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14. ABSTRACT

Long term effects of cancer treatment such as fatigue, pain, emotional distress and cognitive limitations may be experienced by breast cancer survivors. Work performance can also be affected by cancer and its treatment. Given this association, we studied the relationship of two approaches to measuring cognitive function and in terms of its relation to work. Methods: A sample of 133 full-time working breast cancer survivors and a non cancer comparison group (n=122) completed measures of symptom burden, cognitive function and perceived work output. Results: Breast cancer survivors were an average 3.1 years post-treatment. Self report of cognitive function was significantly related to work output (R2 change = 0.298, p < 0.001) while performance measures were not. Conclusions: Self-report assessment of cognitive limitations provides an efficient and valid measurement related to work output for use in future studies on work limitations and cancer survivors.

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Abstract

Introduction: Long term effects of cancer treatment such as fatigue, pain, emotional distress and cognitive limitations may be experienced by breast cancer survivors. Work performance can also be affected by cancer and its treatment. Given this association, we studied the relationship of two approaches to measuring cognitive function and in terms of its relation to work.

Methods: A sample of 133 full-time working breast cancer survivors and a non cancer comparison group (n=122) completed measures of symptom burden, cognitive function and perceived work output.

Results: Breast cancer survivors were an average 3.1 years post-treatment. Self report of cognitive function was significantly related to work output (R^2 change = 0.298, $p < 0.001$) while performance measures were not.

Conclusions: Self-report assessment of cognitive limitations provides an efficient and valid measurement related to work output for use in future studies on work limitations and cancer survivors.

Relation of Cognitive Measures to Perceived Work Limitations in Cancer Survivors

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Thesis submitted to the Faculty of the
Department of Psychology Graduate Program
of the Uniformed Services University of the Health Sciences
in partial fulfillment of the requirements for the degree of
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Dedication

This work is dedicated to all past and present cancer survivors. It is my hope that this work brings light to the struggles that many cancer survivors face and the resiliency that is the hallmark of the cancer survivor.

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Relation of Cognitive Measures to Perceived Work Limitations in Cancer Survivors

Introduction

Working age cancer survivors in the United States today number nearly 5.5 million (Ries et al., 2008; Jemal et al., 2008). Of this group, the largest growing segment of cancer survivors is that of breast cancer survivors. More than 2.4 million survivors (predominantly women) of breast cancer are living in the United States today (Ries et al., 2008; Elkin, Hudis, Begg, & Schrag, 2005; Jamal et al, 2008; American Cancer Society, 2007), and the number of cancer survivors is expected to double by 2050 (Edwards et al., 2002). Breast cancer accounts for more than 25% percent of all cancers diagnosed in women today (American Cancer Society, 2007).

Cancer:

Cancer is one of the top public health concerns in much of the industrialized world. In the United States and elsewhere, considerable resources have been leveraged in an attempt to reduce the mortality associated with cancer. It is estimated that 45% of men and 38% of women in the United States will be diagnosed at some time in their life with an invasive form of cancer (Ries et al., 2008; Jemal et al., 2008).

Cancer Survivors:

Traditionally, the operational biomedical definition of a cancer survivor is a person who has survived and is cancer free for a period of five years after primary treatment (Mullan, 1985; Boyle, 2006). In contrast, the psychosocial definition used by many in the field of psycho-oncology, states that cancer survivorship is defined as the period of life following diagnosis (Mullan, 1985). Cancer survivors fall into three distinct

categories according to Mullan (1985) who coined the term "cancer survivor". In his view the three phases of survivorship include the acute, extended, and permanent phases. The acute phase begins at diagnosis and exists until treatment of the disease begins. Many acute survivors struggle with feelings of anxiety and fear associated with the cancer diagnosis. Physical symptoms that occur concomitantly can impact the ability of the cancer survivor to fulfill major life roles and responsibilities. These symptoms can include a general malaise, reduced endurance, and other physical limitations associated with the cancer (Aziz & Rowland, 2003; Mullan, 1985).

The extended phase of survival begins at the termination of primary treatment, and although the cancer may be in remission at this point, many cancer survivors find themselves concerned about recurrence. Many cancer survivors struggle with what it means to have survived the disease and are unsure with what "the new normal" is (Feuerstein & Findley, 2006). In an effort to regain normalcy, many cancer survivors seek to rejoin the workforce or engage in activity they had prior to the onset of cancer (Aziz & Rowland, 2003; Mullan, 1985). In many cases, the likelihood of the cancer returning is low and survivors oftentimes maintain an internal schema of success against the disease (Aziz & Rowland, 2003; Mullan, 1985). It is during this phase that patients come to realize that chemotherapy and other cancer interventions may have long term effects that are slow to remit or may never remit (Silverman et al, 2007). This is the permanent phase of cancer survivorship.

Breast Cancer Epidemiology:

Cancer is a word that still strikes fear into families and individuals diagnosed with the condition. Cancers were once equated with a near certain death sentence for those afflicted by the disease (Homles & Eburn, 1989). Today that story has changed dramatically, and although cancer still claims many victims, medical technology has allowed many to escape what was previously a terminal condition. Much of this improvement can be attributed to the early detection and treatment of many cancers. In the case of breast cancer in 1994 there were roughly 1.7 million American women survivors of breast cancer, and as of Jan 1st, 2005, that number has increased to a staggering 2.4 million according to the latest estimate available from the National Cancer Institute (Ries et al., 2008; Elkin, Hudis, Begg, & Schrag, 2005; Jamal et al, 2008).

One area that early detection and treatment of cancer has had a profound effect is in the area of breast cancer. The average tumor size has continued to decrease as imaging technology and campaigns to increase screenings for women have taken hold. One study suggests that the early detection of breast cancer may be responsible for as much as 61% of the reduction in mortality from 1975 to 1999 (Elkin, Hudis, Begg, & Schrag, 2005). According to statistics published in 2008, the five year survival rate in breast cancer patients with localized carcinomas is above 98% for American women (Jemal et al., 2008).

Five year survival rates haveincreased from 90.7%????? to 97.4% between 1975 to 1999 for those diagnosed with localized tumors. Those with regional tumors have seen five year survival rates increase dramatically from 67.8% to 79.6% during the same

period, and according to the latest data available are now above 83% (Elkin, Hudis, Begg, & Schrag, 2005).

Breast Cancer Treatment:

Modern treatment of breast cancer can involve many different forms of treatment. The most commonly used treatments are chemotherapy, radiation, surgery, and adjuvant therapies including angiogenesis inhibitors and hormonal therapy. It is not uncommon to use many of these treatment options in concert to achieve the highest likelihood of long term survival in the patient (Carlson et al., 2008).

Surgery is perhaps the most common treatment used in all cases of breast cancer; save those specific instances where it may be contraindicated. Side effects attributed to surgical intervention include a loss of physical strength in the upper extremities, swelling in the arm or hand, pain, and fatigue (Lange, 1998). The lumpectomy is the most common surgical intervention of choice with the goal of using the least invasive method of treatment, multiple studies have shown that the lumpectomy may be no less effective when used in concert with adjuvant therapy than radical mastectomy when comparing 20 year mortality (American Cancer Society, 2008).

Radiologic treatment of cancer is used to kill cells that may have remained after surgery and/or chemotherapy. Typical side effects of radiation therapy include skin irritation, scarring, pain, tenderness, as well as coughing, shortness of breath, and fatigue (Engel, 1996; Courneya, 2003).

Chemotherapy, the application of cytotoxic drugs, kills rapidly dividing cells through the use of a chemical cocktail. Chemotherapy side effects include nausea,

anemia, anorexia, and fatigue as well as other side effects (Courneya, 2003). The scientific literature has made a compelling case for cognitive deficits, such as working memory loss, difficulties in shifting attention, and executive functioning, associated with chemotherapy (Ahles et al, 2002 & 2003; Staat & Segatore, 2005; Silverman, 2007).

Hormonal, biological, and anti-angiogenesis therapies are other forms of therapy that are used to fight breast cancer (American Cancer Society, 2008). These therapies can prevent the re-growth of estrogen sensitive tumors but can also precipitate pre-mature menopause and the physiological symptoms that accompany menopause (Carlson et al, 2008).

Advances in detection have been responsible for the increase in early stage treatment of breast cancer, which in turn, has lead to the increase in the use of adjuvant therapy and lumpectomy as the primary treatment for breast cancer (Carlson et al, 2008; Clarke et al, 2005).

The price of survival:

The treatment for breast cancer can have serious side effects, and often times cognitive deficits associated with treatment are not discussed with the patient prior to treatment. Recent studies indicate that there are significant psycho-social implications for breast cancer survivors and that these survivors may share some experiences in common during their transition from their pre-cancerous life to their new role as a cancer survivor. This is especially true for those who decide to return to work or who continue to work during their treatment (Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Spelten, Sprangers, & Verbeek, 2002).

Some survivors of breast cancer endorse a wide range of symptoms that persist well beyond treatment for their cancer. Surgery, chemotherapy and radiation therapy have long been suspected to be associated with increased fatigue and possibly linked with cognitive deficits (Ahles et al., 2002; Hansen, Feuerstein, Calvio, & Olsen, 2008). While there is a substantial amount of evidence that increased fatigue and cognitive deficits may be linked to cancer treatment, other research raises some doubt in reaching this conclusion. Donovan and colleagues (2005) did not find a difference in cognitive function between breast cancer survivors utilizing adjuvant therapy and those breast cancer survivors who did not utilize an adjuvant therapy in the treatment of their cancer.

Research suggests that traditional treatment methodologies may be responsible for a wide range of side effects in cancer survivors. Breast cancer survivors may experience symptom burdens associated with radiation therapy, chemotherapy, and anti-estrogen compounds such as Tamoxifen and Letrozole. The estrogen suppressive properties associated with hormone therapy can be responsible for menopausal like symptoms in otherwise pre-menopausal women leading to side effects that include hot flashes, headaches, and fatigue. Chemotherapy and Tamoxifen have also been associated with decreased basal ganglia activity in the brain (Silverman, 2007). All of these side effects can impact productivity and the ability to work and, in the most debilitating cases; these side effects do not remit even after treatment has been discontinued for an extended period of time (Silverman, 2007).

While there are a great number of psychosocial implications from the treatment of breast cancer some common themes exist that affect overall quality of life. Additionally,

existing studies of breast cancer survivors indicate that common themes and concerns exist in those cancer patients that decide to return to work (Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Spelten, Sprangers, & Verbeek, 2002). These concerns include acceptance in the workplace, the ability to perform work tasks as they did prior to cancer, and concerns regarding fatigue (Feuerstein & Findley, 2006).

Although a great deal of the experience is unique to the individual, substantial evidence exists to suggest that these cancer therapies can have a negative impact on the ability of some workers to function at work. At this time much of the literature is cross-sectional in design and documenting pre-morbid functioning can be problematic at best. Although few longitudinal studies do exist, there is insufficient data to make a definitive statement regarding the causality of the effects of cancer treatment due to small sample sizes or methodological concerns. One study of cancer survivors showed that cancer patients were 2.25 times more likely to experience a negative cognitive shift in functioning 18 months post treatment when compared to functioning at four weeks post treatment(Shilling, Jenkins, Morris, Deutsch, & Bloomfield, 2005). Animal research has shown the blood brain barrier is permeable to Tamoxifen which can deregulate serotonin and dopamine levels (Lien et al., 1991; Wefel, Witgert, & Meyers, 2008).

The ability to work is highly correlated with maintaining a high quality of life for breast cancer survivors three years post-diagnosis (Maunsell, Brisson, DuBios, Lauzier, & Fraser, 1999). Despite this, more than one in ten cancer survivors stop working within 4 years of diagnosis because of cancer related symptoms that prevent these survivors from working effectively (Short, Vasey, & Tunceli, 2005). These symptoms include

fatigue, feelings of confusion, mental fogginess/slowness, decreased attention span, and difficulty focusing or concentrating (Taillibert, Voillery, & Bernard-Marty, 2007).

Chemobrain:

Chemobrain, as stated by Staat and Segatore (2005) "presents as weakened cognitive abilities, speed of information processing or reaction time, and organizational skills." More specifically, chemobrain affects attention, motor function, visuospatial processing, memory, and executive functioning. The consensus in the scientific community is that some functioning is expected to return over time after the termination of treatment. However research has shown that some effects persisting from 5 to 10 years can be detected through neuro-imaging (Silverman et al., 2007). These effects include specific alterations in neural activity in the cerebellum, frontal cortex, and basal ganglia in breast cancer survivors using positron emission tomography (Silverman et al., 2007).

Cognitive deficits including difficulties with memory, executive function, and attention can range from subtle to severe and can be interpreted by patients as life changing impairments that are extremely disturbing. Silverman (2007) found that delayed recall was the single most significantly impaired cognitive function in the participants in his study who were between five and ten years post primary treatment for cancer.

The impact of these deficits can be "devastating, demoralizing, and frightening (Staat & Segatore, 2005)." Not much is known about the particular mechanism of damage to the brain that occurs during the course of chemotherapy and radiation therapy in some patients (Ahles et al., 2002). Although it has been demonstrated that the blood brain barrier is effective at limiting the exposure to chemotherapy drugs, several studies has shown that significant differences in brain

imaging exist after treatment for breast cancer. A neurophysiological study demonstrated that breast cancer survivors who received chemotherapy and Tamoxifen treatment were more likely to show a pattern of hypometabolism in the lentiform nucleus than breast cancer survivors who only received chemotherapy treatment (Silverman et al., 2006). Tamoxifen can potentially affect brain activity that may lead to changes in cognitive or emotional functioning (Wefel, Witgert, & Meyers, 2008). Another study found that the corpus callosum may be affected as the result of chemotherapy (Abraham et al, 2005). The corpus callosum is responsible for communication between the hemispheres and this could affect a variety of cognitive functions.

Work

Breast cancer survivors are one of the largest populations of cancer survivors that return to work, with over five million cancer survivors of working age (Hansen et al, 2008). Many cancer survivors have managed to adapt to a number of chronic or persistent symptoms associated with their cancer treatment, including fatigue, pain, depression, and anxiety (Hansen et al, 2008). In addition, some cancer survivors experience the cognitive limitations described above. Early cancer survivors, defined as less than five year post-diagnosis, experience greater symptom burdens. Previous research has found that cancer survivors, when matched to controls, are no different than others when comparing absenteeism or salary seven years post diagnosis (Hansen et al, 2008) indicating either an adaption to the symptom burden or a lessening of symptoms in these survivors. However, other research indicates that some cancer survivors continue to experience long term symptom burden more than ten years post-diagnosis (Yabroff et al, 2004).

Cognitive Measures of Performance in Cancer Survivors:

It has been shown in other studies that workplace productivity and cognitive limitations (Hansen et al., 2008) are related in those with breast cancer. The gold standard for detecting and measuring cognitive performance has been performance testing. While it is clear that performance testing is a useful method to evaluate individual performance, in certain clinical conditions, it also has limitations. - e.g., is it appropriate for testing patients who may not be physically able to participate in performance testing. An example of this are patients who have suffered a traumatic brain injury in combat or an accident. Neuropsychological testing is relatively expensive and time consuming. Performance tests can take as much as 30-40 minutes to achieve valid results even in computer based environments and often require trained personnel to administer, score, and interpret. Additionally, neuropsychological testing lacks the ability to predict previous cognitive performance without testing prior to the suspected loss of cognitive functioning. Finally, the external validity of some of the performance based measures remain questionable for certain populations, especially for those with subtle cognitive limitations such as breast cancer survivors (Mehnert et al., 2007; Wefel, Witgert & Meyers, 2008).

