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# DO NEGATIVE EXPECTATIONS AFFECT SELF-REPORTED COGNITIVE FUNCTIONING AND TREATMENT SATISFACTION AFTER CHEMOTHERAPY

# TREATMENT FOR CANCER?

#### By

# BROOK ELIZABETH CLARK

#### Bachelor of Arts, University of Montana, Missoula, MT, 2001

Associate of Arts and Sciences, University of Montana, Missoula, MT, 1997

Thesis

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Approved by:

Scott Whittenburg, Dean of The Graduate School Graduate School

> Stuart Hall, Ph.D., Chair Clinical Psychology

Chris Comer, Ph.D. Dean of the College of Humanities and Sciences

> Craig McFarland, Ph.D. Clinical Psychology

Allen Szalda-Petree, Ph.D. Experimental Psychology Clark, Brook, M.A., May 2017

Do Negative Expectations Affect Self-Reported Cognitive Functioning and Treatment Satisfaction After Chemotherapy Treatment for Cancer?

Chairperson: Stuart Hall, Ph.D.

This study investigated the effect of negative expectations on self-reports of cognitive functioning, treatment satisfaction, and endorsement of a common, negative chemotherapyrelated stereotype in 56 adults who had completed systemic chemotherapy for cancer treatment. Participants were assigned to either a negative expectation group or a control group. The negative expectation group had the relationship between chemotherapy and cognitive deficits overtly brought to their attention, while the control group did not. Both groups completed selfreport measures of cognitive functioning and treatment satisfaction, and then rated their degree of identification with a chemotherapy-related stereotype. It was hypothesized that the experimental group would report more negative cognitive symptoms, less treatment satisfaction, and greater endorsement of the stereotype than the control group. Results revealed no significant differences between the two groups on these measures. Mean scores for both groups indicated high ratings of cognitive functioning and treatment satisfaction, however on a different measure, participants from both groups endorsed a moderate level of cognitive difficulties. Potential explanations for this inconsistent finding will be discussed. Further investigation may add to existing knowledge about the influence of negative expectations on self-reported functioning and may help inform optimal methods of interacting with cancer patients and others with chronic disorders.

Do Negative Expectations Affect Self-Reported Cognitive Functioning and Treatment Satisfaction After Chemotherapy Treatment for Cancer?

Worldwide, there are approximately 14.5 million people alive today who are survivors of cancer (American Cancer Society, 2014). By 2024, that number is expected to reach nearly 19 million (American Cancer Society, 2014). While rates of cancer diagnosis continue to rise, cancer mortality rates have declined due to factors such as increased screening, early detection, and advances in treatment. As ever more people survive a diagnosis of cancer, issues related to cancer survivorship become increasingly important.

Returning to the activities of daily life after treatment for cancer can be a difficult process. For example, persisting physical symptoms such as fatigue and pain may impede a successful transition back to the workplace or to school (Horneber, Fischer, Dimeo, Ruffer, & Weis, 2012; Pertl, Quigley, & Hevey, 2014). Psychological symptoms such as anxiety and depression are common experiences both during and after treatment and can negatively impact the recovery process for cancer survivors (Hinz, Krauss, Hauss, Hockel, Kortmann, Stolzenburg, & Schwartz, 2010; Linden, Vodermaier, MacKenzie, & Greig, 2012; Mitchell, Chan, Bhatti, Halton, Grassi, Johansen, & Meader, 2011; Raffa & Tallarida, 2010; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012).

#### **Chemotherapy-Related Cognitive Impairment (CRCI)**

Individuals undergoing, or who have undergone chemotherapy treatment for cancer, frequently describe negative changes in their cognitive abilities (Ahles & Saykin, 2007; Ferguson & Ahles, 2003; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Johnston, 2013; Porter, 2013; Pullens, De Vries, Van Warmerdam, Van De Wal, & Roukema, 2013; Simo, Rifa-Ros, Rodriguez-Fornells, & Bruna, 2013). Colloquially referred to as "chemo-brain" (Mann,

1999) or "chemo-fog" (Mitchell & Turton, 2011; Raffa & Tallarida, 2010), chemotherapyrelated cognitive impairment, or CRCI (Argyriou, Assimakopoulos, Iconomou, Giannakopoulou, & Kalofonos, 2011; Holmes, 2013), consists of a constellation of frequently reported symptoms that include problems with attention, concentration, and memory (Joly, Rigal, Noal & Giffard, 2011; Matsuda, Takayama, Tashiro, Nakamura, Ohashi, & Shimozuma, 2005; Schagen, van Dam, Muller, Boogerd, Lindebloom, & Bruning, 1999; Vardy & Tannock, 2007; Wieneke & Dienst, 1995). A subset of cancer patients treated with chemotherapy (12-68%) demonstrate impairment on neuropsychological tests (Ahles & Saykin, 2007; Johnston, 2014; Joly, Rigal, Noal, & Giffard, 2011; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014; Shilling, Jenkins, & Trapala, 2006). Problems with attention, concentration, and memory may contribute to a lower quality of life after cancer diagnosis and treatment (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Meyers, 1999; Mitchell & Turton, 2011; Short, Vasey, & Tunceli, 2005; Simo, Rifa-Ros, Rodriguez-Fornells, & Bruna, 2013). Although cognitive difficulties after chemotherapy have been shown to diminish over time (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Hutchinson et al., 2012; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014), Ahles and Saykin (2002) and Reneman, et al. (2011) demonstrated enduring cognitive deficits in a sample of cancer survivors more than 10 years after treatment had ended.

#### **History and Etiology of CRCI**

It was likely Silberfarb, Philibert, and Levine (1980) who first reported a possible link between chemotherapy and declines in cognitive functioning. Silberfarb and colleagues administered cognitive tests (Trail Making Test B, Digit Symbol Coding, Cognitive Capacity Screening Test) and self-report measures (Self-Rating Depression Scale and Multiple Affect Adjective Check List) to 50 medical oncology patients. Results revealed cognitive impairment as

a "common occurrence" in the absence of affective disorders or other psychopathology (Silberfarb et al., 1980). Based on these findings, Silberfarb and colleagues identified chemotherapy as the underlying common factor amongst the patients and cautioned that consulting mental health providers be aware that changes in cognitive and emotional functioning may be due, in part, to treatment with chemotherapy (1980).

Inquiries regarding chemotherapy-related cognitive impairment (CRCI) have become increasingly complex and intensely debated since the work of Silberfarb, Philibert, and Levine (1980). While use of the term "chemo-brain" has become widespread among patients, medical providers, and researchers, its etiology is not well understood (Ahles & Saykin, 2001; Anderson-Hanley, Sherman, Riggs, Agocha & Compas, 2003; Jansen, Miaskowski, Dodd, Dowling & Kramer, 2005; Wieneke & Dienst, 1995). Attempting to isolate the factors that contribute to CRCI has become a major challenge. Numerous biological and psychological factors likely interact to produce the phenomenon of CRCI. For example, cognitive impairments in individuals with cancer often occur alongside fatigue, pain, anxiety, and depression (Horneber, Fischer, Dimeo, Ruffler & Weis, 2012; Linden, Vodermaier, MacKenzie & Greig, 2012; Pertl, Quigley & Hevey, 2014; Singer et al., 2013; Spiegel & Giese-Davis, 2003). Consequently, there is uncertainty regarding whether CRCI should be considered a cause or a consequence of these negative affective states (Hermelink, 2011; Jacobs, Jacobsen, Booth-Jones, Wagner, & Anasetti, 2007; Tope, Ayles, & Silberfarb, 1993). The fact that not all patients experience cognitive deficits suggests that some patients may be more susceptible to CRCI than others. This susceptibility could be associated with many factors such as premorbid impairments, comorbidities, genetic predisposition, cancer type, and treatment protocol (Argyriou, Assimakopoulos, Iconomou, Giannakopoulou, & Kalofonos, 2011; Wefel, Saleeba, Buzdar, &

Meyers, 2010; Zucca, Boyes, Linden, & Girgis, 2012). The ability to identify the subset of patients most susceptible to CRCI would permit comprehensive treatment strategies before chemotherapy begins, such as establishing an individual's baseline level of cognitive functioning, psycho-education around CRCI, psychotherapy for coping with emotional distress, and the addition of supportive pharmacotherapies (Joly, Rigal, Noal & Giffard, 2011; Raffa, 2011).

#### **Measurement of CRCI**

A thorough understanding of cognitive impairment after chemotherapy requires that changes in functioning be detected and measured. Perhaps the most universal and puzzling finding associated with the measurement of CRCI is the discrepancy that exists between individuals' scores on self-report measures of cognitive functioning and their scores on neuropsychological measures of cognitive functioning (Bender, Sereika, Berga, et al., 2006; Evenden, 2013; Myers, 2012; Rugo & Ahles, 2003; Schilder et al., 2012; Weis, Poppelreuter, & Bartsch, 2009). It is common for survivors to self-report a high degree of cognitive impairment yet demonstrate minimal to moderate impairment on objective measures of cognitive functioning (Ferguson, McDonald, Saykin, & Ahles, 2007; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Rugo & Ahles, 2003; Schilder et al., 2012). In numerical terms, 83% of individuals treated with chemotherapy self-report cognitive impairments (Jenkins et al., 2006; Kohli et al., 2006; O'Schaughnessy, 2003), yet only 12-68% demonstrate impairments on neuropsychological tests (Ahles & Saykin, 2007; Shilling, Jenkins, & Trapala, 2006). The lack of congruence between subjective and objective evaluations suggests that these evaluations are measuring either different facets of one construct, or two separate constructs (Hermelink et al., 2010; Hutchinson, Hosking, Kichenadasse, Mattiske & Wilson, 2012). The lack of a strong association between

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scores on self-reports (subjective measures) and scores on neuropsychological tests (objective measures) may have multiple explanations. Methodological issues have been identified as contributing to the discrepancy between subjective and objective measurements of functioning (Kaiser, Bledowski, & Dietrich, 2014; Porter, 2013; Pullens, De Vries, Van Warmerdam, Van De Wal, & Roukema, 2013; Schagen et al., 2002; Schagen, 2007; Seigers & Fardell, 2011).

