.6
Compression wrap lymphedema bandages (n = 153)		
Yes	11	7.2
No	142	92.8

Childcare responsibilities. Respondents were asked to list the ages of children living in the household who were dependent upon them for assistance with daily life activities, including self-care, chores, school activities or play. Ninety-eight respondents (N = 158, 60.8%) had at least one child who depended upon them for assistance with daily tasks. The mean ages for all dependent children are described in Table 6. Sixty-

one BCS had one child; 15 were ≤ 10 years of age, 37 were between 11 and 20, 8 were

between 21 and 30, and 1 was younger than 40. Thirty BCS had 2 children; 14 were ≤

10 years of age and 16 were between 11 and 20. Six BCS had 3 children; 3 were ≤ 10

years of age and 2 were between ages 11 and 20. One BCS had four children; that

child was between 11 and 20 years of age.

Table 6
Number of Children Dependent on BCS for Daily Activities (n = 98)

	n	Percent	Mean Age	SD
Child 1	61	62.9	14.64	6.86
Child 2	30	30.9	11.64	4.87
Child 3	6	6.2	9.2	4.75
Child 4	1	1.0	14.0	0

Fatigue during daily activities. The FACIT-F focuses on the perceived

experience of fatigue, however the impact of fatigue on specific daily activities with the

exception of eating, sleep, "usual activities" (Yellen et al., 1997), and socialization are

not delineated. Investigator designed questions on the demographic portion of the

survey therefore queried respondents about the following using categories from the

International Classification of Function [ICF] (WHO, 2001) and the Occupational

Therapy Practice Framework [OTPF], 2nd edition (AOTA, 2008): "Do you have fatigue (a

tired feeling) at least twice a week that keeps you from completing any or all of these

daily activities?" Fatigue was reported most often while performing household tasks (56

BCS, n = 157, 35.7%), when attempting to socialize with friends and family (38 BCS, n

= 154, 24.7%), while shopping or running errands (45 BCS, n = 154, 29.2%), during

leisure or socialization (33 BCS, n = 150, 22%), at work (26 BCS, n = 148, 17.6%),

while taking care of others (25 BCS, n = 153, 16.3%), and least often during self-care (16 BCS, n = 151, 10.6%).

Outcome of Cancer-Related Fatigue and Upper Extremity Function

RQ1. Is there a relationship between self-reported cancer-related fatigue and perceived upper extremity functional deficits in breast cancer survivors (BCS)?

Ha.1. There is a relationship between self-reported cancer-related fatigue and perceived upper extremity functional deficits in BCS

An analysis using Pearson's correlation coefficient demonstrated that there was a moderate statistically significant inverse relationship between CRF and upper extremity function, r = -.661 (two-tailed), p < .001, such that women who had low scores on the FACIT-F (more disability or decreased health-related quality of life [HRQOL]) had higher scores on the DASH (more disability or decreased HRQOL). For these data, the FACIT-F mean score was 41.25 (SD = 10.419, n = 157), and the DASH mean score was 11.77, SD 13.850, n = 153).

A simple linear regression analysis was used to further determine if the overall model was predictive. The regression model was negative and significant F(1, 150) = 116.617, p < .001, with 43.4% of the variance in fatigue accounted for by perceived upper extremity function. The model indicated that as DASH scores increased by 1 point, indicating higher levels of functional disability in the extremity, FACIT-F scores decreased by .05 points, also indicative of higher levels of fatigue and disability (β = .504, t = -10.799, p < .001).

A one-sample student t-test compared the study sample to the FACIT-F normative score for the general United States population using the raw cut-off score of ≤

43 established by Cella, Lai et al. (2002). The study sample, on average, was significantly more fatigued than the expected fatigue level for the general U.S. population (M = 41.25, SD = 10.41), t (156) = -2.10, p = .037 (two-tailed). A one-sample student t-test was also used to compare the study sample to the cut-off raw score of ≤ 34 defined by Van Belle et al. (2005) as the score on the FACIT-F that would meet the proposed diagnostic ICD-10 criteria for cancer-related fatigue. The BCS, on average, exceeded the proposed diagnostic score (t(156) = 8.724, p < .001), indicating that on average the study sample had less fatigue than those individuals who would meet the ICD-10 diagnostic cut score. However, a subset of the population, 22.3% (n = 25), demonstrated scores of 34 or less, thus meeting the criteria for a diagnosis of CRF.

A one-sample student t-test used to compare the DASH scores for the study sample (n = 153, M = 11.77, SD = 13.85) to the general U.S. population of women using a cut-score of ≥11.96 (Kennedy et al., 2011), found that on average, BCS in the study sample experienced less disability than the U.S. normative sample, t(153) = 7.953, p < .0001 (two-tailed) for upper extremity function. It is noteworthy that of the 22.3% of BCS who scored below or equal to 34 on the FACIT-F thus meeting the diagnostic criteria for CRF, 45.5% also had higher DASH scores indicating that this subset of the study sample exhibited greater disability or lower HRQOL on both measures (Figure 1).

Figure 1
BCS with Increased CRF and Upper Extremity Disability
(N=158)
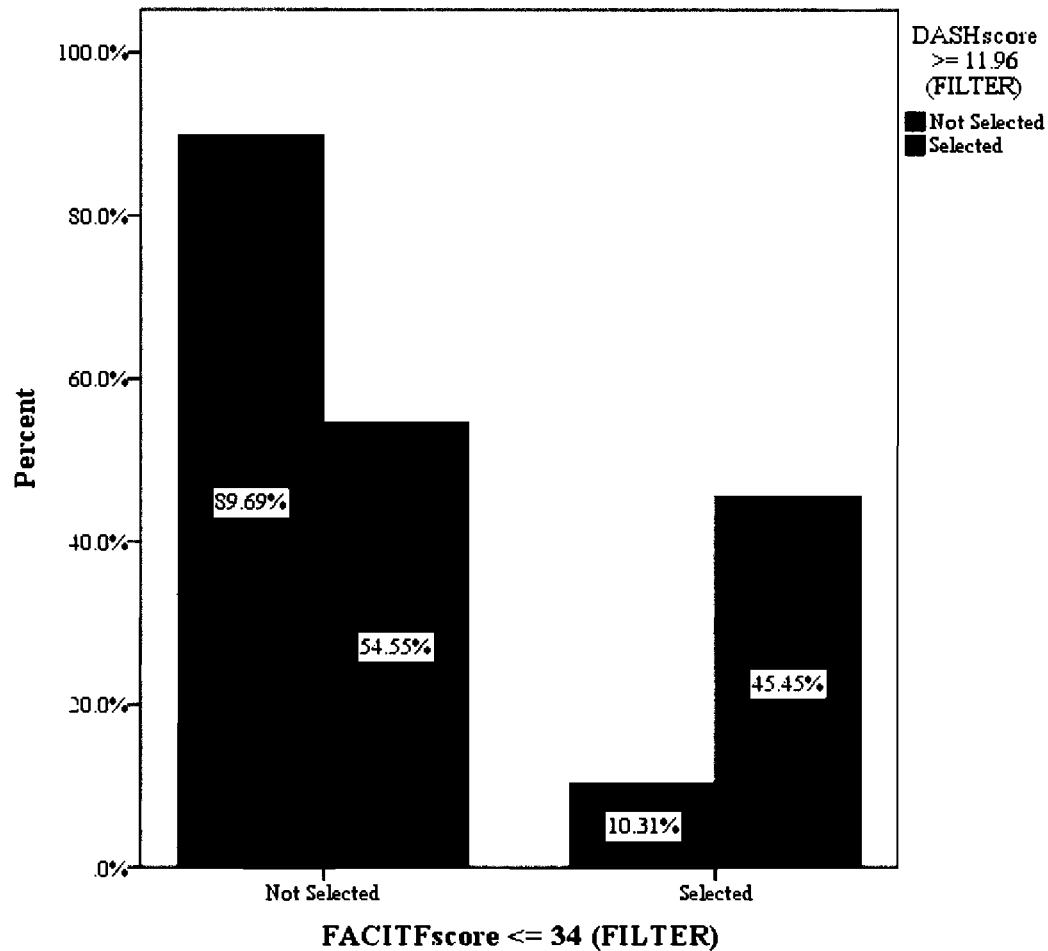
Outcome of Node Dissection Status

RQ2. Is there a difference in perceived upper extremity function and fatigue

between breast cancer survivors (BCS) who underwent sentinel node dissection

and those who underwent axillary node dissection?

Ha.2.1: There is a difference in perceived upper extremity function

between BCS who underwent various node dissection procedures,

including axillary node dissection, sentinel node dissection and both

axillary and sentinel node dissection.

Ha.2.2: There is a difference in perceived cancer-related fatigue between

BCS who underwent various node dissection procedures, including

axillary node dissection, sentinel node dissection and both axillary and

sentinel node dissection.

A nonparametric Kruskal Wallis test was used to test for differences in node

dissection status and perceived upper extremity function and cancer-related fatigue

respectively because normality was questionable and unequal sample sizes violated the

use of an ANOVA. The equality of the reported node dissection procedures was skewed

with 51.3% of BCS undergoing `sentinel node biopsy. Results indicated that there was

not a statistically significant difference in the distribution of the fatigue scores of BCS

undergoing various node dissection procedures $\chi^2(2) = 2.46$, p = .292). There was also

not significant in the distribution of scores measuring upper extremity function $\chi^2(2) =$

4.67, p = .097). Node dissection status in this sample was not related to perceived

fatigue or upper extremity function.

Outcome of Adjuvant Cancer Therapies

RQ3. Is there is a difference in perceived upper extremity function and fatigue

between breast cancer survivors (BCS) who underwent differing types of

adjuvant cancer therapies, including chemotherapy, radiation, or combination

therapies?

Ha3.1: There is a difference in perceived upper extremity function between BCS who underwent chemotherapy, radiation, immunotherapy, hormone therapy or combination therapies.

Ha3.2: There is a difference in perceived cancer-related fatigue between BCS who underwent chemotherapy, radiation, immunotherapy, hormone therapy or combination therapies.

One hundred and forty-five BCS reported receiving adjuvant treatment, with 13 women recording no adjuvant therapies following diagnosis and surgical intervention (Table 7). A nonparametric Kruskal Wallis test was used to test for differences in cancer treatment and perceived upper extremity function due to violations of the distribution across all adjuvant therapies resulting in non-normality of the sample. Results indicate that there was not a statistically significant difference in upper extremity function in BCS who received adjuvant cancer therapies, χ^2 (2) = 1.057 and p = .590. The Kruskal Wallis analysis indicated that there was also not a statistically significant difference in the distribution of the fatigue scores of BCS undergoing various adjuvant therapy procedures χ^2(2) = .558, p = .757).

