CANCER TREATMENT-RELATED FATIGUE: PSYCHOMETRIC TESTING OF THE CANCER TREATMENT-RELATED FATIGUE REPRESENTATION SCALE (CTRFREP) IN PATIENTS UNDERGOING RADIATION TREATMENT FOR CANCER

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ABSTRACT

Kristina M. Reuille

CANCER TREATMENT-RELATED FATIGUE: PSYCHOMETRIC TESTING OF THE CANCER TREATMENT-RELATED FATIGUE REPRESENTATION SCALE (CTRFREP) IN PATIENTS

UNDERGOING RADIATION TREATMENT FOR CANCER

Cancer treatment-related fatigue (CTRF) is recognized as a prevalent and bothersome symptom for patients with cancer. In a model of the CTRF experience, CTRF representation, or the beliefs, thoughts and emotions surrounding the experience of CTRF, is believed to mediate the relationship between CTRF intensity and CTRF distress. To date, there is no reported measure of CTRF representation. The purpose of this descriptive, cross-sectional study guided by Leventhal's Common Sense Model of Self-Regulation was to evaluate an instrument designed to measure CTRF representation, the CTRF Representation scale (CTRFRep), based on an existing measure, the Illness Perception Questionnaire (IPQ-R).

The study included 47 patients (mean age=57.7 years) receiving radiation therapy for cancer interviewed one month post-treatment. 77% of patients had fatigue during treatment. Three content experts and one theory expert assessed content validity of the CTRFRep. The content experts included three behavioral oncology nurse researchers whose focus is on symptom management and/or fatigue. The theory expert was a nurse researcher who is an expert in the area of self-regulation theory. As tested, the CTRFRep consisted of 105 items in 10 subscales addressing beliefs about the Identity, Timeline (Acute vs. Chronic/Cyclical), Consequences (positive/negative), Cause, Control

(Treatment/Personal), Symptom Coherence, and Emotional Representation of CTRF. When evaluating psychometrics, the Identity and Cause subscales are analyzed independent of the other subscales. For the Identity subscale, symptoms most reported as related to CTRF were lack of energy, loss of strength, and feeling blue. For the Cause subscale, the most common beliefs regarding causes of CTRF were cancer treatment(s), having cancer, and stress or worry.

Results indicate adequate reliability in six of eight remaining subscales ($\alpha >= 0.70$); the item N in those subscales was reduced from 56 to 34. To address construct validity, logistic regression assessed whether CTRFRep mediated the relationship between CTRF intensity and CTRF distress. After controlling for negative affect, the Identity and Consequences subscales were significant mediators – the Acute vs. Chronic Timeline and Emotional Representation scales were partial mediators – of the relationship between CTRF intensity on CTRF distress. These findings indicate fatigue is a problem for people undergoing treatment for cancer, and the CTRFRep may be a reliable and valid measure of CTRF representation for patients undergoing radiation treatment for cancer. Small sample size prevented successful factor analysis of the CTRFRep. Further research of the CTRFRep is warranted.

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CHAPTER 1: THE NATURE OF THE STUDY

Introduction

In 2009, nearly 1.5 million Americans will be diagnosed with cancer (American Cancer Society, 2009). Many of those diagnosed with cancer elect to receive treatment with surgery, radiation, and/or biotherapies with the hope of curing or controlling their disease. Although symptoms such as pain, nausea and depressive symptoms are common side-effects of cancer and its treatment, fatigue affects 61% to 96% of those undergoing treatment for cancer (Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Nail, Jones, Greene, Schipper, & Jensen, 1991; Nail & King, 1987; Schwartz, 1998). Many patients report that it is the most bothersome or distressing symptom associated with cancer and its treatment (Holley, 2000a).

Fatigue is a problem for patients undergoing treatment for cancer, with 39% reporting significant fatigue over the course of radiotherapy (Prue, Rankin, Allen, Gracey, & Cramp, 2006). Given the significance of the problem of Cancer Treatment-Related Fatigue (CTRF), participants in the National Institutes of Health (NIH) State of the Science Conference on Symptom Management for Pain, Depression, and Fatigue in Cancer Patients (National Institutes of Health, 2002) identified a need to "develop conceptual models to direct systematic research into pain, depression and fatigue alone and together that have well-delineated criteria for definition and assessment of their interrelationships" (p. 16).

Cancer Treatment-Related Fatigue

Although CTRF is a nearly universal side effect of cancer treatment, it has received relatively little attention compared to other symptoms in cancer patients

(National Institutes of Health State-of-the-Science Panel, et al., 2004). CTRF is defined as fatigue that “is a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (Berger, et al., 2009, pp. FT-1). Fatigue in the context of the proposed study is described as a “subjective, multidimensional sensation … best measured by the patient’s self-report” (Piper, 2003, p. 209) and defined as “a debilitating, unusual sense of tiredness that differs significantly from the transient, more easily relieved sense of tiredness … more commonly … experienced by healthy individuals” (Piper, 2003, p. 210). CTRF is common with reported incidence of 68% in patients undergoing radiation treatment for cancer (Hickok, Morrow, Roscoe, Mustian, & Okunieff, 2005).

The precise contribution of biological factors to the intensity of CTRF has not been clearly established. It is likely that multiple physiologic factors (e. g., decreased oxygenation due to decreased hemoglobin, endocrine disorders such as hypothyroidism, and cachexia caused by substances such as Tumor Necrosis Factor – Alpha (TNF-a), Interleukin (IL)-1 and IL-6 and Interferon 12 contribute to the development of fatigue (Berger, et al., 2009). Biological researchers have found objective muscular fatigue in prostate cancer patients undergoing radiation therapy by conducting tests of voluntary skeletal muscle strength and endurance (Stone, Hardy, Huddart, A'Hern, & Richards, 2000). Evidence suggests that fatigue is associated with anemia, and those patients who respond to treatment with erythropoietin resulting in a hemoglobin rise of 2 gm/dl experience a significant decrease in fatigue (Berger, et al., 2009; Cella, Kallich, McDermott, & Xu, 2004). However, other research has found a correlation between high baseline red blood cell count and fatigue in patients receiving radiotherapy for breast cancer (Wratten, et al., 2004). Improvement in fatigue has been seen in patients who engage in exercise during treatment for cancer (Berger, et al., 2009; Mock, et al., 1997; Mock, et al., 2001; Schwartz, Mori, Gao, Nail, & King, 2001)

The lack of evidence for definitive biological correlates for CTRF is expected given the subjective nature of fatigue. As with other symptoms, patient self-report is the most appropriate means of understanding the CTRF experience (Berger, et al., 2009; Piper, 2003). Research suggests a relationship between the intensity of CTRF and factors such as depressive symptoms, feelings of hopelessness, and pain in patients with cancer (Dodd, Miaskowski, & Paul, 2001; Pasacreta, 1997; Ringdal, 1995). In the context of cancer treatment, factors such as reaction to the cancer diagnosis, symptom distress, and social support have been related to CTRF (Berger & Walker, 2001). Furthermore, CTRF remains a problem for cancer patients even after treatment has ended, affecting all dimensions of quality of life including psychological and spiritual well-being (Berger, et al., 2009; Ferrell, et al., 1996; Longman, Braden, & Mishel, 1996).

Cancer Treatment-Related Fatigue Distress

Perhaps the most important component of CTRF is the distress that it causes for cancer patients. CTRF distress is defined as suffering or mental anguish specifically related to the CTRF experience (Holley, 2000b). CTRF distress is a unidimensional construct (Holley, 2000a, 2000b). Research suggests CTRF distress is associated with symptom intensity, perceived ability to cope with symptoms, depressive symptoms, and disruption in daily life (Pasacreta, 1997; Richardson, Ream, & Wilson-Barnett, 1998; Winningham, et al., 1994). CTRF distress has been understudied in comparison to the other components of the CTRF experience, with little attention given to factors explaining the development of CTRF distress. However, there is evidence that ability to manage CTRF may decrease distress associated with the symptom (Johnson, 1996, 1999; Johnson, Fieler, Wlasowicz, Mitchell, & Jones, 1997). In addition, interviews with patients suffering from CTRF distress suggest that distress may result from the impact of CTRF on the physical, social, emotional, and cognitive aspects of their lives (Holley, 2000a, 2000b).

Theoretical Model of the CTRF Symptom Experience

The CTRF symptom experience as proposed for this study is grounded in the symptom experience literature, which conceptualizes symptoms as consisting of two components: symptom occurrence and symptom distress. Symptom occurrence includes features of intensity, quality, and duration. In the proposed study, the broad concept of CTRF occurrence is labeled as CTRF. The features of CTRF occurrence are labeled specifically throughout this proposal as CTRF intensity, quality, or duration. The distress component of the CTRF experience is labeled throughout as CTRF distress.

The model of symptom experience (Rhodes & Watson, 1987) and the Common Sense Model of Self-Regulation, (Keller, Ward, & Baumann, 1989; Leventhal & Diefenbach, 1991; Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004; Leventhal, Meyer, & Nerenz, 1980; Skelton & Croyle, 1991; Ward, 1993) along with empirical and theoretical literature related to symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997; UCSF School of Nursing Symptom Management Faculty Group, 1994) and CTRF (Nail, 2002; Nail & King, 1987; Nail & Winningham, 1995) guided the selection of variables for model development.

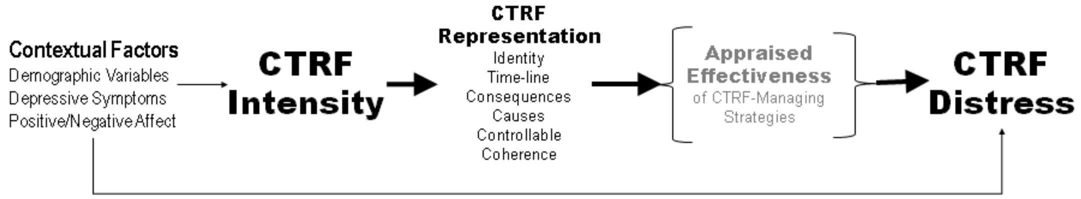


Figure 1: Proposed model of the Cancer Treatment-Related Fatigue symptom experience

Note: Partial model used to assess the construct validity of the CTRFRep instrument

The proposed model (Figure 1) postulates that patients' CTRF Representation mediates the development (or absence of) CTRF distress among patients with CTRF. This model will be used to test the construct validity of the CTRFRep instrument.

Assumptions implicit in the model of CTRF presented in Figure 1 include: 1) symptom perception involves cognitive, active, constructive organization of bodily sensations; 2) abstract, perceptual, and procedural memory systems are involved in converting somatic sensations into representations; and 3) specific procedures and ways of responding to somatic sensations work to transform symptom perception into representations, and ongoing efforts are aimed at reducing the impact of the threat of the symptom or illness and its emotional consequences (Leventhal & Leventhal, 1993).

As shown in Figure 1, contextual factors are particular constructs that have been shown to be associated with the development of CTRF and CTRF distress.

Characteristics such as demographic variables, (e.g., age, race, marital and employment status) depressive symptoms, and affect have been found to be associated with symptom reporting and/or CTRF intensity and distress (Cameron, Leventhal, & Love, 1998; Mora, Robitaille, Leventhal, Swigar, & Leventhal, 2002). CTRF intensity is defined as the perceived degree or relative strength of CTRF.

Cancer Treatment-Related Fatigue Representation

The common sense model of illness representation (Leventhal, Brissette, & Leventhal, 2003; Leventhal, et al., 2004; Leventhal & Leventhal, 1993) is an information-processing model proposing that “individuals are … motivated to construct meanings for body sensations in order to engage in self-regulating behaviors” (Keller, et al., 1989, p. 55). In the proposed model, it is hypothesized that CTRF representation mediates the relationship between CTRF intensity and CTRF distress.

Representations can be on very concrete (e. g., living with the side effects of chemotherapy) and on more abstract levels (e. g., believing that chemotherapy is killing cancer cells), which may or may not be congruent with one another (Johnson, 1997). In addition, information processing of representations occurs on both cognitive and affective levels. CTRF representation is the set of beliefs, thoughts and related emotions cancer patient uses to organize, analyze, and interpret information about CTRF (Leventhal & Leventhal, 1993). CTRF representation is unique to each person and is based upon the individual’s perception and evaluation of the meaning of CTRF. Representations have attributes in six categories (Leventhal, et al., 2004).

- Identity (e. g., concurrent symptoms that are related to or contribute to the CTRF experience);

- Time-line or the pattern of CTRF (e. g., comes and goes, predictable vs. unpredictable, always there, improving or worsening);
- Consequences of CTRF (e. g., positive or negative short-or long-term outcomes of having CTRF);
- Causes of CTRF (e. g., the patient's beliefs about the causes of CTRF);
- Controllability or curability of CTRF (e. g., whether CTRF can be improved);
- Symptom Coherence (e.g. making sense of the CTRF experience).

CTRF representations develop over time and are influenced by life experiences, including interaction with friends and relatives. For this reason, representational beliefs may be somewhat resistant to change and may or may not be objectively accurate (Leventhal, et al., 1980). To illustrate, a person with new-onset CTRF may believe that sleeping a lot more will improve it. However this behavior is reported to worsen CTRF, whereas exercise is reported to improve CTRF in patients undergoing treatment for cancer (Mock, et al., 2005). Although representational beliefs can be resistant to change, it is hypothesized that they can be influenced by interaction with a health care provider and by accurate disease and treatment information (Leventhal, et al., 2004).

In terms of interacting with health care providers, Bowen (2006) has identified a need for health care providers to receive training that helps them develop and elicit from patients their stories to develop a problem representation that is accurate and allows them to generate a hypothesis about the illness script to arrive at a diagnosis for the patient. The development of problem representations and selection of illness scripts have been discussed by Fisch (2009) as being the missing pieces in fatigue evaluation for cancer patients. This discussion is very analogous to the developmental process for representations in cancer patients presented in Chapter 2.

To date, there are no reported measures of CTRF representation. The Cancer Treatment-Related Fatigue Representation scale (CTRFRep) is designed to capture self-reported representations of CTRF. The elements of CTRF representation to be included are 1) beliefs about the causes and consequences of CTRF, 2) perceptions of identity, time-line, and controllability and 3) emotional representations. The proposed study involves the development and testing of a crucial link (i.e., a reliable and valid measure of CTRF Representation) for use in testing the model of CTRF experience in Figure 1. This model can provide the foundation of a program of research to elucidate the cognitive/affective and concrete/abstract dimensions of CTRF representation, and the relationship of these variables to the development of CTRF distress.

Appraised Effectiveness of CTRF-managing Strategies

CTRF representations drive behaviors to decrease or eliminate representations. The outcomes of these behaviors are appraised for effectiveness. Appraised effectiveness of CTRF-managing strategies is defined as one’s evaluation of the adequacy of CTRF-managing strategies in terms of the outcome desired from the strategies (e. g., did the strategy relieve the CTRF or did the strategy reduce the threatening impact of the fatigue?) and the costs of the strategies (e. g., did using the strategy negatively effect social, physical, or emotional well-being?) (Leventhal, et al., 2004; Leventhal & Leventhal, 1993; Paul, West, Lee, & Miaskowski, 2003). Appraisal of effectiveness is a way for the patient to evaluate his or her competency to manage the threat of CTRF (Leventhal & Leventhal, 1993). However, because the purpose of this study is to begin to establish the construct validity of the CTRFRep scale, and not to test the model as proposed in Figure 1, appraised effectiveness has been bracketed out of the proposed study.