## Methodological Contributors to the Discrepancy in Findings

# **Comparison Groups**

One primary methodological problem faced by CRCI researchers lies in the selection of an appropriate comparison group to whom survivors' scores are compared (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jansen et al., 2005; Kaiser, Bledowski, & Dietrich, 2014; Pullens, De Vries, Van Warmerdam, Van De Wal, & Roukema, 2013; Schilder et al., 2012). Group differences may cause patients' scores on neuropsychological tests to appear "better" or "worse" depending on whether the scores are compared to those of healthy controls, cancer patients who received only localized treatment, or to patients' own baseline levels of cognitive functioning. The last comparison (comparing patients to their own baseline) is particularly scarce in the literature, as a limited number of studies have successfully collected pre-chemotherapy data. Contributing to a lack of baseline data may be the pressure that patients feel to begin treatment following a life-threatening diagnosis (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Joly, Rigal, Noal, & Giffard, 2011; Mitchell & Turton, 2011; Stewart, Bielajew, Collins, Parkinson, & Tomiak, 2006). Neuropsychological findings based on withingroup comparisons have often not reached statistical significance (Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014). Some researchers have suggested that the small sample sizes used in this type of

comparison do not allow for sufficient power to detect an effect if one is there (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Porter, 2013; Seigers & Fardell, 2011). Other hypotheses that have been put forth to explain inconclusive findings propose that effects may vary with treatment type, treatment intensity and duration, and that effects may vary depending on when (during or after treatment) data are collected (Evenden, 2013; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Quesnel, 2009; Schilder, Eggens, Seynaeve, et al., 2009; Simo, Rifa-Ros, Rodriguez-Fornells, & Bruna, 2013). Research indicates that the most striking effects occur either during, or shortly after treatment, however the duration of impairments is not well understood and effects have been found many years after treatment has ended (Ahles & Saykin, 2002; Evenden, 2013; Mitchell & Turton, 2011; Monje & Dietrich, 2012; Porter, 2013; de Ruiter et al., 2011; Simo, Rifa-Ros, Rodriguez-Fornells, & Bruna, 2013; Wigmore, 2013).

#### **Instrument-Related Confounds**

A second methodological problem that could contribute to the discrepancy between scores on self-report and objective measures includes instrument-related confounds (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jansen, Miaskowski, Dodd, & Dowling, 2007; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014; Porter, et al., 2013; Schilder et al., 2012). One challenging problem when attempting to make comparisons across studies, regards the classification of neuropsychological tests to particular domains of cognitive functioning (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014). Multiple tests can be used to measure a single cognitive domain and researchers differ in their preference for particular tests for particular domains. Consequently, it can be difficult to link individual tests with the scores that are provided. Lindner and colleagues (2014) suggest

guidelines that would facilitate the objective measurement of impairments in future studies. Examples that are germane to this discussion include the following guidelines: the use of shorter neuropsychological batteries that specifically focus on certain cognitive functions; when using neuropsychological tests, strive to use very similar versions of the same cognitive tests between research groups and report the same scores; and consistently group test scores into cognitive functions, as the high number of neuropsychological tests makes it difficult to understand whether two different results refer to the same function (Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014).

A second instrument-related problem includes the use of measures that are insensitive to mild to moderate impairments (Jacobs, Jacobsen, Booth-Jones, Wagner, & Anasetti, 2007; Mitchell & Turton, 2011; Porter, 2013). Neuropsychological measures that are used to capture more profound deficits in cognitive functioning, such as The Mini Mental State Examination, are of little use in the detection of mild to moderate cognitive changes (Evens & Eschiti, 2009; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 20142014; Meyers, Geara, Wong, & Morrison, 2000; Mitchell and Turton, 2011). As research continues, it will become imperative to establish a consistent neuropsychological battery that is both brief, sensitive, and as resistant to practice effects as possible (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jacobs, Jacobsen, Booth-Jones, Wagner, & Anasetti, 2007; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014; Vardy, Wefel, Ahles, Tannock, & Schagen, 2008).

Numerous factors limit the detection and objective measurement of impairments in cognitive functioning after chemotherapy. The two broad methodological problems discussed above (appropriate comparison groups and instrument-related confounds) should also be considered within the larger context of CRCI research in general. The systematic study of the

effect of chemotherapy on cognitive functioning is in its early stages. There are only a handful of meta-analyses that offer effect sizes for the effect of chemotherapy on specific domains of cognitive functioning (Falleti, Sanfilippo, Maruff, Weih, and Phillips, 2005; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Stewert, Bielajew, Collins, Parkinson, & Tomiak, 2006) and these few meta-analyses base their effect sizes on scores on objective neuropsychological tests only. Direct comparisons between studies are often impractical because of inconsistencies in the literature about *what* to measure and *how* to measure it (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). Despite these challenging factors, conclusions based on objective neuropsychological testing have been put forth regarding the effects of chemotherapy on cognition.

#### Neuropsychological Measurement of CRCI

Meta-analyses that have summarized the objective, neuropsychological findings of earlier studies have shown that individuals treated with chemotherapy demonstrate a wide range of small to moderate cognitive deficits when compared to normal controls. These deficits occur in the following areas: attention, processing speed, verbal and visual memory, long-term and working memory, visuospatial skills, executive functioning, and motor functioning (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003; Falleti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Stewart, Bielajew, Collins, Parkinson, & Tomiak, 2006).

Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi (2014) built on the investigation of the objective measurement of cognitive functioning after chemotherapy by conducting a meta-analysis of the results from 44 studies published between 1980 and January

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2011. Studies were subdivided into cross-sectional and longitudinal designs. Results from studies using cross-sectional designs showed impairments on immediate free recall, delayed memory, verbal memory, delayed recognition memory, selective attention, and attention capacity, with small effect sizes at or slightly above d = 0.20. Results from studies using longitudinal designs showed more moderate effect sizes across multiple functions, but that patients performed better in follow-up evaluations than at baseline (Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014).

#### Subjective Report versus Objective Measurement

A difference of opinion exists within CRCI literature regarding the etiology of the discrepancy between scores on self-report versus objective measures. Some research has attributed the difference in scores on objective versus subjective measures solely to flaws in methodology or issues in neuropsychological testing (Hermelink et al., 2010, Jansen, Miaskowski, Dodd, Dowling & Kramer, 2005; Shilling & Jenkins, 2007). For example, it has been proposed that if neuropsychological tests were improved, larger effects would be observed. Improvements in objective measures likely would increase the size of the observed effects, but may not fully explain the discrepancy between subjective objective measures. Alternatively, other research has considered scores on subjective measures to be the most accurate indicators of cognitive functioning (Hermelink et al., 2010). The utility of this perspective is limited by research that has demonstrated the effect of secondary factors (e.g., negative affective states like depression) on self-reports of functioning (Joly, Rigal, Noal, & Giffard, 2011; O'Connor et al., 2012; Zucca, Boyes, Linden, & Girgis, 2012). In addition to cognitive impairment, self-reported negative symptoms may reflect factors such as the experience of emotional distress (depression, sadness, anxiety, fear, worry, anger, panic) involved in coping with a life-threatening disease

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(Andrykowski, Lykins, & Floyd, 2008; Argyriou, Assimakopoulos, Iconomou, Giannakopoulou, & Kalofonos, 2011).

#### Secondary Factors that Influence the Experience of CRCI

The literature is replete with examples of research that demonstrate the influence of secondary factors on test performance (Croizet & Claire, 1998; Levy, 1996; Spencer, Steele, & Quinn, 1999; Steele & Aronson; 1995, & Steele, 1997) and it is widely accepted that physical and psychological symptoms affect cognitive functioning (Joly, Rigal, Noal, & Giffard, 2011; O'Connor et al., 2012; Zucca, Boyes, Linden, & Girgis, 2012). For cancer survivors, the discrepancy between scores on objective versus subjective measures of cognitive functioning may be due, in part, to factors such as negative affective states. Undoubtedly, it is common for individuals to experience symptoms of depression and anxiety immediately following a diagnosis of cancer (Anderson, Golden-Kreutz, Emery, & Thiel, 2009; Andrykowski, Lykins, & Floyd, 2008; Hill et al., 2010; Mehnert et al., 2012; Spiegel & Giese-Davis, 2003), and numerous studies have reported an association between depression, anxiety, and cognitive complaints (Cimpich, Ronis, & Trask, 2005; Cull et al., 1996; Schagen, Boogerd, & Muller, 2008; Schagen, van Dam, Muller, Boogerd, Lindeboom, & Bruning, 1999; Schilling & Jenkins, 2007, Velde, Linn, Nortier, Schilder, Seynaeve, Gundy, ... & van Dam, 2012). Increased symptoms of depression and anxiety may serve to intensify the perception of negative cognitive symptoms after chemotherapy.

#### Stereotype Threat

Another possible explanation for the discrepancy between scores on subjective and objective measures of functioning may be related to the idea of *stereotype threat* (Steele & Aronson, 1995). Steele and Aronson (1995) describe stereotype threat, "... as a social-

psychological predicament that can arise from widely known stereotypes about one's group," (1995, p. 797). Stereotype threat occurs when a person experiences the threat of being judged or treated stereotypically, or fears fulfilling a stereotype (Steele & Aronson, 1995). Research in the field of social psychology has shown that the activation of a stereotype can greatly impact the way individuals think and behave (Hamilton & Sherman, 1994; Steele & Aronson, 1995; Steele, 1997). Stereotypes, or fixed schemas, can be described as mental representations of prior knowledge and experiences (Kunda, 1999; Schagen, Das, & van Dam, 2009). These schemas can be made accessible through the process of priming, whereby contextual information is provided to the individual that results in the activation of the mental representation or stereotype (Steele, 1997). Both positive and negative stereotypes may be activated. For example, Margaret Shih and colleagues (2002) showed that activation of a positive stereotype "boosted" performance for Asian students on a math test when this positive stereotype was subtly called to their attention (Shih, M., Ambady, N., Richeson, J. A., Fujita, K., & Gray, H. M., 2002). Conversely, Kaye & Pennington (2016) examined the performance of females and males on a computer gaming task where females were told (prior to the task) that they have been shown to underperform males on various gaming tasks. Results showed that females performed more poorly than males (negative stereotype activation) on the task (Kaye, L. K., & Pennington, C. R., 2016). The process of activating a *negative* stereotype is referred to as *stereotype threat* (Steele & Aronson, 1995).

One of the first published examples of Stereotype Threat involved a series of experiments that focused on Black and White students and intellectual test performance (Steele & Aronson, 1995). The experimental group consisted of both Black and White students. This group was told that their performance on a test (Graduate Record Exam (GRE) items) would be diagnostic of academic ability. This statement served to make negative racial stereotypes about the intellectual

ability of Blacks salient to Black participants. The control group also consisted of Black and White students. This group was *not* told that the test measured academic ability before taking the test. Results showed that Black students performed more poorly than White students under the threat condition (being told the test measured academic ability), but matched White students under the neutral condition (not being told the test measured academic ability). This study clearly demonstrated the power of Stereotype Threat; negative expectations affected African Americans' performance and served to lower their scores. The influence of negative expectations on test performance has been demonstrated extensively in the literature (Croizet & Claire, 1998; Levy, 1996; Spencer, Steele, & Quinn, 1999; Suhr & Gunstad, 2002; Suhr & Gunstad, 2005; Steele & Aronson; 1995, & Steele, 1997).

#### **Diagnosis** Threat

In 2002, Suhr and Gunstad applied the concept of negative expectancies to the study of traumatic brain injury (TBI). Suhr and Gunstad recruited participants with a previous diagnosis of TBI. The participants, who all had a prior history of TBI, were assigned to either the experimental group or the control group. Participants in the experimental group (N = 17) were told that individuals with a history of prior TBI would likely perform poorly on measures of cognitive functioning *due to their prior TBI*, whereas participants in the control group (N = 19) were simply told to put forth their best effort. Both groups completed measures of functioning (memory, intellect, attention, and psychomotor speed) and the results were compared. The experimental group did, in fact, perform more poorly than the control group on objective measures of cognitive functioning. Because decrements in performance were observed following activation of negative expectations related to a prior *diagnosis*, Suhr and Gunstad named this process *diagnosis threat* (2002).