An adjunct or alternative to objective performance testing is the use of self-report data. In general, self-report data also have their limitations. It is subject to bias, both retrospectively and through inaccurate self perception. In some cases, reported limitations can be exacerbated due to the inherent face validity of the questions used to measure

cognitive functioning. This can make it more difficult to prevent obvious attempts to malinger (Robinson et al., 1997). Again, it is important to consider the population and the problem under study prior to assuming some exaggerated or inaccurate response. The other side of the argument though is that the patients perception of their cognitive functioning in a specific situation (e.g. work) is more sensitive to actual function in that context than a performance based measure of general cognitive function. Therefore these self-report data may capture deficits or limitations that might otherwise escape detection in objective performance tests.

Hypotheses:

Chemotherapy patients have often complained that they experience cognitive limitations that affect their work performance, unfortunately efforts to document these changes in cognitive performance through performance based testing have not yielded definitive results. No previous study has compared performance based measurement ,the gold standard of assessing cognitive function, and self-report measures of cognitive impairment at work and in general in terms of their relation to workplace limitations in occupationally active breast cancer survivors. Given that performance based measures are more expensive, more time consuming, and require greater control of the testing environment it seems logical to evaluate the effectiveness of self-report measures against the current gold standard, the performance based neuro-cognitive assessment in the context of work in order to determine external validity of such self report measures of cognitive function.

Hypothesis 1:

Symptom burden will be higher in the breast cancer survivors than it will be in the non-cancer control group and this will explain more of the variance in the work limitations output scale. It is expected that breast cancer survivors will experience greater depressive symptoms, anxiety, fatigue, and job stress than non-cancer controls and that these particular markers of symptom burden in cancer survivors will explain more of the variance in cancer survivors than non cancer controls.

Hypothesis 2:

Performance based tests will be less sensitive than self-reported cognitive performance to workplace performance in both breast cancer survivors and the non-cancer control group, before or after controlling for demographic, medical, occupational, and other group differences. The proposed model includes specific components all of which impact our outcome measurement of workplace limitations as measured by the WLQ output score. The three parts of the model include confounding demographic variables, psychological and physical wellbeing, and cognitive functioning measured either by performance based tests or self-report instrument.

Step one was a univariate analysis of demographic factors, symptom burden, self-reported cognitive limitations, and selected performance measures. The results of this were used to identify the variables that would be later controlled for in our analysis and entered into the regression analysis.

The second step was to enter the variables into the regression analysis. Two separate two step linear regressions were conducted in order to determine which factors

contributed significantly to the work output score of the WLQ and explained the variance within each of the groups. Separate regressions examining the variance that symptom burden and cognitive measures for the entire sample were conducted as well. All three regressions were computed separately for both self-report measures of cognitive limitations and for the performance based measures of cognitive performance.

Methods

A total of 255 participants were recruited for the study consisting of 133 breast cancer survivors and 122 non-cancer control group participants. All study participants used a web based interface. The data analysis was conducted using SPSS Gradpack version 17.0 and data was stored at the Uniformed Services University of the Health Sciences. All participants were asked to complete a series of demographics questions, self-report measures of cognitive limitations, anxiety, depression, fatigue, and workplace productivity. Participants were randomized to participation in an objective performance based measure of cognitive performance, with some participants taking the performance based measure before the self-report measures and the others taking the performance based measure following the self-report measures. The USUHS Internal Review Board approved this protocol.

Symptom burden

The self-report measures of symptom burden used for this group of participants included the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) to measure anxiety and depression, and the Multidimensional Fatigue Symptom Inventory - Short Form (MFSI-SF; Stein et al., 2004) total score to measure fatigue. The

Cognitive Symptoms Checklist - modified (CSC-m; Feuerstein et al., 2007; Hansen et al., 2008; Calvio, 2009) were used to measure perceived cognitive function at work. The performance based measure of cognitive function CNS Vital Signs (Gualtieri & Johnson, 2006) measured executive function, attention, and verbal, visual, and composite memory. All of the measures for symptom burden have been used for other studies on breast cancer survivors and have a demonstrated history of strong psychometrics. The MFSI-SF has shown acceptable test-retest reliability and internal consistency (Stein et al., 1998). The HADS anxiety and depression scales have demonstrated acceptable internal consistency (Bjelland et al, 2002) and higher levels of sensitivity when used in cancer survivors (Katz et al, 2004), and the CSC-m has been shown to have high internal consistency with Cronbach alphas of α=0.93 for working memory, α=0.91 for executive function, and α=0.86 for attention (Hansen et al., 2008).

Work Limitations

The Work Limitations Questionnaire (WLQ), a 25 item self-report questionnaire that measures the impact of chronic health concerns on workplace productivity and the perceived ability to function in the workplace environment was used to measure work productivity (Lerner et al, 2003). There are four subscales within the WLQ, these include time demands, physical demands, mental-interpersonal demands, and output demands. Research has shown that of these subscales, the output demand scale had the highest internal consistency and more accurately predicted productivity loss (Lerner et al, 2001; Lerner et al, 2003). The subscale of interest in the present study was the output demands scale because other studies have shown that a ten percent rise in the WLQ output score

was reliably associated with a four and a half percent decrease in productivity (Lerner et al, 2001.).

Measurement of other potential confounds

Measures of caffeine and alcohol use prior to performance based testing and perceived job were taken from the 2007 Behavioral Risk Factor Surveillance System Questionnaire (accessed 23 July, 2009 from: http://www.cdc.gov/brfss/questionnaires/pdf-ques/2007brfss.pdf). Distraction was measured with a simple yes or no question asking if the participant had been distracted during the performance based testing session and the nature of the distraction (Calvio, 2009).

Statistical Analyses

The purpose of the analyses were to: 1) identify any differences in participant characteristics between the breast cancer survivors and non cancer comparison group, 2) determine if there were differences between the two groups on the symptom burden measures and self reported cognitive function at work and the generic performance based measures of cognitive function. Additionally, an exploratory analysis of group by symptom burden will be conducted to explore the possibility that a more complex relationship exists.

Results

Demographics

There were differences in the demographics of the two participant groups as detailed in Table 1 (N=254). A Chi-Square analysis revealed that the participant groups differed on age ($p < 0.01$), race ($p < 0.01$), ethnicity ($p < 0.05$), and marital status ($p < 0.01$) but not on education. On average breast cancer survivors were more likely to be older ($M = 45.02$, s.d. = 9.70) than non-cancer control group participants ($M = 38.75$, s.d. = 12.02). Additionally a disproportionate number of breast cancer survivors were Caucasian as opposed to other races ($\chi^2 = 19.379$, d.f. = 3, $p < 0.01$) while more racial diversity existed in the non-cancer control group. A difference in ethnicity between the two groups was also detected with non-Hispanics being disproportionately higher in the breast cancer survivor group ($\chi^2 = 5.477$, d.f. = 1, $p < 0.05$) than in the non-cancer control group. Breast cancer survivors were more likely to be married when compared to the non-cancer control group ($\chi^2 = 16.801$, d.f. = 4, $p < .001$).

Job characteristics were explored to see if significant differences could be detected between the two groups. Chi-square analyses of current job characteristics, primary occupation, years in current employment, and job satisfaction showed no significant differences between the two groups. It was only in income where a significant difference was detected ($\chi^2 = 20.069$, d.f. = 6, $p < 0.01$) and breast cancer survivors were more likely to have over $100,000 in annual household income than members of the non-cancer control group.

Treatment

As detailed in Table 3, breast cancer survivors on average were 3.1 years post treatment and 51.5% (68) reported breast cancer in the right breast only. Only 3.8% (5)

participants had cancer detected in both breasts with the remaining 44.7% (59) reporting cancer in their left breast. The majority of cancer survivors that participated in the study had stage II tumors (47%) followed by stage I tumors (36%) and finally stage III cancer survivors (17%). Nearly all breast cancer survivors underwent surgery (97%), most had chemotherapy (83%), and many had radiation treatment (74%), nearly identical to what was seen in the previous study.

The majority (54%) of breast cancer survivors reported becoming menopausal after being treated for breast cancer. A smaller number (34%) were pre-menopausal both before and after treatment for breast cancer. Post menopausal women accounted for 11.5% of the overall sample.

Return to work and lost work days

Most breast cancer survivors participating in the study returned to work within 6 months (71.4%) and nearly a third (32%) reported no missed work. In the sample, just over a quarter (26%) of the participants missed from 6 to 18 months of work, while only 2% missed more than 18 months of work over the average 3 year post treatment survivorship reported by our sample. All participants were currently employed at the time that they participated in the study.

Hypothesis 1

A MANCOVA was performed controlling for marital status, race and age were controlled for (see Table 4). It can be seen in Table 4 that breast cancer survivors experienced higher levels of self-reported symptom burden ($F(1,234)=12.57$, $p < 0.01$). Specifically, the breast cancer survivors had higher levels of anxiety ($F(1,234)=6.30$, p

< 0.01 and depression related symptoms (F(1,234)=3.88, $p < 0.01$), fatigue MFSI ($F(1,234)=3.06$, $p < 0.05$) and fatigue VASF ($F(1,234)=11.11$, $p < 0.01$), pain ($F(1,234)=4.92$, $p < 0.05$) as illustrated in figure 1. Self-reported work related memory difficulties ($F(1,234)=16.77$, $p < 0.01$), attention ($F(1,234)=5.58$, $p < 0.01$), executive functioning ($F(1,234)=7.73$, $p < 0.01$) were higher in cancer survivors as well and this is further illustrated in figure 2. Finally, there were significant differences detected between the two groups on the measure of executive function ($F(1,234)=3.47$, $p < 0.01$) and attention ($F(1,234)=4.34$, $p < 0.01$) as measured by the CNSVS where the cancer survivors scored higher than the non cancer comparison group indicating better levels of these two areas of performance based scores, this is also illustrated in figure 3.

Analysis of performance based and self-report measures

The relationship between performance based measures and the self report measure were evaluated for three conditions using partial correlational testing controlling for age, marital status, and race. The three conditions evaluated were the entire sample as a whole (N=234), breast cancer survivors only (N=122), and non-cancer comparison group only (N=112). In both the breast cancer survivors and the total aggregate sample, it was clear that no relationship existed between the performance measures and the self report measures of symptom burden as can be seen in Table 5 and Table 6. Table 7 shows a relationship at the $p < 0.01$ level between the performance measure of verbal memory and the cognitive symptoms checklist memory measure. In general, it is difficult to make any assumption about this relationship as it also occurred in the control group suggesting that there may be more strength in the relationship of some of these measures in those who

have not been exposed to breast cancer. The following relationships were detected in the non-cancer comparison group that did not exist in the other correlational analyses. It is important to remember that higher self-report scores indicate poorer function and lower performance scores indicate poorer function. Performance based verbal memory scores were related to self-report memory ($r = -0.31$, $p < 0.01$), self-report executive function ($r = -0.23$, $p < 0.05$), and the overall mean of all three self-report subscales ($r = -0.22$, $p < 0.05$) in the non cancer comparison participants. Additionally self reported memory was correlated with the performance measure of verbal memory ($r = -0.20$, $p < 0.05$) in non cancer comparison group participants. The performance measures are not measures of cognitive limitations in a work situation and, as such these measures while related measure different aspects of function. Work specific perceptions of the specific limitations were captured by the self reported changes.

Hypothesis 2.

Two independent two step linear regressions were conducted for each group in order to determine which factors contributed significantly to the work output score of the WLQ and explained the variance within each of the groups as shown in Table 8 and Table 9. The proposed model includes six specific symptom burden components all of which impact our outcome measurement of workplace limitations as measured by the WLQ output score and measures of either self-report cognitive limitations or objective measures of cognitive performance. The three parts of the model include confounding demographic variables, psychological and physical wellbeing (symptom burden), and cognitive functioning measured either by performance based tests or self-report

instrument. Since none of the demographic variables were significantly related to the work output limitations scale, they were not included in the regression analysis. The first portion of the regression analysis examined the impact that symptom burden had on the model as confounders. For breast cancer survivors (N=133) job stress, fatigue as measured by the MFSI, anxiety, depression, pain, and fatigue measured using a visual analog scale were all entered into the model. Of these variables, job stress (β=.27, $p < 0.01$) and fatigue as measured by the visual analog instrument (β=.18, $p < 0.05$) accounted for much of the variance ($R^2 = 0.37$, $p < 0.01$). The performance measures of cognitive performance only accounted for 1.5 percent of the total variance (R^2 change= 0.02, $p < 0.01$) and was not statistically significant. The non-significant R^2 change = 0.02 was weak and would have only been detected as statistically significant had the sample consisted of 721 participants and then the question of clinical significance over such a small effect size would have come into question. This was the case for the non-cancer control group which also did not have significant findings when considering performance testing. Self-report measures were able to account for a more substantial amount of the total variance ($R^2 = 0.17$, $p < 0.01$), but only in the breast cancer survivor group, two of the individual measures reached statistical significance. The cognitive symptom checklist memory (β=.34, $p < 0.01$) and executive function (β=.22, $p < 0.05$) were found to be significant contributors to workplace limitation output scores. Self-report measures and symptom burden were able to account for 55% of the variance in this regression analysis ($R^2 = 0.55$, $p < 0.01$).

In the non-cancer comparison group (N=122) depression (β=.30, $p < .01$) was a significant confounder in the model when considering this group but accounted for less of the variance ($R^2 = 0.27$, $p < 0.01$) than in the breast cancer group. Symptom burden and self-report measures accounted for 32.1 percent of the total variance ($R^2 = 0.32$, $p < 0.01$) in the non cancer comparison group and of that self-report measures of cognitive function at work accounted for 4.7 percent of the variance (R^2 Change= 0.05, p= *n.s.*).

Relationship of Group and Symptom Burden on Work Limitations

A separate multivariate regression was conducted for each of the significant symptoms on work limitations by group (BCS and NCCG). A similar regression for all participants explained 36% of the variance in work output limitations ($R^2 = 0.36$, $p < 0.01$) with the following five factors as significant main effects: group (cancer) (β=-0.12, $p < 0.05$), job stress (β=0.20, $p < .01$), HADS depression score (β=0.15, $p < 0.05$), VAS Fatigue (β=0.15, $p < .05$), and CSC Memory (β=0.31, $p < .01$). The interaction between group and the significant variables in the above regression were evaluated as part of an exploratory analysis and the cancer and job stress interaction was significant (β=-0.56, $p < .01$). There was a trend for VAS fatigue (β=-0.25, p =.056) and work output. Additionally pain (β=-0.38, $p < .05$) and work output had a significant group interaction. These interactions are presented in Figures 4, 5, 6 and 7. These figures indicate that a relationship exists in both groups however the slope is steeper in the cancer survivor group indicating a more rapid decrease in work output related to an increase in job stress and also fatigue.

Discussion

Overall Findings.