Several studies have investigated the use of self-care strategies for fatigue and other symptoms in patients with cancer. Often-used CTRF-managing strategies were: 1) activity/rest related strategies such as taking more frequent naps and engaging in light physical activity (Berger, Farr, Kuhn, Fischer, & Agrawal, 2007; Berger, et al., 2005; Nail, et al., 1991; Richardson & Ream, 1997); 2) psychological strategies such as maintaining hope (Seegers, et al., 1998), relaxing (Richardson & Ream, 1997), and keeping busy (Nail, et al., 1991); and 3) social interaction strategies such as engaging in hobbies and socializing with friends (Graydon, Bubela, Irvine, & Vincent, 1995; Richardson & Ream, 1997). As with other research on CTRF, many of these studies examined self-care strategies for women undergoing chemotherapy for breast cancer (Badger, Braden, & Mishel, 2001; Graydon, et al., 1995; Seegers, et al., 1998). A few studies included men in their samples, but these studies were of chemotherapy patients (Nail, et al., 1991; Richardson & Ream, 1997). None of the strategies used were completely effective in managing CTRF intensity, (Nail, et al., 1991; Richardson & Ream, 1997) and CTRF distress was not evaluated as an outcome in these studies. Thus, the influence of the strategies themselves – or the perceived effectiveness of the strategies on CTRF distress – is not known.

Cancer Treatment-Related Fatigue Distress

CTRF distress, the suffering and mental anguish specifically related to the CTRF experience, can be related to physical, psychological, spiritual, social and cognitive difficulties that arise from CTRF intensity (Holley, 2000a, 2000b). Level of CTRF distress is the outcome variable in the proposed model. Historically, measures of CTRF have primarily focused on CTRF intensity. Recently researchers have begun to recognize the need to assess the distress component of the fatigue experience and the factors that relate to CTRF distress (Holley, 2000b). Instruments have been developed to measure CTRF distress as well as intensity (Rhodes & Watson, 1987).

Conclusion

In summary, current research on fatigue in chronic illnesses has several limitations (Paterson, Canam, Joachim, & Thorne, 2003) including: 1) attributing fatigue exclusively to disease and isolating it from the context in which it occurs; 2) seeing fatigue as being the same for all who have it; and 3) seeing it as necessarily problematic. The proposed model of the CTRF experience addresses these limitations by exploring CTRF representation as a mental link to fatigue that may have been present prior to cancer treatment, and evaluating CTRF in the context of demographic and treatment variables, concurrent symptoms, and affective variables. The proposed model also allows for consideration of individual differences in representations of fatigue while seeking to identify factors that contribute to the development or absence of CTRF distress.

However, before the proposed model can be used to test the CTRF experience in people with cancer, the CTRFRep scale, a crucial component of model must be validated. The model as described in Figure 1 serves to diagram the relationships to be tested when evaluating the construct validity of the CTRFRep instrument. Therefore, the purpose of this cross-sectional study is to report on the development of a measure of CTRFRep and describe its psychometric properties in patients undergoing radiation treatment for cancer.

Specific Aims

1. Identify the factor structure of the CTRFRep scale.

Research Question 1a: What is the factor structure of the CTRFRep Cause subscale?

Research Question 1b: What is the factor structure of the Timeline, Consequences, Control, and Emotional Representation subscales?

2. Describe the internal consistency reliability of the CTRFRep scale.

Research Question 2: What is the internal consistency reliability of the CTRFRep Identity, Timeline, Consequences, Cause, Control, and Emotional Representation subscales?

3. Describe the construct validity of the CTRFRep scale.

Hypothesis 3a: The CTRF Identity subscale will show a significant difference between the symptoms experience subscale and those associated with CTRF (Moss-Morris, et al., 2002).

Hypothesis 3b: CTRFRep subscales mediate the relationship between CTRF intensity and CTRF distress.

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

The prior chapter introduced the nature of the proposed study, including the problem, purpose, specific aims and research questions, and the conceptual definitions of the variables of interest in the study. This chapter provides an overview of chronic illness and the common sense model of self-regulation (CSMSR) – the theoretical framework that undergirds the present study. The chapter concludes with a review of the literature involving the variables of interest in the study.

Chronic Illness

The common sense model of self-regulation (CSMSR) is a framework through which chronic illnesses can be understood from the perspective of the patient. The model has been refined over the past three decades, (Leventhal, et al., 2004; Leventhal & Leventhal, 1993; Leventhal, et al., 1980) including development and refinement of key concepts in the model and their relationship to patient outcomes (Leventhal, et al., 2004). In order to discuss the CSMSR it is first necessary to understand the biologic characteristics of chronic illness. As described by Leventhal et al. (2004), chronic illnesses may be characterized as being

- systematic, affecting multiple body systems and a wide range of physical and social functions(Leventhal, et al., 2004, p. 198);
- diseases or disorders that develop over many years though most become clinically visible later in life;
- controllable but often not curable;
- often insidious in character impinging gradually on a wide range of life activities;

- often noted to have indolent and acute phases, which can be severe and unpredictable in nature (p. 198).

According to Leventhal et al., (2004) chronic illnesses such as cancer can affect patients in ways that are similar to non-illness stressors (e. g., divorce, combat service, job loss). However, chronic illnesses share several characteristics that distinguish them from non-illness stressors. First, chronic illnesses are widespread in the community, and are likely to be shared experiences that affect patients for the rest of their lives. Second, they affect one's ability to gather the internal resources (e.g., physical and psychological) needed to effectively adapt to the illness (Leventhal, et al., 2004). Third, most "develop over years and decades" (Leventhal, et al., 2004, p. 200). Fourth – and particularly in the case of cancer – the treatments necessary to control chronic illnesses "may have side effects that are seemingly as disruptive of life and physically invasive and life threatening as the illness itself" (Leventhal, et al., 2004, p. 201). Fifth, chronic illnesses and their side effects can cause lengthy and severe emotional distress. Finally, chronic illnesses occur within a cultural and institutional context that presents a complicated set of issues for those facing them (Leventhal, et al., 2004).

Cancer as a Chronic Illness

In recent years, given the improvements in treatments and concurrent lengthening of life after diagnosis with cancer, cancer is increasingly being viewed as a chronic illness (Bahls & Fogarty, 2002). According to the American Cancer Society (2008) the five-year survival rate for all cancers has increased to 66% in the years 2003-2006 from 50% in the years 1975-1977. While this is a fortunate situation, living with cancer also means living with the short- and long-term side effects of treatment as well as the follow-up care that is required to identify relapse and maintain remission. For these reasons, cancer can be viewed as a chronic illness for many patients.

Self-Regulation Models

There are several benefits of using self-regulation models to study chronic illness. First, self-regulation models encourage understanding of chronic illness as greater than appraisal of its size as related to coping resources (Leventhal, et al., 2004). Second, this type of model is flexible and oriented toward the process. This allows the formation of hypotheses that respect the information processing that patients do based on their own experiences and activity in order to monitor changes and problem solve over time (Leventhal, et al., 2004). Third, these models use a problem-solving approach that speaks to the close “relationship between the physiological and biomechanical events that [cause symptoms and the beliefs regarding the] targets and procedures for disease management” (Leventhal, et al., 2004, p. 208).

Common Sense Model of Self Regulation (CSMSR)

The CSMSR is similar to other stress-coping frameworks in that it is formulated upon control systems principles in which behavior is in harmony with one’s goals, methods of attainment of those goals, and appraisal of the outcome of those methods. However, the CSMSR is based upon different assumptions and attempts to integrate key concepts from stress-coping frameworks as well as other models to provide a more comprehensive model of the experience of having a chronic illness (Leventhal, et al., 2004).

Assumptions

As stated by Leventhal et al., (2004), the underlying assumptions of the CSMSR include:

1. The individual patient is viewed “as a common-sense ‘scientist’ [e.g., biologist, doctor, or psychologist] trying to make sense of her/his world ... [in order to] understand and manage [the] chronic-illness experience” (p. 209);
2. “The adaptive process is based on common sense beliefs and appraisals” (Leventhal et al., 2001, p. 20);
3. The model consists of a hierarchical structure including the problem space (e.g. the experience of chronic illness) within the context of the self and the self within the socio-cultural perspective.

This process results in a dynamic interpretation of illness experiences with engagement of any number of methods of management. Within the problem space exist illness representations, which include the illness label and symptoms as well as an “elaborate set of meanings that defines the problem … for self-management” (Leventhal, et al., 2004, p. 210). Expanding upon these assumptions, viewing the patient as a common sense scientist (assumption 1) allows for identification of multiple procedures or rules of thumb for the construction of representations of illness threats (Leventhal, et al., 2004).

Concepts

The major concepts within the CSMSR include the somatic stimulus (e.g., cancer or fatigue) and the meanings attached to them; representation, or the beliefs thoughts and emotions surrounding the experience of illness and its treatment; coping procedures used to manage illness and side-effects of treatment; action plans for the coping procedures and the outcome appraisals of the effectiveness of the coping procedures.

The somatic stimuli for this study include cancer, its treatment, and CTRF. The heuristics are those things from the patient's history or knowledge base that lead to an interpretation of the event, an example of a heuristic is symmetry – matching symptoms to labels.

Hierarchical Structure

The CSMSR assumes a nested hierarchical structure (see Figure 2), which includes the problem space, the self-structure, and the socio-cultural and ecological context. The fundamental level – or the problem space – includes the disease label, its signs and symptoms, and the procedures used for managing and coping with them (Leventhal, et al., 2004). Over time, continuing interpretation of symptoms and appraisal of the efficacy of specific procedures for dealing with these symptoms create an ever more complex representation. According to Leventhal et al., (2004) "a central proposition of the [CSMSR] is that *patients regulate experiences, symptoms, and functional changes over time*. This functional level, the 'problem space,' is at the heart of the self-regulation process" (p. 209).

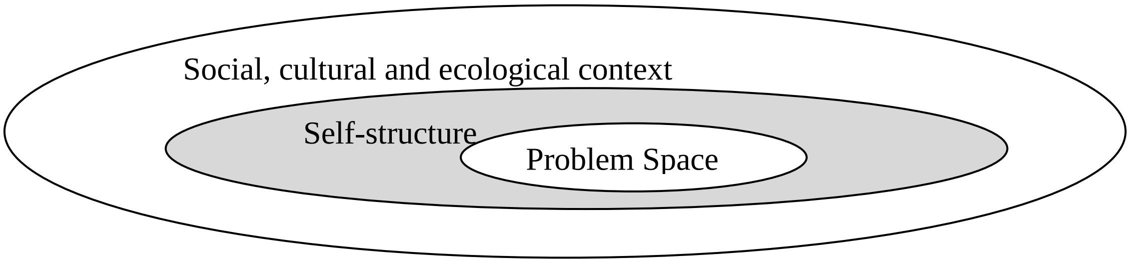


Figure 2: Nested hierarchical structure of the CSMSR

Within the nested hierarchy, the problem space is contained within the structure of the self. The self-system is further nested in the context of society, culture and ecology (Leventhal, et al., 2004), which integrates many concepts recognizable from bio-behavioral research. These concepts include perceived control, self-efficacy regarding illness and symptom management (Bandura, 1977), and self-assessed health.

Self-management in the problem space

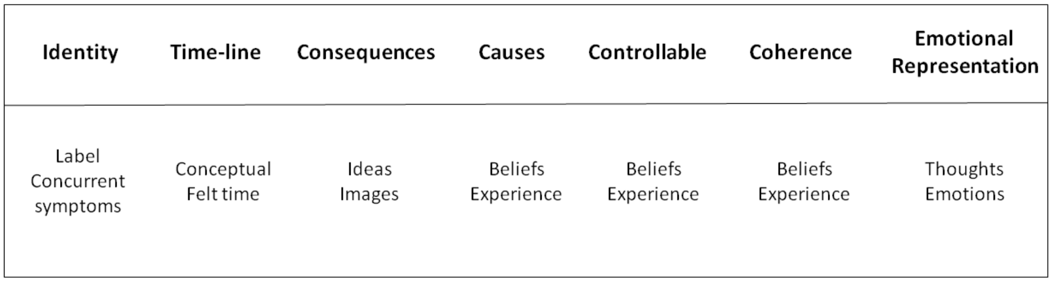
Illness representations.

Illness representations (see Figure 3) consist of the beliefs, thoughts, and emotions surrounding the experience of having an illness and are characterized by beliefs about the identity, time-lines, consequences, causes, controllability, and the emotional response to having an illness. According to Leventhal et al., (2004) representations of chronic illness contain five cognitive factors which vary both among illnesses and within the individual's experience of having a chronic illness: 1) illness *identity* or the "names or labels which carry expectations about how they will impact life" [… these include the …] "experienced symptoms, signs and changes in function" (p. 210). The names or labels and the actual experience of the illness combine to describe illness identity; 2) *control*, both actual and perceived control of chronic illness; 3) *time-lines* involved with both chronic illness and its treatment; 4) illnesses are seen as having multifaceted *causes*, and beliefs about these causes can vary based on an individual's age and past experience; 5) chronic illness presents a "set of expected and perceived *consequences* with respect to its physical impact and how these physical changes will affect daily function" (Leventhal, et al., 2004, p. 210). Because representational beliefs develop in both the cognitive and affective domains, there is also a component of emotional representation, which represents the thoughts and emotions surrounding the illness experience.

Each of the factors within illness representation can also apply to treatments and symptoms (Horne, 2003; Leventhal, et al., 2004). Thus, a patient's experience of cancer includes representational beliefs about the cancer, its treatment(s) and side effects, and symptoms such as fatigue or pain, which can be the result of cancer or of its treatment.

Multilevel Structure.

According to Leventhal et al., (2004) within the five cognitive domains of representation, factors are represented at two levels, experiential (or concrete) and abstract. Concrete experiences are symptoms, signs, or functional difficulties that often lead to the realization of a problem, for example through the experience of fear or anxiety (Martin, Lemos, & Leventhal, 2001). Abstract phenomena include the symptom or illness label, and clock or calendar time (Leventhal, et al., 2004). It is through the connection of the concrete and abstract experiences, for example the symptom labeled headache felt over the course of days or weeks that may prompt one to seek identification of an illness



Identity	**Time-line**	**Consequences**	**Causes**	**Controllable**	**Coherence**	**Emotional Representation**
Label Concurrent symptoms	Conceptual Felt time	Ideas Images	Beliefs Experience	Beliefs Experience	Beliefs Experience	Thoughts Emotions

Adapted from: Leventhal, H., Halm, E., Horowitz, C., Leventhal, E. A., & Ozakinci, G. (2004). Living with Chronic Illness: A Contextualized, Self-Regulation Approach. In S. Sutton, A. Baum & M. Johnston (Eds.), *The Sage Handbook of Health Psychology* (pp. 299-325). London: Sage Publications.

Figure 3: Contents of illness, treatment, and symptom representations

label, that depth is given to the representation. Patients must recognize a significant disturbance to their daily lives or a significant change in their functional abilities in order to seek out care (Scheier & Carver, 2003).

When the abstract notions of time and label are applied to concrete (experienced) symptoms such as fatigue and pain in patients with cancer, different people will react in different ways. Depending on one's interpretation of the symptoms, the individual with cancer may believe that these symptoms are cues to the 'common' side effects of treatment or the worsening of the cancer itself. In the absence of illness representations including both concrete and abstract levels, patients may not realize the significance of the symptoms in the context of cancer and its treatment (Leventhal, et al., 2004).

Heuristics.

Heuristic is defined as "of or relating to exploratory problem-solving techniques that utilize self-educating techniques … to improve performance" (2002). More casually, heuristics are "rules of thumb" (Heuristic, 2009) patients develop based on their prior experience or knowledge and use to make sense of their experience with chronic illnesses such as cancer. One common heuristic is the "*age-illness* heuristic" which involves beliefs or attribution of signs and symptoms to aging rather than to an illness. Another heuristic is the "*stress-illness*" heuristic in which attributions are made to stress rather than illness. According to Leventhal et al., (2004) other heuristics include:

- *locational*, where symptoms are attributed to the location of the effect versus the location causing the symptom [e.g. dyspnea and foot swelling (location of effect) because of heart failure (location of the cause)].