Table 7

Number and Type of Adjuvant Cancer Therapies (N = 158)

	n	Percent
0 Modalities (no treatment) (N = 13)[a]	13	8.2
1 Modality (N = 44)[a]		
Radiation	21	13.3
Chemotherapy	12	7.5
Hormone Therapy	11	7.0
2 Modalities (N = 75)[a]		
Chemotherapy + Radiation	43	27.3
Radiation + Hormone Therapy	16	10.1
Chemotherapy + Hormone Therapy	15	9.5
Chemotherapy + Immunotherapy	1	0.6
3 Modalities (N = 25)[a]		
Chemotherapy + Radiation + Hormone	20	12.7
Chemotherapy + Radiation + Immunotherapy	3	1.8
Chemotherapy + Immunotherapy + Hormone	2	1.3
4 Modalities (N = 1)[a]		
Chemotherapy + Radiation + Immunotherapy + Hormone therapy	1	0.6

[a] Percentages based on total respondents

Outcome of Dependent Caregiver Responsibilities

RQ4. Is there a difference in perceived upper extremity function and fatigue between breast cancer survivors (BCS) who have dependent caregiver responsibilities and those without dependent caregiver responsibilities?

Ha4.1: There is a difference in perceived upper extremity function between BCS who have dependent caregiver responsibilities and those without dependent caregiver responsibilities.

An independent sample t-test was used to assess the difference in upper extremity function and fatigue in BCS with and without caregiver responsibilities. On

average, women with at least one child experienced slightly higher upper extremity

disability (M = 13.87, SE = 1.945) than those without children (M = 10.41, SE =

1.338), however the results were not statistically significant, t(df =151) = -1.515, p =

.132).

Ha4.2: There is a difference in perceived cancer-related fatigue between

BCS who have dependent caregiver responsibilities and those without

dependent caregiver responsibilities.

On average, BCS who had at least one child experienced greater fatigue than

women without children, t (df = 155) = 2.089, p = .038. Mean fatigue values were lower

for women with children (M = 39.10, SE = 1.453) than those without children (M = 42.63,

SE = .979), signifying greater disability or decreased HRQOL.

Impact of Upper Extremity Function and Fatigue on Other Activities

Twenty-two BCS (N = 133, 16.5%) responded to the optional question, "Are there

any other daily activities that have been impacted by problems with arm function

(Please list)?" The most frequent impact (n = 11, 8.3%) was related to physical

symptoms such as pain, diminished strength particularly when performing heavy tasks,

decreased speed of performance, and swelling. Addition impact was found in IADLS (n

= 7, 5.3%), including caregiving of young and adult disabled children, and work-related

tasks (n = 6, 4.5%). The least frequent impact statements were in sleep and leisure.

See Table 10, Appendix C for a complete listing of verbatim comments detailed

according to ICF (WHO, 2001) and OTPF (AOTA, 2008) classifications.

Twenty-nine BCS in the second data collection (n = 133, 21.8%) responded to

the optional question, "Are there any other daily activities that have been impacted by

having fatigue (Please list)?" with one respondent indicating no other activities impacted by fatigue. The most frequent impact from fatigue reported by the respondents involved generalized feelings of fatigue that interfered with the timing and completion of a multitude of tasks (n = 9, 6.8%), exercise (n = 5, 3.8%), work (n = 4, 3.0%), sleep and IADL activities, including caregiving (n = 3 respectively, 2.3%). The least frequently mentioned daily activities impacted by fatigue involved ADL activities (self-care) and socialization. See Table 11, Appendix C for a complete listing of verbatim comments detailed according to ICF (WHO, 2001) and OTPF (AOTA, 2008) classifications.

Outcome of Employment

Although employment was not the primary area of focus of this study, several questions were asked regarding work status in order to more fully understand the impact of breast cancer survivorship on this critical area of occupation. Respondents were asked, "Has your work situation changed as a result of problems from your breast cancer?" Twenty-two BCS (N = 158, 13.9%) reported that there had been employment changes following breast cancer. Respondents were also asked, "Has your work situation changed as a result of the economy?" Twenty-three BCS (N = 158, 14.6%) identified changes in their employment as a result of the current state of the U.S. economy, although only 6 women (3.8%) were unemployed.

A one-sample student t-test used to compare the DASH Optional Work Module (DASH-W) scores for the study sample (n = 134, M = 7.99, SD = 15.45) to the general U.S. population of women using a cut-score of ≥ 11.96 (Kennedy et al., 2011), found that on average, BCS in the study sample experienced less disability than the U.S. normative sample, $t(133) = -2.974$, $p = .003$ (two-tailed) for upper extremity function.

Data from the DASH Optional Work Module (DASH-W) was analyzed relative to node dissection status and number of adjuvant therapies received. A nonparametric Kruskal Wallis test was used to test for differences in the type of node dissection performed during diagnosis and perceived ability to complete work-related tasks due to violations of the distribution across node dissection categories, resulting in non-normality of the data, as well as non-normality of the DASH-W data. Results indicated that there was no significant difference in perceived physical abilities during work based on node dissection status, $n = 111$, $\chi^2 (2) = 3.88$, $p = .14$.

A nonparametric Kruskal Wallis test was used to test for differences in number of adjuvant cancer treatments and perceived physical ability to complete work-related tasks due to violations of the distribution across node dissection categories, resulting in the non-normality of the data. Results indicated that there was a positive trend in the data, but not a statistically significant difference in perceived physical abilities during work in BCS who received adjuvant cancer therapies, $n = 122$, $\chi^2 (3) = 7.81$ and $p = .05$.

Job classification by SOC category. The Standard Occupational Classification System (SOC) (U.S. Department of Labor, 2010) was used to categorize responses from participants to the Optional Work Module of the DASH. The question, "please indicate what your work/job is" precedes the four DASH questions assessing perceived impact of arm function on work activities. The SOC is the preferred job classification system used by federal agencies to aggregate job-related statistical data (U.S. Department of Labor, 2010). The 23 major classifications and 97 minor classification categories were used to sort participant responses into meaningful occupational categories.

Seventeen participants (14.5%, n = 117) were employed in Management Occupations (11-0000): 2 in Top Executive positions; 4 in Management Occupations; 3 in Advertising, Marketing, Promotions, PR, or Sales Manager positions; 4 as Operations Specialties Managers; and 4 in Other Management Occupations.

Five participants (4.2 %, n = 117) were employed in Business and Finance Operations Occupations (13-0000): 3 as Business Operations Specialists; and 2 as Financial Specialists. Three participants (2.5%, n = 117) were employed in Computer and Mathematical Operations (15-000); all were employed in Computer Occupations. Four participants were employed in Life, Physical, and Social Science Occupations (19-000); all were employed as Social Scientists and Related Workers. Five participants were employed in Community and Social Service Occupations: all were employed as Counselors, Social Workers, and Other Community and Social Service Specialists. One participant (.8%, n = 117) was employed in Occupations (23-000); that participant was employed under Lawyers, Judges, and Related Workers.

Twenty participants (17.1%, n = 117) were employed in Education, Training, and Library Occupations (25-000): 2 as Postsecondary Teachers; 10 as Preschool, Primary, Secondary, and Special Education Teachers; 4 as Other Teachers and Instructors; 3 as Librarians, Curators, and Archivists; and 1 as Other Education, Training, and Library Occupations. Seven participants were employed in the Arts, Design, Entertainment, Sports, and Media Occupations (27-000): 2 as Arts and Design Workers; 1 in Entertainers, Performers, Sports, Sports and Related Workers; and 4 as Media and Communications Workers.

Sixteen BCS (13.7%, n = 117) were employed in Healthcare Practitioners and Technical Occupations (29-000); all were employed in Health Diagnosing and Treating Practitioners. Five participants (4%, n = 117) were employed in Personal Care and Service Occupations (39-000): 3 were employed as Personal Appearance Workers, and 2 were employed as Other Personal Care and Service Workers.

Seven participants were employed under Sales and Related Occupations (41-000): 1 was employed as a Supervisor of Sales Workers; 2 were employed as Sales Representatives, Services; and 4 were employed as Other Sales and Related Workers.

Twenty participants (17%, n = 117) were employed as Office and Administrative Support Workers (43-000): 3 as Supervisors of Office and Administrative Support Workers; 1 in Financial Clerks; 1 in Information and Record Clerks; 9 in Secretaries and Administrative Assistants; and 6 in Other Office and Administrative Support Workers positions.

One person (.8, n = 117) could not be formally classified since she listed her employment as "consulting", a descriptor that falls within numerous SOC categories. Six women (5.1%) listed their primary occupation as homemaker, an appropriate response for the DASH Optional Work Module but not one that can be classified using SOC categories.

Ceiling and Floor Effects of Instrumentation

Ceiling and floor effects were examined. Twenty-one BCS (n = 153, 13.7%) reached the ceiling on the DASH, producing a score of 0, indicating maximum upper quadrant functioning or least disability, although none reached the floor indicating maximum disability. On the DASH-W, the Optional Work Module, 88 BCS (n = 134,

55.7%) scored at the ceiling indicating no disability during physical tasks at work, with none reaching the floor indicating maximum disability performing physical work tasks. The FACIT-F scores revealed only 6 BCS (3.8%) who scored at the ceiling, indicating least fatigue and no participants scored at the floor indicating maximum fatigue.

Summary

The data revealed a statistically significant inverse relationship between CRF and upper extremity function in a bivariate correlational analysis. This result indicated that BCS in this sample who perceived higher levels of CRF, indicating higher levels of disability or decreased HRQOL, also perceived higher levels of disability or decreased HRQOL in upper extremity function. The simple regression model was predictive, finding that an increase of 1 point in perceived upper extremity function as measured by the DASH, indicating higher levels of disability, results in a decrease on the FACIT-F of .05, indicating higher levels of fatigue and increased disability. In addition, BCS who had at least one child dependent on them for caregiving tasks reported higher levels of fatigue than respondents who did not have dependent children living at home.

When compared to normative national cut-off scores for fatigue using the FACIT-F, the study sample exhibited statistically significant higher scores than the general U.S. population, although they exhibited better perceived arm function than the general population of women on the DASH. There was a subgroup of 22.3% BCS (n = 25) who exhibited increased fatigue, meeting the ICD-10 diagnostic criteria for CRF. Of this subgroup, 45.5% (n = 11) also had higher DASH scores indicating there was a small group of BCS who exhibited greater disability or lower HRQOL on both measures.

There were no significant differences in fatigue or upper extremity function between node dissection status or adjuvant therapies received during cancer treatment. DASH-Work scores did not identify significant differences in fatigue or upper extremity function between node dissection status or number of adjuvant therapies received during cancer treatment, although there was a positive trend ($p = .05$) toward impairment in perceived function during physical work tasks with an increasing number of adjuvant cancer modalities.

Chapter V

DISCUSSION

Upper extremity functional deficits and cancer-related fatigue, the two most common symptom complexes facing women following breast cancer diagnosis and treatment, have the potential to limit performance of daily tasks and resumption of life roles. Both problems can challenge the daily lives of BCS, however it is not known if these two underreported and underdiagnosed concerns indeed represent separate entities as described in the majority of the literature, or if some women perceive late effects from both symptoms complexes. Breast cancer survivorship is accompanied by a myriad of unique challenges across the trajectory of the survivor's lifespan, including potential physical, psychosocial and economic consequences. Diagnostic procedures and treatment may result in late or persistent problems that continue to impact the survivor for years or decades after surgery or the conclusion of adjuvant therapies (CDC, 2012; Sadler et al., 2002, Portenoy & Itri, 1999, Andrykowski et al., 1998).