In the context of our a priori hypotheses, it was found that performance based measures of cognitive performance were not significantly related to the work limitations questionnaire output score in occupationally active breast cancer survivors. It was found symptom burden as measured by self report was a significant predictor of work limitations as represented by the work limitations questionnaire output measure. The work limitations output score has been validated in other studies as a reliable indicator of actual work output (Mattke, Balakrishnan, Bergamo, & Newberry, 2007; Lofland, Pizzi, & Frick, 2004; Hansen et al., 2008; Presad et al, 2004). Symptom burden was in fact higher in breast cancer survivors than in the non-cancer comparison group. Breast cancer survivors reported significantly greater symptoms of depression and anxiety, they also reported greater levels of fatigue, and perceived work related cognitive impairments. Finally the self report measures or work related cognitive limitations was related to the work limitations questionnaire output score while the performance measures of cognitive function was not. .

This is consistent with the findings of other research that show depression, fatigue, job stress, and other symptoms are related to self report cognitive measures but fail to be associated with the outcomes on performance based measures (Shilling &Jenkins, 2007; Vardy et al., 2008). The symptom burden in the breast cancer survivors showed distinctly different levels of depression, fatigue, and self-reported cognitive limitations three years post treatment than non-cancer comparison group.. After

controlling for demographic differences observed in the present study breast cancer survivors experience a higher level of symptom burden than their non-cancer control group counterparts (Shilling et al, 2004; Hansen et al, 2008). It is important to note that the symptoms of depression and anxiety measured in all participants were below the established clinical cut offs for these measures (Zigmond & Snaith, 1983).

Many studies have found that the majority (79%-88%) of breast cancer survivors return to work within one year (Bouknight, et al., 2006; Bradley & Bednarek, 2002; Maunsell, et al., 2004) . The sample used in this study continues to represent that trend, with roughly 85% of all breast cancer respondents returning to work within one year. As reported by Maunsell and colleagues (2004), there was no significant difference in the type of jobs held by cancer survivors and the non cancer comparison group after controlling for education.

One workplace difference was that breast cancer survivors (72%) were more likely to experience work limitations than the non cancer group (51%). Interestingly, job satisfaction was not a factor in accounting for variance in work limitations and was higher in the breast cancer survivors than in the non cancer group. The difference in job satisfaction between the groups was not significant. A finding as a result of the exploratory two-way interactions indicate that job stress, pain, and fatigue are related to work output in both groups although the breast cancer survivors work output was more responsive (i.e., steeper slope) to higher levels. Earlier detection and management may improve work output. Such an implication of the current findings requires specific study.

This study has limitations that could affect the generalizability of the data collected. The study employed a convenience sample and does not represent a general adult working population. Our sample was highly educated, with nearly 50% of the sample having a graduate level education. Additionally our sample of cancer survivors had a much higher average household income than the average U.S. household income. While an effort was made to recruit a diverse sample, the web based nature of the assessment could have inadvertently skewed the participant pool and resulted in a self-selection of computer savvy, highly educated, high income earners. Other studies have encountered similar shifts in the participant pool, showing that typically Internet based studies appeal to a younger and more educated participant (Pereira, et al., 2000) .While this study did control for a number of factors including age, there still may be a significant difference between our population and the older women who are technologically savvy. A possible problem with Internet based research is the possibility of participant misrepresentation. Internet research allows for the efficient collection of more data than would have been possible with traditional means, those who might wish to misrepresent themselves would have less impact due to the greater number of participants. Research indicates that most breast cancer patients attempt to accurately report their medical history (Maunsell et al., 2005) and evidence that our participants may have misrepresented their medical status was not detected in the course of the data collection process. In our sample, breast cancer survivors were also more likely to be married than the non cancer control group and this factor may have been partially responsible for the higher overall household income, which exceeded the national

average in either case. Some studies show that a more diverse population is utilizing the Internet today for health information and that selection bias may be decreasing in online samples (Whitehead, 2007), this does not appear to be the case in this study where most of the participants are white, highly educated, and have the ability to maintain a high standard of living. Another important limitation is the fact that the study is cross-sectional in nature, as such; the ability to prospectively evaluate both performance and perceived cognitive performance is limited. As with all cross-sectional research it is impossible to establish causation, in this case one potential limitation is the inability to establish a causal link between cognitive limitations and work limitations.

This study represents the first attempt to address these questions in breast cancer survivors that the author is aware of. This study shows that self-report measures of work related cognitive limitations are more closely related to workplace limitations than performance based measures in occupationally active cancer survivors. Future research should consider a longitudinal approach where pre-treatment baselines (Shilling et al., 2005) can be used to better establish the relationship that may exist between cognitive limitations and workplace limitations. A minority of breast cancer survivors (27%) did not report experiencing any limitations in work output, possibly the result of some yet to be identified protective factors or other yet to be identified environmental factors. Creating more sensitive measures of the various long term effects of cancer survivorship in many areas may lead to identifying protective mechanisms or environmental factors important for improving the quality of life for cancer survivors. Future research may also benefit from using a comparison group that does not experience workplace limitations in

order to reduce the overall variance and improve the specificity of the findings.

Table 1: Participant Characteristics

	BCS (n=132)		NCCG (n=122)	
	n	**%**	**N**	**%**
		Age**		
≤ 40 years old	43	32.6	73	59.8
41-50 years old	43	32.6	21	17.2
51-65 years old	46	34.8	28	23.0
Mean (Standard Deviation)	45.02 (9.70)		38.75 (12.02)	
		Race**		
Caucasian	116	87.2	80	65.6
African American	8	6.0	26	21.3
Asian American/Pacific Islander	7	5.3	8	6.6
Other	2	1.5	8	6.6
		Ethnicity*		
Hispanic	4	3.4	13	11.3
Non-Hispanic	115	96.6	102	88.7
		Education		
Some College or less	30	22.6	27	21.9
Associates/Bachelors	41	30.8	43	35.2
Some Graduate School	11	8.3	14	11.5
Graduate Degree	51	38.3	38	31.1
		Marital status**		
Single	20	15.0	39	32.2
Cohabitating	5	3.8	8	6.6
Married	95	71.4	58	47.9
Divorced	12	9.0	16	13.2
Widowed	1	0.8	0	0

*p<0.05
**p<0.01

Table 2: Job Characteristics

	BCS (n=132)		NCCG (n=122)	
	n	**%**	**N**	**%**
Current Job Characteristics				
Managerial	48	36.4	42	34.4
Non-Managerial	73	55.3	74	60.7
Self-Employed	11	8.3	6	4.9
Primary Occupation				
Clerical	14	10.8	14	11.5
Sales	7	5.4	4	3.3
Management/Administration	47	36.2	41	33.6
Professional/ Technical/Science	58	44.6	58	47.5
Service Worker	4	3.1	5	4.1
Years at Current Job				
1 year or less	13	10.7	28	27.5
2-5 years	53	43.4	37	36.3
6-10 years	25	20.5	17	16.7
11-15 years	14	11.5	8	7.8
16-20 years	7	5.7	4	3.9
21-25 years	5	4.1	6	5.9
26+ years	5	4.1	2	2.0
Mean (Standard Deviation)	7.33	(6.98)	5.88	(7.08)
Job Satisfaction				
Enjoy Job/Work Hard	97	72.9	75	61.5
Enjoy Job/Don't Work Hard	15	11.3	23	18.9
Don't Like Job/Work Hard	10	7.5	19	11.4
Don't Like Job/Don't Work Hard	8	6.0	4	3.3
Work Harder for Better Pay	3	2.3	1	0.8
Annual Income**				
0-19,000	3	2.3	4	3.3
20-39,000	5	3.8	19	15.8
40-59,000	15	11.3	22	18.3
60-79,000	22	16.5	24	20.0
80-99,000	19	10.7	13	10.8
100,000 or more	69	51.9	38	31.7

¥ For breast cancer survivors only

Note: Not all participants responded to all questions

*$p<0.05$

Table 3: Breast Cancer Survivors: Treatment and Work Absence (n= 133)

	N	%		n	%
Tumor Location			Time Since Primary Treatment		
Right Breast	68	51.5	1 year	45	34.9
Left Breast	59	44.7	2 years	23	17.8
Both Breasts	5	3.8	3 years	19	14.7
Tumor Stage			4 years	13	10.1
			5 years	12	9.3
I	47	35.9	6 years	4	3.1
II	62	47.3	7 years	4	3.1
III	22	16.8	8 years	1	0.8
Treatment			9 years	4	3.1
Chemotherapy	110	82.7	10 years	4	3.1
Radiation Therapy	98	73.7	Mean (S.D.)	3.07	(2.39)
Surgery	129	97.0			
Tamoxifen or Ralozifene	59	44.4	Work absence after cancer diagnosis		
			No absence	43	32.3
Herceptin (Trastuzumab)	18	13.5	1 day to < 6 months	52	39.1
			6 to < 12 months	18	13.5
Other Treatment	31	23.3	12 to < 18 months	17	12.8
Menopausal Status			≥ 18 months	3	2.3
Premenopausal Pre and Post-Cancer	45	34.4			
Premenopausal Pre-Cancer/ Menopausal Post-Cancer	71	54.2			
Menopausal prior to cancer	15	11.5			

Table 4: Symptom burden: BCS (N=122) and NCCG (N=112)

Overall Model F=6.39**		BCS N=122	NCCG N=112		
	Mean	Std Dev	Mean	Std Dev	F
Anxiety (HADS-A)Φ	7.76	3.04	7.03	2.63	6.30**
Depression (HADS-D)Φ	4.55	3.37	3.17	2.58	3.88**
BRFS (Job Stress)Φ	1.61	0.96	1.29	0.96	3.06*
Fatigue (MFSI)Φ	5.64	4.82	2.25	2.51	11.11**
Fatigue (VAS Fatigue)Φ	6.08	2.31	4.87	2.15	4.92**
Pain (VAS Pain)Φ	3.29	2.04	2.66	1.88	1.80
Memory (CSC)Φ	8.71	6.11	3.54	3.26	16.77**
Attention (CSC)Φ	4.95	3.75	3.29	3.05	5.58**
Executive Function (CSC)Φ	4.21	4.36	1.80	2.18	7.73**
CSC OverallΦ	17.43	12.66	8.43	7.03	12.57**
CNSVS Composite MemoryΨ	101.73	18.09	96.78	19.63	1.85
CNSVS Verbal MemoryΨ	99.83	16.56	95.76	19.90	2.13
CNCVS Visual MemoryΨ	102.84	17.13	99.05	16.99	1.92
CNSVS Executive FunctionΨ	98.63	9.16	94.50	16.42	3.47**
CNSVS AttentionΨ	83.84	10.26	80.08	17.72	4.34**

*p<0.05
**p<0.01

NOTE: Covariates = marital status, race, age
BCS = Breast Cancer Survivors, NCCG = Non Cancer Control Group
Φ = Higher scores indicate poorer functioning
Ψ = Lower scores indicate poorer functioning

Table 5: Relationship between performance test scales and self-report scales with all participants (N=234)

	1	2	3	4	5	6	7	8	9	10
1. CNSVS Composite Memory	--	0.86**	0.86**	0.34**	0.35**	0.00	0.01	-0.02	0.00	0.05
2. CNSVS Verbal Memory		--	0.49**	0.28**	0.31**	-0.02	-0.04	-0.04	-0.04	0.02
3. CNSVS Visual Memory			--	0.30**	0.30**	0.00	0.06	0.00	0.03	0.05
4. CNSVS Executive Function				--	0.23**	-0.03	-0.03	-0.05	-0.04	-0.04
5. CNSVS Attention					--	0.03	0.09	0.07	0.08	0.12
6. CSC Attention						--	0.71**	0.60**	0.84**	0.51**
7. CSC Memory							--	0.79**	0.95**	0.63**
8. CSC Executive Function								--	0.89**	0.57**
9. CSC Overall Mean									--	0.64**
10. WLQ Output Limitations										--

*p<0.05
**p<0.01
Note: Control variables were Age, Marital Status and Race

Table 6: Relationship between performance test scales and self-report scales with BCS (N=122)

	1	2	3	4	5	6	7	8	9	10
1. CNSVS Composite Memory	--	0.85**	0.87**	0.22*	0.20*	-0.06	0.06	0.01	0.02	0.03
2. CNSVS Verbal Memory		--	0.48**	0.15	0.12	-0.06	0.03	0.02	0.00	0.05
3. CNSVS Visual Memory			--	0.23*	0.23*	-0.06	0.07	0.00	0.02	0.00
4. CNSVS Executive Function				--	0.31**	-0.06	0.00	-0.05	-0.04	-0.08
5. CNSVS Attention					--	-0.01	0.05	0.03	0.04	0.07
6. CSC Attention						--	0.76**	0.65**	0.86**	0.54**
7. CSC Memory							--	0.77**	0.95**	0.64**
8. CSC Executive Function								--	0.89**	0.60**
9. CSC Overall Mean									--	0.66**
10. WLQ Output Limitations										--

*p<0.05
**p<0.01
Note: Control variables were Age, Marital Status and Race

Table 7: Relationship between performance test scales and self-report scales with NCCG (N=112)

	1	2	3	4	5	6	7	8	9	10
1. CNSVS Composite Memory	--	0.87**	0.85**	0.40**	0.46**	0.01	-0.20*	-0.17	-0.14	0.03
2. CNSVS Verbal Memory		--	0.49**	0.33**	0.40**	-0.02	-0.31**	-0.23*	-0.22*	-0.09
3. CNSVS Visual Memory			--	0.35**	0.38**	0.05	-0.02	-0.06	-0.01	0.14
4. CNSVS Executive Function				--	0.19	-0.07	-0.18	-0.10	-0.14	0.09
5. CNSVS Attention					--	0.00	0.05	0.04	0.04	0.13
6. CSC Attention						--	0.60**	0.40**	0.81**	0.33**
7. CSC Memory							--	0.73**	0.92**	0.36**
8. CSC Executive Function								--	0.81**	0.24*
9. CSC Overall Mean									--	-0.38**
10. WLQ Output Limitations										--

*p<0.05
**p<0.01
Note: Control variables were Age, Marital Status and Race

Table 8: Self-report measures of cognitive limitations relation to work limitations: BCS and NCCG in separate regressions

	BCS (n= 133) Beta (β)	NCCG (n=122) Beta (β)
	Step 1: Confounding Factors	
BRFS (Job Stress)	0.27**	0.06
MFSI (Fatigue)	0.15	-0.15
HADSA (Anxiety)	-0.04	0.15
HADSD (Depression)	0.12	0.30**
VAS Pain	0.15	0.16
VAS Fatigue	0.18*	0.15
	R^2=0.372**	R^2=0.274**
	Step 2: Self Reported Measures of Cognitive Impairment	
CSC Memory	0.34**	0.20
CSC Attention	0.00	0.12
CSC Executive Function	0.22*	-0.06
	R^2= 0.546**	R^2= 0.316**
	R^2 Change= 0.174**	R^2 Change= 0.042

*p<0.05
**p<0.01
BCS = Breast Cancer Survivors
NCCG = Non Cancer Control Group

Table 9: Performance measures of cognitive performance relation to work limitations: BCS and NCCG in separate regressions