- *prevalence*, in which symptoms or signs are graded as less severe if an individual sees that not only oneself but numerous others are at risk of contracting a certain disease.
- *affective*, in which individuals with depressed mood or anxiety may view themselves as more vulnerable to illness, or more likely to be ill than those with euthymia.
- *duration*, in which symptoms of longer duration are viewed as more threatening than symptoms of brief duration.

An example of a rule of thumb regarding cancer treatment-related fatigue is the idea that fatigue will improve if he/she rests more. Based on prior experiences with severe tiredness from other severely tiring illnesses such as a bout of the flu, the patient develops the belief that resting more will help the cancer treatment-related fatigue. However, in the case of CTRF too much rest can lead to deconditioning, which can increase levels of fatigue (Barsevick, Newhall, & Brown, 2008). In addition, patients may believe that a ‘good day,’ when their fatigue level is relatively low, is an ideal time to put in a full day at work or fulfill other obligations. When the patient’s problem is CTRF, however, working a full day or overexerting oneself may result in extreme fatigue with a prolonged recovery period relative to the amount of exertion normally felt before cancer and its treatment.

Temporal change: dynamics.

Symptom and illness representations are formed and remodeled “by changes in the disease process, by feedback from professional care and self-care, and by social information” (Leventhal, et al., 2004, p. 212). Patients can learn about the experience of cancer treatment and its side effects from multiple sources such as family members, observation of, and comparison to other cancer patients, and reports in the popular media. Personal experience over time will interact with ongoing self-appraisal heuristics and become a key component in efforts to understand concrete illness and symptom experiences (Leventhal, et al., 2004)

Procedures for self-regulation

The CSMSR suggests that the intensity and length of signs and symptoms, along with the implications and understanding of them, will affect the selection of procedures for management, and that the selection of a procedure is infrequently random. The CSMSR recognizes a variety of particular procedures that may be chosen by an individual with chronic illness (Leventhal, et al., 2004). These actions include traditional and complementary or alternative medicine, herbal supplements, and modifying lifestyle activities. Procedures may be selected for a variety of reasons, such as control of signs, symptoms, functional abilities, or emotions, or a mix of these events, and these procedures may or may not be believed to be usefully controlling the disease itself (Leventhal, et al., 2004).

Illness representations and choice of procedures

Patients with cancer treatment-related fatigue may have symptom representations that affect their perception of fatigue and its associated distress. Anecdotal evidence suggests that patients who received chemotherapy treatment for recurrent Non-Hodgkin’s Lymphoma had lower levels of fatigue distress than patients who received first-time chemotherapy treatment for primary Hodgkin’s Lymphoma, even though the level of fatigue intensity was similar in both groups (Reuille, 2002).

Treatment and symptom representations

The five domains of illness representation are also seen in treatment representation. “Beliefs about [treatment] identities (symptoms), time-lines for efficacy, consequences (side effects), and causal mode of action” apply to the evaluation and choice of treatments (Leventhal, et al., 2004, p. 213). Thus, “there is more to the evaluation and selection of a treatment than the perception of its … effectiveness … [or its potential] for curing and/or controlling disease” (Leventhal, et al., 2004, p. 213).

An example of an illness with complex treatment representations is prostate cancer. Surgical options connote ‘getting rid’ of the cancer but involve surgery that has possible side effects of incontinence and impotence, whereas radiation treatment may be as effective as surgery, but has its own side effects and negative stigma. Selecting no treatment at all (i.e. watchful waiting) is also an option, which can be fraught with side effects such as increased anxiety (Allaf & Carter, 2004)

Action plans

Patients “may be motivated to act, that is perceive a treatment or self-care behavior as necessary, have specific goals (symptom control), and specific coping procedures in mind, yet fail to act if they have not formed an action plan” (Leventhal, et al., 2004, p. 214). Strategic action planning may be of benefit either by minimizing memory burden and “the need for conscious retrieval by shifting the control of behavior from internal thoughts and intentions to stable external cues, or because they promote rehearsal of the behavior and generate commitments to action” (Leventhal, et al., 2004, p. 214).

Performance and performance appraisals

According to Leventhal et al., (2004) individuals often assess the efficacy of treatment for chronic illness based on the performance of the treatment in controlling the condition. However, feedback can be quite ambiguous for many chronic conditions and the feedback that is recognized may be negatively valenced. Often the individual is not sure if the treatment is working or not, and the evidence that it is working (e.g. alopecia from chemotherapy) can be distressing (Boehmke & Dickerson, 2005). “The target of self management, for example the chronic disease versus its symptoms can have important consequences both for the appraisal of control efforts and for emotional adjustment”(Leventhal, et al., 2004, p. 215). Patients may experience higher levels of emotional distress if they focus on curing what may be an incurable condition (i.e. cancer). On the other hand, less distress may be felt when efforts are focused on managing symptoms (e. g., fatigue) (Leventhal, et al., 2004).

Coherence in the problem space

According to Leventhal et al., (2004) when feedback reveals patients are successful in moving toward goal attainment while using self- or medically-based treatments, (i.e. “goals established by the illness representation are being met” (pp. 215-216)) the problem solving process (the problem space) is coherent. Coherence allows for behavioral consistency, until there is inconsistent feedback, but it does not assure constructive health results. “Coherence is at the heart of expertise in self regulation” (Leventhal et al., p. 216).

CTRF Experience Model (Figure 1) Variables

The model of the CTRF experience contains the variables presented in Figure 1 in the previous chapter. Below is a review of the literature for the major variables within this model as they are used for hypothesis testing in the present study.

Depressive Symptoms

Depressive symptoms are defined as having components of depressed mood and feelings of guilt or unworthiness, and hopeless or helplessness, as well as problems with eating, sleeping, and psychomotor retardation (Radloff, 1977). Depressive symptoms have been found to be correlated with fatigue in patients with cancer.

In a cross-sectional study of 109 women receiving adjuvant treatment (40 percent chemotherapy; 10 percent RT; 39 percent both chemo and RT) or surveillance for breast cancer, Bennett, Goldstein, Lloyd, Davenport, and Hickie (2004) found that 20 percent of patients reported significant levels of both fatigue (as measured by the Functional Assessment of Cancer Therapy fatigue (FACT-F) and psychological distress as measured by the SOMA-6). Seventeen percent reported only fatigue and ten percent reported only psychological distress, while 52 percent of women reported no symptoms (Bennett, et al., 2004).

In a mixed sample of 1129 patients undergoing radiation therapy for cancer, Hickok et al., (2005) found that nearly 50 percent of patients reported ‘feeling upset’ as rated on a 0-10 scale on a symptom inventory at the beginning of radiation therapy, with nearly 20 percent expressing moderate (rating of 4-6) or severe (rating of 7-10) problems with ‘feeling upset’ at baseline. Among 419 patients for whom longitudinal data was available, problems with ‘feeling upset’ remained relatively stable over time, with slightly over 30 percent reporting worsening of the symptom, and slightly under 30 percent reporting improvement in the symptom at week 5 as compared with their baseline levels (Hickok, et al., 2005).

In a cross-sectional controlled comparison study of 227 persons with various cancers and 98 controls, Stone, Richards, A'Hern, & Hardy (2000) defined severe fatigue as being a level that was at the 95th percentile of the control group. This study found that the prevalence of severe fatigue in patients with cancer was 48% overall and ranged from 15% in women with breast cancer to 78% in persons with advanced cancer. The results of this study showed that depression as measured by the Hospital Anxiety and Depression (HADD-8) subscale was significantly correlated (r = 0.60) with fatigue (as measured by the Fatigue Severity Scale) and that after dyspnea, depression accounted for 14% of the variance in fatigue.

In a study of 105 patients newly diagnosed and treated for prostate cancer Monahan et al, (2007) found that depressive symptoms at four weeks post-treatment (as measured by the CES-D) significantly predicted vitality at one year post-treatment (as measured by the MOS SF-36 vitality subscale) after controlling for demographic and treatment information. Those with lower depressive symptoms at 4 weeks had significantly higher vitality scores at one year.

The above studies suggest that depressive symptoms are related to fatigue intensity in patients with cancer. A limitation of the current research in this area is that a wide variety of instruments were used to measure both depressive symptoms and fatigue. However, the consistent findings of a relationship between fatigue intensity and depressive symptoms suggest that depressive symptoms may be useful in testing the construct validity of the CTRFRep.

Negative affect and symptom reporting

Negative affect is defined as a state of being in which people express a “general dimension of subjective distress and unpleasurable engagement that subsumes a variety of averse mood states … [e.g.,] anger, … guilt,… fear, and nervousness” (Watson, Clark, & Tellegen, 1988, p. 1063). By contrast, people expressing low levels of negative affect express “a state of calmness and serenity” (Watson, et al., 1988, p. 1063). Studies suggest a correlation between negative affect and symptom reporting, in which patients with higher levels of negative affect report more symptoms (Mora, et al., 2002). However, few studies have evaluated this relationship in patients with cancer.

In a study of 114 in- and out-patient surgical cancer patients, Koller, Heitmann, Kussmann, and Lorenz (1999) found a strong positive correlation ($r=0.72$; $p<0.01$) between somatic symptom reports as measured by the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ)-C30 version 2.0 and negative affect as measured by the EORTC QLQ emotional functioning subscale. In a study of 105 patients with advanced cancer Voogt et al. (2005), found that negative affect was strongly correlated with anxiety ($r=0.72$; $p<0.001$) and depression ($r=0.48$; $p<0.001$) as measured by the Hospital Anxiety and Depression Scale (HADS). Negative affect was also significantly correlated with higher levels of fatigue ($r=0.22$; $p=0.02$), and pain ($r=0.20$; $p=0.04$) as measured by the EORTC QLQ C30 quality of life scale. Patients participating in this study were at least six months post diagnosis of their advanced cancer.

In a longitudinal study of 72 breast cancer survivors in their first 18 months post treatment, Kernan and Lepore (2009) examined searching for meaning from their experience. A higher level of searching for meaning was correlated with a higher level of negative affect. This research suggests that continued searching for meaning may be distressing for women with breast cancer (Kernan & Lepore, 2009). Searching for meaning is a concept that is somewhat similar to the concept of coherence in CTRF representation, in which patients attempt to “make sense of” their CTRF.

The above studies suggest a relationship between negative affect and symptom reporting, including fatigue symptom reporting, in patients with cancer. There is also evidence that negative affect may be related to key constructs within the CTRFRep. These studies support the notion that negative affect may be an important concept in relation to fatigue intensity and CTRF concepts and may be useful in testing the construct validity of the CTRFRep.

Fatigue incidence and severity

Fatigue has been identified as a problem for patients who receive radiation therapy (RT) treatment for cancer. Radiation therapy is defined as “The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors” (National Cancer Institute, 2009). In a study of 208 patients undergoing RT for various types of cancer, Strauss et al. (2007) found that patients experienced significant levels of fatigue (as measured by the Multidimensional Fatigue Inventory (MFI-20)) both before and after RT treatment for cancer. Levels of fatigue were higher in palliatively vs. curatively treated patients; in those reporting more symptoms; and in those with lower Karnofsky Performance Status (Strauss, et al., 2007).

One research group examined fatigue in patients undergoing radiation therapy (Stone, Richards, A'Hern, & Hardy, 2001) and hormone therapy (Stone, Hardy, et al., 2000). The study of radiation therapy patients (N=62) included patients with breast and prostate cancers (Stone, et al., 2001), and all of the patients with prostate cancer had received neo-adjuvant hormone therapy. In the combined sample 69% of patients reported that their fatigue worsened over the course of treatment, and 28% reported severe fatigue after treatment (Stone, et al., 2001). In a study of 36 veterans undergoing radiation therapy for prostate cancer, Monga, Kerrigan, Thornby, and Monga (1999) controlled for the presence of co-morbid conditions (e. g., previous myocardial infarction, insulin-dependent diabetes, history of depression), and found a significant increase in CTRF during treatment (Monga, et al., 1999).

Several studies of prostate cancer quality of life (QOL) outcomes have included measures of fatigue. In a study that examined long-term morbidity of radiation (N=154) or surgical (N=108) treatment for prostate cancer, fatigue was found to be significantly correlated with overall QOL and, along with emotional and physical functioning, was an independent predictor of QOL one year after treatment (Lilleby, Fossa, Waehre, & Olsen, 1999).

In a study of patients undergoing neo-adjuvant or primary hormone therapy for prostate cancer (N=62), median fatigue scores increased significantly during treatment, and 66% of patients reported an increase in fatigue during therapy. In addition, fatigue was significantly correlated with psychological distress at baseline (Stone, Hardy, et al., 2000). In a QOL study of 144 men with asymptomatic prostate cancer, those who underwent hormone treatment (N=79) reported significantly higher fatigue scores than those who elected observation (Herr & O'Sullivan, 2000).

In a study of 353 women within one year of diagnosis for breast cancer, Reuter et al., (2006) found a mild to moderate level of fatigue as measured by the Profile of Mood States (Mean=9.8, SD=6.8, Range=0-28) among these women. Although 94% of the women had received post-surgical treatment of their cancer, the percentages receiving RT alone vs. chemotherapy alone vs. RT and chemotherapy were not made clear.

In a prospective study of 52 breast cancer patients receiving RT, Wratten et al., (2004) identified 43% had significant fatigue throughout treatment as measured by the Functional Assessment of Cancer Therapy fatigue (FACT-F) subscale, with the nadir occurring during the fifth week of treatment. Fifty-four percent of patients experienced minimal fatigue throughout treatment. Those patients who had significant fatigue had more fatigue at baseline and had higher counts of neutrophils and red blood cells at baseline.

In a study of 82 men receiving RT for prostate cancer, Miaskowski et al. (2008) found that men experienced mild to moderate fatigue with increasing fatigue during treatment. Fatigue levels returned to baseline by 25 weeks after treatment (Miaskowski, et al., 2008).

In a study of 1129 patients undergoing RT for various types of cancer, Hickok et al., (2005) found that over 60 percent of patients reported fatigue at baseline, and that just under half of those patients experienced moderate to severe fatigue. In a sub-sample analysis of 419 patients who provided longitudinal data Hickok et al., (2005) also found that fatigue severity increased over the course of five weeks of treatment, with approximately 45 percent of patients reporting increased fatigue during treatment, whereas approximately 20 percent reported that their fatigue decreased in severity.

In a study of 221 patients receiving chemotherapy plus RT (N=100) or RT alone (N=121) and age-matched controls without cancer Jacobsen et al., (2007) found that breast cancer patients reported significantly more days with fatigue in the past week than healthy controls, and that significantly more of the women with breast cancer reported abnormal levels of fatigue as measured by the Fatigue Symptom Inventory (FSI).

The above studies suggest that fatigue is indeed a problem for patients with cancer. The information contained within these studies and others contributes to the knowledge base of the fatigue experience in patients with cancer. However, these studies also reflect the limitations in the current knowledge base with regard to illness and symptom representation.

Cancer Treatment-Related Fatigue Distress

Cancer treatment-related fatigue distress is defined as the suffering or mental anguish specifically related to the cancer treatment-related fatigue experience. It has been relatively understudied when compared to fatigue intensity and severity. Holley (2000a, 2000b) used qualitative techniques to develop an instrument to measure cancer related fatigue distress (CRFDS). The CRFDS was the result of interviews of 17 cancer patients and identified distress in the physical, social, spiritual, psychological, and self-care domains. The body of work in fatigue distress in patients with cancer is very limited in terms of distress when defined as the suffering or mental anguish specifically related to the experience of having cancer treatment-related fatigue.

Other studies have focused primarily on symptom distress as a concept distinct from fatigue distress. For example, Leak, Hu, & King, (2008) conducted a descriptive correlational study of 30 African-American breast cancer survivors who were at least one year post treatment. Twenty-three per cent of the women had moderate symptom distress, and there was a significant correlation between symptom distress and poorer quality of life. However the Symptom Distress Scale used to measure distress had the anchors of 1="normal or no distress" to 5="experiencing the symptom almost constantly," which appears to mix symptom intensity with symptom distress (Leak, et al., 2008).