This exploratory cross-sectional study examined the relationship between these two multifaceted constructs and further examined the impact of node dissection, number of adjuvant therapies received, and caregiving responsibilities in a convenience sample of 158 BCS who completed all surgery and treatment and were between 1 year and 6 years post-diagnosis. Additional information on the impact of fatigue and upper extremity morbidity was also explored by examining these key constructs in relation to physical work tasks. This chapter discusses the findings of the study within the broader

context of the biopsychosocial model, ICF, and permanent survivorship (Mullan, 1985; Miller et al., 2008; WHO, 2001).

The findings from this study appear to provide primary outcome findings for the first time describing a statistically significant bivariate relationship between CRF and upper extremity function. Survivorship numbers are increasing with population estimates of 18.1 million individuals by 2020 (Mariotto et al., 2011), the majority of whom will be female breast cancer survivors if current trends continue. Indeed, one in eight American women will be diagnosed with breast cancer in her lifetime (National Cancer Institute, 2011). Persistent problems during post-treatment survivorship can interfere with daily task performance, particularly for instrumental activities of daily living, which includes household management and caregiving tasks, as well as impair socialization and employment (de Boer et al., 2009; Obserst et al., 2010; Stone et al., 2000; Servaes, Verhagen, S., & Bleijenberg, 2002). A more thorough understanding of these two symptom complexes and the accompanying activity performance limitations may assist healthcare professionals to screen and identify BCS in need of services.

Demographics

This group exhibited demographics that were typical of respondents to other breast cancer studies with a high percentage of educated BCS (Collins et al., 2004; Dhruva et al., 2010). The inclusionary criteria excluded women over 65 since caregiving responsibilities for dependent children and employment were variables of interest, therefore it was anticipated and confirmed that the mean age of the sample, 52, would include some younger survivors. The majority of respondents were Caucasian (n = 147, 93%), educated at the graduate (n = 71, 44.9%) or college level (n = 52, 32.9%),

married (n = 117, 70.9%), and employed full-time (n = 98, 62.0%). Women who completed the study resided in 21 different states, plus the District of Columbia. They resided most often in the Middle Atlantic (n = 104, 66.2%) and South Atlantic (n = 23, 14.7%) regions of the country with the largest number of respondents identifying NJ (n = 74, 47.1%), NY (n = 24, 15.3%), and CA (n = 9, 5.7%) as their state of residency.

Respondents were primarily right-dominant (n = 146, 92.4%) identified the tumor stage at diagnosis as Stage 0 (n = 25, 15.8%), Stage I (n = 60, 38.0%), Stage II (n = 49, 31.0%), Stage III (n = 22, 13.9%), and 2 women (1.3%) reported that they did not know the stage of the tumor. There were equal numbers of BCS identifying the original tumor location as right versus left sided (75, n = 47.5) respectively and 6 women (3.8%) reported bilateral tumors at diagnosis. Of the 69 BCS who underwent lumpectomies (43.7%), none had reconstructive surgery. Of the 68 respondents who underwent mastectomies (36.7%), 45 had undergone reconstructive surgery (66.1%). Twenty BCS had lumpectomies and mastectomies (12.6%). Of those BCS who underwent both procedures, 15 had reconstruction (75%), and 1 BCS had no surgery.

Women in this study had surprisingly high rates of mastectomy compared to breast conserving surgery and the majority of women who underwent dual procedures, lumpectomies and mastectomies, had breast reconstruction. Two recent studies documented the increase in mastectomy rates following several years of decline (McGuire, 2009, Katipamula et al. 2009). Identified factors accounting for this unexpected rise include an increase in contralateral prophylactic mastectomies as genetic testing provides women with increased information that may alter their collaborative decision-making with the oncology team, as well as decisions by women to

request more extensive surgery in order to try to avoid or decrease radiation or chemotherapy (McGuire et al., 2009). It is difficult to ascertain why the mastectomy incidence rates were high in this sample. It is possible that the purpose of the study attracted respondents who had undergone more extensive surgery, as noted in the high number of women who reported having undergone both lumpectomies and mastectomies, or BCS who might experience persistent symptoms. It could be suggested that the higher education level of the BCS with the majority of women holding graduate degrees led women to make alternative decisions about surgical options, or that the Northeast geographic region with access to major research cancer centers may offer a different array of surgical and treatment options. Diagnostic information on type of breast cancer, exact TMN staging, number of positive lymph nodes, and potential genetic variations were unavailable for analysis and this might also influence decision-making for surgical options. Despite these increased incidence numbers, mean DASH scores were high indicating lower levels of arm morbidity and higher reported levels of HRQOL.

Lymphedema. Twenty-five women identified a diagnosis of lymphedema (15.8%); 7 (39%) BCS with axillary node dissection, 12 (15%) BCS with sentinel node biopsy, 4 (13%) BCS who underwent both types of node biopsies and 2 (20%) BCS who did not know the type of node biopsies they received. Ten (6.4%) were receiving treatment for the lymphedema from an occupational or physical therapist at the time of survey completion; 4 (40%) with axillary node dissection, 4 (40%) with sentinel node biopsy and 2 (20%) with both types of node biopsies. Eleven (7.2%) BCS used compression wrapping to treat the lymphedema. The findings for this sample

documented mean levels of self-reported lymphedema in BCS who underwent ALND,

SLNB or both that were reported in some previous studies (Penha, Slangen, Heuts,

Voogd, & Von Meyenfeldt, 2011; Gärtner et al., 2010).

Prevalence statistics for lymphedema vary dramatically, depending upon whether

lymphedema was measured through objective measures or self-report, as well as when

in the time period post-diagnosis this information is obtained. BCS were asked whether

they had received a diagnosis of lymphedema, rather than whether they had noted

signs of swelling indicative of lymphedema, as have been previously documented in the

self-report literature on lymphedema prevalence, however as this information could not

be confirmed through medical records it was treated as self-report data. The self-

reported lymphedema prevalence rate of 15.8% from this study fall within the range of 8

– 17% reported by Penha et al. (2011) from a cross-sectional study of 145 BCS using

multiple assessment modalities. McLaughlin et al. (2008) reported that prevalence rates

calculated on less than 5 years of survivorship may underestimate the size of the

population with lymphedema since lymphedema rates increase during the first few

years post-diagnosis and treatment. Self-report rates in the literature may document

estimated prevalence rates that exceed the objective measurements in the same study,

possibly due to persistent sensory changes in the affected limb that alter BCS

perceptions of arm swelling (Hayes et al., 2008; Haid et al., 2002), however other

studies document reliable self-reporting in that individuals who underwent SLNB

appropriately reported significantly less symptoms, including swelling, than individuals

who underwent ALND when objective measures confirmed these results (Schrenk,

Rieger, Shamiyeh, & Wayand, 2000).

Compression Sleeves. Compression sleeves were worn by 33 BCS during air travel (n = 98, 33.7%), by 12 participants (n = 82, 14.6%) while exercising, by 14 (n = 86, 16.3%) when performing heavy housework, and 4 wore the compression garment at all times (n = 76, 5.3%). Of the 25 BCS reporting diagnosed lymphedema, 86% wore their garment during air travel, 75% during exercise, 71% during heavy housework, and 40% at all times. Only one study was located describing compression sleeve use patterns in BCS diagnosed with lymphedema. Ridner, Dietrich, and Kidd (2011) documented frequencies for self-care behaviors, including compression garment use, in 51 BCS with lymphedema in a cross-sectional study and found that 92% reported wearing their compression garments during the day and 49% at night (p.634). In this study, BCS with lymphedema reported lower percentages of garment use than noted in Ridner et al. (2011) in relation to garment use during specific daytime activities typically associated with recommendations for BCS (National Lymphedema Network, 2012). Use during sleep was not queried in this study due to the focus on functional performance. Based upon these inconsistencies one must question what recommended guidelines were provided to previous and current study participants and what happens to use patterns over a period of years following initial recommendations. Results from a qualitative study of 24 BCS in Australia found that women were confused about compression sleeve use since BCS are commonly cautioned to avoid compression of the ipsilateral arm through tight garments, jewelry or blood pressure cuffs, and the compression garments are designed to provide consistent compression to the extremity when worn (Collins et al., 2004).

Compression sleeves are one aspect of self-care advice management strategies provided to BCS to prevent or manage lymphedema. The National Lymphedema Network recently updated their risk-reduction practices information for lymphedema prevention (NLN Medical Advisory Committee, 2012) alerting BCS with lymphedema to follow the manufacturer's guidelines for wear and replacement with suggested use during "air travel, exercise and exertion" (p.2). The same organization also updated recommendations for those at risk of lymphedema but not yet diagnosed (Thiadens, 2011), suggesting that compression garments, if worn, can be used for "strenuous activity" and "air travel" (p. 2). The organization documented a disclaimer on the site stating that the evidence in the research literature supporting or refuting preventive self-care strategies is insufficient (Thiadens, 2011). Information on compliance with compression garment use is also lacking in the literature, although these garments are regularly recommended by clinicians for prevention of lymphedema. Assessed in its totality, the data from this and previous studies supports the importance of clinicians assisting survivors to continually assess and appropriately weigh the risk factors and evidence surrounding garment use for self-care prevention or lymphedema management.

Caregiving for Dependent Children. Participation in caregiver roles were noted by the majority of the study sample. Ninety-seven BCS (N = 158, 61.4%) reported responsibilities for at least one child who was dependent upon them for assistance with daily life activities, 30 BCS had two children, 6 BCS had 3 children and 1 BCS had 4 children. Mean ages for the children were from 9.2 years to 14.64 years, but ranged

from 1 – 38. One participant reported caring for an older adult son, age 38, with a disability.

While we utilized the FACIT-F to assess key information about perceived fatigue, it offers little insight into specific activities that are impacted by persistent fatigue symptoms. Categories from the International Classification of Function [ICF] (WHO, 2001) and the Occupational Therapy Practice Framework [OTPF], 2nd edition (AOTA, 2008) support that fatigue was reported most often while performing household tasks (56 BCS, n = 157, 35.7%) and least often during self-care (16 BCS, n = 151, 10.6%). Household tasks, errands and caregiving fall under the category of instrumental activities of daily living (IADLs). These higher order life tasks require additional and more complex skill sets, including more physical capacity, to complete than self-care (ADL) tasks. It was surprising that reported fatigue during caregiving on the demographic survey was limited (25 BCS, n = 153, 16.3%) since findings from the study demonstrate that increased fatigue during dependent caregiving, as measured by the FACIT-F, was statistically significant. It is possible that BCS did not report fatigue when faced with the dichotomous question on caregiving on the demographic survey versus choosing from the potential range of responses on the Likert scale used in the FACIT-F.

Dhruva et al. (2010) assessed diurnal fatigue levels in BCS before and after radiation therapy and revealed that women with children at home and employed women experienced higher levels of fatigue. Their research indicated that evening fatigue in this population might be impacted by "behavioral factors" (Dhruva, 2010, p. 210). This was the only study located that examined caregiving as a predictive factor in fatigue in breast cancer survivors. Many of the women in this study were also employed, had

received radiation therapy and had dependent children at home. If behavioral factors or lifestyle factors are partially responsible for fatigue, it is possible that non-pharmaceutical interventions that address energy conservation, work simplification and pacing could be initiated to address the fatigue.