	BCS (n= 122) Beta (β)	NCCG (n=113) Beta (β)
	Step 1: Confounding Factors	
BRFS (Job Stress)	0.30**	0.07
MFSI (Fatigue)	0.15	-0.11
HADSA (Anxiety)	-0.03	0.11
HADSD (Depression)	0.13	0.24*
VAS Pain	0.14	0.21
VAS Fatigue	0.18*	0.13
	R^2=0.379**	R^2=0.236**
	Step 2: Performance Measures of Cognitive Impairment	
CNSVS Comp Memory	1.24	1.86
CNSVS Verbal Memory	-0.61	-1.30
CNSVS Visual Memory	-0.83	-0.89
CNSVS Exec Function	-0.08	-0.15
CNSVS Attention	0.03	0.15
	R^2= 0.393**	R^2= 0.303**
	R^2 Change= 0.015	R^2 Change= 0.067

*p<0.05
**p<0.01
BCS = Breast Cancer Survivors
NCCG = Non Cancer Control Group

Table 10: Factors and interactions related to work limitations (Continuous WLQ Output Score)

	N = 255 Beta (β) Step 1: Confounding Factors	N = 235 Beta (β) Step 1: Confounding Factors	
Cancer Status	-0.13*	-0.12*	
BRFS (Job Stress)	0.18**	0.20**	
MFSI (Fatigue)	0.11	0.13	
HADS-A (Anxiety)	0.04	0.02	
HADS-D (Depression)	0.17*	0.15*	
VAS Pain	0.11	0.13	
VAS Fatigue	0.16*	0.15*	
	R^2= 0.362**	R^2= 0.364**	
	Step 2: Self Report of Cognitive Impairment	Step 2: CNSVS Cognitive Performance	
CSC Memory	0.31**	1.27	Composite Memory
CSC Attention	0.07	-0.72	Verbal Memory
CSC Executive Function	0.15	-0.72	Visual Memory
		-0.09	Executive Function
		0.04	Attention
	R^2= 0.488**	R^2= 0.375**	
	R^2 Change= 0.126**	R^2 Change= 0.011	
		Group Interactions	
		Group x Job Stress	-0.56**
		Group x Fatigue	-0.25
		Group x Depression	-0.20
		Group x Pain	-0.38*

*p<0.05
**p<0.01

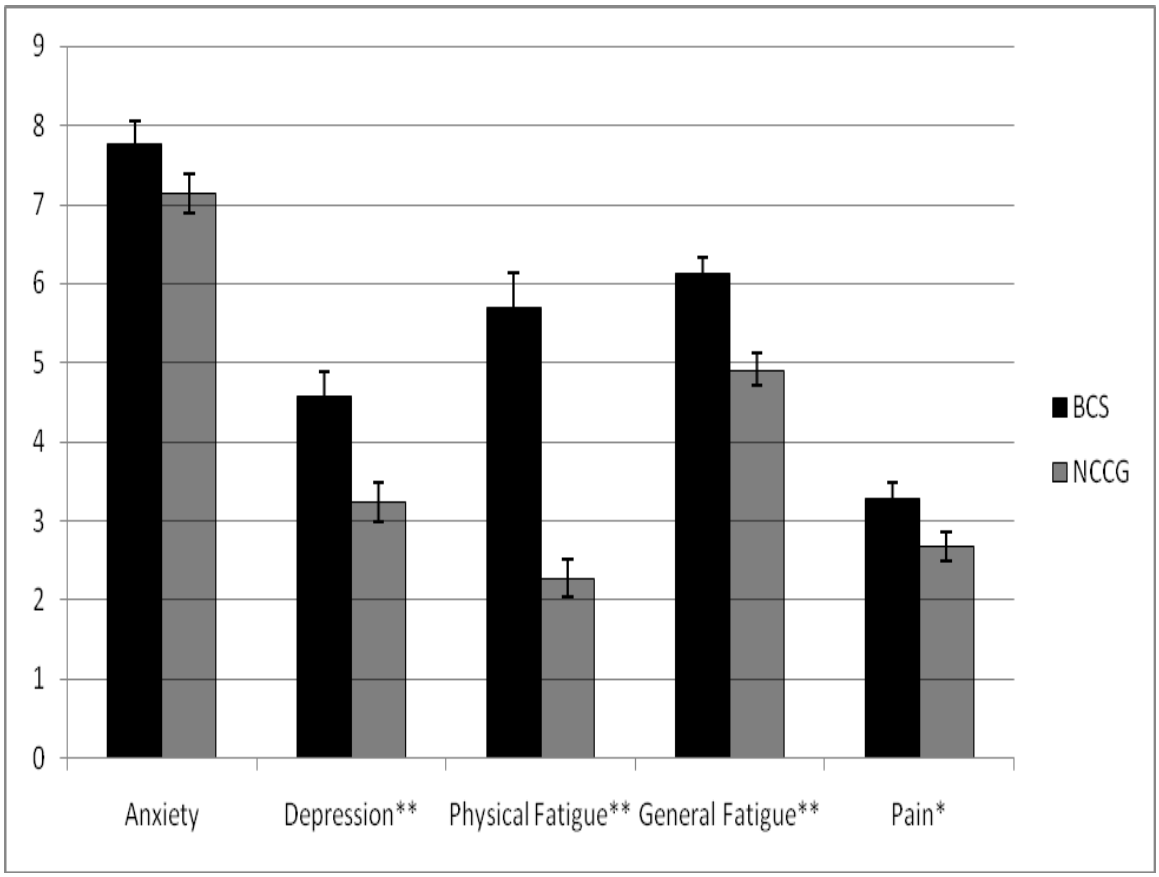

Figure 1: Self-report measures of mood, fatigue and pain (+SE) for BCS and NCCG. Items that are significant were calculated from the MANCOVA analysis.
NOTE: For all measures in this figure, higher scores indicate greater impairment.

*$p < 0.05$ **$p < 0.01$

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

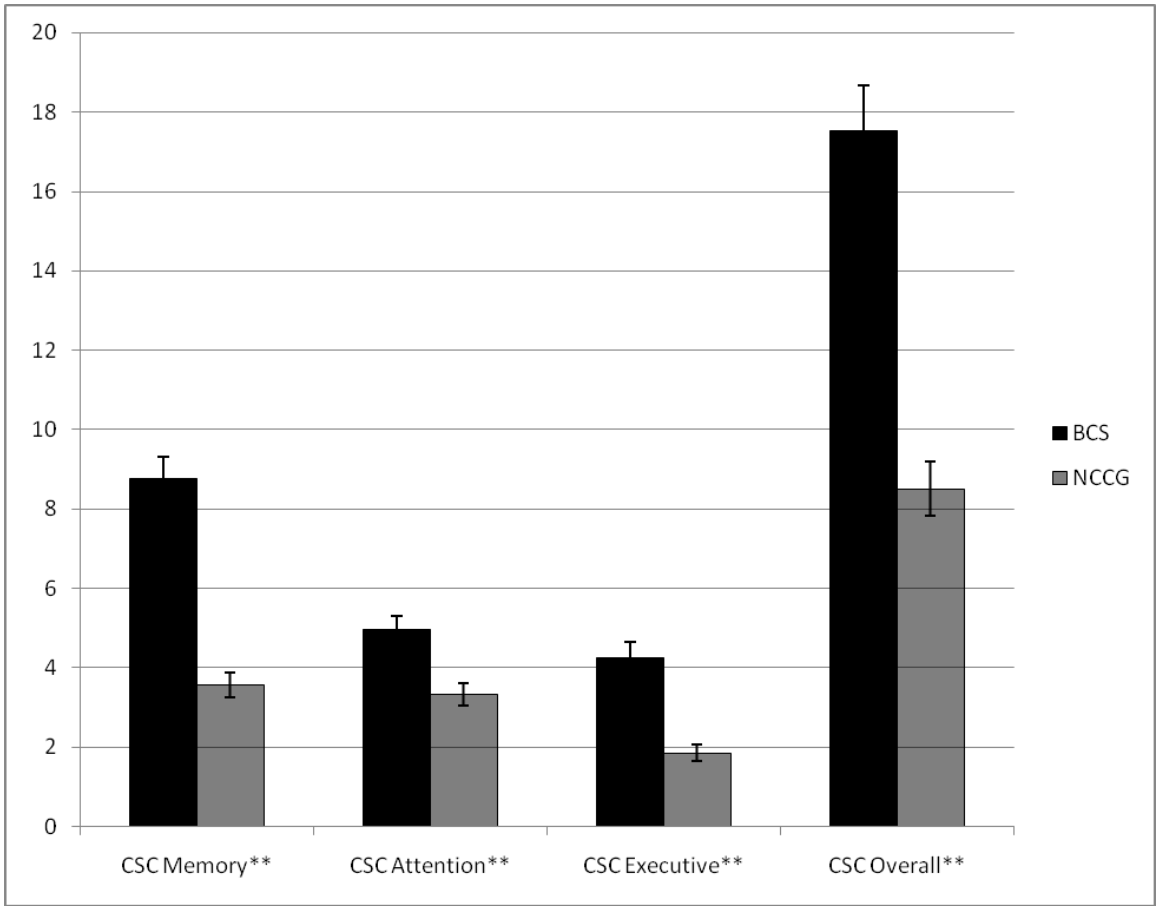

Figure 2: Self-report measures of cognitive function (+SE) for BCS and NCCG. Measures include CSC and Fact-Cog scales.

NOTE: For all measures in this figure, higher scores indicate greater impairment

**$p < 0.01$

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

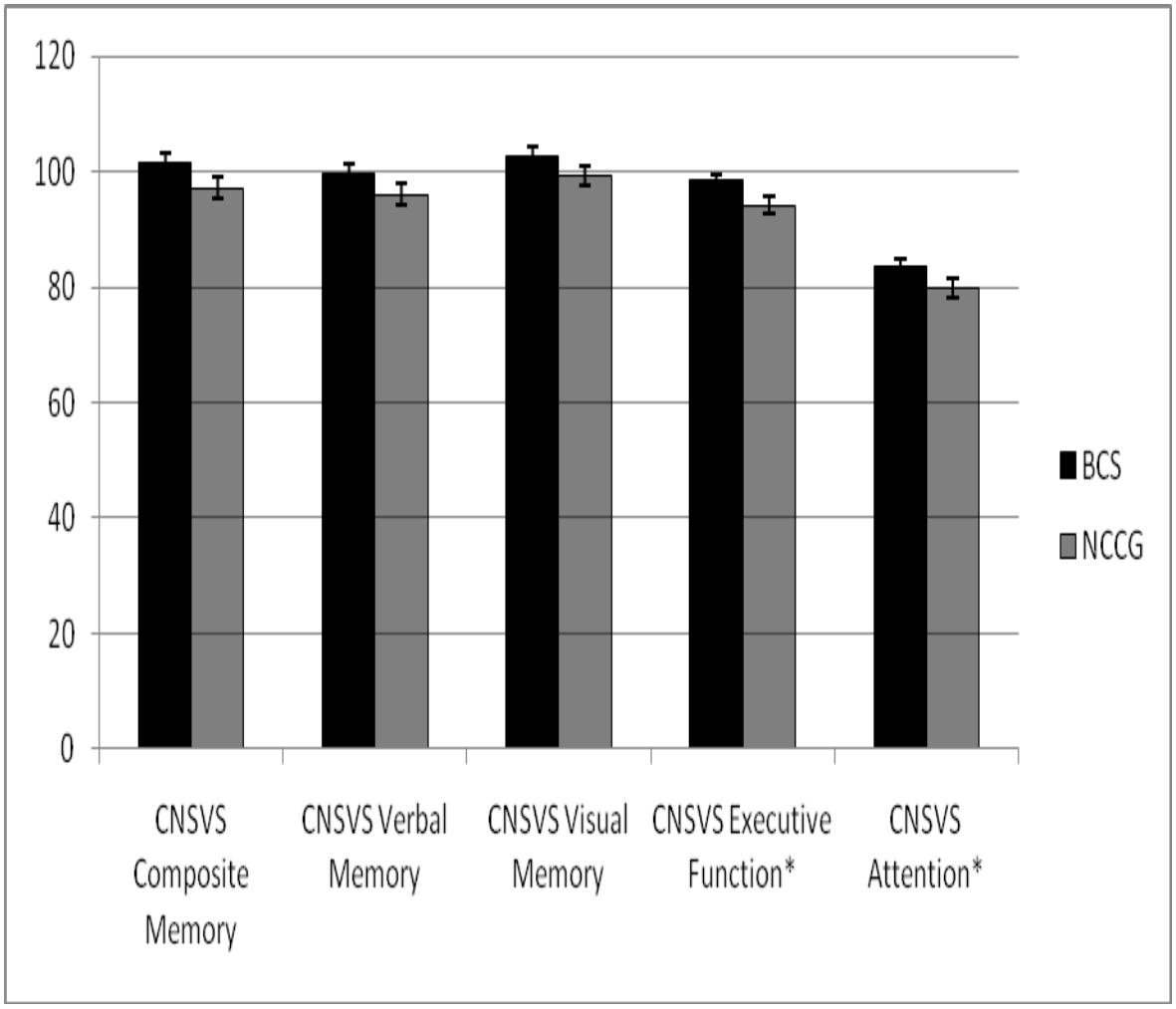

Figure 3: Cognitive performance tests (+SE) for BCS and NCCG.

NOTE: For all measures in this figure, lower scores indicate poorer functioning.

*$p < 0.05$

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

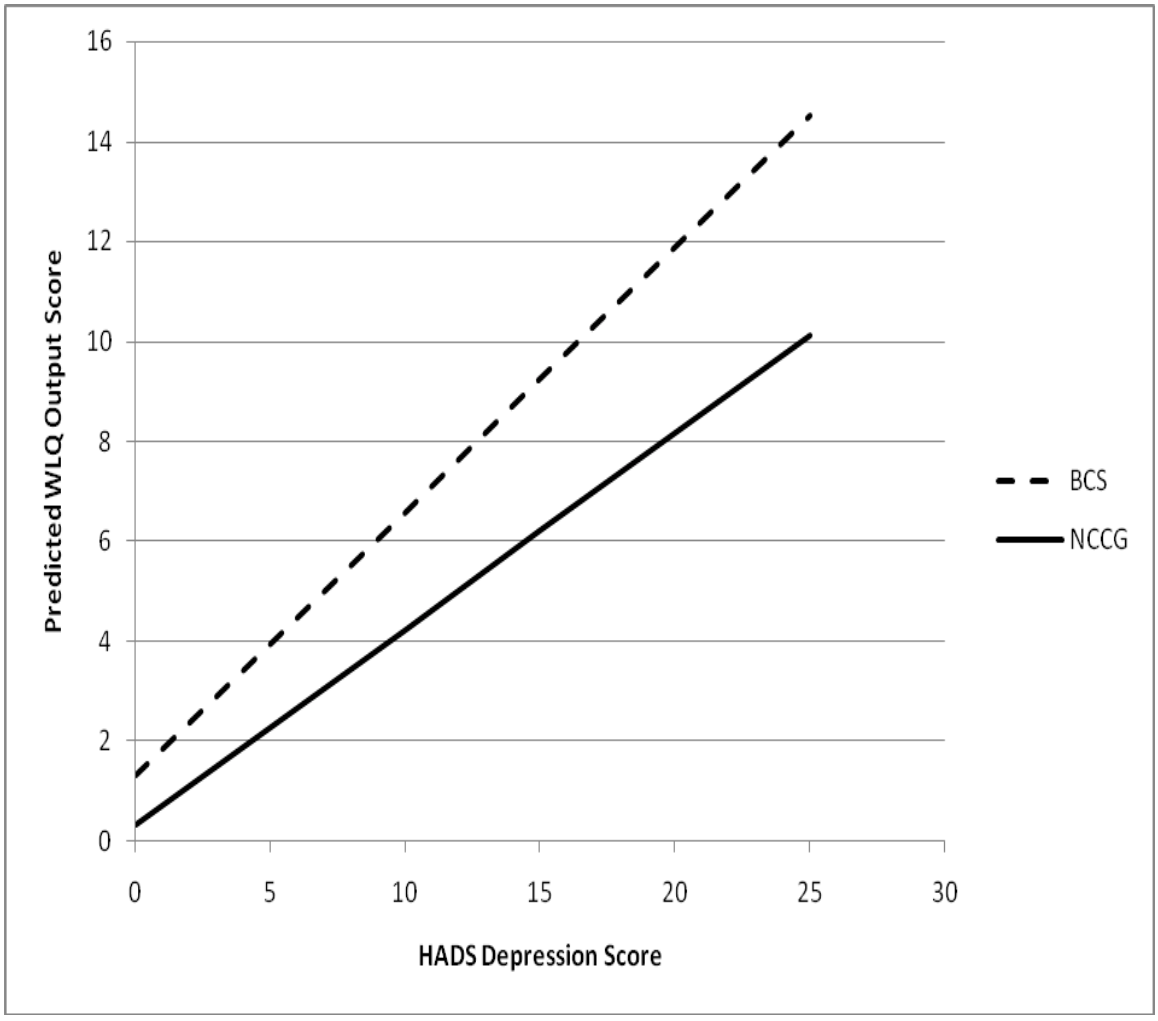

Figure 4: Predicted Work Limitations Questionnaire Output Score by HADS-Depression Score for BCS and NCCG.