Measurement of Illness and Symptom Representations

The development of instruments to assess illness representation has been ongoing for the past several years. One of the more prominent of these efforts has been the development of the Illness Perception Questionnaire-Revised, which has been translated into several languages and has seen the development of instruments to measure the illness representation of several illnesses (2009). These instruments are notable for their psychometric trueness (Moss-Morris, et al., 2002) to the Common Sense Model of Self Regulation.

Measures of symptom representations are being developed by nurse researchers, but their development has lagged behind that of illness representations. One instrument, the Symptom Representation Questionnaire (SRQ) was recently developed by Donovan, Ward, Sherwood, & Serlin (2008). This instrument is based in the CSMSR and was derived from the IPQ-R. In these ways, it is very similar to the CTRFRep. It was tested

Table 1

Conceptual Definitions of the Concepts Embedded in CTRF Representation

Term	Definition
CTRF Representation	The set of beliefs, thoughts and related emotions through which the cancer patient organizes, analyzes and interprets information about CTRF
Identity	Symptoms or labels used to define the CTRF experience.
Time-line	Beliefs, thoughts, or related emotions about the acute, chronic, and/or cyclical nature of CTRF
Consequences	Beliefs, thoughts, or related emotions about the positive or negative long- or short-term outcomes of having CTRF
Symptom Coherence	Beliefs, thoughts, or related emotions about the ability to "make sense of" having CTRF
Cause	Beliefs, thoughts, or related emotions about the causes of CTRF, including perceived internal, external, and behavioral causes
Emotional Representation	Emotional reactions to the threat or danger of having CTRF

by mailed survey to 713 members of the National Ovarian Cancer Coalition. It is a multi-symptom questionnaire and appears to have good psychometric properties although it is not as theoretically robust as the IPQ-R (The Identity, Consequence, and Emotional Representation items loaded onto a single factor). However, its scope and focus is different from that of the CTRFRep, which attempts to capture information about a single symptom that is troubling for cancer patients. A valid and reliable measure of CTRF representation can serve a complementary role to instruments such as the SRQ.

Cancer Treatment Related Fatigue Representation

To date, there is no measure of CTRFRep. The instrument being tested was developed based on the Illness Perception Questionnaire-Revised (Moss-Morris, et al., 2002). The instrument as being tested appears in Appendix A. Further explanation of the instrument and the methods of its development and testing are available in Chapter 3. Table 1 provides an overview of the conceptual definitions embedded in the development of the instrument.

Conclusion

Cancer is a chronic illness that affects millions of people every year. The Common Sense Model of Self-Regulation is a theoretical model that has been useful in examining chronic illnesses, as well as their symptoms and treatments. The concept of representation can be applied to problematic symptoms such as Cancer Treatment-Related Fatigue in order to guide the development of knowledge about how beliefs, thoughts, and emotions surrounding the experience of CTRF affect patients. A reliable and valid measure of CTRF representation is a crucial missing link in a theoretical model of the experience of CTRF.

CHAPTER 3: METHODS

Introduction

This chapter provides information describing the development CTRFRep and its content validity testing. The study design, procedures for data collection and protection of human subjects are presented. Operational definitions are presented for all study variables, and the reliability and validity of study instruments are presented. Finally the specific aims, research questions, and hypotheses are presented with plans for data analysis.

Scale development

The development of the CTRFRep (see Appendix A) relied on adaptation of an existing measure of illness perception (The Illness Perception Questionnaire-Revised, (IPQ-R), see Appendix B) (Moss-Morris, et al., 2002). The IPQ-R consists of three sections; the Identity and Cause subscales are separate from the remaining subscales (Moss-Morris et al., 2002). The items in the IPQ-R were adapted to reflect the experience of Cancer Treatment-Related Fatigue (e.g., I expect to have CTRF for the rest of my life). Additional items were generated from research reports on the experience of Cancer Treatment-Related Fatigue. For example, items were added to the Cause subscale to reflect treatments for cancer (i.e. radiation and chemotherapy) as possible causes for CTRF. In the Identity subscale, several items were added, such as difficulty falling asleep, difficulty staying asleep, and difficulty waking up. Table 2 provides a summary of the changes made to the Identity and Cause subscales of the CTRFRep, while Table 3 presents the changes made to the other subscales of the CTRFRep. See Table 4 for information about the items in the subscales of the IPQ-R and the CTRFRep, as well as information about the internal consistency reliability of the IPQ-R subscales.

Methods for Content Validity

According to Nunnally and Bernstein (1994) there are “two major standards for ensuring content validity: 1) a representative collection of items and 2) sensible methods of test construction” (p. 102). Each expert was provided with a draft copy of the instrument as well as a content validity survey. The content validity survey included the conceptual definitions of each of the CTRFRep constructs as they were developed at the time (see Appendix C). For the Identity subscale, raters were asked to rate the representativeness of the items on a 1-4 scale where 1=not representative and 4=representative. They were also asked to rate the uniqueness of individual items by choosing yes or no, and were asked to cross out items that they would identify as redundant. Finally, raters were asked to assess the completeness of the list of symptoms in the identity subscale and invited to add their own suggestions for additional items. Based on the suggestion of reviewers, nine items were added to the Identity subscale.

For each of the other subscales (Timeline, Consequences, Controllability, Symptom Coherence and Emotional Representation), raters were asked to judge the representativeness, uniqueness and clarity (on a 1-4 scale where 1=not at all clear and 4=completely clear) of the items in the subscale, and to rate whether each set of items captured the entirety of the subscale component being evaluated. Generally, the reviewers rated the subscales as being complete.

Table 2.

Summary of Differences between the IPQ-R and the CTRFRep Identity and Cause Subscales

Identity Subscale – Items deleted from the CTRFRep
- Sore throat*
- Fatigue*
- Sore eyes*
- Sleep difficulties*

Identity Subscale – Items added to the CTRFRep
- Difficulty falling asleep*
- Difficulty staying asleep*
- Difficulty waking up*
- Muscle soreness*
- Loss of appetite*
- Poor concentration*
- Short attention span*
- Muscle weakness**
- Sadness**
- Lack of energy**
- Difficulty moving**
- Low endurance**
- Numbness or tingling sensations**
- Feeling blue**
- No desire to move**
- Heavy limbs**

Cause Subscale – Items added to the CTRFRep
- Having cancer*
- My radiation treatment for cancer*
- My surgical treatment for cancer*
- My hormone treatment for cancer*
- My chemotherapy treatment for cancer*

*Revision made by investigator
**Revision suggested by content expert(s) and added by the investigator

Table 3.

Summary of Differences between the IPQ-R and CTRFRep Subscales

- Items removed from the CTRFRep
  - My treatment will be effective in curing my illness*
  - My treatment can control my illness*
- Items revised
  - There is very little that can be done to improve my illness
    - Revision: Nothing can be done to improve my illness**
- Items added to the CTRFRep
  - I believe medication can help my CTRF get better*
  - I believe that eating a healthy diet will help my CTRF*
  - I know why I have CTRF**
  - My CTRF makes me feel sad**
  - What I do has no effect on my CTRF*
  - If I could sleep more, my CTRF would get better*
  - I take naps during the day for my CTRF**
  - I make sure I sleep at least 8 hours every night*
  - My doctor knows that I have CTRF*
  - Eating well-balanced meals helps my CTRF*
  - I ignore my CTRF as much as I can*
  - I wish my CTRF would just go away*
  - I asked my doctor if there are any medicines or treatments for my CTRF*
  - There are things I can do to make my CTRF better*
  - There is nothing I can do to make my CTRF better*
  - I have asked others (family, friends) for help with my CTRF*
  - Having CTRF helps me realize what is really important in my life*
  - My CTRF helps me spend more time with my family*
  - I can “take it easy” because I have CTRF*
  - All things considered, some good things have come from having CTRF*

*Revision made by investigator
**Revision suggested by content expert(s) and added by the investigator

Table 4.

IPQ-R Subscale Internal Consistency Reliabilities and Comparison of IPQ-R Subscale Item N with the CTRFRep Subscale Item N

IPQ-R/ CTRFRep subscale	IPQ-R Item N	IPQ-R Alpha	CTRFRep Item N	Response Choice
Identity	12	N/A	26	Yes or No*
Cause	18	N/A	23	5 Point Likert Type Scale: Strongly Agree to Strongly Disagree**
Timeline Acute vs. Chronic	6	0.89	6	5 Point Likert Type Scale: Strongly Agree to Strongly Disagree**
Timeline Cyclical	4	0.79	4	
Consequences	6	0.84	6	
Personal Control	6	0.81	16	
Treatment Control	5	0.87	7	
Symptom Coherence	5	0.87	6	
Emotional Representation	6	0.88	7	
Positive Consequences	N/A***	N/A	4	

*Endorsement of a) symptom experienced since having CTRF and b) symptom is related to or contributes to CTRF

** For testing purposes, the Likert-type items allow a “does not apply to me” option.

***Items developed for CTRFRep, not included in IPQ-R

Psychometric evaluation of the content validity surveys involved calculation of inter-rater agreement and content validity. The content validity index for each subscale was calculated from the coding the frequencies of the representativeness data (4=1.0, 3=0.75, 2=0.50, and 1=0.25), summing these frequencies, dividing by the number of content experts (N=4) and dividing by the number of items in the scale. Inter-rater agreement was calculated using a similar method, but taking into account the missing data in some of the responses, therefore the N for the number of content experts was less than four for some of the items. There was no pattern to the missing data within the content analysis questionnaires. The inter-rater agreement and content validity indices are shown in Table 5.

Based on the input of the content experts, the scale was evaluated for item retention and item addition. The face validity of the items was taken into account. In addition, for this initial test of the instrument, items appearing in the original IPQ-R were retained in order to facilitate comparison between the psychometric properties of the IPQ-R and the CTRFRep. Twelve items with a content validity index of less than 0.70 were evaluated for editing or deletion. Four of these items were edited prior to inclusion in the instrument. These items and the eight additional items will be evaluated for deletion from the scale after testing. In addition, items rated as redundant are being retained in the instrument during testing and will be evaluated for deletion from the scale after testing.

As seen in Table 5, both the Control and Identity subscales have inter-rater agreement of less than 0.70. In the case of the Identity subscale as published in the IPQ-R, it contains multiple independent symptoms that may or may not be related to CTRF. Although there was some disagreement among the content validity experts about the

Table 5.

Content Validity Index and Inter-Rater Agreement of CTRFRep Items

CTRFRep Subscale in Content Validity Questionnaire	Item N	Inter-rater Agreement	Content Validity Index
Cause	23	.96	.99
Symptom Coherence	5	1.0	.90
Consequences	11	.82	.93
Control (Personal and Treatment)	20	.60	.85
Emotional Representation	8	1.00	.94
Identity	17	.40	.78
Timeline (Acute vs. Chronic and Cyclical)	10	1.00	1.0
Total Scale	94	.78	.91

applicability of the some of the symptoms to the CTRF experience, all symptoms listed in the IPQ-R were retained in the instrument as tested to allow for comparison to the factors found in the original IPQ-R (Moss-Morris, et al., 2002). Criteria for deletion from the final scale will include 1) lack of face validity in the experience of CTRF, 2) item did not load on any factor or loaded on multiple factors, and 3) item not endorsed by at least 10% of the sample. In terms of the Control subscale, there are two possible reasons for low inter-rater agreement. First, this subscale contains the largest number of items added by the author. Second, the content validity experts were asked to evaluate the Personal and Treatment Control subscales together, and the heterogeneity of the items may contribute to lower inter-rater agreement. Several additional items for the Control subscale were suggested by the content validity experts. Sample items from the various CTRFRep subscales are presented in Table 6.

Design and methods for psychometric testing

The purpose of this cross-sectional study is to describe the psychometric properties of the CTRFRep instrument in patients undergoing radiation treatment for cancer.

Specific Aims

1. Identify the factor structure of the CTRFRep scale.

Research Question 1a: What is the factor structure of the CTRFRep Cause subscale?

Research Question 1b: What is the factor structure of the Timeline, Consequences, Control, and Emotional Representation subscales?

Table 6

Sample CTRFRep Subscale Items

Subscale	Item Examples
Cause:	“Stress or worry” “Having cancer” “My emotional state” “My radiation treatment for cancer”
Symptom Coherence:	“My CTRF is puzzling to me” “I have a clear picture or understanding of my CTRF”
Consequences:	“My CTRF has major consequences on my life” “Having CTRF helps me realize what is really important in my life”
Control (Personal and Treatment):	“I can do a lot to control my CTRF” “What I do will determine whether my CTRF gets better or worse” “There is nothing I can do to make my CTRF better”
Emotional Representation:	“My CTRF makes me feel angry” “I wish my CTRF would just go away” “My CTRF does not worry me”
Identity:	“Pain” “Difficulty falling asleep” “No desire to move”
Timeline (Acute vs. Chronic and Cyclical):	“I go through cycles in which my CTRF gets better and worse”

2. Describe the internal consistency reliability of the CTRFRep scale.

   Research Question 2a: What is the internal consistency reliability of the CTRFRep Acute vs. Chronic Timeline, Timeline Cyclical, Consequences, Cause, Personal Control, Treatment Control, Symptom Coherence, Emotional Representation, and Positive Consequences subscales?

3. Describe the construct validity of the CTRFRep scale.

   Hypothesis 3a: The CTRF Identity subscale will show a significant difference between the symptoms experience subscale and those associated with CTRF (Moss-Morris, et al., 2002)

   Hypothesis 3b: CTRFRep subscales mediate the relationship between CTRF intensity and CTRF distress.

Sample eligibility criteria.

Following the obtaining of human subjects approval, 47 patients were recruited for this study over a 3-5 month period. In the event that recruitment progressed quickly, recruitment would end when the sample size was adequate (N=100) for the planned factor analysis. Patients were eligible for this study if:

- They are older than 21 years of age
- They are receiving external beam radiation for cancer AND the duration of the treatment is greater than three weeks
- They are able to speak and read English.

Exclusion criteria include:

- Radiation treatment to the brain
- Known brain metastases

The inclusion and exclusion criteria were developed after discussion with the medical director of the radiation oncology clinic and the clinic's research nurse. The rationale for the exclusion criteria was that patients with known brain metastases or who were receiving whole-brain radiation would be more likely to have cognitive difficulties that would make assessing their beliefs and answering the questionnaires overly burdensome for them.

Participant recruitment and enrollment.

Participant recruitment and enrollment involved several steps: (a) identifying potentially eligible patients; (b) verifying eligibility criteria and patient receptiveness; and (c) approaching the patient regarding potential participation in the study. Research nurses at the radiation oncology clinic prepared a list of potentially eligible patients including patient names, appointment times, and treatment machine location. This list and its identifying information were not removed from the radiation oncology clinic. The Principal Investigator (PI) reviewed the list and eligibility criteria with therapists at the treatment machines and approached patients who may have been eligible for the study. The PI then briefly introduced the study. If the patient expressed interest in participating, the PI provided the patient with further information about the purpose and design of the study, and the requirements for participation. She obtained written informed consent and an authorization for release of health information for research from interested patients. Those who declined participation were immediately removed from the list of potential subjects.

Research Design, Methods and Procedures

For this cross-sectional study, upon obtaining informed consent, the PI informed the Radiation Oncology Center's staff of the patient's willingness to participate in the study. Data collection occurred at the patient's four-week follow-up appointment. This appointment was scheduled during the patient's last radiation treatment. The Radiation Oncology Center staff informed the PI of the follow-up appointment date and time for consented patients. At the patient's follow-up appointment, the PI collected data through a face-to-face interview in a private area of the radiation oncology office suite.