Occupational Performance. Rates of impairment in the ability of BCS to complete daily activities range from 13% - 51% (Lash & Stillman, 2002) with activities requiring heavy work by the upper extremity musculature most often implicated as problematic. The findings of this study supported results from Fu and Rosedale (2009), demonstrating that basic self-care was not identified as problematic by survivors. The impact of fatigue on specific IADL tasks is not well described in the literature (Collins et al., 2004). An examination of the questions from the investigator-designed fatigue survey questions and the FACIT-F revealed that the FACIT-F examines more global aspects of fatigue and energy, whereas the investigator-designed questions queried participants about ICF activity categories. It is possible that perceptions of fatigue are not related to task-specific behavior, distinct for example from awareness of upper arm function where difficulties can be easily ascertained when it is not possible to open a jar or vacuum the house. It is possible that the investigator-generated questions may not have captured the key tasks that are most impacted by fatigue, despite covering major activity areas from the ICF that have been documented in the breast cancer core sets and research literature.

CRF and Upper Extremity Function

The first question explored the relationship between the two most common symptom complexes experienced by BCS; CRF and upper extremity function. Findings

supported the hypothesis determining that there was a moderate significant inverse relationship between CRF and upper extremity function, $r = -.661$, $p < .001$, such that BCS who perceived increased levels of fatigue, producing lower scores on the FACIT-F scale, also perceived increased arm dysfunction, thereby producing higher scores on the DASH. A simple linear regression analysis further determined that the overall model was negative and significant ($p < .001$), with 43% of the variance in fatigue accounted for by perceived upper extremity function. For this sample population, the model indicated that as DASH scores increase by 1 point, indicating higher levels of functional disability in the extremity, FACIT-F scores decrease by .05, also indicative of higher levels of fatigue and disability ($p < .001$). Since other key variables of interest did not further explain the model, it is likely that the variance is accounted for by other factors.

The multifactorial nature of these two symptom constructs confounds efforts to discern the exact underlying etiologies with any certainty. Studies on CRF have implicated other factors in the development of CRF that were not examined in this study, such as underlying inflammatory markers including C-Reactive Protein (Alexander et al., 2009), other immune system dysfunction, sleep dysfunction, additional disease comorbidities, and medication use (Mortimer et al., 2010; Portenoy & Itri, 1999; Yellen et al., 1997). Gerber et al. (2010) noted significant correlations between fatigue and white blood cell values >8,000. Other co-morbidities, such as arthritis that may limit arm function or increase fatigue, and an increased BMI (Gerber et al., 2010) were not documented for this study sample and remain a limitation of the study.

Pain emerged in the literature as a factor in the development of CRF and upper extremity morbidity (Hack et al., 2010; Peuckmann et al., 2009), however the only

questions regarding pain for this study were part of the DASH questionnaire which required retrospective examination of perceived pain over the course of one week located anywhere in the upper quadrant, or pain experienced during activity in the upper quadrant (Kennedy et al., 2011). Despite high overall mean DASH scores that exceeded the national normative values indicating lower levels of disability, 47% of the BCS reported mild to extreme pain in the arm, shoulder, or hand during activities and 42.8% of the sample experienced mild to severe pain in the arm, shoulder, or hand in general. Other upper extremity symptoms were revealed by the DASH, including 46.7% reporting mild to severe stiffness, 44.4% of the same sample identifying mild to extreme weakness in the affected extremity, and 40.8% reporting mild to extreme tingling.

Some researchers have proposed the development of separate scales within the DASH to examine facets of upper quadrant function (Dixon et al., 2008; Lehman, Woodbury, & Velozo, 2011). The five symptom questions, currently clustered on the DASH questionnaire, have the potential to be aggregated as a subscore that could be used by researchers to consider contributing factors to upper extremity dysfunction. As 43% of the variance in fatigue in this sample was explained by upper extremity function, it is possible that perceived pain and other persistent upper extremity physical symptoms identified by Dixon et al. (2008) and categorized under the impairment construct of the ICF, contributed to perceived fatigue.

Comparison of the study sample to the FACIT-F normative score for the general United States population using the raw cut-off score of ≤ 43 established by Cella and Lai et al. (2002) revealed that the study sample, on average, was significantly more fatigued than the expected fatigue level for the general population (p = .037). Further

comparison of the study sample to the raw cut-off score of ≤ 34, defined by Van Belle et al. (2005) as the score on the FACIT-F that would meet the proposed ICD-10 criteria for CRF, indicated that the study sample, on average, was significantly less fatigued than those cancer survivors who would meet the diagnostic definition for CRF (p < .001). However, a subset of the study sample, 22.3%, did meet the criteria for CRF. The finding of a subset of BCS experiencing higher levels of fatigue representing approximately one-quarter of the overall sample is consistent with the research literature (Bower et al., 2006; Servaes, Verhagen, S., & Bleijenberg, 2002; Bower et al., 2000). These BCS do not represent outliers in the data set. They are part of a consistently documented subset of cancer survivors experiencing fatigue as an ongoing concern. While attention needs to be directed toward all survivorship concerns, it is imperative that this subset receive better identification and delivery of services to address their needs.

In addition, the study sample responses to perceived arm function using the DASH were compared to established normative values for women in the U.S. population using a cut-score of ≥ 11.96 (Kennedy et al., 2011). This comparison found that, on average, the BCS in the study sample experienced significantly less disability than the reference sample (p < .001). Of the subset of 22.3% of the sample that met the criteria for CRF, it is noteworthy that 11 participants (45.5%) of the fatigued subset also exhibited greater disability on the DASH as well.

The second research question examined differences in perceived upper extremity function or fatigue in BCS who underwent node dissection procedures, specifically sentinel node biopsy, axillary node biopsy, or both sentinel and axillary node

biopsy. The hypothesis was not supported for differences in upper extremity function or fatigue based on the node dissection procedures reported by the BCS. The majority, 51.3%, of BCS underwent sentinel lymph node biopsy (n = 81) and 19% (n = 30) underwent both SLNB and ALND. SLNB is considered to be the standard of care for BCS who have negative nodes with increasing evidence that there are no differences in locoregional recurrence between those BCS with negative nodes who have early stage disease and will undergo adjuvant therapies, versus the use of ALND (Giuliano et al., 2010). The literature suggests that SLNB causes less upper extremity disability than axillary node dissection (Hack et al., 2010; Schrenk et al., 2000) with the result that SLNB is increasingly the standard of care for node dissection. The higher number of women who underwent sentinel node biopsy may suggest one reason why differences were not detected for upper extremity function since less invasive surgical procedures were used in the axillary region. It is also plausible that the higher number of women who underwent SLNB suggests a higher proportion of node-negative respondents; none of the women with SLNB had mastectomies also suggesting less invasive disease at the time of diagnosis.

The third research question examined differences in perceived upper extremity function and fatigue in BCS who underwent adjuvant therapies including chemotherapy, radiation therapy, immunotherapy, hormone therapy or combination therapy. The hypothesis was not supported for differences in upper extremity function or fatigue based on the number of adjuvant modalities that were reported by the BCS. One hundred and forty-five BCS received adjuvant therapies, with 13 women reporting no use of adjuvant therapies following diagnosis and surgical intervention. The majority of

women (n = 43, 27.3%) received chemotherapy and radiation, with the next most frequent treatment as radiation only (n = 21, 13.3%), followed by chemotherapy, radiation and hormone therapy (n = 20, 12.7%).

The research literature examining the relationship of radiation and chemotherapy to upper extremity function and fatigue has been inconclusive and the results of this exploratory study do not further clarify these inconsistencies. Women in this study received a variety of adjuvant therapy combinations and the study sample was too small to explore the results from each adjuvant modality in relation to arm function and fatigue, therefore the overall number of adjuvant modalities received was examined in relation to CRF and upper extremity function. It is of interest that the majority of women (n = 101) were treated with two or more adjuvant modalities, most receiving chemotherapy and radiotherapy (27.3%). Prior studies have indicated that radiotherapy is more often associated with long term sequelae in the upper extremity than chemotherapy (Peuckmann et al., 2009) and that chemotherapy (Broeckel et al., 1998, Bower et al., 2000), radiotherapy (Lee et al., 2007), or combined adjuvant therapies (Jacobsen, Donovan et al., 2007; Bower et al., 2006) have been associated with higher levels of fatigue in early stages of the survivorship process.

In a case-control study, 1,929 German BCS retrospectively rated fatigue and quality of life before, during and following adjuvant therapies approximately 6 years post-surgery; findings revealed slightly higher fatigue levels for women who received both chemotherapy and radiation among women with chemotherapy emerging with the highest fatigue ratings (Schmidt et al., 2012). BCS who had more fatigue one year post-surgery also reported more symptoms in the surgical side and affected arm, including

pain, and decreased overall functioning; those who had persistent fatigue up to six years post surgery had reduced QOL ratings and reported worse functioning in all dimensions (Schmidt et al., 2012). This is one of the few studies to describe persistent arm morbidity in relation to CRF (Schmidt et al., 2012) and is supported by the findings in this study that there is a subset of women whose combined symptoms diminish HRQOL. This study lends credence to the idea that there are multiple trajectories for women who have persistent fatigue post-surgery and treatment.

The fourth research question examined differences in perceived upper extremity function and fatigue in BCS who reported caregiving responsibilities for dependent children living at home who required assistance with daily activities. The hypothesis was not supported for the difference in upper extremity function between women who do and do not have caregiving responsibilities, although mean scores on the DASH indicated that women with at least one child experience slightly higher upper extremity disability than those without children. Round, Hayes, and Newman (2006) found that women with children under the age of 14 reported more upper extremity disability than women without children using the DASH as a measure of arm function. Their findings were not fully supported by this study which failed to find increased upper extremity disability in relation to care of dependent children. Two BCS provided optional comments identifying difficulties with childcare responsibilities.

"Helping my disabled son is sometimes painful, so I ask my husband for help."

"Lifting my children, moving things."

However, results supported the hypothesis that there is a difference in perceived fatigue between BCS who have dependent caregiver responsibilities and those who do

not (p = .038). Mean fatigue values were lower for women with children than those without children signifying greater disability for women with caregiver roles. Only one mother reported a comment in the optional query on other daily activities that are impacted by fatigue, noting that:

> "[It is] challenging to take care of three small children and I am exhausted driving them to school, extra-curricular activities, etc."

This was an unexpected finding in the study. On average, the BCS in this sample experienced higher levels of fatigue than the national normative values, even though the majority did not reach a level that would warrant a diagnosis of CRF. Most women were also employed full or part-time. It is possible that the increased demand for energy output from responsibilities at home and at work throughout the course of the week-long retrospective reporting on the FACIT-F increased reports of perceived fatigue.

Little is reported about the impact of dependent childcare responsibilities on fatigue and arm function after breast cancer. Research describing dependent children is more likely to report the psychoemotional responses of women recently diagnosed or undergoing adjuvant therapies in relation to talking to children about the cancer or concerns about mortality, rather than focusing on the impact of reduced energy or diminished arm function on caregiving responsibilities. Round et al. (2006) generated one of the few studies to document outcomes related to caregiver roles, but only focused on upper extremity use. Dhruva et al. (2010) focused on the impact of radiation therapy on diurnal fatigue noting caregiving of dependent children as a predictive factor for evening fatigue.