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

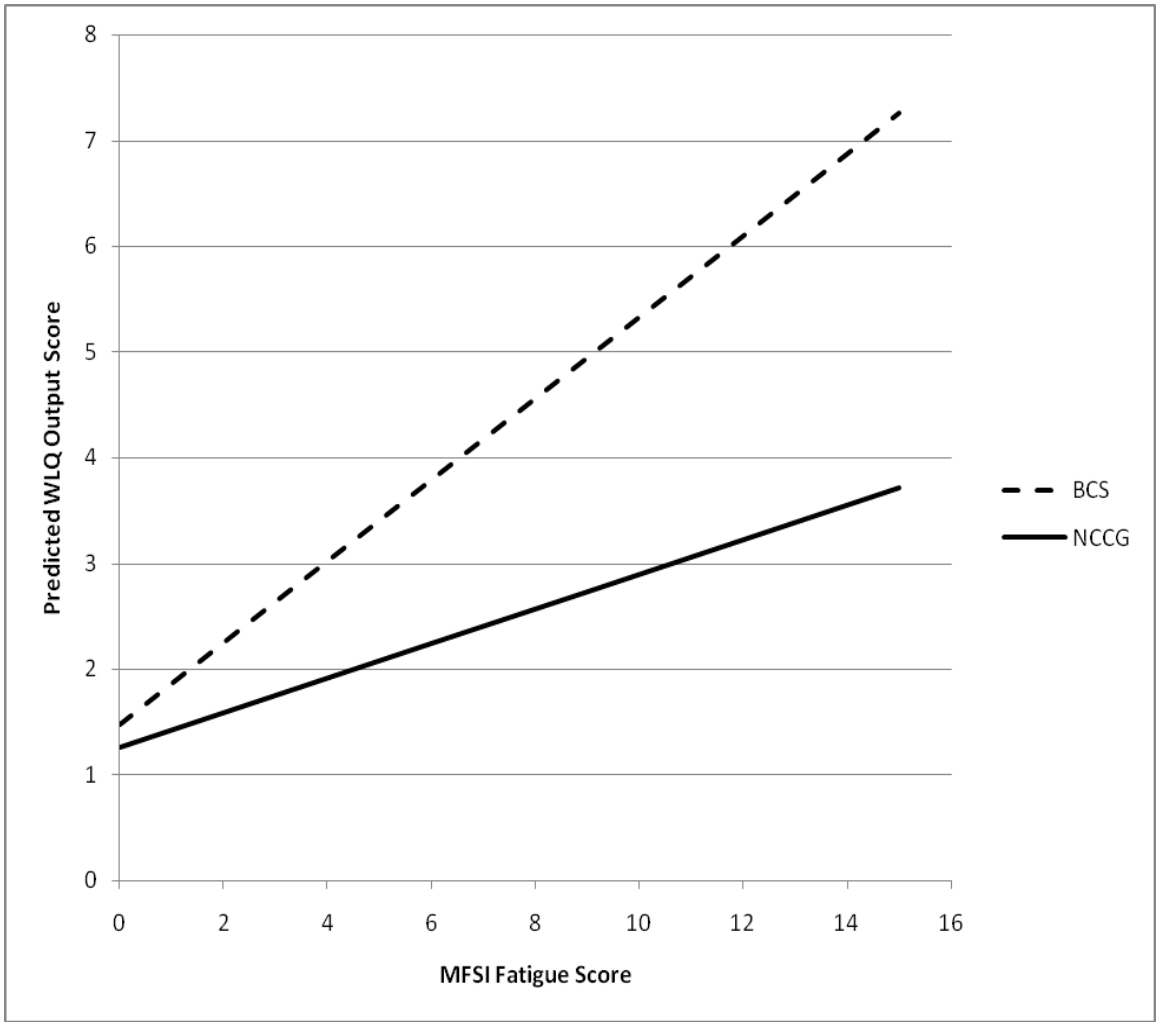

Figure 5: Predicted Work Limitations Questionnaire Output Score by MFSI-SF Physical Fatigue Score for BCS and NCCG.

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

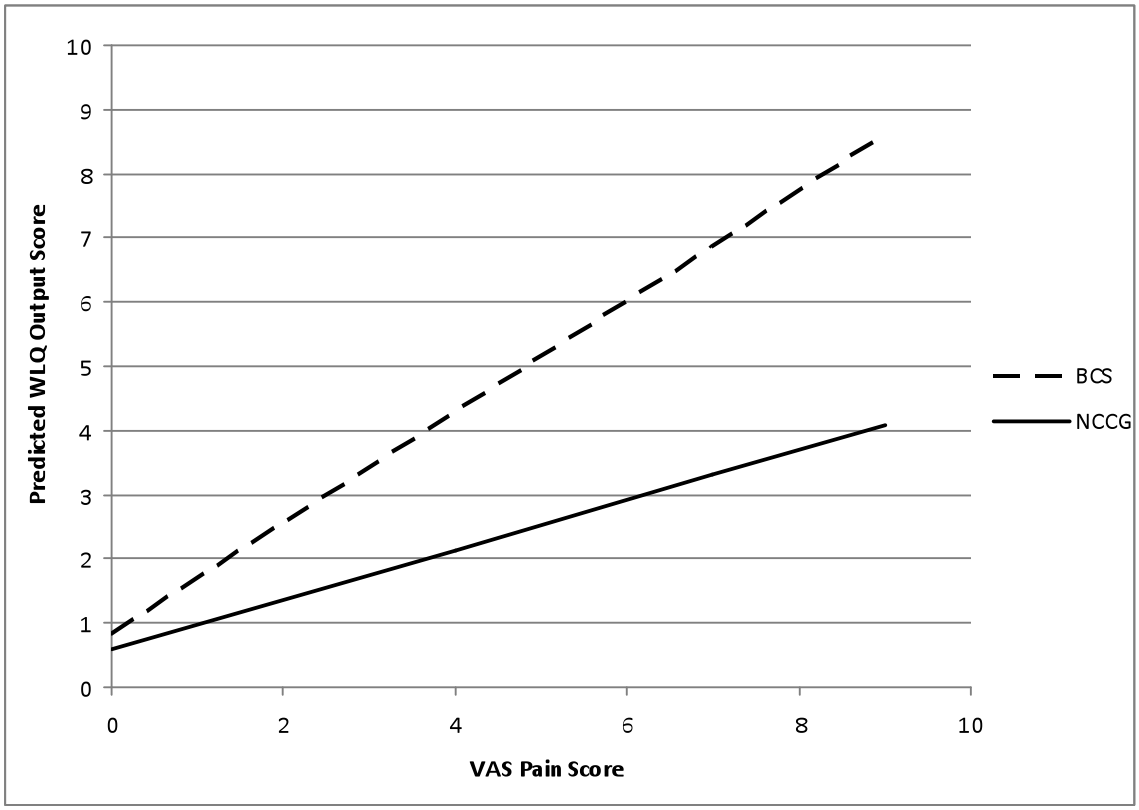

Figure 6: Predicted Work Limitations Questionnaire Output Score by VAS Pain Score for BCS and NCCG.

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

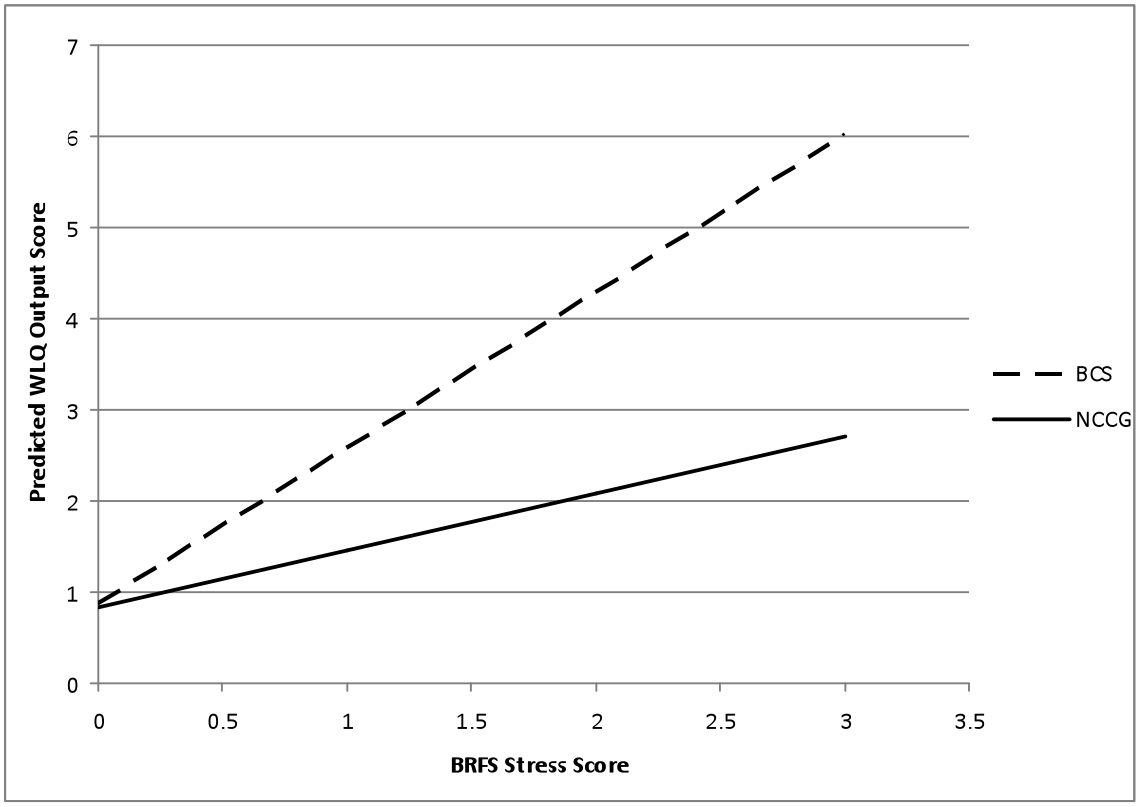

Figure 7: Predicted Work Limitations Questionnaire Output Score by Job Stress Score for BCS and NCCG.

BCS = Breast Cancer Survivors, NCCG = Non Cancer Comparison Group

Appendix A: Advertisements

Advertisements for Newspaper and Craig's list

Are You a Working Breast Cancer Survivor OR Would You Like To Help Breast Cancer Survivors?

Women breast cancer survivors, 1 to 10 years after primary cancer treatment, whose breast cancer has not spread AND women without cancer history are needed for on-line study on cognitive function and work. Must be currently working full-time, ages 18 through 65, and without a history of adult ADHD (prior to cancer), dementia, brain injury, epilepsy, drug or alcohol abuse. You will need Internet access with connection speed faster than dial-up. Study includes completing questionnaires and a short online test of memory. The study will take approximately 60 to 75 minutes to complete. To see if you are eligible for our study, go to:

http://cim.usuhs.mil/cancerstudy

For more information call Lisseth Calvio at (301) 295-9660 or email cogworkstudy@gmail.com.

Are You A Working Breast Cancer Survivor?

Women breast cancer survivors, **1 to 10 years** after primary cancer treatment, whose breast cancer has not spread are needed for on-line study on cognitive function and work. Must be currently working full-time, ages 18 through 65, and without a history of adult ADHD (prior to cancer), dementia, brain injury, epilepsy, drug or alcohol abuse. You will need Internet access with connection speed faster than dial-up. Study includes completing questionnaires and a short online test of memory. The study will take approximately 60 to 75 minutes to complete. To see if you are eligible for our study, go to:

http://cim.usuhs.mil/cancerstudy

For more information call Lisseth Calvio at (301) 295-9660 or email cogworkstudy@gmail.com.

Do You Want To Help Breast Cancer Survivors?

Women without cancer history are needed for on-line study on cognitive function and work. Must be currently working full-time, ages 18 through 65, and without a history of dementia, brain injury, epilepsy, drug or alcohol abuse or adult ADHD. You will need Internet access with connection speed faster than dial-up. Study includes completing questionnaires and a short online test of memory. The study will take approximately 60 to 75 minutes to complete. To see if you are eligible for our study, go to:

http://cim.usuhs.mil/cancerstudy

For more information call Lisseth Calvio at (301) 295-9660 or email cogworkstudy@gmail.com.

Advertisement for Flyers

Are You a Working Breast Cancer Survivor?

An investigation into working and cognitive function after primary treatment for cancer

In order to participate, you must be:

1) Female breast cancer survivors between 1 and 10 years since primary treatment (surgery, chemotherapy, and/or radiation) whose breast cancer has not spread
2) Currently working full-time
3) Between the ages of 18 and 65
3) Without a history of dementia, brain injury, epilepsy, drug or alcohol abuse or adult ADHD (prior to cancer diagnosis)
4) Have access to the Internet (any connection speed other than dial-up)

We will ask you to take a short online questionnaire and test of memory, attention and organization that will require 60 to 75 minutes of your time**.** The study is 100% online and can be taken from any computer that does not use dial-up connection.

To see if you are eligible for our study, please go to:

http://cim.usuhs.mil/cancerstudy

For more information, you may contact Lisseth Calvio at (301)295-9660 or via email at: cogworkstudy@gmail.com

This research project is being run by the Uniformed Services University of Health Sciences, Bethesda M.D.

Want To Help Breast Cancer Survivors?