Measures and data collection instruments

Six instruments were used, including the CTRF Representation instrument (CTRFRep) that is being evaluated and several scales that were used to assess the construct validity of the CTRFRep. The instruments were the Positive and Negative Affect Scales (PANAS) (Watson, et al., 1988), the Center for Epidemiologic Studies-Depression (CES-D) (Radloff, 1977), the Profile of Mood States–Short Form (POMS-SF) (McNair, Lorr, & Droppleman, 1992), the Multidimensional Fatigue Inventory (MFI-20) (Smets, Garssen, Bonke, & De Haes, 1995), and the Cancer Related Fatigue Distress Scale (CRFDS) (Holley, 2000b). Table 7 presents the operational definitions of all study variables, as well as the instrument and number of items in each scale.

Demographic variables

Demographic data were collected using an investigator-developed chart audit form addressing age, race, marital and employment status and spiritual affiliation. Disease and treatment information, including time since diagnosis, stage, and additional information such as hemoglobin levels, radiation type and dosage, and hormone dosages were obtained from the medical record. This data was collected in order to describe the demographic characteristics of the sample.

Psychological variables

The Positive and Negative Affect Scale (PANAS) (Watson, et al., 1988) was used to measure trait positive and negative affect. The PANAS contains two 10-item scales. The items are on five-point scales anchored by “very slightly or not at all” to “very much” with higher scores indicating higher levels of positive or negative affect. The scale was administered with a temporal instruction (i.e. “In general, that is on the average”) intended to capture trait affect (Watson, et al., 1988). Cronbach alpha reliabilities for the general scale in a sample of 663 adults were .88 for PA and .87 for NA (Watson, et al., 1988). In addition, the intercorrelation of PA and NA was -.17, indicating that the shared variance of the two scales was less than 3% (Watson, et al., 1988). Test-retest reliabilities for an 8-week interval were .68 (PA) and .71 (NA) for the general temporal instruction which was used in this study to assess trait positive and negative affect (Watson, et al., 1988).

The Center for Epidemiological Studies – Depression, (CES-D) Radloff, (1977) was used to measure depressive symptoms. The CES-D is a 20-item scale on which respondents rate the frequency of experienced symptoms on a 0-4 scale ranging from “Rarely or none of the time” to “Almost all the time” with higher scores indicating higher levels of depressive symptoms (Radloff, 1977). The scale has had Cronbach alpha reliabilities ranging from .85 to .90 (Radloff, 1977). In addition, the CES-D has advantages for use in cancer patients because it contains few somatic items (Andrykowski, et al., 1996).

Table 7

Operational Definitions of Variables Used in the Study

Concept	Operational Definition/How measured	Total Item N
Affect	Trait Positive and Negative Affect Scale (PANAS)	20 items with 2 subscales
Depression	Center for Epidemiological Studies-Depression Scale (CES-D)	20 items
Fatigue Intensity	Profile of Mood States short-form_Fatigue (F_POMS-sf)	5 items
	Multi-dimensional Fatigue Inventory (MFI-20)	20 items with 5 subscales
Cancer Treatment-Related Fatigue Representation	Cancer Treatment Related Fatigue Representation (CTRFRep) Scale (See Table 4)	105 total items with 10 subscales
Fatigue Distress	Cancer-Related Fatigue Distress Scale (CRFDS)	20 items

Fatigue intensity

The Profile of Mood States short form (POMS-sf) - fatigue subscale (F_POMS-sf) (McNair, et al., 1992) and the Multidimensional Fatigue Inventory (MFI-20) (Smets, et al., 1995) were used to measure CTRF intensity. Two scales were used for several reasons: 1)The NIH State of the Science Conference on Symptom Management in Cancer Patients has identified the need to “compare simple screening strategies with more complex screening and diagnostic approaches in clinical practice”(National Institutes of Health, 2002, p. 17). 2) The POMS-sf is an established, widely used scale with a brief (five-item) unidimensional measure of fatigue intensity (the F_POMS-sf). Thus, this brief scale may be more appropriate for clinical populations. In contrast, the MFI-20 is a relatively new scale that is multi-dimensional. 3) The dimensions measured in the MFI-20 may correlate individually with the outcome measure of CTRF Distress, thus providing important information in testing the effects of mediating variables. 4) Testing these instruments concurrently in this population will allow determination of the possible benefit of additional information provided by the MFI-20 weighed against the cost of subject burden of additional items.

The F_POMS-sf is a 5-item self-administered adjective checklist on a 5-point Likert scale. Subjects were directed to indicate how they felt during the last 7 days in relation to each adjective. Answer choices on the 0-4 scale are anchored by “not at all” and “extremely.” Thus, the range of scores is 0-20, with higher scores indicating more fatigue. The scale has had excellent internal consistency, from 0.93 to 0.94 in psychiatric outpatients (McNair, et al., 1992). In addition, ease of use and construct validity have been established in a population of adult patients with cancer (Meek, et al., 2000).

Although this fatigue scale is part of a larger scale measuring mood, it is not considered to be a pure measure of mood when used with patients experiencing physical illness (Nail & King, 1987). The POMS-sf, a 30-item scale, was administered in its entirety in order to maintain the integrity of the fatigue-inertia subscale score and the ability to compare the patients in the proposed study to other patients for whom the POMS-sf has been used to measure mood.

The MFI-20 is a 20-item scale with five dimensions: general fatigue, physical fatigue, mental fatigue, reduced motivation, and reduced activity. The items are measured on 5-point scales anchored by “yes, that is true” and “no, that is not true” with higher scores indicating higher levels of fatigue (Smets, et al., 1995). The Cronbach alpha in patients undergoing radiation therapy has ranged from .77 for the metal fatigue subscale to .86 for the physical fatigue subscale. Construct validity was established by comparisons among various healthy and fatigued groups (Smets, et al., 1995).

Cancer Treatment-Related Fatigue Representation (CTRFRep)

The Cancer Treatment-Related Fatigue Representation Scale (CTRFRep) was used to measure CTRF representation. Qualitative research reports of the experience of CTRF, (Barsevick, Whitmer, & Walker, 2001; Mock, et al., 2000; Nail, 2002; Nail & King, 1987; Nail & Winningham, 1995; Ream & Richardson, 1996, 1997) illness perception, (Moss-Morris, et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996) and psychometric theory (Lyberg, 1997) guided the development of the CTRFRep.

As shown in Table 4, and as tested in the present study, the CTRFRep consists of 105 items in 10 subscales. The Identity subscale contains 26 items representing symptoms that patients may or may not have experienced since they began having CTRF.

Subjects are asked to endorse items (Yes or No) if they have had the symptom since they began having CTRF. If the answer for a given symptom (e.g., pain) is ‘Yes’ then the subject is asked whether he believes it is related to or contributes to his CTRF. The remaining subscales use a 5-point Likert-type scale with anchors of ‘strongly disagree’ to ‘strongly agree.’ The Cause subscale contains 23 items representing things (e.g., Stress or worry, radiation treatment for cancer) subjects may or may not believe caused their CTRF. None of these items is reverse-scored. The Timeline Acute vs. Chronic subscale contains six items of which three are reverse scored. Higher scores indicate stronger belief that CTRF is chronic (i.e. long lasting), whereas lower scores indicate stronger belief that CTRF is acute. The Timeline Cyclical subscale contains four items, none of which is reverse scored. Higher scores indicate stronger belief that CTRF is predictable or cyclical, whereas lower scores indicate a stronger belief that CTRF is unpredictable. The Consequences subscale contains six items of which one is reverse-scored. Higher scores indicate a stronger belief that CTRF has negative consequences vs. lower scores, which indicate weaker belief that CTRF has negative consequences for the subject. The Personal Control subscale contains 16 items of which four are reverse scored. Higher scores reflect stronger belief in the subject’s own ability to control his/her CTRF. The Treatment Control subscale has seven items of which two are reverse-scored. Higher scores indicate a stronger belief that there are treatments available that can help control the subject’s CTRF. The Symptom Coherence scale contains six items of which four are reverse-scored. Higher scores indicate stronger belief in the subject’s ability to ‘make sense of’ his or her own experience of CTRF. The Emotional Representation scale contains seven items of which one is reverse-scored. Higher scores indicate stronger negative emotional representations of fatigue. The Positive Consequences scale was developed by the author in an attempt to elicit any positively valenced consequences of the CTRF experience. This scale contains four items, of which none are reverse scored. Higher scores would indicate a stronger belief that there are some positive consequences that result from having CTRF.

Fatigue distress

The Cancer Related Fatigue Distress Scale (CRFDS) (Holley, 2000b) was used to measure CTRF Distress. The CRFDS was developed using content analysis of interviews with cancer patients. The instrument has 20 items on a 0-10 scale anchored by “no distress” and “severe distress” with higher scores indicating a higher level of fatigue distress. The items are summed and the mean is taken, resulting in a scale score of 0-10 where higher scores indicate more fatigue distress. The CRFDS contains items addressing the physical, social, psychological, cognitive, and spiritual aspects of fatigue distress. This single-factor scale has strong internal consistency with a reported alpha coefficient of 0.98 (Holley, 2000b). Construct validity was established when all items loaded on a single factor representing fatigue distress.

Statistical analyses

Preliminary analysis: Prior to any data analysis, the data were screened using frequency analyses for normality and outliers will be identified. Distributions that are highly skewed were evaluated for possible standardization of scores.

Specific Aim #1: Identify the factor structure of the CTRFRep Scale.

Research Question 1a: What is the factor structure of the CTRFRep Cause subscale?

Although sample size is smaller than recommended for factor analysis (minimum 3 subjects per item, with some recommending up to 10 subjects per item) this is the initial study of the instrument. In addition, it should be noted that the items on the Cause subscale were factored separately from the other items. Thus, the maximum number of items entered into factor analysis would be 54 items. There is some argument that factor analyses can be used with sample sizes as low as 50-100 subjects if there are at least 5 items per subscale to be factored (Sapnas & Zeller, 2002)

Research Question 1b: What is the factor structure of the Timeline, Consequences, Control, Symptom Coherence, and Emotional Representation subscales?

In terms of the remaining subscales, several steps are involved in identifying the factor structure of the CTRFRep Scale. The Cause subscale contains 23 items that were analyzed using principal components analysis (PCA). Pett, Lackey, and Sullivan (2003) recommend that items analyzed with PCA either be standardized or measured on a similar scale. Because the Cause items share a common 5-point Likert-type scale, the analysis plan will not include standardization of the scores. The Cause subscale is entered into a separate PCA because it is expected that the analysis will result in identification of factors structured around beliefs about the causes of CTRF (Moss-Morris, et al., 2002). For example, one could hypothesize the emergence of a “treatment component” which could include “My chemotherapy treatment for cancer” and “My radiation treatment for cancer.” The purpose of the PCA of the Cause subscale is to identify items that are relevant to patients with CTRF and those that are less relevant. After completion of the PCA, causal items may be deleted from the final scale. The criteria for item deletion include 1) lack of face validity in the experience of CTRF, 2) item did not load on any factor or loaded on multiple factors, and 3) item not endorsed by at least 10% of the sample.

Principal components exploratory factor analysis (PCEFA) will be used to evaluate the factor structure of the Timeline Acute/Chronic, Timeline Cyclical, Consequences, Personal and Treatment Control, Symptom Coherence, Emotional Representation, and Positive Consequences scales. In an iterative process, the first analysis will include all 56 items in these scales in a PCEFA. Preliminary inclusion criteria for retaining factors will include Eigenvalues>1.0 and evaluation of Scree plots. Items loading on multiple factors will be evaluated for deletion from the scale. Subsequent iterations will evaluate the factor loadings of individual items with criteria of 0.4-0.5 considered satisfactory loading on a single factor.

Specific Aim #2: Describe the internal consistency reliability of the CTRFRep Scale

Research Question 2: What is the internal consistency reliability of the CTRFRep Identity, Cause, Timeline Acute vs. Chronic, Timeline Cyclical, Consequences, Personal Control, Treatment Control, Symptom Coherence, Emotional Representation, and Positive Consequences subscales?

The sample size of 47 is adequate to perform Pearson correlations and internal consistency reliability. If alpha was low, items were assessed to evaluate their contribution to the overall alpha coefficient. Items with low (<0.30) or high (>0.70) item-to-total correlations were evaluated for deletion from the scale for low coherence or redundancy. In terms of the internal consistency reliability of the subscales, scales with a high (>0.90) Cronbach alpha were evaluated for redundant items in order to reduce the total number of items in the scale.

Specific Aim #3: Describe the construct validity of the CTRFRep scale.

Hypothesis 3a: The CTRFRep Identity subscale will show a significant difference between the symptoms experience subscale and those associated with CTRF (Moss-Morris, et al., 2002)

The Identity subscale consists of a series of symptoms for which the subject indicates yes or no as to whether a) the symptom has been present since the subject has had CTRF and b) whether the subject believes the symptom is related to or contributes to the patient's CTRF. The Identity subscale is the only subscale that was not evaluated using factor analytic techniques. Instead, frequency analyses identified which symptoms were endorsed as causes of their fatigue. Symptoms that were endorsed by a relatively low number of subjects will be candidates for deletion from the final scale. In addition, paired samples t-tests were used to identify differences in beliefs about the presence of symptoms and their contribution to their CTRF. This provided information about whether subjects believed that certain symptoms were related to their CTRF but not others.

Hypothesis 3b: CTRFRep subscales mediate the relationship between CTRF intensity and CTRF distress.

Construct validity of items used to measure CTRFRep was tested by using a mediation model in which the components of CTRFRep were hypothesized to mediate the relationship between CTRF intensity and CTRF distress. As described by Baron & Kenny (1986), mediating variables account for the correlation of predictor and criterion variables. In this study, the mediating variables of the CTRFRep subscales were hypothesized to account for the relation between CTRF intensity (after controlling for negative affect and depressive symptoms) and CTRF distress. In this analysis, the CTRFRep subscales functioned as mediating variables if the following conditions were met: (a) variations in the level of CTRF intensity accounted for variations in CTRFRep subscale scores; (b) variations in CTRFRep subscale scores significantly accounted for variations in CTRF distress; and (c) when CTRFRep subscale scores were controlled, a previously significant relationship between CTRF intensity and CTRF distress was no longer be significant, with the strongest demonstration of mediation occurring if the relationship between CTRF intensity and CTRF distress equaled zero (Baron & Kenny, 1986). In terms of the analysis plan, the intercorrelation of the PANAS, CES-D and CTRF intensity, finalized CTRFRep subscales and CTRF distress will be evaluated using Pearson correlations.

The analysis plan included the following multiple linear regressions:

Model 1: The PANAS and CES-D entered in to the analysis as independent variables, with CTRF distress entered as the dependent variable.

Model 2: The PANAS and CES-D (Block I) entered first, followed by CTRF intensity (Block II) as independent variables, with CTRF distress as the dependent variable.

Model 3: Mediation model PANAS and CES-D (Block I), CTRF intensity in (Block II), CTRFRep subscales (Block III), and CTRF distress as the dependent variable.

It is hypothesized that the variance accounted for by the effect of CTRF intensity on CTRF distress will be less in Model 3 than in Model 2.

CHAPTER 4: RESULTS

Introduction

Chapter 4 consists of three major sections. The first section deals with the procedures for data cleaning. The second portion deals with description of the study variables, including reliability analyses of all scales and subscales exclusive of the CTRFRep. The final section involves answering research questions and testing hypotheses regarding the CTRFRep.

Data Cleaning

Data for this study were collected using two primary methods. Questionnaire data was collected via in-person interviews of patients that took place in the radiation oncology clinic. Medical record audits were used to gather demographic data and disease and treatment information. All data were coded with a subject identification number and entered into the SPSS statistical software program (SPSS, 2009). Data were checked for accuracy of input. In addition, univariate statistics were examined for means, standard deviations, outliers and out-of-range values (Tabachnick & Fidell, 2001). Any errors discovered were corrected using the original interview form. Missing values in the interview data were rare and mean substitution was used to correct this. Missing data from the medical audit data is more frequent, and will be explained further presently. However, analysis using these variables is limited to univariate descriptives to describe the sample.