Employment

Efforts to explore the experience of work in BCS were preliminary and are regarded as secondary findings of the study. However, work is important to BCS and resumption of work is often viewed as sign of recovery from cancer (Maunsell et al, 2004). The optional work module for the DASH, the DASH-W, was used to assess physical aspects of work in relation to node dissection status and number of adjuvant therapies received. Results indicated that there was no significant difference in perceived physical abilities during work based on node dissection status. However, results did demonstrate a positive trend in the data, but not a statistically significant difference, in perceived physical abilities during work in BCS who received adjuvant cancer therapies (n = 122, p = .05).

Cancer survivors may report changes in employment status as a result of a cancer diagnosis or persistent changes following cancer treatment. In this study, 22 BCS (13.9%) reported that there had been employment changes following their breast cancer. Due to major changes in the U.S. economy impacting a large number of employed Americans, respondents were also asked if changes in the economy had altered their work situation. Twenty-three BCS (14.6%) identified changes in employment as a result of the current state of the U.S. economy, although only 6 women (3.8%) were unemployed and only 2 (1.3%) were on disability. The U.S. jobless rate during the same period was 8.9% (U.S. Department of Labor, 2012), indicating that this study sample experienced less unemployment than the U.S. population during the data collection time period. It was not possible to clarify the reason for changes in

employment secondary to the breast cancer however this is an area that requires additional research.

DASH-W scores for the study sample were compared to the general U.S. population scores for women using a cut-off score established by Kennedy et al. (2011). On average, BCS in the study sample experienced less disability performing upper extremity physical work tasks than the U.S. normative sample (p = .003).

Data from the DASH-W was also analyzed relative to node dissection status and number of adjuvant therapies received. Results indicated that there was no significant difference in perceived physical abilities during work based on node dissection status. Results examining differences in the number of adjuvant cancer treatments received and perceived physical ability to complete work-related tasks indicated that there was a positive trend in the data, but not a statistically significant difference in perceived physical abilities during work in BCS who received adjuvant cancer therapies (n = 122, p = .05).

The first question of the DASH-W asks a general question requesting identification of the participant's work or job. One-hundred and seventeen responses were analyzed using the Standard Occupational Classification System (SOC) (2010), the preferred job classification system used by federal agencies to aggregate job-related statistical data (Department of Labor, 2010). The 23 major classifications and 97 minor classification categories were used to sort participant responses into meaningful occupational categories. Participants' employment situations were represented by 10 of the 23 major classification areas (Department of Labor, 2010): management occupations; business and finance operations; computer and mathematical operations;

life, physical and social science occupations; occupations (law); education, training and library professionals; office and administrative support work; arts, design, entertainment, sports, and media occupations; healthcare practitioners and technical occupations; sales and related professions; and one person could not be classified.

The optional question requesting comments about other daily activities that are impacted by fatigue or upper extremity yielded remarks about work-related activities impacted by arm function:

"I used to take care of a patient who was semi-comatose and I had no mobility. Because of my diagnosis and subsequent physical limitations (could lift no more than 5 – 10 lbs with my left arm), I had to leave my job."

"Working at my desk is sometimes uncomfortable because of arm, shoulder pain/pins and needles."

"Trying to close a padlock or a 3-ring binder."

Work activities were also impacted by fatigue.

"I am a lecturer/teacher – I tire more easily so while it does not affect work, when I am done, I am very tired."

"Going out for long periods of time. Just can't. Night deliveries (babies) tire me out much more now."

The comments may increase our understanding of the differences between perceptions of arm function versus perceived fatigue. Comments responding to the question about other areas impacted by changes in arm function revealed specific observations related to task behaviors, specific job tasks that were more difficult to complete. Documented remarks about fatigue appeared to express a more global

viewpoint about the impact of this symptom on work, i.e., impacting time spent on task rather than the tasks themselves and may suggest one reason why the investigator-designed questions on fatigue produced lower frequencies than would have been expected based on the FACIT-F scores. Insights gleaned from this information can assist in the development of further research, but may also assist clinicians to ask different questions when addressing fatigue or upper extremity morbidity.

The biopsychosocial model approaches survivorship as a complex, multifactorial entity unique to each survivor but identifies commonalities experienced by this population. The ICF Core Sets for Breast Cancer (Brach et al., 2004) describe the consensus document of ICF categories specific to breast cancer survivors. Activities identified as critical to this population that coincided with results from this study included "family relationships, hand and arm use, carrying out daily routine, doing housework, remunerative employment and lifting and carrying objects" (Brach et al., 2004, p. 124). While the majority of women in this study were able to function in multiple life spheres, there were others who identified mild to severe difficulties completing daily life tasks. This study affirms results from previous research that subsets of BCS are continuing to experience mild to significant problems in daily function, even long after surgery and adjuvant therapies conclude. Limitations at the ICF activity and participation level disrupt quality of life.

Limitations

Design and instrumentation. CRF is not a stagnant entity and therefore the cross-sectional design had inherent limitations in describing the fatigue experience for this sample of respondents. The FACIT-F captures the perceived average fatigue

experience over the course of one week, but does not distinguish self-reported fatigue variability that may occur during a given day or week. Recall error is possible since responses to the FACIT-F are assessed retrospectively.

There are questions that were not asked as part of the cross-sectional design due to the inability to have direct contact with participants or access medical records for data accuracy, including body mass index (BMI), comorbidities that could impact fatigue or upper extremity function such as arthritis, cardiovascular disease or the influence of proinflammatory biomarkers.

While self-perception is well accepted as a measurement of fatigue, research on upper extremity morbidity typically includes actual measurement of ROM through goniometry and arm circumference by tape measure, volumetric or bioimpedence technology although significant inconsistencies in measurement methodology limit study comparisons (Hayes et al., 2008; Haid et al., 2002; Schrenk et al., 2000). Some studies found that self-report of lymphedema, for example, resulted in increased percentages of women reporting this condition versus actual measurement of the extremity compared to the unaffected limb (Hayes et al., 2008; Haid et al., 2002). Participants in this study were asked if they were diagnosed with lymphedema, rather than their opinion regarding the presence of lymphedema, but there was no ability to confirm the diagnostic information.

Internal validity. The survey was brief with limited participant burden and was completed, on average, in 15 minutes. However, it is noteworthy that individuals answered the survey at various times of day, including in the middle of the night and close to typically scheduled mealtimes, and therefore BCS may have experienced

maturation effects due to hunger, fatigue or competing interests for their time.

Distraction is also a potential factor in internet-based research methodology. It is not

known if BCS were attending to other on-line or real time activities during completion of

the survey.

Typically, cross-sectional studies collect data at one data point. This study was

deployed at two different times of year with the pilot study deployed in February of 2011

and the final data collection deployed in October 2011 during Breast Cancer Awareness

Month with data collection continuing until January 2012. While deployment during

October was intentionally designed, it is also a consideration that individuals might have

reached saturation from breast cancer media awareness campaigns, requests for

donations or event participation requests that might have resulted in a negative impact

to receipt of the study invitation.

External validity. The potential for sampling bias must be explored. A

convenience sample was used for this study and required access to the internet as part

of the inclusionary criteria. It is therefore anticipated that there was sampling bias within

the pool of respondents. The internet divide continues to be a limiting factor in internet-

based research and was a known limitation of the study at its inception. The Pew

Research Organization recently noted that 78% of women had access to the internet as

of August 2011, noting that significant factors in on-line use included being younger

than 65, having a minimum of a high school education and reporting an annual

household income of greater than $30,000 (2011). Race emerged only as an issue in

terms of access to sufficient broadband (Pew Research Organization, 2011). They

further noted that despite improvements over the past decade, 20% of Americans

choose not use the internet (Pew Research Organization, 2011), further limiting the pool of potential respondents in the sampling frame and potentially creating non-sampling bias. Therefore respondents who chose not to participate for any reason may represent a different facet of the larger population.

The response rate was extremely low for the final data collection (10.4% for the pilot study and 0.4% for the final data collection), although this was anticipated based on the decision to use snowball recruitment sampling with a large non-targeted population as the primary contact to locate participants via the study invitation. It is not possible to know how many BCS received the original invitation from the PI, versus how many received a forwarded e-mail from a second or third-level contact. It is also not possible to know whether individuals receiving the e-mail from a known contact influenced response rates, or how many initial contact recipients decided to forward the invitation to others. Individuals can also change e-mail addresses and initial forwards may not have reached respondents, even if primary recipients of the participation invitation attempted to forward the information to an eligible BCS. It was also possible that the invitation to participate was forwarded to a spam file, thus removing the e-mail from an eligible respondent's mailbox.

It was not feasible to authenticate the eligibility of the respondents since contact information was not obtained and additional anonymity controls, such as discarding IP addresses collected by SurveyMonkey immediately following data downloads, were practiced. Three participants contacted the investigator via e-mail with problems related to the link to the survey. No errors were found in the SurveyMonkey mechanism, but broadband differences, user error and browser conflicts could have reduced response

rates. It is therefore likely that there were other women who experienced difficulty and chose not to take the additional step to contact the investigator to receive assistance. Furthermore, twenty-seven participants were ineligible to participate once their demographic data was reviewed due to failure to meet the time-since-diagnosis inclusionary parameter.

While minority access to the internet has increased, it was extremely difficult to recruit a representative sample of BCS approximating U.S. minority population estimates for this population. Only 3.2% of the study sample self-identified as Black/African American (n = 5) or Hispanic (n = 5) respectively, and only 1 person identified herself as Asian (0.6%). Im and Chee (2005) in a study on internet recruitment for breast cancer research, reported significant difficulty recruiting BCS in minority communities due, in part, to the inability to establish trust since the researchers remained outside the organizational structure and lacked the face-to-face contact of traditional research methods. Experiences in recruitment for this study mirror their findings. Attempts to secure participants from breast cancer support groups serving minority communities were unsuccessful; multiple organizations in NY and NJ simply did not respond to outreach efforts. Anecdotally, two key stakeholders in non-profit organizations serving minority members told the PI that they have increasing requests from researchers asking for internet or direct access to their members. They further reported that their non-profit organizations, struggling with reduced budgets, limited staff and a primary mission of service delivery, do not always have time to vet requests and decide on the merit and benefits of a particular study to their members. The racial background of the researcher must be considered as well when using snowball

recruitment to obtain a convenience sample. The majority of the primary personal and professional contacts requested to forward the study invitation were Caucasian. While the Seton Hall recruitment announcements to the South Orange and Newark campuses reached a diverse population, it is also more likely that individuals who knew the primary investigator directly or peripherally would be more responsive to forwarding the recruitment announcement to others. This was confirmed by examining the survey collectors on Survey Monkey. Individual URLs were generated by the software in response to naming the origin point for the collector. As an example, support groups from cancer organizations yielded 4 responses, whereas professional contacts known to the investigator yielded 36 responses.