In 2005, Suhr and Gunstad continued their investigation of the effect of diagnosis threat on cognitive performance in a sample of college students with a history of mild TBI. Suhr and Gunstad wanted to know whether anxiety, effort, and depression in fact drive the experience of diagnosis threat. Participants were assigned to either a diagnosis threat condition (n = 28) or a control condition (n = 25). Participants completed measures of anxiety (State Trait Anxiety Inventory and a Likert scale that provided self-reported pressure during testing), measures of effort (Word Memory Test and a Likert scale that provided self-reported effort during testing), and a measure of depression (Beck Depression Inventory, Second Edition). Neuropsychological tests measured memory, psychomotor speed, attention, and executive functioning. Results were consistent with prior findings and demonstrated that those in the diagnosis threat condition performed worse than those in the control condition on neuropsychological tests. However, contrary to predictions, no differences arose between the groups on anxiety, effort, or depression. These findings suggest that anxiety, effort, and depression did not account for the differences between the groups on objective measures of functioning. Questions remain regarding the causes of diagnosis threat. Wheeler and Petty (2001) contend that activation of schemas related to a stereotype explains the experience of diagnosis threat more than affect or motivational changes due to that threat.

Trontel, Hall, Ashendorf, and O'Conner (2013) further explored diagnosis threat by examining its impact on academic self-efficacy and neuropsychological test performance in individuals with mild traumatic brain injury. All participants had prior diagnoses of mild TBI and were randomly assigned to either a diagnosis threat group or a control group. Individuals in the diagnosis threat group were told that they were selected for participation based on their prior diagnosis of TBI, while those in the control group were told to perform to the best of their ability

(Trontel, Hall, Ashendorf, & O'Connor, 2013). Results revealed that the groups performed differently on just one objective neuropsychological measure. However, the participants in the diagnosis threat group self-reported significantly lower academic self-efficacy than participants in the control group. This finding suggests that diagnosis threat may have a larger impact on self-report than on objective cognitive performance.

#### **Other Examples of Negative Expectations**

In 2009, Schagen, Das, and van Dam examined CRCI using a diagnosis threat type of methodology. The researchers conducted interviews with patients at the Netherlands Cancer Institute. Patients were interviewed about the occurrence of fatigue, insomnia, and memory and concentration problems. Patients were asked to rate the extent of each complaint using a 5-point Likert type scale, where 1 indicated 'not at all,' and 5 indicated 'extremely.' For half of the interviews, participants were told that 'some patients treated with cytotoxic agents (chemotherapy) experience cognitive problems,' and that the goal of the study was to 'obtain more insight into the relationship between chemotherapy and cognitive problems. The other half of patients (the control group) received a neutral introduction with no mention of the association between chemotherapy and cognitive impairments. After the interviews, all patients were asked whether they were familiar with, or had knowledge of, the CRCI stereotype.

Results of this experiment were somewhat surprising. First, physical symptoms such as fatigue, insomnia, and limited endurance were the most frequently reported symptoms. Second, individuals with prior knowledge about the CRCI stereotype (those who had heard of the CRCI stereotype unrelated to the experiment) reported more complaints than individuals without prior knowledge of the CRCI stereotype regardless of the type of complaint (cognitive v. physical). And third, activating the CRCI stereotype had an overall greater effect on the cognitive

complaints made by individuals with no prior knowledge of the CRCI stereotype than those with prior knowledge of the CRCI stereotype (Schagen, Das, & van Dam, 2009). This study demonstrated that activating the CRCI schema increased all individuals' reports of cognitive complaints, and that these complaints increased most significantly for individuals with *no prior knowledge* of the CRCI schema. This result suggests that patients with little to no knowledge about CRCI may be the most susceptible to the experience of CRCI. This finding is especially poignant in light of the fact that patients often report having received little pre-treatment education about the effects of chemotherapy on cognition (Evens & Eschiti, 2009; Mitchell & Turton, 2011; Myers, 2012; Porter, 2013, Schagen, Das, & van Dam, 2009).

Negative expectations related to *treatment* with chemotherapy may operate by a mechanism like that involved in negative expectations related to a prior *diagnosis*. Negative expectations related to treatment with chemotherapy may influence the degree and frequency with which cancer survivors report symptoms of cognitive decline. It may also be true that activation of negative expectations related to treatment produces effects that are not limited to cognitive functioning. Understanding the full impact of negative expectations on different aspects of survivors' health may help inform pretreatment psycho-education strategies and periand post- treatment coping and remediation strategies. The current work sought to expand the investigation of negative expectations in cancer survivors by examining not only its impact on cognitive functioning in individuals who have received treatment with chemotherapy, but also its impact on treatment satisfaction, and endorsement of a chemotherapy-related stereotype both during and after treatment. It was hypothesized that individuals in the negative expectations group would report more negative cognitive symptoms, less treatment satisfaction, and greater endorsement of a chemotherapy-related stereotype than participants in the control group.

#### Hypotheses Related to Cognitive Functioning (Primary Hypotheses)

- Participants in the negative expectations group will report significantly more perceived cognitive impairments than participants in the control group, as measured by the mean scores of the two groups on the 'Perceived Cognitive Impairments' subscale of the FACT-Cog (Version 3).
- 2) Participants in the negative expectations group will report significantly more negative comments from others about their cognitive functioning than participants in the control group, as measured by the mean scores of the two groups on the 'Comments From Others' subscale of the FACT-Cog (Version 3).
- Participants in the negative expectations groups will report significantly fewer cognitive abilities than participants in the control group, as measured by the mean scores of the two groups on the 'Cognitive Abilities' subscale of the FACT-Cog (Version 3).
- 4) Participants in the negative expectations group will report that perceived cognitive impairments have a significantly greater negative impact on quality of life than participants in the control group as measured by the mean scores of the two groups on the 'Impact on Quality of Life' subscale of the FACT-Cog (Version 3).

#### Hypotheses Related to Treatment Satisfaction

- 5) Participants in the negative expectations group will report significantly lower scores related to satisfaction with physician communication than the control group, as measured by the mean scores of the two groups on the 'Physician Communication' subscale of the FACIT-TS-PS (Version 4).
- 6) Participants in the negative expectations group will report significantly lower scores

related to satisfaction with treatment staff communication than the control group, as measured by the mean scores of the two groups on the 'Treatment Staff Communication' subscale of the FACIT-TS-PS (Version 4).

7) Participants in the negative expectations group will report significantly lower scores related to overall treatment satisfaction than will the control group as measured by the mean total scores of the groups on the FACIT-TS-PS (Version 4).

#### Hypotheses related to Endorsement of a Chemotherapy-Related Stereotype

- 8) Participants in the negative expectations group will report greater endorsement of a stereotype during treatment than participants in the control group, as measured by the mean scores on the Perceived Impairments Scale *during* treatment.
- 9) Participants in the negative expectations group will report greater endorsement of a stereotype after treatment than will participants in the control group, as measured by mean scores on the Perceived Impairments Scale *after* treatment.

#### Method

#### **Participants**

A total sample of 56 male and female participants between the ages of 25 years and 93 years (M = 63.7 years, SD = 15.38) was collected over a three-month period at an outpatient cancer treatment center in the northwestern United States. Participants received a gift card valued at \$20.00 for participation in the study. All participants were 18 years of age or older, had completed chemotherapy for the treatment of cancer prior to study participation, were not between courses of treatment, and were not entering palliative care.

#### Instruments

#### **Demographic Questionnaire (see Appendix A)**

The demographic questionnaire includes questions about the participant's age, education, psychological history (such as prior diagnoses and treatment), medical history (such as prior neurological conditions or history of traumatic brain injury), and oncology history (such as type of cancer, treatment duration, and time since last treatment).

#### **Instructions for Negative Expectations Group (see Appendix B)**

Participants in the negative expectations group will be told in writing that they were chosen to participate due to their prior diagnosis of cancer and treatment with chemotherapy. The instructions will draw their attention to the fact that some oncology patients report experiencing problems with thinking and memory after chemotherapy. The instructions will then ask participants to complete the self-report questionnaires as thoroughly and accurately as possible. Participants in the negative expectations group will be asked to sign a form indicating that they read and understood the instructions.

#### **Instructions for Control Group (see Appendix C)**

Instructions for the control group will not overtly draw participants' attention to the relationship between chemotherapy and cognitive impairments. Instructions will simply ask participants in the control group to complete all questionnaires as thoroughly and accurately as possible. Control group participants will be asked to sign a form indicating that they read and understood the instructions.

#### Self-Report Measures (see Appendices D and E)

The self-report measures that will be used in the current study are a part of the Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System developed by David

1 Q

Cella, Ph.D. and colleagues. The FACIT Measurement System includes a range of health-related, quality of life questionnaires for individuals with chronic illnesses. The questionnaires have been validated and are targeted for the management of chronic illness. A subset of FACIT questionnaires, The Functional Assessment of Cancer Therapy (FACT) instruments, were specifically designed to assess cancer therapy and have been validated for use with individuals who are currently receiving treatment and with individuals who have finished receiving treatment (Cella et al., 1993; Webster, Cella, & Yost, 2003; Webster, Odom, Peterman, Lent, & Cella, 1999, Yellen, Cella, Webster, Blendowski, & Kaplan, 1997).

The FACT-Cognitive Function (Version 3) is a self-report measure consisting of four subscales: 'Perceived Cognitive Impairments' (PCI) with 20 items, 'Impact On Quality Of Life' (IQOL) with 4 items, 'Comments From Others' (CFO) with 4 items, and 'Perceived Cognitive Abilities' (PCA) with 9 items. Participants were asked to indicate the frequency with which they experienced symptoms on each of the four scales over the course of the previous week. Response options included: 'Never', 'About once a week', 'Two to three times a week', 'Nearly every day', and 'Several times a day'. Negatively worded items on the FACT-Cog are reverse-scored such that *higher scores on this measure indicate better functioning*. Per FACT-Cog, V3 scoring guidelines, adding subscale scores to obtain total scores is not applicable. Internal consistency reliability coefficients for PCI, IQOL, CFO, and PCA scales were r = .94, r = .67, r = .90, and r = .92, respectively. Test-retest reliability coefficients for the PCI, IQOL, CFO, and PCA scales were r = .82, r = .82, r = .79, and r = .86, respectively. Wagner et al. (2008) found good to excellent convergent validity (>.70) with the Cognitive Difficulties Scale (CDS), another frequently used self-report measure of cognitive functioning.