All independent and dependent study variables were assessed for normality using a Shapiro-Wilk test using a p value of 0.05. This test is appropriate for small sample sizes

(N<50) (Field, 2009). Further discussion of normality and transformations will be undertaken when describing the study variables.

Description of Study Variables

Table 8 provides descriptive statistics for the demographic and treatment variables for the sample. Table 9 presents descriptive statistics for all variables included in the questionnaire aside from the variables in the CTRFRep. Descriptive statistics for the CTRFRep are presented later in this chapter (see Table 29).

Sample Considerations

The sample consists of 47 patients who received external beam radiation treatment for cancer. Of these 47 patients, 36 patients (77%) experienced fatigue during their cancer treatment. These patients completed the entire interview packet. However, those patients who did not experience fatigue answered neither the questions for the CTRFRep nor the questions for the CRFDS. Also, as of this writing, the missing medical record audit data mentioned above is largely due to the fact that chart audits were not complete for patients who did not experience fatigue during their treatment.

To clarify explanation of the variables and analyses, when discussing ‘the sample’ the writer is referring to the entire sample of 47 subjects. When discussing the ‘fatigued (sub-)sample’ the writer is referring to the sample of 36 patients who experienced fatigue during their treatment for cancer. Finally, when referring to the ‘non-fatigued (sub) sample’ the writer is referring to the 11 patients who did not experience fatigue during their cancer treatment.

Demographic and Treatment Variables

Demographic and treatment variables were collected using medical record audits. Table 8 presents a summary of the demographic and treatment information.

Depressive symptoms

Depressive symptoms were measured using the CES-D scale. Items on the scale were recoded as necessary so that higher scores indicate higher levels of depression. Table 9 presents the measures of central tendency for the CES-D. The mean level of depressive symptoms in the group was 14.43, suggesting a moderate level of depressive symptoms. Using the z distribution, scores in the full sample exhibited a significant positive skew ($z=2.2$; $p<0.05$) but minimal kurtosis. However, in the fatigued sample, the positive skewness decreased to a non-significant level ($z=1.13$).

Positive and Negative Affect

Positive and Negative Affect (PA and NA) were measured using the Positive and Negative Affect Scale (PANAS). Higher scores indicated higher levels of positive and negative affect, respectively. Mean scores were calculated for the entire sample as well as the subsamples. Using the z distribution, the scores for positive affect showed non-significant negative skewness and kurtosis. The scores for negative affect showed non-significant positive skewness and negative kurtosis.

Cancer Treatment-Related Fatigue Intensity

Cancer treatment-related fatigue intensity was measured using two scales, the Multidimensional Fatigue Inventory (MFI-20) and the Profile of Mood States Short-Form_Fatigue (F_POMS-sf). Items on the MFI-20 were recoded according to instructions

Table 8.

Sample Descriptive Statistics

Construct	Mean (SD)
Age	57.7(11.4) years
Hemoglobin	13.34 (1.60) gm/dl
Radiation Dose	5967 (1092) cGy

Construct	Category	N	%
Gender	Male	23	49
	Female	24	51
Race	Caucasian	42	89
	African-American	5	11
Ethnicity	Latino	1	2
	Non-Latino	46	98
Marital Status	Married	18	38
	Unmarried	4	9
	Divorced	5	11
	Widowed	1	2
	Unknown	19	40
Employment Status	Full- or Part-Time	16	34
	Retired	5	11
	Not Employed	4	9
	Unknown	22	46
Cancer Site	Breast	14	30
	Prostate	7	15
	Head and Neck	6	13
	Colorectal/Anal	3	6
	Other Site	6	13
	Unknown	11	23
Cancer Stage	Stage 0	2	4
	Stage I	6	13
	Stage II	5	11
	Stage III	10	21
	Stage IV	5	11
	Unknown	19	44
Cancer Treatments	External Beam Radiation	47	100
	Surgery	16	34
	Chemotherapy	14	30
	Hormone Treatment	1	2
Disease Status	Primary Cancer	34	72
	Recurrent Disease	2	4
	Unknown	11	23
Fatigue Before Cancer Diagnosis	No	33	70
	Yes	11	24
	Unknown	3	6
Fatigue During Cancer Treatment	Yes	36	77
	No	11	23

provided by the author of the scale so that higher scores reflect more fatigue (Smets, 2002; Smets, et al., 1995). A summed score was computed for each of the five subscales of the MFI-20. All of these subscale scores demonstrated non-significant negative kurtosis and positive skewness using the z distribution. The F_POMS-sf was calculated as a summed score of all variables in the subscale. The scores for the F_POMS-sf showed non-significant positive skewness and significant ($z=1.96$; $p=.05$) negative kurtosis using the z distribution.

Cancer Treatment-Related Fatigue Distress

Cancer treatment-related fatigue distress was measured using the CRFDS. The scale score was calculated by summing all variables and calculating the mean score for each individual. The scale scores showed a non-significant positive skewness and nearly significant ($z=-1.91$) negative kurtosis.

The dependent variable fatigue distress (CRFDS) was found to be significantly non-normal ($p=0.005$). Logarithmic (*ln*) transformation of the variable was suggested after consultation with a statistician. Unfortunately, the LN transformation failed to correct the normality and, in consultation with the statistician it was suggested that the variable be dichotomized .

Comparison of fatigued and non-fatigued groups

As a manner of testing the validity of the instruments used in this study, non-parametric testing was undertaken to compare the median levels of variables among the 36 fatigued and 11 non-fatigued subjects in the study. Table 10 reveals that all but two subscales had significantly different medians – in the expected directions – using the

Table 9.

Descriptive Statistics for Non-CTRFRep Variables

Instrument	Subscale	Item N	Mean (SD)	Median	Actual Range (Possible Range)	Skewness	Kurtosis	Cronbach's Alpha
MFI-20	General Fatigue	4	11.28 (4.95)	10.50	4-20 (4-20)	.15	-1.14	.87
	Physical Fatigue	4	10.87 (4.51)	10.50	4-20 (4-20)	.24	-1.07	.84
	Reduced Activity	4	10.04 (4.71)	9.00	4-20 (4-20)	.58	-.75	.90
	Reduced Motivation	4	8.52 (3.78)	8.00	4-17 (4-20)	.63	-.53	.69
	Mental Fatigue	4	9.37 (5.11)	8.00	4-20 (4-20)	.53	-.98	.92
POMS	Tension/ Anxiety	5	5.80 (4.74)	5.00	0-16 (0-20)	.60	-.68	.87
	Depression/ Dejection	5	4.48 (4.72)	3.00	0-16 (0-20)	.93	-.30	.89
	Anger/ Hostility	5	5.46 (5.22)	4.00	0-20 (0-20)	.99	.24	.95
	Vigor/ Activity	5	9.65 (5.48)	10.00	0-20 (0-20)	.06	-.89	.95
	Fatigue/ Inertia	5	7.37 (5.97)	6.5	0-18 (0-20)	.25	-1.34	.95
	Confusion/ Bewilderment	5	5.07 (3.74)	5.00	0-13 (0-20)	.50	-.83	.84
PANAS	Positive Affect	10	38.61 (7.87)	40	19-50 (5-50)	-.42	-.56	.94
	Negative Affect	10	18.91 (6.61)	17	10-33 (5-50)	.56	.69	.88
CRFDS*	Cancer Fatigue Distress	20	3.76 (2.99)	3.8	0-9 (0-10)	.14	-1.47	.98
CES-D	Depressive Symptoms	20	14.43 (12.76)	12.00	0-48 (0-60)	.73	-.30	.94

Sample N=47
*Sample N=36

Mann-Whitney U test. The two subscales that did not have significant differences were the positive affect scale and the MFI reduced motivation subscale.

It is expected that the positive affect subscale would not differ significantly based on levels of cancer treatment-related fatigue. However, the non-significant results for the MFI reduced motivation subscale are somewhat surprising. There are at least two hypotheses as to why this result was not significant: 1) small sample size and 2) the items on this subscale include ‘I have a lot of plans’ and ‘I feel like doing all sorts of nice things,’ which may be more often rated as true for patients in spite of their cancer treatment-related fatigue.

Research Questions and Hypothesis Testing

The following section will deal with analyzing the research questions and testing the hypotheses of the study. All statistical analyses used the PASW statistical software package, Version 17.0.2 (SPSS, 2009).

Specific Aim #1: Identify the factor structure of the CTRFRep Scale

Research Question 1a: What is the factor structure of the CTRFRep Cause subscale?

In order to answer this research question, the 23 items in the Cause subscale were entered into a principal components analysis with Varimax rotation. The results of this analysis were not definitive and suggest that a larger sample size will be needed in order to properly factor the CTRFRep Cause subscale. The specific issues with the factor analysis include:

Table 10.

Comparison of Fatigued and Non-Fatigued Groups

Instrument	Subscale	Fatigued	Median	Mann-Whitney U	z-score	Exact Sig.
MFI-20	General Fatigue	No	6.00	53.00	-3.66	.000
		Yes	13.50			
	Physical Fatigue	No	8.00	83.50	-2.89	.003
		Yes	11.00			
	Reduced Activity	No	6.00	98.00	-2.52	.011
		Yes	10.00			
	Reduced Motivation	No	7.00	153.50	-1.12	.268
		Yes	9.00			
	Mental Fatigue	No	5.00	116.00	-2.10	.039
		Yes	10.00			
POMS	Vigor/ Activity	No	14.00	87.00	-2.80	.004
		Yes	8.00			
	Fatigue/ Inertia	No	0.00	40.50	-3.98	.000
		Yes	10.00			
PANAS	Positive Affect	No	44.00	149.00	-1.23	.227
		Yes	39.00			
	Negative Affect	No	12.00	58.00	-3.53	.000
		Yes	19.50			
CES-D	Depressive Symptoms	No	2.00	57.50	-3.54	.000
		Yes	15.50			

Sample N=36

1) The determinant of the correlation matrix was 2.44E-008. This is smaller than the value of 0.00001 recommended as the minimum value for a satisfactory correlation matrix (Field, 2009).
2) The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy test statistic – which has values between 0 and 1.0 – was 0.477. According to Kaiser, as cited in Pett, Lackey and Sullivan (2003), KMO test statistics of less than 0.60 are “mediocre, miserable or unacceptable” (p. 70). According to Kaiser as cited in Field (2009) values of 0.50 are “barely acceptable” and should lead one to collect more data or rethink variable selection. According to Field (2009) values near 0 mean that the “sum of partial correlations is large relative to the sum of correlations…[and as a result]… factor analysis is likely to be inappropriate (p. 647).”
3) Bartlett’s test of sphericity had a negative value for its Chi-Square test statistic, which violates the assumptions of the Chi-Square distribution and suggests that the correlation matrix is an identity matrix, which would make interpretation of factor analyses ill-advised (Field, 2009).

For these reasons, the results of the factor analysis are not presented here. Instead, Table 11 shows the percentage of subjects who answered either ‘agree’ or ‘strongly agree’ for each of the Cause items. According to the criteria laid out in the previous chapter, two items – ‘chance or bad luck’ and ‘accident or injury’ – will be deleted from the Cause subscale in future analysis because they were endorsed by less than 10% of the respondents. In terms of the face validity of the Cause subscale, subjects identified items such as ‘hereditary, it runs in my family’ and ‘poor medical care in the past’ as causes for cancer treatment-related fatigue. When evaluating face validity, these items may be more likely viewed as causes of cancer itself versus CTRF. Therefore, consideration will be given to removing these items from the subscale in future analyses. In addition, instructions for this section of the interview may be revised to stress the idea that the questions refer to causes of their cancer treatment-related fatigue, not causes of the cancer itself.

Research Question 1b: What is the factor structure of the Timeline, Consequences, Control, Symptom Coherence, and Emotional Representation subscales?

As with the previous research question, items from these subscales were entered into a Principal Components Analysis. However, prior to doing so, all subscales were tested for internal consistency reliability (See Specific Aim #2, Research Question 2a for more detail as to the method and results of these analyses). After the reliability analysis was used to reduce the number of items entered into factor analysis, 34 items were entered into a Principal Components Analysis with Varimax rotation. As with the Cause subscale, the analysis was not definitive and suggests that more data will need to be collected before evaluating the scale using factor analysis. Specific issues with this analysis were:

1) The determinant of the matrix was 4.34E-023, which is substantially smaller than the recommended value of 0.00001 (Field, 2009).
2) The KMO test statistic was 0.271, well below the acceptability threshold (Field, 2009).

For these reasons, the results of the factor analysis are not presented here, and no further item reduction will take place at this time.

Table 11.

*Summary Statistics for CTRFRep Cause Subscale **

My chemotherapy treatment for cancer**	96%
Having cancer	94%
My radiation treatment for cancer**	83%
My surgical treatment for cancer**	73%
My hormone treatment for cancer**	67%
Stress or worry	61%
Diet or eating habits	58%
Aging	56%
Altered immunity	53%
My emotional state	47%
My own behavior	39%
My mental attitude	33%
Overwork	33%
Family problems or worries	31%
My personality	31%
Heredity	28%
Smoking	28%
Pollution in environment	19%
Alcohol	15%
Germ or virus	14%
Poor medical care in past	11%
Chance or bad luck	8%
Accident or injury	6%

*Cronbach's Alpha =.65

**Valid percent – i.e. percentage of those who had this type of treatment for their cancer

Specific Aim #2: Describe the internal consistency reliability of the CTRFRep Scale

Research Question 2: What is the internal consistency reliability of the CTRFRep Identity, Cause, Timeline Acute vs. Chronic, Cyclical Timeline, Consequences, Personal Control, Treatment Control, Symptom Coherence, Emotional Representation and Positive Consequences subscales?

In order to answer this research question, each set of items for the hypothesized subscales was entered into a separate reliability analysis. Table 11 presents the Cronbach alpha for the Cause subscale. The reported value of 0.65 is lower than the recommended value of 0.70. However, there are several possible reasons for this: 1) the scale has not been factor analyzed; 2) as a result of this, the scale is not additive – there is not a linear relationship between the individual scores and the total score. This violates one of the assumptions of reliability testing (SPSS, 2009).

The results for the Identity subscale are presented in Table 12. The Kuder-Richardson 20 statistic for the scale was 0.86. Tables 13-28 present the correlation matrices and item statistics for all of the CTRFRep subscales. Table 29 presents the descriptive statistics for the subscale scores of the CTRFRep as they are following the internal consistency reliability testing. Table 30 shows the items retained in after several iterations of reliability analysis and item deletion. Table 31 shows the two subscales (see next paragraph) that did not have adequate internal consistency reliability, as well as the items that were deleted from the subscales during reliability testing.

The Treatment Control and Timeline Cyclical subscales had poor alpha coefficients ($\alpha <= .52$). Further examination of these subscales finds that these results are not unexpected. The Treatment Control subscale has items that deal with beliefs about medications and treatments for CTRF, but there are few treatments for CTRF. In order to evaluate the possible utility of the Treatment Control items, they were added to the Personal Control items and evaluated for deletion along with those items. Two Treatment Control items were retained in the Personal Control subscale as it was entered into the factor analysis.

The Timeline Cyclical subscale deals with beliefs about the cyclical nature of CTRF. There are a couple of reasons why this subscale may not be internally consistent in this sample of patients with CTRF. First, there is a small sample size. Second, this is a heterogeneous sample of patients who had various treatments aside from radiation treatment for their cancer. It also may be that beliefs about periodicity may not be relevant for CTRF. Further testing would be needed in other samples to verify the reasons for the lack of internal consistency reliability for this subscale.

As shown in Tables 29 and 30, at the end of the reliability analyses, all subscales had Cronbach alpha coefficients of at least 0.85 except for Positive Consequences, a three-item subscale that has an alpha of 0.70. Table 31 shows the two subscales with the low Cronbach alpha coefficients, as well as the other items that were deleted from the subscales as a result of reliability testing. Following reliability testing, the 56 items that were part of the non-Cause and non-Identity subscales were reduced to 34 items. The primary reason for deletion of items from the scale was either high or low inter-item correlations. Preference for retention of items was given to those items based upon items that were in the original IPQ-R.