An investigation into working and cognitive function after primary treatment for cancer

In order to participate, you must be:

1) Female who has never been diagnosed with cancer
2) Currently working full-time
3) Between the ages of 18 and 65
3) Without a history of dementia, brain injury, epilepsy, drug or alcohol abuse or adult ADHD
4) Have access to the Internet (any connection speed other than dial-up)

We will ask you to take a short online questionnaire and test of memory, attention and organization that will require 60 to 75 minutes of your time**.** The study is 100% online and can be taken from any computer that does not use dial-up connection.

To see if you are eligible for our study, please go to:

http://cim.usuhs.mil/cancerstudy

For more information, you may contact Lisseth Calvio at (301)295-9660 or via email at: cogworkstudy@gmail.com

This research project is being run by the Uniformed Services University of Health Sciences, Bethesda M.D.

Are You a Working Breast Cancer Survivor
OR
Would You Like To Help Breast Cancer Survivors?

An investigation into working and cognitive function after primary treatment for cancer

In order to participate, you must be:

1) Female breast cancer survivors between 1 and 10 years since primary treatment (surgery, chemotherapy, and/or radiation), whose breast cancer has not spread
OR Female who has never been diagnosed with cancer
2) Currently working full-time
3) Between the ages of 18 and 65
3) Without a history of dementia, brain injury, epilepsy, drug or alcohol abuse or adult ADHD (for breast cancer survivors, no ADHD diagnosis prior to cancer diagnosis)
4) Have access to the Internet (any connection speed other than dial-up)

We will ask you to take a short online questionnaire and test of memory, attention and organization that will require 60 to 75 minutes of your time**.** The study is 100% online and can be taken from any computer that does not use dial-up connection.

To see if you are eligible for our study, please go to:

http://cim.usuhs.mil/cancerstudy

For more information, you may contact Lisseth Calvio at (301)295-9660 or via email at: cogworkstudy@gmail.com

This research project is being run by the Uniformed Services University of Health Sciences, Bethesda M.D.

Appendix B: Informed Consent Form

Consent for Participation in a Research Study

The following information is provided to inform you about the research project and your participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and/or about the information given below.

It is important that you understand that your participation in this study is totally voluntary. You may refuse to participate or choose to withdraw from this study at any time. If, during the course of the study, you should have any questions about the study or your participation in it, you may contact:

Lisseth C. Calvio, M.S. at 301-295-9660
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799
cogworkstudy@gmail.com

Michael Feuerstein, Ph.D., MPH at 301-295-9677
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799
mfeuerstein@usuhs.mil

Institutional Review Board Office at (301) 295-9534
USUHS, Bethesda, Maryland 20814
cogworkstudy@gmail.com

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1. INDICATED BELOW ARE THE FOLLOWING:

    a. THE PURPOSE OF THIS STUDY
    b. THE PROCEDURES TO BE FOLLOWED
    c. THE APPROXIMATE DURATION OF THE STUDY

1a. THE PURPOSE OF THIS STUDY:

- Over 80% of breast cancer survivors return to work within months of diagnosis and treatment.

- Some survivors experience memory or concentration problems that may impact their ability to work.
- This study will look at how tests and questionnaires of memory, attention, and organization might relate to each other and to your performance at work.
- If you agree to participate in this study, you will be asked to take an online questionnaire and a short test of your memory, organization and attention. The study will take approximately one hour to one hour and fifteen minutes to complete.

1b. THE PROCEDURES TO BE FOLLOWED:

Individuals meeting qualifications below may be asked to participate in the study.

You may qualify for this study based on the following:

- Adult female ages 18 to 65 years old
- Currently working full-time
- Computer/Internet access and usage; computer speed faster than dial-up (Only people with an Internet speed connection faster than dial-up will be able to continue with the study.)
- Breast Cancer Survivors Only: Between 1 and 10 years since completion of primary treatment (surgery, chemotherapy, radiation); working 1 year prior to diagnosis of cancer, and currently working.

You are not qualified of you have any of the following:

- Metastasized Cancer
- Dementia or Brain Disorder (For Example: Traumatic Brain Injury or Epilepsy)
- Drug and/or Alcohol Abuse
- Existence of adult Attention Deficit Hyperactivity Disorder (ADHD) prior to Cancer treatment

Participation in this study includes completing

1. online questionnaire (approximately 30 minutes to complete)

and

2. a short online test of memory, organization and attention (approximately 30 minutes to complete)

1c. DURATION OF THE STUDY

Approximately 1 hour to approximately 1.25 hours

2. THIS STUDY IS BEING DONE SOLELY FOR THE PURPOSES OF RESEARCH

There will be no direct benefit to you by participating in this study. It is the goal of this research to help other cancer survivors in the future related to their ability to work.

3. DISCOMFORTS AND/OR RISKS THAT CAN BE REASONABLY EXPECTED ARE:

- The risks associated with this study are minor
    - You may find the questionnaires ask questions that may make you uncomfortable
    - You may skip questions at any time
    - Also, you may decline to participate at any time and/or withdraw your participation at any time

- You may experience discomfort or fatigue while completing the test segment
    - There will be a ample opportunities to take a break built into the study, in between sections and after each test

- If you have any questions or concerns, you can reach the principle investigators:
    - By telephone (301)295-9660
    - By email: cogworkstudy@gmail.com
    - A researcher will get back to you within one business day

4. POSSIBLE BENEFITS TO YOU THAT MAY BE REASONABLY EXPECTED ARE:

- You may gain a better understanding of the relationship between your memory, organization and attention (perceived and actual) and your productivity at work.
- Through completing this study, you will be providing information that will be helpful in expanding scientific knowledge about work productivity and memory, organization and attention function in breast cancer survivors.
- Our long-term goal is to gain a better understanding of the measurement of memory, organization and attention limitations and its impact on work productivity, and ultimately, work towards improving work productivity in cancer survivors.

5. PRIVACY AND CONFIDENTIALITY:

- All information you provide as part of this study will be confidential and will be protected to the fullest extent provided by law.
- Information that you provide and other records related to this study will be accessible to those persons directly involved in conducting this study and members of the Uniformed Services University of the Health Sciences Institutional Review Board (IRB), which provides oversight for protection of human research volunteers.
- All questionnaires, results and forms will not have identifying information and will be kept in a restricted access, password protected computer, in a locked office. Data from questionnaires will be entered into a database in which individual responses are not identified.
- Paper copies of the data will not be kept.
- Personal information will be collected for payment purposes. This information will be kept separate from the database, in a password protected computer in a locked office at the Uniformed Services University of the Health Sciences.
- If you are a military member, please be advised that under Federal Law, a military member's confidentiality cannot be strictly guaranteed.

Note: YOU ARE FREE TO WITHDRAW THIS CONSENT AND TO STOP PARTICIPATING IN THIS STUDY OR ANY ACTIVITY AT ANY TIME FOR ANY REASON.

6. COMPENSATION

- You will be given the option of receiving a book on stress reduction for completing both phases of this study
- At the end of the study, you will be asked for some personal information (e.g., name, address, social security number, phone number)in order to receive the book.
- This information is collected for tax tracking information by our institution. We must receive this information in order to render compensation.
- This information will be stored separately from the study data and will be stored in a secure, password protected computer in a locked office with restricted access.

7. RECOURSE IN THE EVENT OF INJURY:

COMPENSATION TO YOU IF YOU ARE INJURED AND LIMITS TO YOUR MEDICAL CARE: This study should not entail any physical or mental risk beyond those described above. It is believed that complications arising from participation should not occur. If, for any reason, you feel that continuing this study would constitute a hardship for you, you may end your participation in the study at any time.

If at any time you believe you have suffered an injury or illness as a result of participating in this research project, contact the Director of Human Subjects Protection Program at the Uniformed Services University of the Health Sciences, Bethesda, Maryland 20814-4799 at (301)295-9534. This office can review the matter with you. They can provide information about your rights as a research volunteer. They may also be able to identify resources available to you. If you believe the government or one of the government's employees (such as a military doctor) has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about judicial avenues of compensation is available from the University's General Counsel at (301)295-3028.

Should you have any questions at anytime about the study you may contact the principal investigator, Lisseth C. Calvio, M.S., Department of Medical and Clinical Psychology, USUHS, Bethesda, Maryland 20814-4799, at 301-295-9660.

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS RESEARCH PROJECT:

I have read this consent form and I understand the procedures to be used in this study and the possible risks, inconveniences, and/or discomforts that may be involved. All of my questions have been answered. I freely and voluntarily choose to participate. I understand that I may withdraw at any time. By clicking on the "yes" button, you are agreeing that you have read the consent form and understand the procedures to be used in this study. You also agree that you freely and voluntarily choose to participate and understand that you may withdraw at anytime. If you wish you may print out a copy of this form for your records.

o **Yes, I agree to participate in this study.**

Appendix C: Screening Questions

Screening Questions:

Thank you for your interest in participating in our study. The following is a list of questions that will determine your eligibility for this study. We will email you within a few days after your completion of this screener.

1. Are you within the ages of 18 and 65?

2. What is your gender?

3. Are you able to access the Internet when needed?

4. Are you able to use the Internet by yourself (without help/assistance)?

5. Are you currently working full-time or self-employed? (Full-time is considered to be on average 40 hours of work or more a week)

6. On average, how many hours do you work a week?

7. Have you ever been diagnosed with any of the following: Dementia, Brain Injury, Adult Attention Deficit Hyperactivity Disorder (Adult ADHD), Epilepsy, Drug or Alcohol Abuse?

1. Have you ever been diagnosed with any form of cancer?
- **If yes, please specify the type of cancer you were diagnosed with:**

9. Have you ever been diagnosed with breast cancer?

*****The following questions are specific cancer questions- Only for those who answered yes to having a history of cancer****

1. Were you diagnosed with stage IV (metastasized) cancer?

2. Did you complete primary cancer treatment (defined as surgery, radiation therapy and/or chemotherapy) between 1 and 10 years ago?

3. Where did you receive primary cancer treatment?

4. What type of treatment have you received for your cancer (for example, lumpectomy, 3 rounds of chemotherapy)?

For all participants:

1. What is an email address where you can be contacted for the purpose of this study?

Please note that within the next few days, we will be emailing you from the following email address: cogworkstudy@gmail.com. Please ensure that your email address allows this email address to bypass any filter settings on your email. Thank you for your interest in our study.

Appendix D: Participant Instructions (Condition I and II)

Instructions (Condition I):
Thank you for your interest and participation in our study. The information that you provide will be looked at very carefully and be used in future efforts to help cancer survivors at work.

This study will be conducted in two parts and will require you to access two separate websites:

- One website will contain questionnaires
- One website will consist of some short tests of memory, attention, and organization (CNSVS).

This study will take one hour to one hour and fifteen minutes to complete. It must be completed continuously. Once you begin the first portion, you must also complete the second portion during the same time period. Also, please ensure that you complete the study in a quiet area with no or little distractions. You will be allowed to take breaks in between the short tests and in between logging into the two websites. You will be required to have a connection speed that is faster than dial-up.

Your Identification Number is:

You will be asked this number several times, including when you log on to the website with the test of memory, attention, and organization.

Please follow the order of events that is provided to you:

Click the link below:
Click Me

Or copy and paste the following website to your browser:
https://www.surveymonkey.com/s.aspx?sm=9J5uaGoq_2fhYErTylDmeycg_3d_3d

1. The first pages that you will see are the informed consent forms. Please read it carefully. You must agree to participate in the study in order to proceed.

2. You will then be presented with a series of questionnaires.

3. Upon completing the questionnaires, when you will click on the link it will open up the test in another window. **DO NOT CLOSE THE INITIAL BROWSER as you will need to return after finishing the test portion**.

4. When you log on to the test portion (CNSVS Web Agent), you will be asked for a test administrator and password. Please put “usuhs” for both.

5. The next window will ask for your "Subject ID and birthdate.

6. Your Subject ID is your participant number (provided above).

7. At the end of the study, you will be asked a few more questions for compensation purposes and given online support resources.

8. You will be done once you see the following message and click the link to end the questionnaire:

This concludes the questionnaire. You may close your browser window now. Thank you again for your participation, if you have any questions you can contact the principle investigators as listed below:

Email: cogworkstudy@gmail.com

Lisseth C. Calvio, M.S. 301-295-9660
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799

Michael Feuerstein, Ph.D., MPH at 301-295-9677
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799

Institutional Review Board Office at (301) 295-9534
USUHS, Bethesda, Maryland 20814

Thank you for your participation.

Sincerely,
Lisseth C. Calvio, M.S.
LT MSC USN
Principle Investigator
Uniformed Services University of the Health Sciences

Instructions (Condition II):

Thank you for your interest and participation in our study. The information that you provide will be looked at very carefully and be used in future efforts to help cancer survivors at work.

This study will be conducted in two parts and will require you to access two separate websites:

- One website will consist of a short test of memory, attention, and organization (CNSVS)
- One website will consist of questionnaires

This study will take one hour to one hour and fifteen minutes to complete. It must be completed continuously. Once you begin the first portion, you must also complete the second portion during the same time period. Also, please ensure that you complete the study in a quiet area with no or little distractions. You will be allowed to take breaks in between the short tests and in between logging into the two websites. You will be required to have a connection speed that is faster than dial-up.

Your Identification Number is:

You will be asked this number several times, including when you log on to the website with the test of memory, attention, and organization.

Please follow the order of events that is provided to you:

Click the link below:
Click Me

Or copy and paste the following website to your browser:
https://www.surveymonkey.com/s.aspx?sm=9J5uaGoq_2fhYErTylDmeycg_3d_3d

1. The first pages that you will see are the informed consent forms. Please read it carefully. You must agree to participate in the study in order to proceed.

2. You will take the test portion of the study first. You will be asked to click on a link that will open up the CNSVS test in another window. **DO NOT CLOSE THE INITIAL BROWSER as you will need to return after finishing the test portion**.

3. On the CNSVS site, you will be asked to log in. When you log in to the test portion (CNSVS Web Agent), you will be asked for a test administrator and password. Please put “usuhs” for both.

4. The next window will ask for your “Subject ID” and birthdate.

2. Your Subject ID is your participant number (provided above).

3. Upon completing the CNSVS test, return to the original window, and continue to fill out a few questionnaires.

4. At the end of the study, you will be asked a few more questions for compensation purposes and you will be provided a list of online support resources.