The FACIT-TS-PS (Version 4) is a self-report measure of patient treatment satisfaction. The FACIT-TS-PS (Version 4) includes six scales: 'Physician Communication,' 'Treatment Staff Communication,' 'Technical Competence,' 'Nurse Communication,' 'Confidence and Trust,' and 'Overall' treatment satisfaction. Two subscales 'Physician Communication' and 'Treatment Staff Communication' along with the FACIT-TS-PS Total Score were selected for analyses. Participants were asked to indicate the quality of the health care services that they received over the course of their medical care. Response options included: 'No, not at all,' 'Yes, but not as much as I wanted,' 'Yes, almost as much as I wanted,' and 'Yes, and as much as I wanted.' Negatively worded items on the FACIT-TS-PS, V4 are reverse-scored such that *higher scores on this measure indicate greater treatment satisfaction*. Reliability and validity data are not available for this measure.

#### Perceived Impairments Scale (see Appendix F)

This scale consisted of two items and was used to assess the degree to which participants endorsed a chemotherapy-related stereotype during and after treatment. Specifically, participants rated how accurately a description of negative cognitive symptoms (based on a common chemotherapy-related stereotype) represented their experience 1) during treatment, and 2) after treatment. A seven-point Likert scale was used for these two items, where a rating of 0 indicated 'not accurately at all' and a rating of 7 indicated 'perfectly accurately.'

#### **Debriefing Statement (see Appendix G)**

A debriefing statement was provided to participants at the end of the study. This form included information about the purposes of the study and provided contact information for the researcher if the participant had questions or concerns regarding participation.

#### **Design and Procedures**

#### Overview

Participants were recruited via flyers provided by physicians during patients' regularly scheduled maintenance appointments. Participants were randomly assigned to either an experimental group or a control group and completed all questionnaires on-site in a quiet location. Participation took approximately 20 minutes and was followed by debriefing and receipt of gift card.

#### Procedure

At the study appointment, participants were escorted to a quiet location on-site where they completed the Informed Consent Form and the Demographic Questionnaire. Each participant was then given an envelope with a letter inside that contained study instructions that also served to assign participants to either an experimental or control group. Participants in the experimental group were informed by their letter that they were selected for participation due to their prior cancer diagnosis and treatment with chemotherapy. Participants in the experimental group also had the relationship between chemotherapy and cognitive impairment brought to their attention by reading a short paragraph describing CRCI (see Appendix B). These statements were intended to activate treatment threat in the experimental group prior to completion of the self-report measures. Participants in the control group were simply instructed to complete the self-report measures as thoroughly and accurately as possible (see Appendix C). The examiner exited the room while the participants read the instructions, thereby ensuring that the examiner was unaware of group assignment at the time of participation. After reading the instructions, participants were required to sign them, place them back into the envelope, and seal the envelope. The examiner then re-entered the room and administered the following self-report

measures: the FACT-Cognitive, Version 3 (FACT-Cog, V3) the FACIT-Treatment Satisfaction-Patient Satisfaction, Version 4(FACIT-TS-PS, V4) and the Perceived Impairments Scale. The session concluded with a debriefing statement (see Appendix G) and distribution of a gift card valued at \$20.00.

#### Results

# **Participant Demographics**

## Gender, Age, and Education

Of the 56 total participants, 26 participants (46.4%) were women and 30 participants (53.6%) were men. A chi-square goodness-of-fit test indicated no significant difference in the proportion of males and females identified in the current sample compared with a sample composed of 50% males and 50% females,  $X^2(1, n = 56) = .29, p = .593$ . Results of the chi-square goodness-of-fit test are shown below in Tables 1A and 1B.

Table 1A. Chi-Square Gender Frequencies

| Gender | Observed <i>n</i> | Expected <i>n</i> | Residual |
|--------|-------------------|-------------------|----------|
| Male   | 30                | 28.0              | 2.0      |
| Female | 26                | 28.0              | -2.0     |
| Total  | 56                | -                 | -        |

Table 1B. Chi-Square Test Statistics

| Statistic               | Participant Gender |
|-------------------------|--------------------|
| Chi-Square              | .286               |
| Degrees of freedom      | 1                  |
| Asymptotic Significance | .593               |

The mean age of participants in the experimental group was 64.14 years (SD = 17.90,

min = 26, max = 93). The mean age of participants in the control group was 63.25 years (SD = 12.69, min = 25, max = 87). The mean years of education for participants in the experimental group was 13.93 (SD = 2.80). The mean years of education for participants in the control group was 13.57 (SD = 2.20). Descriptive statistics for age and education of each group are reported below in Table 2.

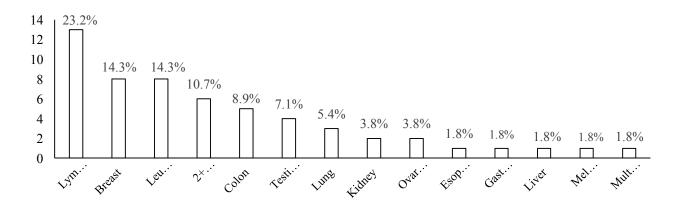
| Variable  | Group        | n  | M(SD)        | Median | Min | Max | Skewness |
|-----------|--------------|----|--------------|--------|-----|-----|----------|
| Age       | Experimental | 28 | 64.14(17.90) | 66     | 26  | 93  | -0.46    |
| Age       | Control      | 28 | 63.25(12.69) | 64.5   | 25  | 87  | -0.94    |
|           | Experimental | 28 | 13.93(2.80)  | 12     | 8   | 20  | 0.33     |
| Education | Control      | 28 | 13.57(2.20)  | 12     | 12  | 18  | 0.82     |

Table 2. Descriptive Statistics for Age and Education

# **Cancer** Types

A variety of cancer types were reported by participants. The top three most frequently occurring cancer types in the sample were (in descending order): lymphoma (23.2%), breast and leukemia (14.3%), followed by individuals with two or more cancer types (10.7%). A frequency distribution of sample cancer types is reported below in Graph 1.

Graph 1. Frequency Distribution of Sample Cancer Types



#### **Treatment Duration and Time Since Last Treatment**

The mean length of treatment for the experimental group was 9.68 months for the (SD = 7.85, min = 2, Max = 36). The mean length of treatment for the control group was 7.73 months (SD = 4.01, min = 2, Max = 18). The mean time since last treatment for the experimental group was 36.39 months (SD = 25.83, min = less than 1, max = 113). The mean time since last treatment for the control group was 27.39 months (SD = 28.62, min = less than 1, max = 130). Descriptive statistics for 'treatment duration' and 'time since last treatment' are reported below in Table 3.

| Variable                   | Group        | n  | M(SD)        | Median | Min | Max | Skewness |
|----------------------------|--------------|----|--------------|--------|-----|-----|----------|
| Treatment                  | Experimental | 28 | 9.68(7.85)   | 6.5    | 2   | 36  | 1.87     |
| Duration<br>(months)       | Control      | 28 | 7.73(4.01)   | 6.0    | 2   | 18  | 0.65     |
| Time Since                 | Experimental | 28 | 26.39(25.83) | 18.5   | 1   | 113 | 1.45     |
| Last Treatment<br>(months) | Control      | 28 | 27.39(28.62) | 16.0   | <1  | 130 | 1.89     |

Table 3. Descriptive Statistics for Treatment Duration and Time Since Last Treatment

# Mental Health Concerns

Of the 56 participants, 12 participants (21.43%) reported mental health concerns and 44 participants (78.57%) reported no mental health concerns at the time of participation. Of the 12 participants who endorsed current mental health concerns, five reported anxiety, four reported depression, and three reported a combination of anxiety and depression. Of the 12 participants who endorsed current mental health concerns, six were receiving treatment for mental health issues at the time of participation and six were not receiving treatment for mental health issues at the time of participation. Of those six participants receiving treatment at the time of participation,

four reported pharmacotherapy only and two reported psychotherapy only. These data, and their relative representation in each group (experimental or control) are shown below in Table 4.

| Table 4. | Mental | Health | by | Group |
|----------|--------|--------|----|-------|
|          |        |        |    | 1     |

| Variable  | Group        | n | Percent of Total<br>Sample ( <i>n</i> = 56) |
|---|--------------|---|---|
| Mental Health Concerns at Time of<br>Participation<br>Total n = 12<br>(21.43% of total sample of $n = 56$ ) | Experimental | 4 | 7.14  |
|   | Control      | 8 | 14.29                                       |
| Anxiety<br>n = 5  | Experimental | 3 | 5.36  |
| n 5   | Control      | 2 | 3.57  |
| Depression<br>n = 4   | Experimental | 1 | 1.79  |
|   | Control      | 3 | 5.36  |
| Anxiety and Depression $n = 3$  | Experimental | 0 | 0   |
| n 5   | Control      | 3 | 5.36  |
| Receiving Treatment $n = 6$   | Experimental | 3 | 5.36  |
| n O   | Control      | 3 | 5.36  |
| No Treatment $n = 6$  | Experimental | 1 | 1.79  |
| n o   | Control      | 5 | 8.93  |
| Pharmacotherapy only $n = 4$  | Experimental | 1 | 1.79  |
|   | Control      | 3 | 5.36  |
| Psychotherapy only $n = 2$  | Experimental | 1 | 1.79  |
| n-2   | Control      | 1 | 1.79  |

# I. The Effect of Group on Self-Reported Cognitive Functioning as measured by the FACT-

# Cognitive, Version 3 (FACT-Cog, V3)

The FACT-Cog consists of 4 independent subscales: 1) 'Perceived Cognitive

Impairments', 2) 'Comments From Others', 3) 'Perceived Cognitive Abilities', and 4) 'Impact

On Quality Of Life.' Four comparisons were planned, thus a Bonferroni adjustment to alpha was obtained (.05/4 = .0125 = .013) to minimize the risk of Type I error.

#### 1. 'Perceived Cognitive Impairments'

An independent samples *t*-test revealed no significant difference in the mean scores on the Perceived Cognitive Impairments subscale of the FACT-Cog, V3 for the experimental (M =51.04, SD = 19.20) and control (M = 50.32, SD = 14.76) groups; t(54) = 0.16, p = .44, d = .04. In other words, those in the experimental group did not report significantly more problems with cognitive functioning than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 5.

#### 2. 'Comments from Others'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 14.68, SD = 2.83) control groups (M = 14.26, SD = 3.01) on the Comments From Others subscale of the FACT-Cog, V3, t(53) = .53, p = .30, d = .15. This result indicated that those in the experimental group did not report significantly more comments from others about their cognitive functioning than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 5.

#### 3. 'Perceived Cognitive Abilities'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 19.19, SD = 7.37) and control groups (M = 19.19, SD = 5.31) on the Perceived Cognitive Abilities subscale of the FACT-Cog, V3, t(51) = -.004, p = .50, d = .001. This finding demonstrated that those in the experimental group did not report significantly fewer cognitive abilities than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 5.

# 4. 'Impact on Quality of Life'

An independent samples *t*-test was revealed no significant difference in the mean scores for the experimental (M = 11.93, SD = 4.72) and control groups (M = 11.50, SD = 5.22) on the Impact on Quality of Life subscale of the FACT-Cog, V3, t(51) = .31, p = .39, d = .09. This result revealed those in the experimental group did not report a significantly greater negative impact on quality of life than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 5.