It is also possible that self-selection bias occurred. The study invitation asked all BCS meeting the eligibility criteria to participate, regardless of whether they were experiencing symptoms at the time of survey completion. It is possible that women who experienced some difficulties now or in the recent past might have been more likely to complete the survey. In light of these factors, interpretation of the data must be considered with caution.

The free-text comments for the optional questions could not be used to generate inferences about the needs of the population due to the limited number of responses but did provide an opportunity to obtain additional information about the impact of fatigue and upper extremity function on daily activities. Garcia, Evans, and Reshaw (2004) noted that free comments tend to contain more negative than positive statements but may be used to generate ideas for future research. In this study, the investigator also could not request clarification of responses generated in the optional questions, the

majority of which were single word responses. In a study designed for direct contact with the respondents, additional questions requesting elaboration would have been posed. As a result, the limited data received from the participants could only be coded into key ICF and OTPF categories, but the opportunity to explore these responses in greater depth was not possible.

Selection-instrumentation interaction. The FACIT-F and the DASH offer well-established psychometric properties that have been documented in other research, as well as nationally normative scores that are described earlier in this thesis. However, there are some concerns about the observation of floor and ceiling effects for the scores in this sample of BCS, particularly for the DASH-W, the optional work module. Ceiling effects result from test items or scales that are not sufficiently difficult for the respondents, resulting in a subset of individuals attaining the highest possible score that indicates maximal functional ability (Canadian Stroke Network, 2012; Polit & Hungler, 1995; Portnoy & Watkins, 1993). Floor effects result from individuals scoring at the lowest possible score that indicates least functional ability (Polit & Hungler, 1995; Portnoy & Watkins, 1993). As noted, a significant number of BCS reached the ceiling scores for the DASH (n = 21, 13.7%) and DASH-W (n = 84, 53.2%) with the least number of BCS reached the ceiling scores for the FACIT-F (n = 6, 3.8%). Polit and Hungler (1995) noted that the presence of ceiling and floor scores can decrease the correlations between the test scores and other attributes of interest (p. 556). This was not observed in this study since the only correlation performed was between the FACIT-F and DASH scores, resulting in a moderate correlation between CRF and upper extremity function (p < .001). However, the number of ceiling scores observed on the

DASH-W raises considerable questions about the ability to interpret the results for the optional scale.

There are few studies that document use of the DASH Optional Work Module (DASH-W) beyond the publisher's website. The DASH-W has been used in one study to identify at-work disability, a concept that examines the impact of disability on individuals while they engage in work as opposed to measuring out-of-work status of individuals experiencing upper quadrant disability (Tang et al., 2009). This study was of interest since the majority of BCS were actively employed at the time of survey completion; 98 BCS (62.0%) were employed full-time ($\geq$ 35 hours), 21 (13.3%) were employed part-time (< 35 hours), and 16 (10.1%) were full-time homemakers which is considered an employment category under the DASH-W.

Tang et al. examined the psychometric properties of the DASH and other at-work instruments in a sample of 80 injured workers employed outside the home who were working with adjustments to their job responsibilities or decreased working hours secondary to their injuries (2009). The authors noted that the DASH-W performed as well as two other work disability scales, the WLQ-16 (Work Limitations Questionnaire) and the RA-WIS (Work Instability Scale for Rheumatoid Arthritis), but they felt that its brevity poses a problem for the psychometric strength of the scale. Scoring is not possible on the DASH-W unless all items are completed, whereas the DASH can be scored if up to 3 responses are missing (Kennedy et al., 2011). The limited number of items on the optional DASH-W, compared to the core DASH evaluation tool, posed interpretive challenges for this study. The small number of items, relative to the comprehensiveness of the global DASH, did not appear to fully capture the work

experiences of the respondents and ceiling effects were reached in 88 BCS (55.7%) of the study sample, yet work was an area that generated additional comments from the BCS in the optional questions. Brach et al. (2004) reported that BCS vocational and financial concerns are areas that are not always adequately addressed in cancer survivorship.

Survivorship Surveillance

The American Society of Clinical Oncology publishes recommended guidelines for surveillance of cancer survivors. Recommendations for breast cancer survivors include visits to a physician "every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter" (Cancer.Net, 2011, p.1). The guidelines focus on physician visits to monitor for recurrence, encourage mammography, and the development of any new breast-related symptoms or long term impact from adjuvant therapies.

A retrospective chart review examining the impact of physician specialty on follow-up of breast cancer survivors revealed that adherence to the guidelines is inconsistent, particularly when examining follow-up six years after initial treatment concluded, and especially for patients followed for their breast cancer by primary care practitioners (PCP) rather than oncology teams (Hollowell et al., 2010). Hollowell et al. (2010) further reported that due to increasing survivorship, it is likely that many BCS will have their care transferred to a PCP after five years. The ASCO guidelines are unclear as to the need for follow-up for any persistent symptoms resulting from the cancer or its treatment, such as CRF or upper extremity function or difficulties in task performance. In fact, the study by Hollowell et al. (2010) represented the only study available that

researched documented follow-up efforts for BCS. Therefore, while guidelines from the

Fatigue Coalition, the National Cancer Institute (NCI) and others have strongly

recommended ongoing fatigue monitoring, the monitoring of persistent problems does

not appear to have been translated into documentation to assist patients or oncology

teams. Longitudinal monitoring for the development of upper extremity dysfunction is

not noted in these materials. Functional performance in critical areas of occupation is

not even alluded to, with the primary emphasis focused on body functions and

structures.

Engel's biopsychosocial model (1977) and the ICF (2001) were conceptualized

as broader holistic frameworks and taxonomies supporting health that require a

paradigm shift away from a biological focus. There is documented recognition for this

shift in the increasing number of published studies that integrate a HRQOL measure

into outcome variables (Gotay et al., 2008), but the question remains as to whether this

recognition will be translated into clinical practice in a manner that meets the changing

needs of survivors.

Chapter VI

Summary and Conclusions

Summary

This cross-sectional exploratory study of 158 BCS examined the relationship between breast cancer survivors' perceptions of cancer-related fatigue (CRF) and upper extremity function one year to six years post-diagnosis. The study further sought to investigate the impact of multiple adjuvant therapies and node dissection procedures on CRF and upper extremity function. In addition, the role of caring for children living at home who are dependent upon the BCS for completion of daily activities was examined using the same key constructs. Finally, the differences in multiple adjuvant therapies and node dissection status on physical aspects of employment were explored.

Cancer-related fatigue and arm morbidity constitute the two most common symptom complexes impacting breast cancer survivors following treatment (Sadler et al., 2002; Portnoy & Itri, 1999; Vogelzang et al., 1997; Curt et al., 2000, Bower et al., 2006; Collins et al., 2004; Reitman et al., 2003), but these multifaceted entities have traditionally been researched as if they were separately occurring events in the survivor's recovery. Many BCS, as noted in this exploratory study, have successfully resumed life roles and desired activities in the years that follow the conclusion of surgery and adjuvant therapies. Yet some women continue to struggle with fatigue and arm morbidity that alter participation and quality of life.

A subset of women identified in this study and others, constituting approximately 17-25% of the overall population (Gerber et al., 2010; NCCN, 2006; Young & White,

2006; Sadler et al., 2002, Cella et al., 2001) and 22% in this study sample, experience prolonged or persistent fatigue symptoms that are significant, persistent and would fulfill the criteria for a diagnosis of cancer-related fatigue. Forty-five percent of the fatigued subset of BCS in this study also demonstrated significant limitations in upper body function. In addition, the overall BCS in this sample demonstrated significantly higher levels of fatigue when compared to a national representative sample of adults. Women who continue to experience persistent fatigue, upper extremity symptoms or activity limitations require more effective identification, follow-up and referral to facilitate successful navigation of post-treatment permanent survivorship. The results from this study support the need for additional research on the relationship between these two common entities, as well as development of interventions that address the needs of this growing population.

Researchers and policy makers, having taken note of the increasing number of cancer survivors and anticipated survivorship population growth, have produced statements supporting the need for healthcare practitioners and community agencies to monitor and address the long-term needs of survivors living with persistent symptoms. NCCN (2006) and the CDC (2005) have statements supporting the longitudinal monitoring of cancer survivors as a chronic disease state. The American Society of Clinical Oncology, 2006 (Cancer.Net, 2011), and the National Comprehensive Cancer Network [NCCN] (2012) publish recommended guidelines for longitudinal clinical surveillance of cancer survivors. Recommendations for BCS include visits to a physician "every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter" (Cancer.Net,

2011, p.1); similarly the more recent NCCN guidelines recommend visits every "4 – 6 months for five years, then every 12 months" (2012, p. BINV-16). Surveillance visits to oncologists or primary care practitioners offer a unique opportunity to identify underreported and underecognized symptoms, such as CRF and arm morbidity. Based on the results from this study, it is suggested that the goal of visits expand beyond monitoring BCS for recurrence of cancer to inquire about the specific impact of any residual symptoms on daily activities and life roles, including employment, socialization and community participation. Assessments could be forwarded prior to patient visits or completed in the waiting room and scored by trained office staff. Individuals who self-identify or are identified by the oncology team could then be referred to appropriate medical services, nurse navigators, rehabilitation services such as occupational or physical therapy, or community-based programming. Reviewing results from assessments would afford the opportunity for a dialogue between the BCS and the team.

The recent study by Thomas-MacLean et al. (2012) confirmed earlier findings (Gerber et al., 2010; Collins et al., 2003; Stone et al., 2003, Passik et al., 2002; Vogelzang et al., 1997) that survivors do not discuss persistent symptoms with their healthcare professional or feel as though they have received sufficient information. Therefore it is imperative that healthcare practitioners and teams take responsibility for asking questions during surveillance visits. The need for continued monitoring of these two entities should not be viewed solely from the perspective of recording fatigue scores or measuring limb circumference for potential lymphedema or ongoing pain in the affected extremity. Moving beyond physiological and anatomical areas of concern that

the ICF defines under body functions and structures (WHO, 2001) can increase the conversation about the more pressing life concerns of BCS. It is of interest that Thomas-MacLean et al. reported one reason for failure of patients to raise their concerns with the treatment team was the "expectation that symptoms would abate if certain activities were ceased" (2008, p. 69). As the focus of the ICF (2001) is to enable individuals to increase participation in all life spheres, self-limiting activities due to perceived impairments may further reduce participation, diminish HRQOL and may not adequately address the experienced symptoms. As higher levels of self-reported HRQOL have been linked in some studies to breast cancer survival (Gotay, Kawamoto, Bottomley, & Efficace, 2008), it is important to be cognizant of women's perceptions of persistent symptoms and their ability to function in daily life.

Limitations in internet recruitment, particularly the use of snowball methodology as the primary source to obtain the sampling frame, posed substantial challenges including a low response rate that left the sample vulnerable to selection bias. In order to further our understanding of the relationship between CRF and upper extremity function identified in this study, in-person population recruitment with a more diverse BCS population is recommended for future research.