5. You will be done once you see the following message and click the link to end the questionnaire:

This concludes the questionnaire. You may close your browser window now. Thank you again for your participation, if you have any questions you can contact the principle investigators as listed below:

Email: cogworkstudy@gmail.com

Lisseth C. Calvio, M.S. 301-295-9660
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799

Michael Feuerstein, Ph.D., MPH at 301-295-9677
Department of Medical & Clinical Psychology,
USUHS, Bethesda, MD 20814-4799

Institutional Review Board Office at (301) 295-9534
USUHS, Bethesda, Maryland 20814

Thank you for your participation.
Sincerely,

Lisseth C. Calvio, M.S.
LT MSC USN
Principle Investigator
Uniformed Services University of the Health Sciences

Appendix E: Data Dictionary

Breast Cancer Study Data Dictionary

Variable	Data Type	Comment
PID	Numeric	Participant ID Number
Age	Numeric	Participant Age
CNSVS Data		
TestDateGMT	Date	CNSVS Test Date
TestTimeGMT	Date	CNSVS Test Time
CompositeMemory	Numeric	Raw Score of Composite Memory
CompositeMemorySS	Numeric	Scaled Score of Composite Memory
CompositeMemoryPR	Numeric	Percent Rank of Composite Memory
VerbalMemory	Numeric	Raw Score of Verbal Memory
VerbalMemorySS	Numeric	Scaled Score of Verbal Memory
VerbalMemoryPR	Numeric	Percent Rank of Composite Memory
VisualMemory	Numeric	Raw Score of Visual Memory
VisualMemorySS	Numeric	Scaled Score of Visual Memory
VisualMemoryPR	Numeric	Raw Score of Visual Memory
ExecutiveFunctioning	Numeric	Raw Score of Executive Function
ExecutiveFunctioningSS	Numeric	Scaled Score of Executive Function
ExecutiveFunctioningPR	Numeric	Percent Rank of Executive Function
TotalTestTimeminssecs	Time	Test Time in mins/secs
VBMCorrectHitsImmediate	Numeric	Verbal Memory Immed Hit Correct
VBMCorrectPassesImmediate	Numeric	Verbal Memory Immed Pass Correct
VBMCorrectHitsDelay	Numeric	Verbal Memory Delay Hit Correct
VBMCorrectPassesDelay	Numeric	Verbal Memory Delay Pass Correct
VSMCorrectHitsImmediate	Numeric	Visual Memory Immed Hit Correct
VSMCorrectPassesImmediate	Numeric	Visual Memory Immed Pass Correct
VSMCorrectHitsDelay	Numeric	Visual Memory Delay Hit Correct
VSMCorrectPassesDelay	Numeric	Visual Memory Delay Pass Correct
CPTCorrectResponses	Numeric	Cont. Performance Test Correct
CPTOmissionErrors	Numeric	Cont. Performance Test Misses
CPTCommissionErrors	Numeric	Cont. Performance Test Errors
CPTChoiceReactionTimeCorrect	Numeric	Average CPT Reaction Time Correct
SATCorrectResponses	Numeric	Shifting Attention Correct Answers
SATErrors	Numeric	Shifting Attention Errors
SATCorrectReactionTime	Milliseconds	Shifting Attention Ave RT Correct

Study Self-Report Survey Data

StartDate	Date	Date Main Survey taken
EndDate	Date	Date Main Survey taken
Speed	Numeric	Internet Connection Speed
DOB	Date	Birthday of participant
Ed	Numeric	Level of Education attained

1. Less than High School
2. High School
3. Some College
4. A.A. or Bachelor's degree
5. Some graduate school
6. Graduate degree

Marital — Numeric — Marital Status

1. Single
2. Single, Cohabitating
3. Married
4. Divorced
5. Widowed

Hispanic — Numeric — Hispanic Ethnicity

1. Yes
2. No

Cancer — Numeric — Breast Cancer Survivor

1. Yes
2. No

TumorLoc — Numeric — Location of Cancer

1. Right Breast
2. Left Breast
3. Both Breast
4. Unsure

BCStage — Numeric — Stage of Breast Cancer

1. Stage I
2. Stage II
3. Stage III
4. Stage IV

Chemo — Numeric — Was Chemotherapy Used?

1. Yes
2. No

Radiation — Numeric — Was Radiation Used?

1. Yes
2. No

Surgery	Numeric	Was Surgery Used?
1. Yes 2. No		
TamoxifenorRaloxifene	Numeric	Was Tamoxifen or Raloxife Used?
1. Yes 2. No		
HerceptinTrastuzumab	Numeric	Was Herceptin Used?
1. Yes 2. No		
OtherTX	Numeric	Was another treatment used?
1. Yes 2. No		
TXDetail	Text	Details of other treatments
LastTX	Numeric 1-10	Years since cancer therapy
DateDX	Date	Date of Cancer Diagnosis
MenoPostCX	Numeric	Menopause Status
1. Pre-menopause prior to cancer, post menopause after treatment 2. Pre-menopause prior to treatment, pre-menopause after treatment 3. Post menopause before diagnosis		
WorkAb	Numeric	Absence from Work Post Dx
1. No absence 2. 1 day – 2 months 3. 3 – 5 months 4. 6 – 11 months 5. 12 – 17 months 6. More than 18 Months		
JobChar	Numeric	Job Status at Diagnosis
1. Managerial 2. Non-Managerial 3. Self-employed		
CurMeno	Numeric	Current Menopause Status
1. Currently going through menopause 2. Pre-menopausal 3. Post-menopausal		
CurJob	Numeric	Current Job Status
1. Managerial 2. Non-Managerial 3. Self-employed		
JobTitle	Text	Current Job Title
PriOcc	Numeric	Disc of current primary job

1. Clerical
2. Sales
3. Management/Administration
4. Professional/Technical/Scientist
5. Craftsman/Carpenter
6. Machine Operator/Factory
7. Service Worker (Beautician/Police Officer)

SickDays	Numeric	Total sick days past year
CurJobY	Numeric	Years at current job
CurJobM	Numeric	Months at current job
PaidJobs	Numeric	Number of current paid jobs
PriJobSat	Numeric	Primary Job Satisfaction

1. I enjoy my job and work hard to do well
2. I enjoy my job, but don't have to work hard
3. I don't like my job, but work hard to do well
4. I don't like my job, and just do what I have to do to earn a paycheck
5. If my pay depended on my productivity, I would work harder

Income	Numeric	Household Income

1. Less than 10k
2. 10-19k
3. 20-39k
4. 40-59k
5. 60-79k
6. 80-99k
7. 100k or more

Med1	Text	Medication Name
Dos1	Text	Dosage
Med2	Text	Medication Name
Dos2	Text	Dosage
Med3	Text	Medication Name
Dos3	Text	Dosage
Med4	Text	Medication Name
Dos4	Text	Dosage
Med5	Text	Medication Name
dos5	Text	Dosage
NP1	Text	Non-Prescription Drug Name
NPD1	Text	Dosage
NP2	Text	Non-Prescription Drug Name
NPD2	Text	Dosage

NP3	Text	Non-Prescription Drug Name
NPD3	Text	Dosage
NP4	Text	Non-Prescription Drug Name
NPD4	Text	Dosage
NP5	Text	Non-Prescription Drug Name
NPD5	Text	Dosage
NeuroPsych 1. Yes 2. No	Numeric	Neuropsych testing history
NeuroTest	Text	Test Details

HADS QUESTIONS Numeric 0-3 Scale

HADS1. I feel tense or wound up

Most of the time	A lot of the time	Occasionally	Not at all
o 0	o 1	o 2	o 3

HADS2. I still enjoy the things I used to enjoy

Definitely as much	Not quite as much	Only a little	Hardly at all
o 0	o 1	o 2	o 3

HADS3. I get sort of frightened feelings as if something awful is about to happen

Quite badly	Not too badly	A little	Not at all
o 3	o 2	o 1	o 0

HADS4. I can laugh and see the funny side of things

As much as always	Not quite so much now	Definitely not so much now	Not at all
o 0	o 1	o 2	o 3

HADS5. Worrying thoughts go through my mind

A great deal of the time	A lot of the time	From time to time	Only on occasion
o 3	o 2	o 1	o 0

HADS6. I feel cheerful

Not at all	Not often	Sometimes	A lot
o 3	o 2	o 1	o 0

HADS7. I can sit at ease and feel relaxed

Definitely	Usually	Not often	Not at all
o 0	o 1	o 2	o 3

HADS8. I feel as if I am slowed down

Nearly all the time	Very often	Sometimes	Not at all
o 3	o 2	o 1	o 0

HADS9. I get a sort of frightened feeling like butterflies in my stomach

Not at all	Occasionally	Quite often	Very often
o 0	o 1	o 2	o 3

HADS10. I have lost interest in my appearance

Definitely	I don't take so much care as I should	I may not take quite as much care	I take just as much care as ever
o 3	o 2	o 1	o 0

HADS11. I feel restless as if I have to be on the move

Very much	Quite a lot	Not very much	Not at all
o 3	o 2	o 1	o 0

HADS12. I look forward with enjoyment to things

As much as ever	Rather less than I used to	Definitely less than before	Hardly at all
o 0	o 1	o 2	o 3

HADS13. I get sudden feelings of panic

Very often	Quite often	Not often	Not at all
o 3	o 2	o 1	o 0

HADS14. I can enjoy a good book or program

Often	Sometimes	Not often	Very seldom
o 0	o 1	o 2	o 3

MFSI QUESTIONS Numeric 0 – 4 Scale data

	Not at all	A little	Moderately	Quite a bit	Extremely
MFSI1 – Q2. My muscles ache	0	1	2	3	4
MFSI2 – Q4. My legs feel weak	0	1	2	3	4
MFSI3 – Q16. My arms feel weak	0	1	2	3	4
MFSI4 – Q19. I ache all over	0	1	2	3	4
MFSI5 – Q26. My body feels heavy all over	0	1	2	3	4

Visual Analog Scales

VASP	Numeric	1-10 Visual Analog Pain
VASF	Numeric	1-10 Visual Analog Fatigue
VASD	Numeric	1-10 Visual Analog Distress
VASI	Numeric	1-10 Visual Analog Intellectual Challenged at work
VASPHYS	Numeric	1-10 Visual Analog Physically Challenged at work

CSCL Item: Yes: 1 No: 0

CSCL1 – I have difficulty doing math in my head
CSCL2 – I have difficult answering questions quickly
CSCL3 – I have difficulty seeing and correcting mistakes on my own
CSCL4 – I have difficulty seeing and correcting mistakes pointed out to me by others
CSCL5 – I have difficulty focusing on a task when there is too much detail or clutter
CSCL6 – I have difficulty making decisions
CSCL7 – I have difficulty understanding what I read without rereading it
CSCL8 – I have difficulty understanding what I hear the first time I hear it
CSCL9 – I have difficulty seeing mistakes that I make as they occur
CSCL10 – I have difficulty seeing mistakes after I have completed the task
CSCL11 – I have difficulty trying new ideas or actions
CSCL12 – I have difficulty planning a speech
CSCL13 – I have difficulty shifting my attention among two or more things
CSCL14 – I have difficulty staying with a task until completion
CSCL15 – I have difficulty planning what to discuss when I meet someone
CSCL16 – I have difficulty following directions to a specific place
CSCL17 – I have difficulty shifting from 1 task or activity to another
CSCL18 – I have difficulty completing all steps of a task or activity
CSCL19 – I have difficulty following step-by-step instructions
CSCL20 – I have difficulty putting steps in order such that the most important steps are done first
CSCL21 – I have difficulty setting up a routine or system to approach tasks
CSCL22 – I have difficulty understanding what a problem is when it occurs and clearly stating what the problem is
CSCL23 – I have difficulty starting a task or activity on my own
CSCL24 – I have difficulty remembering where my car is parked
CSCL25 – I have difficulty focusing on a task when there is a sudden movement around me
CSCL26 – I have difficulty knowing where to look for information to solve a problem
CSCL27 – I have difficulty using new information to re-evaluate what I know
CSCL28 – I have difficulty choosing a solution to a problem from several possible sources
CSCL29 – I have difficulty focusing on a task when there is a lot of movement happening around me
CSCL30 – I have difficulty focusing on a task when there is a sudden loud noise
CSCL31 – I have difficulty following written instructions

CSCL32 – I have difficult writing to other people in an organized manner
CSCL33 – I have difficulty organizing information to be remembered
CSCL34 – I have difficulty focusing on a task when more than one person is speaking at a time
CSCL35 – I have difficulty focusing on a task when a radio or TV is playing in the background
CSCL36 – I have difficulty following or retracing steps to solve a problem
CSCL37 – I have difficulty remembering to perform daily routines
CSCL38 – I have difficulty remembering things someone has asked me to do
CSCL39 – I have difficulty remembering he content of telephone conversations
CSCL40 – I have difficulty focusing on a task when I feel hot or cold
CSCL41 – I have difficulty remembering the content of conversations and/or meetings
CSCL42 – I have difficulty remembering a word I wish to say
CSCL43 – I have difficulty acting on a decision that I made
CSCL44 – I have difficulty putting together the materials needed for a task
CSCL45 – I have difficulty understanding a system
CSCL46 – I have difficulty remembering my train of thought as I am speaking
CSCL47 – I have difficulty remembering the name of a familiar object or person
CSCL48 – I have difficulty understanding graphs or flowcharts
CSCL49 – I have difficulty understanding how a task fits into a plan or system
CSCL50 – I have difficulty understanding systems and models
CSCL51 – I have difficulty remembering information that is “on the tip of my tongue”
CSCL52 – I have difficulty remembering what I intended to write
CSCL53 – I have difficulty figuring out how a decision was reached
CSCL54 – I have difficulty following the flow of events
CSCL55 – I have difficulty considering all aspects of what I hear or see instead of focusing on only one part
CSCL56 – I have difficulty remembering to schedule appointments
CSCL57 – I have difficulty staying focused in places where there are many sights and sounds
CSCL58 – I have difficulty remembering to keep appointments once they are scheduled
CSCL59 – I have difficulty focusing on a task when I am in a large area

WORK LIMITATION QUESTIONAIRE:

WLQ1 Numeric Difficulty with workload?
0 Not at all or Does Not Apply
1 Some of the time
2 Half of the time
3 Most of the time
4 All of the time or 100 percent

WLQ2 Numeric Difficult to work fast enough?
0 Not at all or Does Not Apply
1 Some of the time
2 Half of the time
3 Most of the time
4 All of the time or 100 percent

WLQ3 Numeric Difficult to finish on time?
0 Not at all or Does Not Apply
1 Some of the time
2 Half of the time
3 Most of the time
4 All of the time or 100 percent

WLQ4 Numeric Difficult to not make mistakes?
0 Not at all or Does Not Apply
1 Some of the time
2 Half of the time
3 Most of the time
4 All of the time or 100 percent

WLQ5 Numeric Difficult to feel you've done what you are capable of?
0 Not at all or Does Not Apply
1 Some of the time
2 Half of the time
3 Most of the time
4 All of the time or 100 percent

FactCog Questions:

FC1 – FC13

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogA1	I have had trouble forming thoughts	0	1	2	3	4
CogA3	My thinking has been slow	0	1	2	3	4
CogC7	I have had trouble concentrating	0	1	2	3	4
CogM9	I have had trouble finding my way to a familiar place	0	1	2	3	4
CogM10	I have had trouble remembering where I put things, like my keys or my wallet	0	1	2	3	4
CogM12	I have had trouble remembering new information, like phone numbers or simple instructions	0	1	2	3	4
CogV13	I have had trouble recalling the name of an object while talking to someone	0	1	2	3	4
CogV15	I have had trouble finding the right word(s) to express myself	0	1	2	3	4
CogV16	I have used the wrong word when I referred to an object	0	1	2	3	4
CogV17b	I have had trouble saying what I mean in conversations with others	0	1	2	3	4
CogF19	I have walked into a room and forgotten what I meant to get or do there	0	1	2	3	4
CogF23	I have had to work really hard to pay attention or I would make a mistake	0	1	2	3	4
CogF24	I have forgotten names of people soon after being introduced	0	1	2	3	4