 Table 5. FACT-Cog, V3 Subscale Scores by Group

| FACT-Cog, V3<br>Subscales* | G            |    | M(CD)                        |      |     |      |
|----------------------------|--------------|----|------------------------------|------|-----|------|
|                            | Group        | n  | M <i>(SD</i> )               | t    | p   | d    |
| Perceived Cognitive        |              |    |                              |      |     |      |
| Impairments                | Experimental | 28 | 51.04 (19.20)                | .16  | .44 | .04  |
| 1                          | Control      | 28 | 50.32 (14.76)                | -    | -   | -    |
| Comments From              |              |    |                              |      |     |      |
| Others                     | Experimental | 28 | 14.68 (2.83)                 | .53  | .30 | .15  |
|                            | Control      | 27 | 14.26 (3.01)                 | -    | -   | -    |
| Perceived Cognitive        |              |    |                              |      |     |      |
| Abilities                  | Experimental | 27 | 19.19 (7.37)                 | 004  | .50 | .001 |
|                            | Control      | 26 | 19.19 <i>(</i> 5. <i>31)</i> | -    | -   | -    |
| Impact On Quality          |              | 07 | 11.02 (4.72)                 | 212  | 20  | 00   |
| Of Life                    | Experimental | 27 | 11.93 (4.72)                 | .312 | .39 | .09  |
|                            | Control      | 26 | 11.50 (5.22)                 | -    | -   | -    |

\* For *all* subscales, higher scores indicate *better* functioning.

Alpha = .05/4 = 0.013 = 98.7% Confidence Interval

Further examination of mean scores on the FACT-Cog, V3 revealed an unexpected

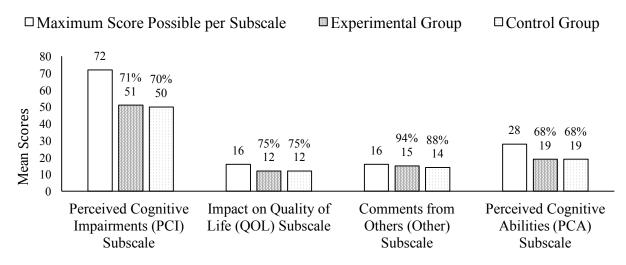
finding; both groups perceived themselves to have strong cognitive functioning across all four

subscales. Recall that higher scores indicate better functioning on each subscale of this measure.

Participants' mean scores on each subscale of the FACT-Cog, V3 represent a large portion of the

total possible score on each subscale. For example, the mean scores for the experimental and control groups on the '*Perceived Cognitive Impairments*' subscale were M = 51 and M = 50, respectively. The highest possible score on this subscale representing the highest possible level of functioning is 72. Therefore, the mean scores for the experimental group (M = 51) and the control group (M = 50) represent 71% and 70% of the highest possible score on this subscale. This pattern of strong ratings continued across the other three subscales of the FACT-Cog, V3. Mean scores and relative percentages for each group on each subscale of the FACT-Cog, V3, as well as maximum scores possible per subscale are reported below, in Graph 2.

Graph 2. Mean Scores on Functional Assessment of Cancer Therapy-Cognitive, Version 3 (FACT-Cog, V3) Subscales by Group





#### **Stereotype During and After Treatment**

The Perceived Impairments Scale asked participants to rate their degree of identification with a chemotherapy-related stereotype over two time periods: 1) 'Perceived Impairments During Treatment' and 2) 'Perceived Impairments After Treatment'. Two comparisons were planned, thus a Bonferroni adjustment to alpha was obtained (.05/2 = .0250 = .025) to minimize the risk of Type I error.

#### 1. 'Perceived Impairments During Treatment'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 3.96, SD = 1.99) and control groups (M = 4.81, SD = 1.73) on the item that asked participants to rate their endorsement of negative cognitive symptoms *during* treatment on the Perceived Impairments Scale, t(53) = -1.69, p = .05, d = .45. The results, along with the means and standard deviations for the two groups, are reported below in Table 7.

#### 2. 'Perceived Impairments After Treatment'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 3.54, SD = 2.12) and control groups (M = 3.89, SD = 1.99) on the item that asked participants to rate their endorsement of a stereotype *after* treatment on the Perceived Impairments Scale, t(53) = -.64, p = .26, d = .17. The results, along with the means and standard deviations for the two groups, are reported below in Table 7.

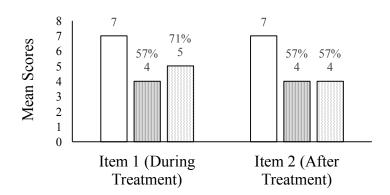
Table 7. Perceived Impairments Scale Scores by Group

| *Perceived<br>Impairments Scale<br>Items              | Group        | n  | M (SD)      | t     | р   | d   |
|---|--------------|----|-------------|-------|-----|-----|
| Degree of perceived impairments during                | Experimental | 28 | 3.96 (1.99) | -1.69 | .05 | .45 |
| treatment   | Control      | 27 | 4.81 (1.73) | _     | _   | -   |
| Degree of perceived<br>impairments after<br>treatment | Experimental | 28 | 3.54 (2.12) | 64    | .26 | .17 |
| u vannonv   | Control      | 27 | 3.89 (1.99) | -     | -   | -   |

\*For both items, higher scores indicate stronger identification with the CRCI stereotype. Alpha = .05/2 = 0.0250 = 0.025 = 97.50% Confidence Interval

Additional examination of the mean scores on both items of the Perceived Impairments Scale offered a second unexpected finding. Both groups endorsed a fair amount of identification with the stereotype of decreased cognitive functioning both during and after chemotherapy. This finding contrasts with patients' high levels of self-reported cognitive functioning on the FACT-Cog. Mean scores for the experimental and control groups on item 1: 'Degree of Perceived Impairments *During* Treatment' were M = 5 and M = 4, respectively. The highest possible score on this item is 7 (indicating strong identification with the stereotype). Thus, the mean scores for the experimental group (M = 5) and the control group (M = 4) represent 71% and 57% of the total possible score on this item. A similar pattern appeared for item 2: 'Degree of Perceived Impairment *After* Treatment. It is worth noting that scores did not decrease from Item 1 to Item 2 for the experimental group, while scores did decrease for the control group. Mean scores and relative percentages for each group on both items of the Perceived Impairments Scale, as well as maximum scores possible per item are reported below, in Graph 4.

Graph 4. Mean Scores on Both Items of the Perceived Impairments Scale



□ Maximum Score Possible per Item □ Experimental Group □ Control Group

# III. The Effect of Group on Self-Reported Treatment Satisfaction as measured by the FACIT Treatment Satisfaction-Patient Satisfaction, Version 4 (FACIT-TS-PS, V4)

The FACIT-TS-PS, V4 consists of five subscales plus a total score, however only 3 subscales 1) 'Physician Communication', 2) 'Treatment Staff Communication', and 3) 'Total

Score' were selected for analyses. Three comparisons were planned, thus a Bonferroni adjustment to alpha was obtained (.05/3 = .0166 = .017) to minimize the risk of Type I error.

#### 1. 'Physician Communication'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 33.27, SD = 5.84) and control groups (M = 33.61, SD = 3.45) on the Physician Communication Subscale of the FACIT-TS-PS, V4, t(54) = -.27, p = .40, d = .07. In other words, the experimental group did not report significantly less satisfaction with physician communication than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 6.

#### 2. 'Treatment Staff Communication'

An independent samples *t*-test revealed no significant difference in the mean scores for the experimental (M = 9.71, SD = 3.33) and control groups (M = 9.78, SD = 2.79) on the Physician Communication Subscale of the FACIT-TS-PS, V4, t(53) = -.08, p = .47, d = .02. This result indicated that the experimental group did not report significantly less satisfaction with treatment staff communication than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 6.

#### 3. 'Total Score'

An independent samples *t*-test revealed no significant difference in the total scores for the experimental (M = 59.55, SD = 10.03) and control groups (M = 60.32, SD = 6.95) on the FACIT-TS-PS, V4, t(54) = -.33, p = .37, d = .09. This finding demonstrated that the experimental group did not report significantly less overall treatment satisfaction than the control group. The results, along with the means and standard deviations for the two groups, are reported below in Table 6.

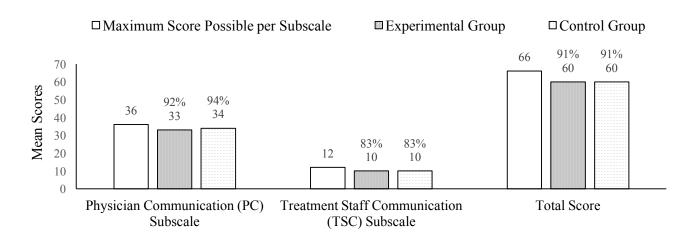
Table 6. FACIT-TS-PS, V4 Subscale Scores by Group

| FACIT-TS-PS,               | G            |    |               |    |          |     |
|----------------------------|--------------|----|---------------|----|----------|-----|
| V4 Subscales*              | Group        | n  | <b>M(SD)</b>  | t  | <i>p</i> | d   |
| Physician<br>Communication | Experimental | 28 | 33.27 (5.84)  | 27 | .40      | .07 |
| Communication              | Control      | 28 | 33.61 (3.45)  | -  | -        | _   |
| Treatment Staff            | Experimental | 28 | 9.71 (3.33)   | 08 | .47      | .02 |
| Communication              | Control      | 27 | 9.78 (2.79)   | -  | -        | -   |
|                            | Experimental | 28 | 59.55 (10.03) | 33 | .37      | .09 |
| Total Score                | Control      | 28 | 60.32 (6.95)  | -  | -        | -   |

\* For *all* subscales, higher scores indicate *better* functioning. Alpha = .05/3 = 0.0166 = 0.017 = 98.3% Confidence Interval

Like the high ratings seen on the FACT-Cog, ratings on the FACIT-TS-PS, V4 were also high, indicating that patients in both groups were highly satisfied with their treatment. Moreover, both groups' mean scores on each subscale of the FACIT-TS-PS, V4 represent a relatively larger portion of the total possible score on each subscale than that demonstrated on the FACT-Cog. Mean scores and relative percentages for each group on each selected subscale of the FACIT-TS-PS, V4, as well as maximum scores possible for those subscales are reported below, in Graph 3.

Graph 3. Mean Group Scores on Selected Subscales of the Functional Assessment of Chronic Illness Therapy-Treatment Satisfaction-Patient Satisfaction, Version 4 (FACIT-TS-PS, V4)



#### Discussion

Results of this study did not support hypotheses that stated that negative expectations would lower patients' self-reports of health-related functioning. Participants scores on the four subscales of the FACT-Cog, V3, indicated no significant differences between the groups in their perceptions of cognitive impairments, comments from others, their quality of life, and of their cognitive abilities.