Table 12.

Identity Subscale – Percentage of Sample Endorsing the Symptom as Related to or Contributing to CTRF*

Symptom	**%**
Lack of energy	92%
Loss of strength	69%
Feeling blue	60%
Sadness	58%
Poor concentration	56%
Short attention span	53%
No desire to move	53%
Falling asleep	50%
Staying asleep	50%
Pain	47%
Muscle weakness	47%
Weight loss	42%
Upset stomach	42%
Loss of appetite	42%
Difficulty moving	42%
Heavy limbs	39%
Nausea	34%
Dizziness	33%
Breathlessness	31%
Difficulty waking up	31%
Muscle soreness	31%
Low endurance	31%
Stiff joints	28%
Headache	22%
Wheeziness	19%
Numbness	17%

* Kuder-Richardson 20 reliability =.86

Table 13.

Correlation matrix for CTRFRep Timeline Acute vs. Chronic Subscale Items

	Short time	Permanent	Long Time	Pass Quickly	Rest of Life	Improve in time
Short time*		0.43	0.81	0.61	0.41	0.22
Permanent			0.64	0.68	0.85	0.72
Long Time				0.66	0.61	0.36
Pass Quickly*					0.62	0.43
Rest of Life						0.74
Improve in Time*						
* Reverse Scored Variable						

Table 14.

Item Statistics for CTRFRep Timeline Acute vs. Chronic Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Short Time*	2.42	1.16	0.63	0.89
Permanent	1.86	0.87	0.81	0.86
Long Time	2.39	1.13	0.79	0.86
Pass Quickly*	2.64	1.07	0.75	0.86
Rest of Life	1.72	0.91	0.77	0.86
Improve in Time*	1.83	0.74	0.56	0.89
* Reverse Scored Variable				

Table 15.

Correlation Matrix for CTRFRep Timeline Cyclical Subscale Items

	Changes Day to Day	Pattern	Unpredictable	Cycles
Changes Day to Day		0.49	0.20	0.22
Pattern			-0.16	0.35
Unpredictable				0.19
Cycles				

Table 16.

Item Statistics for CTRFRep Timeline Cyclical Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Changes Day to Day	3.31	1.09	0.46	0.30
Pattern	2.78	0.93	0.34	0.43
Unpredictable	3.08	1.05	0.12	0.62
Cycles	3.33	1.01	0.37	0.40

Table 17.

Correlation Matrix for CTRFRep Consequences Subscale Items

	Serious Symptom	Major Consequences	Not much effect	Others reaction to me	Financial Consequences	Affects those close to me
Serious Symptom		0.65	0.58	0.41	0.44	0.28
Major Consequences			0.80	0.21	0.66	0.57
Not much effect*				0.21	0.51	0.45
Others reaction to me					0.39	0.34
Financial Consequences						0.65
Affects those close to me						
* Reverse Scored Variable						

Table 18.

Item Statistics for CTRFRep Consequences Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Serious Symptom	3.19	1.19	0.62	0.83
Major Consequences	3.08	1.23	0.80	0.79
Not much effect*	3.33	1.31	0.69	0.81
Others reaction to me	2.75	1.05	0.38	0.87
Financial Consequences	2.56	1.25	0.71	0.81
Affects those close to me	2.92	1.16	0.50	0.83
* Reverse Scored Variable				

Table 19.

Correlation Matrix for CTRFRep Personal Control Subscale Items

	Can do a lot	I determine	Depends on me	Nothing I do	I have power	No effect	Nothing can be done	Nothing can help	Diet	Well-balanced meals
Can do a lot		0.38	0.25	0.30	0.46	0.14	0.32	0.49	0.30	0.29
I determine			0.43	0.35	0.29	0.39	0.40	0.47	0.56	0.53
Depends on me				0.29	0.31	0.38	0.19	0.27	0.46	0.41
Nothing I do*					0.37	0.64	0.54	0.70	0.50	0.30
I have power						0.22	0.42	0.36	0.27	0.24
No effect*							0.51	0.69	0.46	0.41
Nothing can be done*								0.67	0.48	0.39
Nothing can help*									0.52	0.49
Diet										0.61
Well-balanced meals										
* Reverse Scored Variable										

Table 20.

Item Statistics for CTRFRep Personal Control Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Can do a lot	3.03	1.13	0.48	0.85
I determine	3.08	0.88	0.62	0.83
Depends on me	3.61	0.96	0.47	0.85
Nothing I do*	4.06	0.58	0.62	0.84
I have power	3.67	0.89	0.49	0.85
No effect*	4.06	0.53	0.58	0.84
Nothing can be done*	4.11	0.71	0.61	0.83
Nothing can help*	4.28	0.66	0.74	0.82
Diet	4.00	0.59	0.67	0.83
Well-balanced meals	3.78	0.72	0.58	0.84
* Reverse Scored Variable				

Table 21.

Correlation Matrix for CTRFRep Treatment Control Subscale Items

	Nothing can be done	Medications	Avoid negative	Nothing can help	MD knows	Asked MD
Nothing can be done*		0.04	0.20	0.66	0.25	0.31
Medications			-0.28	-0.03	0.33	0.18
Avoid negative				0.43	-0.20	-0.20
Nothing can help*					0.05	0.23
MD knows						0.30
Asked MD						
* Reverse Scored Variable						

Table 22.

Item Statistics for CTRFRep Treatment Control Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Nothing can be done*	4.11	0.71	5.45	0.24
Medications	3.06	0.86	0.05	0.51
Avoid Negative	3.06	0.96	-0.06	0.59
Nothing can help	4.28	0.66	0.53	0.26
MD knows	3.72	0.66	0.26	0.40
Asked MD	2.53	9.10	0.25	0.39
* Reverse Scored Variable				

Table 23.

Correlation Matrix for CTRFRep Symptom Coherence Subscale Items

	Puzzling	Don't understand	Makes no sense	Clear picture
Puzzling*		0.63	0.56	0.42
Don't understand*			0.80	0.68
Makes no sense*				0.61
Clear picture				
* Reverse Scored Variable				

Table 24.

Item Statistics for CTRFRep Symptom Coherence Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Puzzling*	3.17	1.11	0.60	0.87
Don't understand*	3.42	1.05	0.84	0.77
Makes no sense*	3.58	1.00	0.77	0.80
Clear Picture	3.47	1.00	0.64	0.85
* Reverse Scored Variable				

Table 25.

Correlation Matrix for CTRFRep Emotional Representation Subscale Items

	Depressed	Angry	Does not worry	Anxious	Afraid
Depressed		0.66	0.55	0.77	0.57
Angry			0.75	0.64	0.74
Does not worry*				0.70	0.66
Anxious					0.61
Afraid					
*Reverse Scored Variable					

Table 26.

Item Statistics for CTRFRep Emotional Representation Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Depressed	2.58	1.13	0.73	0.89
Angry	2.42	0.97	0.81	0.88
Does not worry*	2.61	1.10	0.76	0.89
Anxious	2.78	1.07	0.80	0.88
Afraid	2.39	0.96	0.74	0.89
* Reverse Scored Variable				

Table 27.

Correlation Matrix for CTRFRep Positive Consequences Subscale Items

	Time with family	Take it easy	Some good from
Time with family		0.47	0.44
Take it easy			0.45
Some good from			

Table 28.

Item Statistics for CTRFRep Positive Consequences Subscale

	Mean	SD	Corrected Item-Total Correlation	Alpha if Item Deleted
Time with family	2.97	0.97	0.53	0.60
Take it easy	2.72	0.91	0.54	0.60
Some good from	2.83	1.21	0.51	0.64

Table 29.

Descriptive Statistics for CTRFRep Subscales

Subscale	Item N	Mean (SD)	Median	Actual Range (Possible Range)	Skewness	Kurtosis	Cronbach's Alpha
Identity	26	14.86 (5.33)	16	5-23 (0-26)	-0.31	-1.137	0.86*
Timeline Acute vs. Chronic	6	12.86 (4.77)	12.5	6-24 (6-30)	0.62	-0.20	0.89
Consequences	6	17.83 (5.44)	18	6-29 (6-30)	-0.21	0.06	0.85
Personal Control	10	38.42 (5.16)	39	24-50 (10-50)	-0.43	1.12	0.85
Symptom Coherence	4	13.64 (3.50)	14.5	4-20 (4-20)	-0.72	0.35	0.86
Emotional Representation	5	12.78 (4.48)	12	5-20 (5-25)	0.20	-0.82	0.91
Positive Consequences	3	8.53 (2.47)	8	3-13 (3-15)	-0.05	-0.50	0.70

*K-R 20 test statistic
Sample N=36

Table 30.

CTRFRep Subscale Items Retained for Factor Analysis with Subscale Cronbach Alpha Reliabilities

- Timeline Acute/Chronic (α=.89)
  - My CTRF will last a short time (r)
  - My CTRF is likely to be permanent
  - My CTRF will last for a long time
  - My CTRF will pass quickly (r)
  - I expect to have CTRF for the rest of my life
  - My CTRF will improve in time (r)
- Consequences (α=.85)
  - My CTRF is a serious symptom
  - My CTRF has major consequences on my life
  - My CTRF does not have much effect on my life (r)
  - My CTRF strongly affects the way others respond to me
  - My CTRF has serious financial consequences
  - My CTRF causes difficulties for those who are close to me
- *Control (α=.85)
  - I can do a lot to control my CTRF
  - What I do will determine whether my CTRF gets better or worse
  - The course of my CTRF depends on me
  - Nothing I do will affect my CTRF (r)
  - I have the power to influence my CTRF
  - My actions have no affect on my CTRF (r)
  - **Nothing can be done to improve my CTRF (r)
  - I believe that eating a healthy diet with help my CTRF
  - **There is nothing which can help my CTRF (r)
  - Eating well-balanced meals helps my CTRF
- Symptom Coherence (α=.86)
  - My CTRF is puzzling to me (r)
  - I don’t understand my CTRF (r)
  - My CTRF doesn’t make any sense to me (r)
  - I have a clear picture or understanding of my CTRF
- Emotional Representation (α=.91)
  - I get depressed when I think about my CTRF
  - My CTRF makes me feel angry
  - My CTRF does not worry me (r)
  - Having CTRF makes me feel anxious
  - Having CTRF makes me feel afraid
- Positive Consequences (α=.70)
  - My CTRF helps me spend more time with my family
  - I can “take it easy” because I have CTRF
  - All things considered, some good things have come from having CTRF

(r) = items reverse scored
*Personal and Treatment Control subscales combined
**Treatment Control subscale items

Table 31.

CTRFRep Items and Subscales Deleted before Factor Analysis

Subscale (Cronbach Alpha)	Item	Reason for deletion
Timeline Cyclical (α=.52)	My CTRF changes a great deal from day to day	Low Cronbach alpha reliability
	My CTRF comes and goes in a pattern	
	My CTRF is unpredictable	
	I go through cycles in which my CTRF gets better and worse	
Treatment Control (α=.45)	*Nothing can be done to improve my CTRF	Low Cronbach alpha reliability
	I believe medications can help my fatigue get better	
	The negative effects of my CTRF can be prevented or avoided	
	*There is nothing which can help my CTRF	
	**My doctor knows that I have CTRF	
	**I asked my doctor if there are any medicines or treatments for my CTRF	
Personal Control	**What I do has no effect on my CTRF	High IIC
	**If I could sleep more, my CTRF would get better	Alpha increased with deletion from scale
	**I take naps during the day for my CTRF	
	**I make sure I sleep at least 8 hours every night	
	**There are things I can do to make my CTRF better	High IIC
	**There is nothing I can do to make my CTRF better	High IIC
	**I have asked others like family or friends for help with my CTRF	Low IIC
Symptom Coherence	My CTRF is a mystery to me	High IIC
	I know why I have CTRF	High IIC
Emotional Representation	When I think about my CTRF I get upset	High IIC
	**My CTRF makes me feel sad	High IIC
	**I ignore my CTRF as much as I can	Low IIC
	**I wish my CTRF would just go away	Low IIC
Positive Consequences	**Having CTRF helps me realize what is really important in my life	Low IIC

* Item retained in Personal Control subscale
** Investigator developed item
IIC=inter-item correlation (Low IIC<.4; High IIC>.7)

Specific Aim #2 Describe the construct validity of the CTRFRep scale

Hypothesis 3a: The CTRFRep Identity subscale will show a significant difference between the symptoms experienced subscale, and those symptoms associated with CTRF.

In order to test this hypothesis, a paired-samples t-test was done to compare the mean number of symptoms reported by subjects (mean=14.86 (SD=5.33)) with the mean number of symptoms attributed as being related to or contributing to their CTRF (mean=11.53 (SD=5.70)). This test statistic was significant (t=-6.66; df=35; 2-tailed sig. p<0.000). This result supports the hypothesis that there is a significant difference between the two means. The relatively large number of symptoms that subjects rated as being related to or contributing to CTRF is perhaps surprising. However, as shown in Table 12, the scale includes several symptoms that are perhaps similar to fatigue or commonly related to fatigue. Further analysis with a larger sample will be necessary in order to examine the contribution of these additional symptoms to the subjects' CTRF experience.

Hypothesis 3b: CTRFRep subscales mediate the relationship between CTRF intensity and CTRF distress.

In order to test this hypothesis a correlation matrix of all the variables in the study was evaluated for highly correlated variables. Table 32 shows the results of that analysis. Fatigue distress as measured by the CRFDS is the dependent variable in the regression analysis. Evaluation of the histogram of the CRFDS showed a bimodal distribution. In order to assess the fitness of the variable for linear regression, a normality test was done using the EXPLORE command in SPSS (Field, 2009; Sage Publications Limited & Field, 2009). The results of this analysis showed that the distribution of CRFDS scores differs

Table 32.

Correlation Matrix of Study Variables

	POMS Fatigue/ Inertia	MFI General Fatigue	MFI Physical Fatigue	MFI Reduced Activity	MFI Reduced Motivation	MFI Mental Fatigue	PANAS Negative Affect	PANAS Positive Affect	CTRFRep Acute vs. Chronic Timeline	CTRFRep Consequences	CTRFRep Positive Consequences	CTRFRep Personal Control	CTRFRep Symptom Coherence	CTRFRep Emotional Representation	CESD Depression	CRFDS Fatigue Distress
POMS Fatigue/Inertia		0.87**	0.76**	0.69**	0.76**	0.69**	0.53**	-0.31	0.63**	0.65**	-0.08	-0.26	-0.25	0.67**	0.82**	0.79**
MFI General Fatigue	0.90**		0.78**	0.64**	0.66**	0.70**	0.45**	-0.49**	0.54**	0.60**	-0.11	-0.41*	-0.25	0.49**	0.63**	0.66**
MFI Physical Fatigue	0.74**	0.80**		0.85**	0.74**	0.64**	0.45**	-0.41*	0.57**	0.55**	0.02	-0.29	-0.33*	0.51**	0.67**	0.68**
MFI Reduced Activity	0.70**	0.68**	0.81**		0.69**	0.43**	0.30	-0.22	0.63**	0.49**	-0.02	-0.30	-0.40*	0.35*	0.57**	0.60**
MFI Reduced Motivation	0.71**	0.65**	0.71**	0.70**		0.57**	0.59**	-0.40**	0.53**	0.49**	-0.11	-0.38*	-0.32*	0.63**	0.82**	0.74**
MFI Mental Fatigue	0.71**	0.71**	0.62**	0.46**	0.58**		0.53**	-0.39*	0.29	0.39*	-0.18	-0.17	-0.02	0.48**	0.68**	0.70**
PANAS Negative Affect	0.66**	0.60**	0.53**	0.40**	0.58**	0.57**		-0.41*	0.23	0.37*	0.04	-0.09	-0.19	0.51**	0.70**	0.51**
PANAS Positive Affect	-0.32*	-0.47**	-0.39**	-0.27	-0.40**	-0.44**	-0.38**		-0.35*	-0.21	0.18	0.42*	0.34*	-0.30	-0.35*	-0.25
CTRFRep Acute vs. Chronic Timeline										0.52**	-0.16	-0.37*	-0.38*	0.49**	0.53**	0.51**
CTRFRep Consequences											0.05	-0.34*	-0.34*	0.71**	0.58**	0.74**
CTRFRep Positive Consequences												0.06	-0.10	-0.17	-0.19	-0.11
CTRFRep Personal Control													0.35*	-0.20	-0.14	-0.10
CTRFRep Symptom Coherence														-0.16	-0.19	-0.23
CTRFRep Emotional Representation															0.73**	0.74**
CESD Depression	0.86**	0.71**	0.71**	0.61**	0.77**	0.72**	0.76**	-0.37*								0.87**

N=36 for top half of matrix (fatigued subjects only)
N=47 for bottom half of matrix (all subjects)
* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

significantly from the normal distribution (Shapiro-Wilk statistic 0.91; df 36; p=0.005). Because one of the assumptions of linear regression is normality of the dependent variable, the CRFDS variable was recoded in to two different groups (low distress<3.7 and high distress>=3.7) and logistic regression was used to test the mediation models.