FactCog Questions: Past 7 Days
FC14 – FC20

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogF25	My reactions in everyday situations have been slow	0....0	1	2	3	4
CogC31	I have had to work harder than usual to keep track of what I was doing	0....0	1	2	3	4
CogC32	My thinking has been slower than usual	0	1	2	3	4
CogC33a	I have had to work harder than usual to express myself clearly	0	1	2	3	4
CogC33c	I have had to use written lists more often than usual so I would not forget things	0	1	2	3	4
CogMT1	I have trouble keeping track of what I am doing if I am interrupted	0	1	2	3	4
CogMT2	I have difficulty shifting back and forth between different activities that require thinking	0	1	2	3	4

FactCog Questions: Past 7 Days
FC21-24

		Not at all	A little bit	Some-what	Quite a bit	Very much
CogQ35	I have been upset about these problems	0.. 0	1	2	3	4
CogQ37	These problems have interfered with my ability to work	0.. 0	1	2	3	4
CogQ38	These problems have interfered with my ability to do things I enjoy	0.. 0	1	2	3	4
CogQ41	These problems have interfered with the quality of my life	0	1	2	3	4

FactCog Questions: Past 7 Days
FC25 – FC29

Below is a list of statements that other people with your condition have said are important. **By circling one (1) number per line, please indicate how often each of the following has occurred during the past 7 days.**

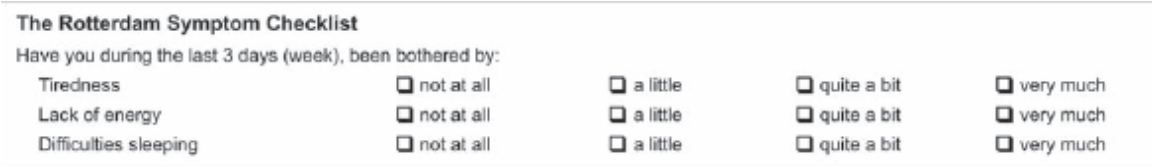
		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
PC30	Other people have told me I seemed to have trouble remembering information	0	1	2	3	4
PC31	Other people have told me I seemed to have trouble speaking clearly	0	1	2	3	4
PC32	Other people have told me I seemed to have trouble thinking clearly	0	1	2	3	4
PC33	Other people have told me I seemed confused	0	1	2	3	4

		Not at all	A little bit	Some-what	Quite a bit	Very much
PC34	Other people have told me my mind seemed really sharp	0	1	2	3	4

BRFS Numeric Job Stress

0 Never
1 Seldom
2 Sometimes
3 Often

ROTTERDAM1 Numeric 0 Not at all – 3 Very much
ROTTERDAM2 Numeric 0 Not at all – 3 Very much
ROTTERDAM3 Numeric 0 Not at all – 3 Very much


The Rotterdam Symptom Checklist

Have you during the last 3 days (week), been bothered by:

Tiredness	❑ not at all	❑ a little	❑ quite a bit	❑ very much
Lack of energy	❑ not at all	❑ a little	❑ quite a bit	❑ very much
Difficulties sleeping	❑ not at all	❑ a little	❑ quite a bit	❑ very much

SMOKER	Numeric	Are you a smoker?

1. Every day
2. Some days
3. Not at all
4. Not sure

SmokeToday	Numeric	Last Smoked

1. Not today
2. Less than 1 hour ago
3. 1 to 2 hours ago
4. More than 2 hours ago

CigToday	Numeric	Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

CigarToday	Numeric	Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

SnuffToday	Numeric	Total Consumed

0. None Today
1. 1 dip today
2. 2 dips today
3. 3 dips today
4. 4 dips or more today

ChewToday	Numeric	Total Consumed

0. None Today
1. 1 dip today
2. 2 dips today
3. 3 dips today
4. 4 dips or more today

PipeToday Numeric Total Consumed

0. None Today
1. 1 bowl today
2. 2 bowls today
3. 3 bowls today
4. 4 bowls or more today

ETOH Numeric Are you a drinker?

1. Every day
2. Some days
3. Not at all
4. Not sure

ETOHToday Numeric Last Drank?

1. Not today
2. Less than 1 hour ago
3. 1 to 2 hours ago
4. More than 2 hours ago

DrinksToday Numeric Total Consumed

0. None Today
1. 1-2 today
2. 3-4 today
3. 5 or more today

Caffeine

1. Every Day
2. Some Days
3. Not at all
4. Don’t Know/Not Sure

Coffee Numeric Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

Decaf Numeric Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today

4. 4 or more today

Tea	Numeric	Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

Soda	Numeric	Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

Choco	Numeric	Total Consumed

0. None Today
1. 1 today
2. 2 today
3. 3 today
4. 4 or more today

HowLongCaffeine	Numeric	Last Drank?

5. Not today
6. Less than 1 hour ago
7. 1 to 2 hours ago
8. More than 2 hours ago

USED ON TEST DAY:

Anacin	Numeric	Yes: 1 No: 0
Appetite	Numeric	Yes: 1 No: 0
Dristan	Numeric	Yes: 1 No: 0
Excedrine	Numeric	Yes: 1 No: 0
ESExcedrine	Numeric	Yes: 1 No: 0
Midol	Numeric	Yes: 1 No: 0
Triaminicin	Numeric	Yes: 1 No: 0
Vanquish	Numeric	Yes: 1 No: 0
NoDoz	Numeric	Yes: 1 No: 0
OTCSleep	Numeric	Yes: 1 No: 0
OtherStim	Numeric	Yes: 1 No: 0
OtherDep	Numeric	Yes: 1 No: 0

TimeSince	Numeric	Time since last used

1. Did not use any of the above today

2. Less than 1 hour ago
3. 1 to 2 hours ago
4. More than 2 hours ago

StudySRC Numeric Where recruited

1. Hosptial/Medical Center/Cancer Clinic
2. Support Group
3. Cancer Survivor Website
4. Website (Craigslist)
5. Cancer Survivor Organization Newsletter
6. Cancer Survivor Organization Email
7. Newspaper
8. Magazine
9. Other

Distraction Numeric Distracted during testing

1. Yes
2. No

DistDetail Text Description of Distraction

SMBook Numeric Wanted Stress Management Book

1. Yes
2. No

HADSA Numeric HADS Anxiety Scale Score

HADSD Numeric HADS Depression Scale Score

HADS A Questions = 1,3,5,7,9,11,13
HADS D Questions = 2,4,6,8,10,12,14

	Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.	
	0-7 = Normal	
	8-10 = Borderline abnormal	
	11-21 = Abnormal	

CSCM – Cognitive Symptom Checklist Memory Scale

CSCM = CSCL1 + CSCL2 + CSCL5 + CSCL7 + CSCL8 +
CSCL9 + CSCL10 +CSCL13 + CSCL17 + CSCL18 + CSCL19 + CSCL31 +

CSCL32 + CSCL33 + CSCL36 + CSCL37 + CSCL38 + CSCL39 + CSCL41 +
CSCL42 + CSCL46 + CSCL47 + CSCL51 + CSCL52

.

CSCA – Cognitive Symptom Checklist Attention Scale

CSCA = CSCL5 + CSCL6 + CSCL14 + CSCL23 + CSCL24 + CSCL25 + CSCL29 +
CSCL30 + CSCL34 + CSCL35 + CSCL40 + CSCL57 + CSCL59

CSCEF – Cognitive Symptom Checklist Executive Function Scale

CSCEF = CSCL3 + CSCL4 + CSCL11 + CSCL12 + CSCL15 + CSCL16 + CSCL20 +
CSCL21 + CSCL22 + CSCL26 + CSCL27 + CSCL28 + CSCL43 + CSCL44 +
CSCL45 + CSCL48 + CSCL49 + CSCL50 + CSCL53 + CSCL54 + CSCL55 +
CSCL56 + CSCL58

FCPCI – Fact Cog Perceived Cognitive Impairments

FCPCI = FC1 + FC2 + FC3 + FC4 + FC5 +
FC6 + FC7 + FC8 + FC9 + FC10 + FC11 + FC12 + FC13 +
FC14 + FC15 + FC16 + FC17 + FC18 + FC19 + FC20

FCPCIQOF- Fact Cog Perceived Cognitive Impairments Quality of Function

FCPCIQOF = FC21 + FC22 + FC23 + FC24

FCOTHER – Fact Cog Others Perception of Impairment

FCOTHER = (4 - FC25) + (4 - FC26) + (4 - FC27) + (4 - FC28) + FC29

WLQOUTPUT Total of WLQ Scores

WLQOUTPUT = WLQ1 + WLQ2 + WLQ3 + WLQ4 + WLQ5

MFSIFATIGUE Total of MFSI Scores

MFSIFATIGUE = MFSI1 + MFSI2 + MFSI3 + MFSI4 + MFSI5

Race Numeric Participants Race

1. White
2. Black
3. Pacific Islander
4. American Indian/Alaskan Native
5. Other

AgeCategory Numeric Age Bracket

1. 18-25
2. 26-30
3. 31-35
4. 36-40
5. 41-45
6. 46-50
7. 51-55
8. 56-60
9. 61-65

Appendix F: Resources for breast cancer survivors

The following is a list of websites that give information on resources that specialize in cancer survivorship issues and/or emotional support. These websites can be utilized to seek support services if you or someone you know may be interested.

Resources

American Cancer Society
The American Cancer Society provides the public with accurate, up-to-date information on all aspects of cancer through a toll-free information line, website and published materials. Patients, family members and friends can learn about cancer and be connected to resources in their communities, 24 hours a day, seven days a week, by calling 1-800-ACS-2345 or visiting the website.
Website: http://www.cancer.org/docroot/home/index.asp

American Psychosocial Oncology Society
APOS has a toll-free Helpline through which cancer patients, caregivers and advocacy organizations may obtain referrals for local counseling services throughout the United States. This referral program aims to connect cancer patients and their caregivers to psychiatrists, psychologists, nurses, social workers and counselors skilled in the management of cancer-related distress.
To request a confidential referral, please call: Toll Free 1-866-276-7443 (1-866-APOS-4-HELP) or you may send an e-mail to the helpline at: sspencer@apos-society.org
Website: http://www.apos-society.org/

Association for Behavioral and Cognitive Therapies (ABCT)
ABCT's Find-a-Therapist service gives you access to therapists schooled in cognitive and behavioral techniques. The therapist listed in Find-a-Therapist are licensed professionals who have met the requirements of membership in ABCT and who have chosen to appear in this directory. Primarily psychologists, psychiatrists, and clinical social workers, the practitioners that participate in this service practice in a range of settings: in private practice, clinics, hospitals, and community mental health settings.
Website: http://www.aabt.org/members/Directory/Find_A_Therapist.cfm

Association of Oncology Social Work
AOSW is a non-profit, international organization of social workers dedicated to the enhancement of psychosocial services to people with cancer and their families. AOSW offers the POWER Directory to provide the opportunity for people with cancer and their families, as well as health care professionals to search this database of clinicians who may meet their needs.
Website: http://www.aosw.org/

Cancer Care, Inc
Cancer Care, Inc. is a national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance.
Website: http://www.cancercare.org/

Cancer Hope Network
Cancer Hope Network is a national, non-profit organization offering free, confidential, one-on-one emotional support to adult cancer patients and their caregivers. Support is provided via telephone (1-877-HOPENET) by over 325 trained volunteers who have all been through a cancer experience, have recovered and are again leading productive lives. By giving recently diagnosed patients the gift of Hope, CHN's survivors help them successfully cope with their cancer and its treatment.
Website: http://www.cancerhopenetwork.org/

Cancer Survivors' Network
The American Cancer Society's CSN is an online community created by and for cancer survivors and their families for the purpose of connecting with others like themselves, sharing practical information, and supporting one another. Listen to personal stories, post questions, chat, and connect with others going through a cancer experience.
Website: http://www.acscsn.org/

Healing Journeys
The mission at Healing Journeys is to promote and support healing by assisting people with cancer or other life-altering illnesses to access their own healing potential and their ability to thrive.
Website: http://www.healingjourneys.org/

I'm Too Young For This! Cancer Foundation For Young Adults
A TIME Magazine Best 50 Website 2007, the *I'm Too Young For This! Cancer Foundation For Young Adults* is a global support community for young adults affected by cancer who get busy living and rock on. Our mission is to end isolation and improve quality of life by providing one-stop access to hard to find resources, peer support and social networks.
Website: http://imtooyoungforthis.org/

Inflammatory Breast Cancer: IBC
The IBC Research Foundation is the only cancer research organization which specifically targets IBC and the research to find its cause. This website details symptoms and offers information and help for patients and their caregivers.
Website: http://www.ibcresearch.org/

Live Strong - Resource for Cancer Survivors
Live Strong - Resource for Cancer Survivors focuses on post-treatment and long-term

survivorship topics (physical, emotional, and practical) for cancer survivors and their caregivers.
Website:
http://www.livestrong.org/site/c.khLXK1PxHmF/b.2660611/k.BCED/Home.htm

Living Beyond Breast Cancer
As a national education and support organization, their goal is to improve your quality of life and help you take an active role in your ongoing recovery or management of the disease, regardless of educational background, social support or financial means.
Website: http://www.lbbc.org/resources-links.asp

Medicare Drug Prescription Plan (Part-D) Information
Medicare's new prescription drug benefit, Medicare Part D, will start January 1, 2006 and will mean changes for many people receiving treatment for mental illness. This website has the latest information from leading mental health organizations.
Website: http://www.mentalhealthpartd.org/

MetaCancer Foundation, Inc.
The MetaCancer Foundation has launched its innovative website and offers resources for everyday living, opportunities for creative reflection, and possibilities for you to live beyond your diagnosis right now with strength, grace, and peace.
Website: http://metacancer.org/

Patient/Partner Project
The Patient/Partner Project is a multi-faceted, long-term program focused on helping cancer patients by helping their partners.
Website: http://www.thepatientpartnerproject.org/

People Living with Cancer
People Living with Cancer (PLWC) is the American Society of Clinical Oncology's (ASCO) patient information website.
Website: http://www.plwc.org/portal/site/PLWC

Pregnant with Cancer Network
The Pregnant with Cancer Network is an organization for women diagnosed with cancer during pregnancy. Their mission is to connect women who are pregnant with cancer with other women who have been pregnant with the same type of cancer. These women lend support, offer hope and share their experiences with one another through phone and e-mail conversation.
Website: http://www.pregnantwithcancer.org/

Steps for Living
Steps For Living is a non-profit clearinghouse of cancer information and human resources that uses the power of the arts to raise awareness about what it means to be a

cancer survivor by educating and empowering those in need with everyday steps for living through and beyond their darkest hours.
Website: http://www.stepsforliving.org/

Strength for Caring
Strength for Caring is a program that addresses the complex needs of a person caring for a loved one with cancer. This community-based program is free of charge and provides comprehensive education and support for caregivers.
Website: http://www.strengthforcaring.com/

SuperSibs!
SuperSibs! is a national not-for-profit organization that works to honor, support and recognize the brothers and sisters of children with cancer. Their goal is to help these "shadow survivors" re-define the cancer sibling experience and move forward in their lives with strength, courage and hope.
Website: http://www.supersibs.org/

Wellness Community
The Wellness Community is a national non-profit organization that provides in-person and online support groups and education programs to people with all cancers and their caregivers.
Website: http://www.thewellnesscommunity.org/

WomenStories
The mission of WomenStories is to produce videos about breast cancer and distribute them nationally and internationally, so information and support about this disease will be readily available to all newly diagnosed women.
Website: http://www.womenstories.org/

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