However, data from this study revealed an unexpected contrast in how patients rated their cognitive functioning on the FACT-Cog, V3 compared with how they rated their cognitive functioning on the Perceived Impairments Scale. On the FACT-Cog, V3 patients in both groups reported few negative cognitive symptoms, while on the Perceived Impairments Scale, patients in both groups identified with the experience of negative cognitive symptoms both during and after chemotherapy. Several factors may have contributed to this puzzling finding. First, the Perceived Impairments Scale expressly refers to the relationship between chemotherapy and negative cognitive symptoms, while the FACT-Cog, V3 does not. The Perceived Impairments Scale commences with a definition of chemotherapy-related cognitive impairment that serves to overtly draw patients' attention to the relationship between chemotherapy and cognitive symptoms. Second, immediately after patients' read that definition they were asked to rate how strongly they identified with the experience of negative cognitive symptoms during and after their treatment with chemotherapy. One conclusion that can be drawn is that these features resulted in greater prime intensity on the Perceived Impairments Scale and this drove higher scores on this measure compared to scores on the FACT-Cog, V3. Research has shown that different levels of prime strength can differentially affect self-report (Simmons, C. M., 2010; Kang, S. K., Galinsky, A. D., Kray, L. J., & Shirako, A., 2015). This is not to say that patients'

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responses on the FACT-Cog, V3 were based on zero prime. Other factors (such as cancer survivor status) could theoretically contribute to a general or broad sense of threat while completing the FACT-Cog, V3. However, it seems likely that individuals would experience less threat activation on a measure that does not overtly attempt to activate it, and more threat activation on a measure that overtly attempts to activate it.

In addition to 'prime intensity', 'prime familiarity' may have played a role in higher scores on the Perceived Impairments Scale. Research in social psychology has demonstrated that familiarity with a stereotype can serve to reinforce that stereotype (Häfner, M., & Stapel, D. A., 2009; Wen, F., Zuo, B., 2008). As individuals who had completed chemotherapy, patients were likely familiar with the CRCI stereotype through their own experience, conversations with medical providers, other patients, family, and friends (Schagen, S. B., Das, E., & Van Dam, Frits S. A. M, 2009). The brief, bite-sized and familiar chemotherapy heuristic provided at the start of the Perceived Impairments Scale could have initiated recognition of that stereotype, thus leading participants to endorse that heuristic at higher levels than their scores on the FACT-Cog, V3 demonstrated (Häfner, M., & Stapel, D. A., 2009; Wen, F., Zuo, B., 2008). In other words, patients' endorsement of the stereotype may have been due to their familiarity with the CRCI stereotype (which they were reminded of immediately before responding) rather than their actual experience with negative cognitive symptoms.

The ideas mentioned above, prime intensity and prime familiarity, can be directly applied to care in real-world treatment settings. These ideas suggest that how others (professionals, other patients, family, and friends) share information with cancer patients about potential side effects of treatment or query them about their cognitive functioning could influence their perceptions of their functioning and consequently their responses on self-report measures. Research that

examines stereotype propagation supports this idea (Clarkson, J. J., Tormala, Z. L., Rucker, D. D, 2008; Clarkson, J. J., Tormala, Z. L., Rucker, D. D., & Dugan, R. G., 2013). For example, Clarkson, Tormala, and Rucker (2008) showed that when group consensus regarding a stereotype was high, individuals rated that stereotype as more "correct" than when group consensus was low. In this study, the CRCI stereotype was presented to participants under high consensus conditions, i.e., as part of an official study taking place at their treatment clinic, authorized by their own oncologist. These conditions may have suggested to participants that a larger group of oncologists and researchers likely endorsed the existence of cognitive impairments during and after chemotherapy, leading them to agree with the stereotype. Therefore, care must be taken in the design of self-report measures and in routine interactions with cancer patients to avoid unintentional reinforcement of unhelpful stereotypes.

While stereotype threat research has mainly examined the role of negative expectations on performance, much is yet to be learned about other possibilities such as whether patients' perceptions or attitudes about their cognitive functioning could be boosted through positive priming. The beneficial effects of positive priming were demonstrated in a study by Aisenberg and colleagues (2015) whereby elderly adults performed better on a cognitive task after receiving a positive prime that highlighted participants' cognitive abilities (rather than the association between older age and cognitive decline. Helping cancer patients to understand the temporary nature of cognitive symptoms (if they are even experienced) and the degree to which everyday cognitive failures (normal, minor thinking errors) occur, may serve to boost perceptions of functioning and ultimately minimize or prevent fears related to cognition after chemotherapy. For example, forgetting where the car keys were placed likely represents a normal thinking error and not cognitive decline associated with chemotherapy.

It is also possible that order effects played a role in participants' relative endorsement of the CRCI stereotype versus symptoms on the FACT-Cog. The Perceived Impairments Scale was not included in the Latin Square technique used to order the measures to avoid interference with the experimental manipulation. Instead, the Perceived Impairments Scale always occurred in the final position, therefore patients always completed it last. Patients may have been ambivalent or fatigued by the time they reached the final measure and therefore may have given mid-range responses to speed completion or to simplify decision-making. These are not uncommon occurrences on questionnaires or on Likert-type scales (Huang, J. L., Liu, M., & Bowling, N. A. 2015; Raaijmakers, Q. A. W., van Hoof, A., Hart, H. '., Verbogt, T. F. M. A., & Vollebergh, W. A. M., 2000).

Further examination of scores on the Perceived Impairments Scale presented another interesting finding: only the control group reported that their cognitive symptoms decreased over time. The experimental group reported no such decrease; they reported experiencing the same level of identification with the CRCI stereotype *after* treatment as they experienced *during* treatment. This result is in opposition to the idea that patients are more likely to report a decrease in negative cognitive symptoms following treatment than during treatment (Wefel, J. S., Saleeba, A. K., Buzdar, A. U., Meyers, C. A., 2010; Raffa, R. B., 2011). For those in the experimental condition, the original experimental manipulation paired with the additional salience of the CRCI stereotype may have reinforced patients' perceptions of cognitive impairment. Research has demonstrated that increasing the number of exposures to a prime through repetition can lead to greater effects on dependent measures (Smith, E. R., Miller, D. A., Maltner, A. T., Crump, S. A., Garcia-Marques, T., & Mackie, D. M., 2006; Wen, F., & Zuo, B., 2008). This finding suggests that treatment threat may have actually occurred for the experimental group because it follows the expected pattern of threat activation followed by endorsement of negative cognitive symptoms; in this case, negative cognitive symptoms that did not decrease over time as they did for the control group. Put in the context of treatment, repeated mention of the "chemo-brain" stereotype, from multiple sources could potentially prime patients to perceive their cognitive functioning as diminished. This intriguing finding suggests an excellent starting point for further investigation.

As noted earlier, the primary hypotheses of the study were not supported by the data. Primary hypotheses postulated that the manipulation (activating treatment threat) would cause the experimental group to self-report more negative cognitive symptoms (as measured by the FACT-Cog, V3) and less treatment satisfaction (as measured by the FACIT-TS-PS, V4) than the control group. These results do not echo results from multiple studies that have shown that negative stereotypes can negatively influence performance (Croizet & Claire, 1998; Levy, 1996; Spencer, Steele, & Quinn, 1999; Suhr & Gunstad, 2002; Suhr & Gunstad, 2005; Steele & Aronson; 1995, & Steele, 1997).

Examination of data from the FACT-Cog, V3 indicate that across all four subscales, participants in both groups reported strong cognitive functioning. Similarly, data across the FACIT-TS-PS indicated a high degree of treatment satisfaction. In other words, treatment threat, if it was produced at all, did not negatively influence self-reports of health-related functioning for this sample of patients, at this specific clinic. Several methodological issues may have contributed to these results.

One primary methodological explanation may be related to the process of threat induction. Other studies examining the phenomenon of stereotype and diagnosis threat have had different levels of success in activation of a threat in participants (Suhr and Gunstad; 2005;

Trontel, H. G., Hall, S., Ashendorf, L., O'Connor, M. K., 2013). Trontel and colleagues (2013) demonstrated that while diagnosis threat was not shown to negatively impact neuropsychological test performance, diagnosis threat *did* lower reports of academic self-efficacy in a traumatic brain injury (TBI) population. Put simply, threat activation can lead to variable effects. As was previously mentioned, differences in prime intensity (such as a 'high intensity prime' vs. a 'low intensity prime') can produce differences in degree of threat activation (Simmons, C. M., 2010; Kang, S. K., Galinsky, A. D., Kray, L. J., & Shirako, A., 2015). Logic would suggest that the largest effects would stem from high intensity prime; however, the low intensity level of the prime in the present study was intentionally selected to prevent emotional distress or feelings of conflict in survivors regarding their prior treatment with chemotherapy. Thus, statements intended to activate threat in the experimental group may not have been of sufficient intensity to produce clear effects on either the FACT-Cog or the FACIT-TS-PS.

A second methodological issue may have been related to the recruitment process. All participants were recruited during their regularly scheduled maintenance appointments with their treating oncologist, therefore, all participants knew they were being recruited due to a prior diagnosis of cancer, and by extension, treatment with chemotherapy. Consequently, there may not have been a "true" control group. In a sense, all participants may have been primed to some degree prior to self-report, which may have produced comparable results between the groups on the FACT- Cog,V3. Likewise, check-up appointments where extremely good news is delivered (such as stable blood counts and continued remission), may serve to block attempts to induce threat. Indeed, overt or strong attempts to persuade others from a currently held belief have been shown to backfire (Tormala, Z. L., & Petty, R. E., 2002). Tormala and Petty (2002) investigated the effects of resisting persuasion on attitude certainty and found that when the persuasive

attempt was perceived to be strong, participants' degree of certainty about their own belief not only increased, but also limited their vulnerability to persuasive attempts in the future.

Another potential problem was small sample size. In the design of this project, several factors were attempted to be weighed and balanced carefully. On one hand, larger sample sizes allow researchers to more easily detect effects if they are present (Hayes, W. L., 1994), however, a larger patient sample was not feasible in this study given constraints around access to patients and the limited number of physicians who chose to recruit participants. On the other hand, two influential and frequently cited papers that examined diagnosis threat in different patient populations found significant results with small sample sizes (Suhr, J. A., & Gunstad, J., 2002; Suhr, J. A., & Gunstad, J., 2005). This project was completed with this research in mind and with the desire to potentially expand the limited information known about the mechanisms that underlie the "chemo-brain" stereotype.

Lastly, differences in cancer type, cancer stage, and treatment protocols could have influenced results. These variables were not controlled to maximize the sample size of this project. It is easy to imagine how these variables might influence patients' perceptions of not only their cognitive functioning, but other types of functioning as well. For example, an individual who experienced an early stage cancer, was treated with less cytotoxic chemotherapy, and experienced a shorter treatment duration may report fewer cognitive complaints and better overall functioning than an individual who experienced a more severe diagnosis and more trying treatment conditions (Argyriou, Assimakopoulos, Iconomou, Giannakopoulou, & Kalofonos, 2011; de Ruiter et al., 2011).