Clarification by expert panels is needed to identify gold standard measurement tools for CRF and particularly for upper extremity morbidity in order to facilitate comparisons between studies. Adoption of a gold standard reference tool for CRF is also indicated in light of the anticipated ICD-10 diagnostic criteria for Neoplastic (Malignant) Related Fatigue. There is a wide array of validated fatigue assessment tools available, including the FACIT-F, but none have emerged as the benchmark tool for use

with oncology patients. Unidimensional assessments such as verbal or visual assessment scales are arguably more efficacious in clinical practice settings, but cannot capture the breadth of the functional concerns of BCS or the variability of the fatigue experience (Butt et al., 2008; Schwartz et al., 2002). The fatigue screening tool recently developed by an expert panel at NCCN (2010) does not incorporate questions about the impact of fatigue on daily performance that supports participation in all life spheres.

Similar dilemmas are found when considering standards for assessment of upper extremity function as there are additional concerns about whether upper extremity assessment for longitudinal surveillance should be measured by objective or subjective means. The lack of congruence noted in some studies between measured arm function and self-perceived function (Hack, 2010; Hayes et al., 2010) is noteworthy. While many studies support the use of objective measures as the gold standard for identification of lymphedema, Park, Lee, & Chung (2008) posited that women may perceive changes in arm function before current objective measures can accurately detect subtle changes. The imperative to address upper arm morbidity systematically is pressing since lymphedema incidence rates increase in the years post-treatment and this condition, once acquired, cannot be cured (Park et al., 2008).

However these two symptoms complexes represent only two facets of survivors' concerns. Indeed, Huber et al. (2010) reminds us that the ICF "takes as its central tenet the individual's experience with illness" (p. 1955). Seaburn (2005) admonishes us to consider Engel's BPS model as a rationale for integrated, collaborative clinical care that focuses on the patient's lived experience with the illness as "a whole fabric, indivisible" (p. 398). Therefore to maintain a more holistic biopsychosocial approach, assessments

and interventions should ultimately begin with the survivor's narrative and address all components within a framework of the impact on daily living and participation in context.

In addition to concerns regarding instrumentation and ongoing surveillance, the findings suggest the need to further our understanding of the relationship of CRF and upper extremity function, including the role of adaptation and compensatory strategies on function. We do not yet understand the extent to which women may be compensating, adapting or giving up activities in order to continue to meet task demands and fulfill life roles. Several women indicated on the optional open-ended questions that they had adapted their method of completing daily tasks at home or work. Collins et al. (2004) noted that women reported using their contralateral extremity to complete tasks, such as heavy household activities and specifically notes the use of attempts to develop compensatory strategies in order to meet task demands. Further elucidation of the extent and manner in which women are adapting, compensating for, or eliminating desired or required occupations is indicated as this is not an area that has been well explored in the literature.

Consequently, it is incumbent upon us to consider Frank's admonishment that current health care practices do not assist the individual to live easily in the world following life-threatening illness (1995). Mullan's (1985) visually compelling metaphor of pulling the survivor out of the water only to leave the person floundering on the dock is apt. There is a surfeit of core research demonstrating that CRF and arm morbidity are present in sufficient numbers to warrant ongoing longitudinal monitoring. Additional research on the development of interventions that address these problems and enhance participation are needed.

The education of BCS about CRF and arm morbidity can begin earlier in the diagnostic and treatment continuum and should include assessment of fatigue and arm function, with circumferential baseline measurements of the upper extremities before surgery that could permit more effective monitoring and comparisons of symptoms that persist over time.

Conclusions

Based on the review of the literature to date, this study constitutes the first attempt to directly explore the relationship between CRF and upper extremity function as a primary research outcome. A moderate significant relationship between these two constructs was demonstrated in this small, exploratory cross-sectional study, as well as an increase in perceived fatigue in women who care for dependent children. Exploration of CRF and upper extremity function in relation to node dissection status and number of adjuvant cancer modalities received resulted in insignificant findings. Exploration of the number of adjuvant cancer therapies received and node dissection status in relation to physical work tasks identified a positive trend for only the number of adjuvant cancer therapies received, but did not reach significance. While the results from this study cannot be generalized, the findings offer insights to stimulate further exploration. Barriers and affordances to facilitate participation of BCS in all environments should be identified. A larger more representative sample is needed to confirm the findings and better understand the factors contributing to these relationships.

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Appendix A

Definitions and Terminology

Definitions and Terminology

The following operational definitions for terminology related to functional activities and occupational performance were used throughout the study.

Activities of Daily Living: "Activities that are oriented toward taking care of one's own body (American Occupational Therapy Association [AOTA] Commission on Practice, 2002, p.620). These activities include the following: bathing, showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal and environmental device care, personal hygiene and grooming, toileting, sexual activity, sleep and rest (American Occupational Therapy Association [AOTA] Commission on Practice, p.620).

Functional status: "An individual's performance of activities and tasks associated with life roles" (Richmond, Tang, Tulman, Fawcett, & McCorkle, 2004, p. 84).

Instrumental Activities of Daily Living: "Essential self-maintenance activities that are used to measure independent living capability that are not considered as basic daily living activities of self-care tasks" (Jacobs, 1999, p.71). These activities include the following: care of others, care of pets, child-rearing, communication device use, community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and clean-up, safety procedures and emergency responses, and shopping (American Occupational Therapy Association [AOTA] Commission on Practice, 2002, p.620).

Occupational performance: "The ability to carry out the activities of daily life, including activities in the areas of occupation: activities of daily living (ADL), instrumental activities of daily living (IADL), education, work, play, leisure, and social participation (American Occupational Therapy Association [AOTA] Commission on Practice, 2002, p.617).

Appendix B

Highest Levels of Impairment

for DASH Functional Activities and Symptoms

Table 8

DASH Functional Activity Items Exhibiting Highest Levels of Perceived Impairment (N = 153)

Activity	No Difficulty (Percent)	Mild Difficulty to Unable (Percent)
Open a Jar	39.2	60.8
Recreational activities requiring force or impact	51.0	49.0
Carry a heavy object (> 10 lbs)	54.9	45.1
Heavy housework	56.9	43.1
Garden or yard work	58.2	41.8

Table 9

DASH Arm Symptoms Exhibiting Highest Levels of Perceived Impairment (N = 153)

Symptoms	None (Percent)	Mild to Severe Difficulty (Percent)
Pain when performing specific activity	53.0	47.0
Stiffness	53.3	46.7
Weakness	55.6	44.4
Pain	57.2	42.8
Tingling	59.2	40.8

Appendix C

Optional Questions: Daily Activities Impacted by Arm Dysfunction or Fatigue

Table 10

Optional Question: Daily Activities Impacted By Problems With Arm Function (n = 22)

ICF and OTPF Classifications	Responses
Domestic Life, household tasks, Caring for household objects and assisting others[a] [IADL[b]]	I cannot write with a pen for more than a few sentences so I no longer keep a journal. My writing and drawing have changed. Gardening. Housework.[1] Driving Helping my disabled son is sometimes painful, so I ask my husband for help. Lifting my children, moving things. Working with my dogs.
Work & Employment[a] [Work[b]]	Since I have implants, my pectoral muscle function limits some manual techniques I need for work as PT, but I have modified. Working at my desk is sometimes uncomfortable because of arm, shoulder pain/pins and needles. Trying to close a pad lock or a 3-ring binder. Delivering babies – some techniques I can't do. I am taking anastrazole daily, and I find in the winter that I have occasional pain in my wrists that makes typing and working out somewhat uncomfortable. It comes and goes, typically indicating when we are going to get rain or snow. I used to take care of a patient who was semi-comatose and I had no mobility. Because of my diagnoses and subsequent physical limitations (could lift no more than 5 – 10 lbs with my left arm) I had to leave my job.
Recreation and Leisure[a] [Leisure[b]]	Exercise (involving use of muscles across chest and heavy weights)[1] Exercise – finding a type of physical activity that does not aggravate my arm.

ICF classifications[a]
OTPF categories[b]

Table 8

Optional Question: Daily Activities Impacted By Problems With Arm Function Symptoms (n = 22)

ICF and OTPF Classifications	Responses
Sleep Functions[a] [Sleep[b]]	The tissue expanders are uncomfortable – especially if I try to lay on my side to sleep [waiting for reconstruction]
Body Functions and Structures[a] [Body Functions and Structures[b]]	Strength, rotation of shoulder.
	I still do everything, but I do less of it at a time and much more slowly than I used to.
	Everyday, everything. The arm has lost a lot of power, strength, energy…I am lucky that my affected arm is my non-dominant arm…so the answers on any survey could change a bit.
	Carrying anything heavy as dead weight. I need to support the weight against my body or suffer increased symptoms.
	No [problems], but wearing jewelry on my left hand/arm (rings/watch) can be annoying depending on swelling.
	Lifting.
	Some pain in breast when opening heavy doors.
	Most noted pulling heavy door, modify with body weight.
	Cannot lift things as heavy as I used to.
	I cannot lift as heavy an object as I used to because I lost some muscle tone while going through treatments. I lost a lot of weight including muscle while in treatment and have been working to get it back. I'm lucky my arm function is fine.
	Very mild occasional pain around reconstruction area but this does not limit my activities.

ICF classifications[a]
OTPF categories[b]

Table 11

Optional Question: Daily Activities Impacted By Problems With Fatigue (n = 29)

ICF and OTPF Classifications	Responses
Self-care[a] [ADL[b]]	Trying on tops and coats.
	Getting ready in the morning takes much longer due to fatigue.
Domestic Life, household tasks, Caring for household objects and assisting others[a] [IADL[b]]	Getting specific things done on time.
	Challenging to take care of three small children and I am exhausted driving them to school, extra-curricular activities, etc.
	Cleaning my house, carrying bags or laundry.
Work & Employment[a] [Work[b]]	I am a lecturer/teacher – I tire more easily so while it does not affect work, when I am done, I am very tired.
	Going out for long periods of time. Just can't. Night deliveries (babies) tire me out much more now.
	Working.
	It impacts my work.
Recreation and Leisure[a] [Leisure[b]]	Exercising.
	Exercising.
	Exercise, reading.
	Trying to just sit and read a book.
	Exercise classes.
	Exercise and gym time.
Support and Relationships[a] [Communication and Social Skills[b]]	Cancel scheduled appointments due to fatigue, social life is greatly impacted by fatigue.

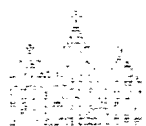ICF classifications[a]
OTPF categories[b]

Table 11

Optional Question: Daily Activities Impacted By Problems With Fatigue Symptoms (n = 29)

ICF and OTPF Classifications	Responses
Sleep Functions[a] [Sleep[b]]	Sleeplessness. I cannot get as many things done as I used to because I get tired easier and I need to rest. I need more sleep, and I go to bed earlier than I used to, usually by 9 PM. Sometimes for no reason I feel extremely exhausted. I need to nap sometimes around 3 PM. I am also having trouble sleeping through the night.
Body Functions and Structures[a] [Body Functions and Structures[b]]	Stairs! I have slightly less energy than I used to, but it doesn't stop me from doing anything in particular. I'm lucky. Walking due to the numbness felt on my feet. This is affected by additional causes, like having a mild cold, for instance. HOT FLASHES. Fatigue impacts everything. I feel my fatigue is just related to working, house chores and running around. Fatigue is only that which is normal for a 58 year old with a fast paced work schedule. I just don't have the energy to do anything. I do almost anything I did prior to breast cancer however the fatigue that follows often is limiting.