While numerous methodological variables may have contributed to the results of the study, other "patient-related" variables may also have been at play. Findings in this study may be

related to a unique quality or set of qualities possessed by this sample of patients that contributed to their ability to repel threat. All participants were cancer *survivors*, and as such, they may have developed strong beliefs and attitudinal characteristics that aided survival following a lifethreatening diagnosis. The emotional and physical challenges of cancer treatment may instill in patients, certain beliefs and characteristics that buffered them from successful threat induction. Research on posttraumatic growth after cancer indicates that survivors frequently report enhanced self-esteem, greater life appreciation and meaning, heightened spitituality, and heightened benefit-finding following their cancer experience (Andrykowski, M. A., Lykins, E., & Floyd, A., 2008). Results from a study by Schagen, Das, & van Dam (2009) supports the idea that treatment experience may inoculate patients to some extent against threat. Schagen and colleagues demonstrated that patients with little to no knowledge about CRCI (those who have had no experience with treatment or exposure to this idea through family and/or friends) may be more vulnerable to the experience of the 'chemo-brain' stereotype than patients with knowledge of CRCI (those who have had experience with treatment and exposure to this idea through family and/or friends). Stated in reverse, Schagen and colleagues found that those with more knowledge were less vulnerable, and this may have been the case for patients in the present study. Other examples of the effect of attitudes on health outcomes are numerous; for example, optimism, has been shown to be positively correlated with better treatment outcomes in cardiac patients and others with chronic illness (Corace, K. M., & Endler, N. S., 2003; Hurt, C. S., Burn, D. J., Samuel, M., Wilson, K., & Brown, R., G., 2014).

In addition to patient-related variables, "provider-related" variables may have helped patients defend against negative expectations and stereotypes. Consistent with patterns of performance on the FACT-Cog, V3, scores on the FACIT-TS-PS, V4 revealed that participants

in both groups were highly satisfied with the treatment they received. The FACIT-TS-PS included items such as, '*Did your doctor show genuine concern for you?'; 'Were you encouraged to participate in decisions about your health care?';* and '*Did the treatment staff discuss how your health and treatment may affect you emotionally?'* Participants in both groups indicated that they received as much physician and treatment staff communication as they wanted and that the quality of their communication was very high. High quality interactions with their physicians and other treatment staff may have infused patients with "protection" from alternative information that may carry a negative valence (such as negative expectations and stereotypes). Studies have shown that high quality physician-patient and nurse-patient interactions can increase patients' confidence in the success of their treatment and create increased levels of hope for the future (Charlton, C. R., Dearing, K. S., Berry, J. A., & Johnson, M. J., 2008; Merckaert, I., Libert, Y., & Razavi, D., 2005).

Results from this study illustrate the challenges involved in investigating chemotherapyrelated cognitive impairment. Often, patients' subjective reports of their cognitive functioning suggest more impairment than that which is observed by objective measurement. Methodological issues such as differences in cancer type, treatment type, treatment intensity, measurement shortcomings, and lack of baseline data have been implicated as causes of disparate findings.

The purpose of this study was to investigate a phenomenon that may influence performance on subjective measures of functioning. It was proposed that negative expectations related to the "chemo-brain" stereotype have the power to negatively influence self-perceptions of cognitive functioning (and perhaps other types of health-related functioning) in cancer survivors. While the manipulation did not cause the experimental group to report significantly more negative cognitive symptoms and less treatment satisfaction, other valuable findings

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emerged. Namely, that on one measure patients *did* identify fairly strongly with the experience of negative cognitive symptoms during and after treatment, yet on another measure, they reported very few negative cognitive symptoms. It may be that patients were psychologically buffered from treatment threat by the attitudes and beliefs that developed through the challenges of coping with a life-threatening illness, and/or by the strength of their relationships with their care providers. However, results on the Perceived Impairments Scale suggest that any protective effect of a psychological buffer diminished under the influence of increasing prime intensity, prime familiarity, and prime repetition and ultimately led participants in the experimental group to rate the degree to which they identified with the CRCI stereotype at a moderate level. Providing patients with a definition and then asking them if their experience fits that definition, could lead them to identify more strongly with that definition or, in this case, the CRCI stereotype.

#### Conclusion

The findings reported here contribute to a growing scientific understanding of the underlying mechanisms of chemotherapy-related cognitive impairment. Advances in early diagnosis and treatment have resulted in many more people surviving a diagnosis of cancer today, than just a short time ago (American Cancer Society, 2014). As the number of survivors continues to grow, issues related to survivorship will become increasingly important. The prevalence of negative cognitive symptoms reported by patients (up to 68%), makes this issue an important topic for consideration by the research community (Ahles & Saykin, 2007; Johnston, 2014; Joly, Rigal, Noal, & Giffard, 2011; Lindner, Phillips, McGabe, Mayes, Wearden, Varese, & Talmi, 2014; Shilling, Jenkins, & Trapala, 2006). Understanding the factors that influence perceived cognitive functioning may facilitate the development of intervention programs that

aim to prevent or moderate the development of unhelpful stereotypes. Eliminating unhelpful stereotypes as factors that influence patients' attitudes and beliefs about their functioning, may ultimately contribute to enhanced quality of life after cancer.

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## Appendix A

## **Demographic Questionnaire**

**INSTRUCTIONS**: Please complete the following screening questionnaire by filling in the blanks or circling your answers.

| Ag | ge: Birthdate:   |             |    |
|----|--|-------------|----|
| 1. | Were there any known difficulties with your birth?   | Yes         | No |
|    | If yes, describe:  |             |    |
| 2. | Do you have a vision problem that requires corrective lens wear (e.g., glasses)?   | Yes         | No |
| Ed | lucation   |             |    |
| 3. | Did you ever have to repeat any grades?  | Yes         | No |
| 4. | Were you ever placed in special education classes?   | Yes         | No |
| 5. | What is the highest level of education you have attained (circle one)?   |             |    |
|    | High School Some college College degree Master's degree Doctoral d   | legree      |    |
| M  | edical and Health History  |             |    |
| 6. | Have you ever been diagnosed with any neurological condition?  | Yes         | No |
|    | If yes, please list:   |             |    |
| 7. | Are you currently experiencing significant problems with your mental health, suc<br>problems with anxiety and/or depression, or any other psychiatric condition?<br>If yes, please list: | h as<br>Yes | No |
| 8. | Are you currently receiving treatment for your mental health?<br>If yes, please explain:   | Yes         | No |

| 9. Have you ever felt you should cut down on your drinking/drug use?  | Yes        | No       |
|---|------------|----------|
| 10. Have you ever been annoyed by people who criticize your drinking/drug use?  | Yes        | No       |
| 11. Have you ever felt bad or guilty about your drinking or drug use?   | Yes        | No       |
| 12. Have you ever had a drink first thing in the morning to steady your nerves or   | Yes        | No       |
| to get rid of a hangover?   |            |          |
| 13. Do you often drive under the influence of alcohol or drugs?   | Yes        | No       |
| 14. Have you ever been diagnosed with cancer?   | Yes        | No       |
| 15. If yes, what type of cancer did you have?   |            |          |
| 16. If yes, when were you diagnosed with cancer?  |            |          |
| 17. If yes, how long did your cancer treatment last?  |            |          |
| 18. If yes, what kind of cancer treatment did you receive?  |            |          |
|   |            |          |
| 19. If yes, are you finished will all treatments for this cancer?   | Yes        | No       |
|   |            |          |
| 20. If yes, when did you finish all cancer treatments?  |            |          |
| <ul><li>20. If yes, when did you finish all cancer treatments?</li><li>21. Have you ever experienced a concussion or brain injury?</li></ul>  | Yes        | No       |
|   |            |          |
| 21. Have you ever experienced a concussion or brain injury?   | Yes<br>Yes | No<br>No |
| <ul><li>21. Have you ever experienced a concussion or brain injury?</li><li>22. Were you knocked unconscious?</li></ul>   | Yes<br>Yes | No<br>No |
| <ul><li>21. Have you ever experienced a concussion or brain injury?</li><li>22. Were you knocked unconscious?</li><li>If yes, how long were you unconscious? (please circle the letter that corresponds)</li></ul>        | Yes<br>Yes | No<br>No |
| <ul><li>21. Have you ever experienced a concussion or brain injury?</li><li>22. Were you knocked unconscious?</li><li>If yes, how long were you unconscious? (please circle the letter that corresponds answer)</li></ul> | Yes<br>Yes | No<br>No |

23. Do you remember the events before or after your head injury? Yes No

If no, how long of a time period were you unable to remember?

- 1. A few seconds
- 2. Less than 5 minutes
- 3. Less than 30 minutes
- 4. 30 to 60 minutes
- 5. More than 60 minutes

Thank you.

### Appendix B

### **Instructions NEG**

When you finish reading these instructions, sign at the bottom indicating that you have read them and understand your task. Then, place this signed sheet back into the envelope, seal it, place an X over the seal and wait for the examiner to return.

You have been invited to participate in this study because you indicated a prior diagnosis of cancer and treatment with chemotherapy. A number of studies report that some individuals treated with chemotherapy have reported problems with thinking and memory such as feeling forgetful, having trouble organizing thoughts, or not being able to think of the right word. Some patients have reported that these problems have made other aspects of life (i.e., work, school, home life) more difficult. This study will examine the role that chemotherapy may play in numerous areas of health-related functioning.

When the experimenter returns to the room, s/he will ask you to complete a collection of health-related questionnaires. Please do not leave any questions blank. Some questions may seem less applicable to your individual situation. Please choose the response that *best* represents your experience. Please answer as thoroughly and accurately as possible. Questions about individual questionnaires will be answered following the testing.

I have read these instructions and will do my best to follow them for the remainder of the experiment.

(Signature)

### Appendix C

### **Instructions CG**

When you finish reading these instructions, sign at the bottom indicating that you have read them and understand your task. Then, place this signed sheet back into the envelope, seal it, place an X over the seal and wait for the examiner to return.

When the experimenter returns to the room, s/he will ask you to complete a collection of health-related questionnaires. Please do not leave any questions blank. Some questions may seem less applicable to your individual situation. Please choose the response that *best* represents your experience. Please answer as thoroughly and accurately as possible. Questions about individual questionnaires will be answered following the testing.

I have read these instructions and will do my best to follow them for the remainder of the experiment.

(Signature)

## Appendix D

## FACT-Cognitive Function (FACT-Cog), Version 3

Below is a list of statements that other people with your condition have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

|         |  | Never | About<br>once a | Two to<br>three | Nearly<br>every | Several<br>times |
|---------|--|-------|-----------------|-----------------|-----------------|------------------|
|         | PERCEIVED COGNITIVE IMPAIRMENTS  |       | week            | times a<br>week | day             | 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,<br>like my keys or my wallet              | 0     | 1               | 2               | 3               | 4                |
| CogM12  | I have had trouble remembering new information,<br>like phone numbers or simple instructions | 0     | 1               | 2               | 3               | 4                |
| CogV13  | I have had trouble recalling the name of an object<br>while talking to someone               | 0     | 1               | 2               | 3               | 4                |
| CogV15  | I have had trouble finding the right word(s) to<br>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                |

## Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

|         |  | Never | About<br>once a<br>week | Two to<br>three<br>times a<br>week | Nearly<br>every<br>day | Several<br>times a<br>day |
|---------|--|-------|-------------------------|------------------------------------|------------------------|---------------------------|
| CogF25  | My reactions in everyday situations have been slow   | 0     | 1                       | 2                                  | 3                      | 4                         |
| CogC31  | I have had to work harder than usual to keep track<br>of what I was doing                    | 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<br>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 trouble shifting back and forth between<br>different activities that require thinking | 0     | 1                       | 2                                  | 3                      | 4                         |

# Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

|       | COMMENTS FROM OTHERS   | Never | About<br>once a<br>week | Two to<br>three<br>times a<br>week | Nearly<br>every<br>day | Several<br>times a<br>day |
|-------|--|-------|-------------------------|------------------------------------|------------------------|---------------------------|
| CogO1 | Other people have told me I seemed to have trouble remembering information | 0     | 1                       | 2                                  | 3                      | 4                         |
| CogO2 | Other people have told me I seemed to have trouble speaking clearly        | 0     | 1                       | 2                                  | 3                      | 4                         |
| CogO3 | Other people have told me I seemed to have trouble <u>thinking clearly</u> | 0     | 1                       | 2                                  | 3                      | 4                         |
| CogO4 | Other people have told me I seemed <u>confused</u>                         | 0     | 1                       | 2                                  | 3                      | 4                         |

# Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

|                 | PERCEIVED COGNITIVE ABILITIES  | Not<br>at all | A little<br>bit | Some-<br>what | Quite<br>a bit | Very<br>much |
|-----------------|--|---------------|-----------------|---------------|----------------|--------------|
| Cog<br>PC1      | I have been able to concentrate  | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PV1      | I have been able to bring to mind words that I wanted to<br>use while talking to someone   | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PM1      | I have been able to remember things, like where I left<br>my keys or wallet                | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PM2      | I have been able to remember to do things, like take<br>medicine or buy something I needed | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PF1      | I am able to pay attention and keep track of what I am doing without extra effort          | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PCH<br>1 | My mind is as sharp as it has always been  | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PCH<br>2 | My memory is as good as it has always been   | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PMT<br>1 | I am able to shift back and forth between two activities that require thinking             | 0             | 1               | 2             | 3              | 4            |
| Cog<br>PMT<br>2 | I am able to keep track of what I am doing, even if I am interrupted                       | 0             | 1               | 2             | 3              | 4            |

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

|            | IMPACT ON QUALITY OF LIFE   | Not<br>at all | A little<br>bit | Some-<br>what | Quite<br>a bit | Very<br>much |
|------------|---|---------------|-----------------|---------------|----------------|--------------|
| CogQ3<br>5 | I have been upset about these problems                              | 0             | 1               | 2             | 3              | 4            |
| CogQ3<br>7 | These problems have interfered with my ability to work              | 0             | 1               | 2             | 3              | 4            |
| CogQ3<br>8 | These problems have interfered with my ability to do things I enjoy | 0             | 1               | 2             | 3              | 4            |
| CogQ4<br>1 | These problems have interfered with the quality of my life 66       | 0             | 1               | 2             | 3              | 4            |

### Appendix E

### FACIT-Treatment Satisfaction-Patient Satisfaction (FACIT-TS-PS), Version 4

These questions are about the quality of the health care services you are currently receiving. All of your responses will be kept confidential. Please mark one answer for each of the following questions. Pleasecircle or mark one number per line to indicate your response as it applies to the past 7 days.

|      | Physician Communication   | No, not at<br>all | Yes, but<br>not as<br>much as I<br>wanted | Yes,<br>almost as<br>much as I<br>wanted | Yes, and<br>as much<br>as I<br>wanted |
|------|---|-------------------|---|--|---------------------------------------|
| TS9  | Did your doctor(s) give explanations that you could understand?                     | 0                 | 1   | 2  | 3                                     |
| TS10 | Did your doctor(s) explain the possible benefits of your treatment?                 | 0                 | 1   | 2  | 3                                     |
| TS11 | Did your doctor(s) explain the possible side effects<br>or risks of your treatment? | 0                 | 1   | 2  | 3                                     |
| TS12 | Did you have an opportunity to ask questions?                                       | 0                 | 1   | 2  | 3                                     |
| TS13 | Did you get to say the things that were important to you?                           | 0                 | 1   | 2  | 3                                     |
| TS14 | Did your doctor(s) seem to understand what was important to you?                    | 0                 | 1   | 2  | 3                                     |
| TS15 | Did your doctor(s) show genuine concern for you?                                    | 0                 | 1   | 2  | 3                                     |
| TS16 | Did your doctor(s) seem to understand your needs?                                   | 0                 | 1   | 2  | 3                                     |
| TS18 | Were you able to talk to your doctor(s) when you needed to?                         | 0                 | 1   | 2  | 3                                     |
| TS27 | Were you encouraged to participate in decisions about your health care?             | 0                 | 1   | 2  | 3                                     |
| TS28 | Did you have enough time to make decisions about your health care?                  | 0                 | 1   | 2  | 3                                     |
| TS30 | Did your doctor(s) seem to respect your opinions?                                   | 0                 | 1   | 2  | 3                                     |

|     | <u>Treatment Staff Communication</u>   | No, not<br>at all | Yes, but<br>not as<br>much as I<br>wanted | Yes,<br>almost as<br>much as I<br>wanted | Yes,<br>and as<br>much as I<br>wanted |
|-----|--|-------------------|---|--|---------------------------------------|
| TS1 | Did the treatment staff discuss how your health and treatment may affect your normal work (including housework)? | 0                 | 1   | 2  | 3                                     |
| TS2 | Did the treatment staff discuss how your health and treatment may affect your normal daily activities?           | 0                 | 1   | 2  | 3                                     |
| TS2 | Did the treatment staff discuss how your health and treatment may affect your personal relationships?            | 0                 | 1   | 2  | 3                                     |
| TS2 | Did the treatment staff discuss how your health and treatment may affect you emotionally?                        | 0                 | 1   | 2  | 3                                     |

|      | <u>Technical Competence</u>  | No, not<br>at all | Yes, but<br>not as<br>much as I<br>wanted | Yes,<br>almost as<br>much as I<br>wanted | Yes,<br>and as<br>much as I<br>wanted |
|------|--|-------------------|---|--|---------------------------------------|
| TS23 | Did you feel your doctor(s) had experience treating your illness?                        | 0                 | 1   | 2  | 3                                     |
| TS24 | Did you feel your doctor(s) knew about the latest medical developments for your illness? | 0                 | 1   | 2  | 3                                     |
| TS25 | Was the treatment staff thorough in examining and treating you?                          | 0                 | 1   | 2  | 3                                     |

|     | Nurse Communication  | No, not at<br>all | Yes, but<br>not as<br>much as I<br>wanted | Yes,<br>almost as<br>much as I<br>wanted | Yes, and<br>as much<br>as I<br>wanted |
|-----|--|-------------------|---|--|---------------------------------------|
| TS3 | Did your nurse(s) give explanations that you could understand? | 0                 | 1   | 2  | 3                                     |
| TS3 | Did your nurse(s) show genuine concern for you?                | 0                 | 1   | 2  | 3                                     |
| TS3 | Did your nurse(s) seem to understand your needs?               | 0                 | 1   | 2  | 3                                     |

|      | <u>Confidence and Trust</u>   | No, not<br>at all | Yes, but<br>not as<br>much as<br>I wanted | Yes,<br>almost as<br>much as<br>I wanted | Yes, and as<br>much as I<br>wanted |
|------|---|-------------------|---|--|------------------------------------|
| TS34 | Did you feel that the treatment staff answered your questions honestly? | 0                 | 1   | 2  | 3                                  |
| TS35 | Did the treatment staff respect your privacy?                           | 0                 | 1   | 2  | 3                                  |
| TS36 | Did you have confidence in your doctor(s)?                              | 0                 | 1   | 2  | 3                                  |
| TS37 | Did you trust your doctor(s)' suggestions for treatment?                | 0                 | 1   | 2  | 3                                  |
|      | Overall   |                   |   |  |                                    |
|      |   | No                | Maybe                                     | Yes                                      |                                    |
| TS38 | Would you recommend this clinic or office to others?                    | 0                 | 1   | 2  |                                    |
| TS39 | Would you choose this clinic or office again?                           | 0                 | 1   | 2  |                                    |

|      |  | Poor | Fair | Good | Very<br>Good | Excellent |
|------|--|------|------|------|--------------|-----------|
| TS40 | How do you rate the care you received? | 0    | 1    | 2    | 3            | 4         |

Thank you! Do you have any comments?

### Appendix F

### **Perceived Impairments Scale**

Current research on cancer recovery describes chemotherapy-related cognitive impairment as the experience of having problems with attention, concentration, and memory during and following treatment with chemotherapy. Due to these problems, some individuals treated with chemotherapy have reported difficulty returning to the activities of daily living following treatment, like following medication regimens, managing medical appointments, returning to work or school, managing a household, and other activities that require multitasking skills.

How accurately does this description represent your experience **during chemotherapy** (circle one)?

| 1              | 2 | 3 | 4 | 5 | 6 | 7         |
|----------------|---|---|---|---|---|-----------|
| Not accurately |   |   |   |   | Р | Perfectly |
| at all         |   |   |   |   | a | ccurately |

How accurately does this description represent your experience **after chemotherapy** (circle one)?

| 1              | 2 | 3 | 4 | 5 | 6  | 7        |
|----------------|---|---|---|---|----|----------|
| Not accurately |   |   |   |   | Pe | erfectly |
| at all         |   |   |   |   | ac | curately |

Comments:

### Appendix G

### **Debriefing Statement**

Thank you for participating in this study. Throughout the course of this experiment, you may have had questions regarding the nature or purpose of this study. If you still have these questions, the experimenter will be glad to answer them for you at this time.

The purpose of this study was to investigate the influence of negative expectations on symptom reporting. Specifically, this study was interested in examining whether or not drawing your attention to your previous diagnosis of cancer and your treatment with chemotherapy influenced your performance on subjective measures of functioning. <u>Your answers to these questions, as well as your performance on the testing measures, will be kept completely confidential.</u>

Although a slight amount of discomfort is normal, if you experienced a significant amount of discomfort during the course of the experiment, please address your concerns to the experimenter at the present time. If you feel uncomfortable doing so, you may contact the faculty supervisor of the project, Dr. Stuart Hall, at 243-5667. If you experience significant discomfort and would like to explore counseling or mental health services, students can be seen at the Clinical Psychology Center, at 243-2367 or at Counseling and Psychological Services through the Curry Health Center, at 243-4711.

#### **IMPORTANT:**

We request that you not discuss the details of this experiment with anyone who may be a future participant in the study. Thank you for your cooperation.