ICF classifications[a]
OTPF categories[b]

Appendix D

IRB Approvals

OFFICE OF INSTITUTIONAL REVIEW BOARD

SETON HALL UNIVERSITY

February 24, 2010

Meryl Picard, MSW, OTR
31 Crest Drive
Murray Hill, NJ 07974

Dear Ms. Picard,

The Seton Hall University Institutional Review Board has reviewed your research proposal entitled "The Relationship between Cancer-Related Fatigue and Upper Extremity Function in Breast Cancer Survivors" and has approved it as submitted under exempt status. Enclosed for your records is the signed Request for Approval form.

Please note that, where applicable, subjects must sign and must be given a copy of the Seton Hall University current stamped Letter of Solicitation or Consent Form before the subjects' participation. All data, as well as the investigator's copies of the signed Consent Forms, must be retained by the principal investigator for a period of at least three years following the termination of the project.

Should you wish to make changes to the IRB approved procedures, the following materials must be submitted for IRB review and be approved by the IRB prior to being instituted:

- Description of proposed revisions;
- *If applicable*, any new or revised materials, such as recruitment fliers, letters to subjects, or consent documents; and
- *If applicable*, updated letters of approval from cooperating institutions and IRBs.
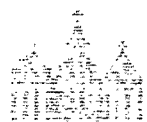
At the present time, there is no need for further action on your part with the IRB.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

OFFICE OF INSTITUTIONAL
REVIEW BOARD

SETON HALL UNIVERSITY

September 28, 2011

Meryl Picard, MSW, OTR
31 Crest Drive
Murray Hill, NJ 07974

Dear Ms. Picard,

The IRB hereby approves the following requested amendments to your research protocol, "The Relationship between Cancer-Related Fatigue and Upper Extremity Function in Breast Cancer Survivors":

1. to change the wording of four questions in the original survey and adding three new questions
2. amending the recruitment e-mail to reduce redundancies and alert potential respondents that they may not complete the new survey if they were participants in the data collection earlier this year
3. adding a paper copy of the letter, directed only to breast cancer survivors, for leaving flyers with interested parties such as support groups.

Your stamped paper recruitment flyer is enclosed. Make copies only of this form.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

A   HOME   FOR   THE   MIND,   THE   HEART   AND   THE   SPIRIT

Dear Breast Cancer Survivor,

Please help increase our understanding of cancer fatigue and
arm symptoms after breast cancer!

My name is Meryl Picard and I am a doctoral student at Seton Hall University in South Orange, NJ. My dissertation project explores the two most common problems, cancer fatigue and arm symptoms, that affect some women after surgery and treatment. I need your help in understanding women's experiences with these problems that might interfere with the ability to complete daily life activities that you want to do or have to do.

At this time there is limited understanding of the relationship between these two problem areas.

Your responses are very important, even if you are not experiencing any of these problems at the present time. You may participate in this research if you:

- Are between 18 – 65 years old
- Can read English and have access to the Internet
- *Have had a diagnosis of breast cancer, Stage 0 – III (please, no metastasis or Stage IV)*
- Completed all your surgery, radiation or chemotherapy a minimum of 1 year ago (> 12 months) and less than 6 years ago (< 72 months).

The questions will only take 15 minutes to complete. Your responses are completely voluntary and will be kept confidential. This is a completely anonymous survey. Please do not complete the survey again if you responded earlier this year.

Click on the link below (or cut and paste the survey link into your Internet browser) to begin. This research study has been approved by the Seton Hall University Institutional Review Board, which monitors all research studies to protect human subjects. If you have any questions about your rights as a participant in this study, please contact the Chairperson of the IRB at (973) 313-6314. Questions about the research study can be answered by contacting Meryl Picard at (973) 275-2910, meryl.picard@shu.edu.

https://www.surveymonkey.com/s/

Thank you for providing your valuable time to help us understand these symptoms in breast cancer survivors.

Seton Hall University
Institutional Review Board

SEP 28 2011

Approval Date

Appendix E

Dash Permission

Meryl M Picard

From:	Greer Palloo [gpalloo@iwh.on.ca]
Sent:	Tuesday, January 26, 2010 12:41 PM
To:	Meryl M Picard
Subject:	DASH use permission

Dear Meryl,

The Institute for Work & Health is pleased to grant you permission to use its DASH Outcome Measure for your doctoral study in the manner described on the user profile form dated and submitted on January 22, 2010.

We wish you all the best with your project.

Sincerely,

Greer

(Ms) Greer Palloo
Information & Events/DASH Coordinator
Knowledge Transfer & Exchange Department
Institute for Work & Health
481 University Avenue, Suite 800
Toronto, Ontario M5G 2E9 Canada
T 416-927-2027 x 2131   F 416-927-4167
gpalloo@iwh.on.ca
www.iwh.on.ca

Appendix F

FACIT-F Permission

Meryl M Picard

Dear Meryl,

Thank you for registering with FACIT! If you've registered for a translation of a FACIT scale, we will contact you with the questionnaire via email. If you've registered to use an English version but require a letter of permission, please send an email to information@facit.org and we will respond. If you don't hear from us within five days, please send an email to information@facit.org. Below is a summary of your information:

Summary of web form submission:

Your Name
Meryl Picard
Email Address
meryl.picard@shu.edu
Case Number
3288022
Company
Seton Hall University
Username
Your record has an existing username. This will be emailed to you. [meryl.picard@shu.edu] - has been ignored.
Password
Your record has an existing password. This will be emailed to you. [nextgenot2910] - has been ignored.
Work Address
400 South Orange Avenue South Orange, NJ 07974 United States Cell Phone Number
973-275-2910

Terms of Use
I Accept the Terms of Use
Department within Company
Occupational Therapy
Study Type
Cancer-Related Fatigue
Study Title
CANCER-RELATED FATIGUE AND UPPER EXTREMITY FUNCTION IN BREAST CANCER SURVIVORS Funding Source
None Total expected or actual number of study participants
130
Questionnaire(s)
FACIT-F, DASH
Countries or Language(s)
United States
Do you require a letter of permission?

Meryl M Picard

From:	Jason Bredle [jbredle@facit.org]
Sent:	Wednesday, September 02, 2009 1:54 PM
To:	Meryl M Picard
Subject:	RE: copyright and permission question

Hi Meryl,

That's totally fine. In fact, we've used survey monkey in the past to carry out some linguistic validation.

Thanks,
Jason

Jason Bredle
FACIT.org
+1.773.807.9094

_____

From: Meryl M Picard [Meryl.Picard@shu.edu]
Sent: Wednesday, September 02, 2009 12:32 PM
To: 'information@facit.org'
Subject: copyright and permission question

Dear FACIT.org:

I wrote to you one year ago and received permission to use the FACIT-fatigue for a dissertation study on cancer-related fatigue and breast cancer survivors. Unfortunately, the original RCT is now in the process of revision due to poor recruitment response for the clinical trial after the U.S. economy collapsed.

Before I complete the new user profile request, I wanted to ask if your organization would permit the use of the FACT-fatigue as part of on-line survey research. I will use Survey Monkey (surveymonkey.com) as the platform to host the dissertation study. The FACT-fatigue would only be available to study volunteers who respond to a participation invitation, and are then directed to a designated URL link established for my research. In other words, the FACT-fatigue would not be placed on a publically available website that anyone could access. Survey Monkey will also permit me to design the research survey to permit copyright credit of the FACT-fatigue on the actual survey site.

Please advise as to whether this is possible.

Sincerely,

Meryl Marger Picard, MSW, OTR
Assistant Professor
Department of Occupational Therapy
School of Health and Medical Sciences
Seton Hall University
400 South Orange Avenue
South Orange, New Jersey 07079
(973) 275-2910
meryl.picard@shu.edu

Appendix G

Demographic Survey Questions

Breast Cancer Survivors Fatigue and Arm Function Survey

*1. What is your age?

*2. What state do you live in?

State:

*3. How do you identify yourself?

◯ Black/African American

◯ Hispanic/Latino

◯ Native Hawaiian/Pacific Islander

◯ Asian

◯ White/Caucasian

Other (please specify)

*4. What is your marital status?

◯ Never married

◯ Single

◯ Married

◯ Living with a significant other

◯ Widowed

◯ Divorced

◯ Separated

*5. What is your highest level of education?

◯ Some high school

◯ High school degree

◯ Associate's degree or some college

◯ College degree

◯ Graduate degree or higher

Breast Cancer Survivors Fatigue and Arm Function Survey

*6. Which term *BEST* describes your current work situation?

◯ Unemployed

◯ Full-time employed (35 or more hours per week)

◯ Part-time employed (<35 hours per week)

◯ Leave of absence

◯ On disability

◯ Full-time student

◯ Part-time student

◯ Full-time homemaker

◯ Retired

*7. Has your work situation changed as a result of problems from your breast cancer?

◯ No

◯ Yes

8. Has your work situation changed as a result of the economy?

◯ No

◯ Yes

9. Which hand do you use to write?

◯ Right hand

◯ Left hand

*10. What year were you diagnosed?

Four digit year [   ]

11. Which side was your breast tumor located?

◯ Right side

◯ Left side

◯ Both sides

*12. Have you had more than one episode (recurrence) of breast cancer?

◯ No

◯ Same side as first episode

◯ Opposite side of first episode

✱13. What was the tumor stage when you were diagnosed?

◯ 0

◯ I

◯ II

◯ III

◯ Do not know

✱14. What type of surgery did you have *(Check all that apply)*?

☐ None

☐ Lumpectomy

☐ Mastectomy

☐ Breast reconstruction

✱15. What type of node dissection did you have to determine the cancer diagnosis?

◯ None

◯ Axillary node dissection

◯ Sentinel node dissection

◯ Both

◯ Do not know

If you had node dissection, how many nodes were removed?

☐

✱16. What type of cancer treatment did you receive after your surgery? (Select all that apply.)

☐ None

☐ Chemotherapy

☐ Radiation

☐ Immunotherapy

☐ Hormone therapy

✱17. Have you ever been diagnosed with lymphedema?

◯ No

◯ Yes

Breast Cancer Survivors Fatigue and Arm Function Survey

*18. Are you currently receiving treatment for your arm from an occupational or physical therapist?

○ No

○ Yes

*19. Do you wear a compression sleeve?

	Yes	No
Never	○	○
While exercising	○	○
While doing heavy household work (laundry, vacuuming, raking)	○	○
When I fly on a plane	○	○
Always	○	○

*20. Do you perform compression wrapping with lymphedema bandages?

○ No

○ Yes

*21. Do you have fatigue (a tired feeling) at least twice a week that keeps you from completing any or all of these daily activities?

	Yes	No
Self-care	○	○
Care of others	○	○
Household tasks such as cooking, cleaning or yard work	○	○
Shopping or errands	○	○
Doing your job at work	○	○
Leisure or relaxation	○	○
Socializing with friends and family	○	○

22. List the ages of children living in your house that depend on you to help them to complete daily life activities, including self-care, chores, school activities or play:

Age of child 1	
Age of child 2	
Age of child 3	
Age of child 4	
Age of child 5	