Because of the small sample size (N=36), the recommendation is to use a maximum of three variables in the logistic regression. To select a measure of CTRF intensity to use for the logistic regressions, the correlation matrix in Table 32 was evaluated for a measure that was not highly correlated with the variables to be controlled for in the logistic regression (negative affect and CES-D). The F_POMS-sf is highly correlated (r>=.79) with both of these variables. The author of the MFI-20 recommends that the General Fatigue subscale be used if choosing only one score to use in analyses (Smets, 2002). The MFI General Fatigue subscale was less highly correlated with the CES-D and negative affect (r<=.66). Therefore, the General Fatigue subscale of the MFI-20 was selected for use as the measure of fatigue intensity in the logistic regression.

In an initial round of logistic regression analyses, the CES-D was entered along with the PANAS NA and the general fatigue subscale for fatigue intensity. When these regressions were analyzed, there was no significant effect of fatigue intensity on fatigue distress. After consulting with a statistician, the CES-D was identified as being too highly correlated with the CRFDS (r=.87). This resulted in an issue with multicollinearity and the suggestion was to eliminate the CES-D from the logistic regression analyses and continue with negative affect and the general fatigue scale.

After these preliminary analyses, the logistic regressions were computed as described below.

Model 1: The PANAS was entered into the analysis as an independent variable (IV). Table 33 summarizes the results of this analysis

Table 33.

Model 1 Logistic Regression Results

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.14*(0.06)	4.99(1)	1.15	1.02	1.30
Constant	-2.81(1.30)	4.71(1)	0.06		

Note: R^2=.13 Hosmer & Lemeshaw; .15=Cox &Snell; .20=Nagelkerke. Model $\chi^2(1)$=5.81 p=.016 *p=.026

Model 2: The PANAS was entered into the analysis as an IV (Block 1) and CTRF intensity was entered as an IV (Block 2), with CTRF distress entered as the DV. Table 34 summarizes the results of the analysis. As is shown in the model, the Odds Ratio for CTRF intensity is significant (p=.014). This can be interpreted as showing that for every 1-point increase in the score for CTRF intensity, the odds of being in the high distress group increase by 1.33. The significance level for CTRF intensity is the item of interest when testing mediation. In future models, if the significance of CTRF intensity is decreased after adding a variable, the variable added can be said to mediate the relationship between CTRF intensity and CTRF distress – after controlling for Negative Affect.

Table 34.

Model 2 Logistic Regression Results

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.07 (.07)	0.91 (1)	1.07	.931	1.229
CTRF Intensity	0.29* (.12)	6.04 (1)	1.33	1.060	1.667
Constant	-5.07 (1.79)	8.05 (1)	0.01		

Note: R^2=.39 Hosmer & Lemeshaw; .32=Cox &Snell; .43=Nagelkerke. Model $\chi^2(2)$=14.02 p=.001 *p=.014

Model 3: Mediation model – PANAS entered as an IV (Block 1) then CTRF intensity as an IV (Block 2), CTRFRep subscales (Block 3) and CTRF distress as the DV. Because of the small sample size, only one CTRFRep subscale could be entered into analysis at a time. Therefore, multiple logistic regressions were performed (i.e. one logistic regression for each CTRFRep subscale). This leads one into the area of multiple comparisons, which is problematic. Although regressions were performed with each CTRFRep subscale, tabular results will be reported only for those subscales that were significant or nearly significant (i.e., p value for CTRF intensity approached non-significance) mediators in the relationship between CTRF intensity and CTRF distress.

The four CTRFRep subscales which performed as mediators of the relationship between CTRF intensity and CTRF distress are the Identity, Acute vs. Chronic Timeline (partial mediator), Consequences and Emotional Representation (partial mediator). Tables 35-38 present the results of the logistic regressions for these subscales.

Table 35.

Model 3 Logistic Regression Results for CTRFRep Identity Subscale

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.02 (0.08)	0.08 (1)	1.02	0.88	1.19
CTRF Intensity	0.22* (.12)	3.30 (1)	1.25	0.98	1.59
CTRFRep Identity	0.14 (.10)	1.96 (1)	1.15	0.95	1.41
Constant	-4.95 (1.81)	7.43 (1)	0.01		

Note: R^2=.48 Hosmer & Lemeshaw; .36=Cox &Snell; .48=Nagelkerke. Model $\chi^2(3)=16.11$ p=.001 *p=.070

Table 36.

Model 3 Logistic Regression Results for CTRFRep Timeline Acute vs. Chronic Subscale

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.07 (0.07)	1.02 (1)	1.08	0.93	1.24
CTRF Intensity	0.26* (.13)	4.25 (1)	1.30	1.01	1.66
CTRFRep Acute vs. Chronic Timeline	0.06 (.01)	0.33 (1)	1.06	0.87	1.28
Constant	-5.53 (2.01)	7.57 (1)	0.04		

Note: R^2=.40 Hosmer & Lemeshaw; .33=Cox &Snell, .44=Nagelkerke. Model χ^2(30=14.36 p=.002 *p=.039

Table 37.

Model 3 Logistic Regression Results for CTRFRep Consequences Subscale

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.06 (0.08)	0.48 (1)	1.06	0.91	1.24
CTRF Intensity	0.17* (.13)	1.68 (1)	1.19	0.92	1.54
CTRFRep Consequences	0.31 (.14)	5.06 (1)	1.36	1.04	1.79
Constant	-8.99 (2.95)	9.33 (1)	0.00		

Note: R^2=.72 Hosmer & Lemeshaw; .44=Cox &Snell; .59=Nagelkerke. Model χ^2(3)=20.91 p=.000 *p=.20

Table 38.

Model 3 Logistic Regression Results for CTRFRep Emotional Representation Subscale

				95% CI for Odds Ratio	
Entered	β(SE)	Wald (df)	Exp(β)	Lower	Upper
Negative Affect	0.06 (0.09)	0.01 (1)	1.01	0.85	1.19
CTRF Intensity	0.25* (.13)	3.83 (1)	1.28	1.00	1.65
CTRFRep Emotional Representation	0..28 (.14)	4.06 (1)	1.33	1.01	1.74
Constant	-6.96 (2.32)	8.97 (1)	0.00		

Note: R^2=.63 Hosmer & Lemeshaw; .42=Cox &Snell; .55=Nagelkerke. Model χ^2(3)=19.32 p=.000 *p=.050

As shown in these tables, the significance level of CTRF intensity approaches or reaches a non-significant p value when these four CTRFRep subscales are added to the logistic regressions. This indicates that these scales act as mediators of the relationship between CTRF intensity and CTRF distress and supports the construct validity of the CTRFRep as well as the model presented in Figure 1. The CTRFRep scales that did not perform as mediators were the Symptom Coherence, Personal Control, and Positive Consequences. Further observation and analysis of these subscales will be necessary in order to understand their relationship to CTRF intensity and CTRF distress.

CHAPTER 5: DISCUSSION

Introduction

This chapter begins with a restatement of the purpose of the study and continues with an examination of the CTRFRep scale and its subscales. The instrument as a whole is discussed. Then the results of each subscale are addressed and the implications for current knowledge and future areas of research are discussed.

Discussion

The purpose of this study was to report on the development of a measure of CTRFRep and describe its psychometric properties in patients undergoing radiation treatment for cancer. The CTRFRep is designed to measure cancer treatment-related fatigue representation, a key component of the model of the fatigue experience depicted in Figure 1. This figure is based upon Leventhal's CSMSR. The main findings of the study were: the subscale factor analyses were not definitive, most likely due to the small sample size; the internal consistency reliability of the majority of the CTRFRep subscales was adequate; and the construct validity of four subscales was supported by mediation models tested using the relationships in Figure 1.

In terms of the utility of the instrument, patients expressed little difficulty in understanding the CTRFRep. In evaluating the CTRFRep using the analysis described, it was found that the majority of the items modified from the original IPQ-R performed well. Since the IPQ-R is based on the CSMSR, these findings tend to support the theoretical consistency of the CTRFRep. Items that were added by the investigator or at the suggestion of the content experts did not perform as well. As a result of the analysis of this study, at least 22 items (see Table 31) will be deleted from future versions of this scale, and it is expected that future research will allow for the deletion of additional items.

The results of the study indicate that parts of the CTRFRep may be a reliable and valid measure of representational beliefs about CTRF, whereas other parts may not. Two subscales (Treatment Control and Cyclical Timeline) from the original IPQ-R, on which the CTRFRep is based, did not show adequate internal consistency reliability. The small size of the sample may be an issue here. However, it is also possible that testing in a more homogeneous group of cancer patients (e.g., patients receiving chemotherapy) may result in improved internal consistency for the Cyclical Timeline subscale, as some chemotherapy patients in this study anecdotally reported that their fatigue was cyclical, and this is also seen in the literature (Mustian, Palesh, & Heckler, 2008).

In terms of the Treatment Control subscale, the reasons for its poor performance as a subscale may also be related to the small sample size. However, there are other questions about the viability of this scale in terms of beliefs about the treatment of cancer treatment-related fatigue. Are patients aware of medications and treatments that can be used for CTRF? The literature suggests that exercise and balancing activities with rest may be useful treatments for CTRF. In what may be the largest gap between current empirical knowledge about CTRF and the CTRFRep instrument, the CTRFRep did not address activity, and had few questions focusing on sleep. In addition, treatment in general connotes something that is done to a person (e.g., radiation treatment) or given to a person (e.g., medication). There are some medical treatments (e.g., erythropoietin therapy) that are helpful for some patients with CTRF, but knowledge or beliefs about these treatments is not assessed in the CTRFRep. Finally, the most effective treatments for CTRF may be things that the patient has to be guided toward or learn how to do for himself (e.g., balancing activities with rest and implementing an exercise program). While these are treatments with proven effectiveness (Berger, et al., 2009), they may not be intuitive for patients. In future versions of the CTRFRep, addressing beliefs about exercise and other activity may be necessary to understand patients’ representations of CTRF and its possible treatments.

The Cause subscale of the CTRFRep showed that most subjects attributed having cancer itself or their cancer treatments as causes of their CTRF, followed by stress, diet, and aging. The factor analysis of the cause subscale was not successful. According to Moss-Morris and Siversten (2009), a sample size of about 85 is necessary to contemplate a successful factor analysis of the causal items of the IPQ-R. Given that the CTRFRep has more items in its Cause subscale than the IPQ-R, the problems with factor analysis at a sample size of 36 are not surprising. Continued data collection should result in a sample size that is adequate to factor the Cause subscale.

A surprising finding is the number of people (28% and 11%) who said that heredity and poor medical care in their past were causes of their CTRF. In terms of face validity, these items could be more likely seen as causes of cancer itself, rather than CTRF. In terms of administration of the questionnaire, the instructions for this section need to be clarified for both face-to-face and possible future self-administration to stress the notion that the interest is in subjects’ beliefs about causes of their CTRF, not their cancer. The Cause subscale has a low Cronbach alpha however, given the independence of the items on the scale and the fact that it likely contains multiple factors this is not surprising. It is not appropriate to interpret alpha reliability on such a scale. Following the accrual of additional subjects and factor analysis of the Cause subscale, the Cronbach alpha of those subscales (e.g., causal beliefs surrounding treatment, causal beliefs surrounding emotional factors) could be properly interpreted for these subscales.

The Identity subscale consists of a list of symptoms patients have experienced since they began having CTRF that they believe are related to their CTRF. This subscale performed fairly well, in both the discriminant validity of the scale and in testing of mediation discussed below. The most common symptoms were those not listed on the original IPQ-R but suggested by the content experts. Some of the more frequently endorsed symptoms are very similar to fatigue (e.g., lack of energy, loss of strength) but others are unique items (e.g., feeling blue, poor concentration) that may add to the information base for helping patients with their CTRF. One thing that is lacking in the current version of the CTRF is a question about what the most salient symptom(s) are for the patient. This question is present in the Symptom Representation Questionnaire (Donovan, Ward, Sherwood, & Serlin, 2008). A question of this nature could be used to focus attention on areas deemed the most important by the patient in future research.

Factor analysis of the CTRFRep subscales with adequate reliability (Acute vs. Chronic Timeline, Consequences, Positive Consequences, Personal Control, Symptom Coherence, and Emotional Representation) could not be completed successfully. There is definitely an issue with sample size here, and it is hoped that a sample size of 100 will be adequate to test the remaining 34 items in these subscales. Interestingly, in general the individual items that performed well in reliability testing were those that came from the original IPQ-R. The items added at the suggestion of content experts or by this investigator did not perform well in the reliability analysis. This finding may support the factor structure of the CTRFRep being similar to that of the IPQ-R, save for the subscales that did not have adequate reliability.

The model of the CTRF experience presented in Figure 1 hypothesizes that CTRF representation mediates the relationship between CTRF intensity and CTRF distress. Thus, construct validity of the CTRFRep scale was tested using the mediation model presented in Figure 1. The distribution of the outcome variable of CTRF distress differed significantly from the normal distribution. The bi-modal distribution of CTRF distress suggested that it may be wise to dichotomize the variable, and so it was dichotomized at the median value of 3.8. This resulted in two samples, one of which could be called “no distress or mild distress,” the other “moderate to severe distress.” Dichotomization of the dependent variable decreased the variability of the sample, and changed the regressions performed from linear to logistic regressions.

In spite of the use of logistic regression, four of the subscales of the CTRFRep at least partially mediated the relationship between CTRF intensity and CTRF distress. The Identity, Acute vs. Chronic Timeline, Consequences, and Emotional Representation subscales acted as mediating variables in the logistic regressions. The strongest mediator was the Consequences subscale, while the least significant partial mediator was the Acute vs. Chronic Timeline subscale. Interestingly, the mediating subscales had higher, statistically significant bivariate correlation with CTRF distress, and all of the mediating subscales had significantly different means between the low distress and high distress groups when compared using a t-test. The subscales that did not act as mediators include the Positive Consequences, Personal Control, and Symptom Coherence subscales. None of the non-mediating variables had a significant bivariate correlation or significantly different means when examined using a t-test.

During preliminary analysis, it was discovered that the CES-D was highly correlated with both the measures of CTRF intensity and CTRF distress. This correlation was such that it created a problem with multicollinearity. Therefore, in spite of wanting to control for both depression and negative affect in the regressions, only negative affect could be included in the regression equations. In addition, the small sample size limited the number of independent variables in the regressions to a maximum of three. Therefore, rather than looking at the combined effect of the CTRFRep subscales, each of the subscales had to be examined individually. A larger sample size could allow inclusion of more of the CTRFRep subscales in the regression analyses.

Limitations

There are several limitations to the current study. First, the non-probability convenience sample limits the generalizability of the findings. The sample of 48 patients was a small sample for analyses of this sort. The recruitment clinic was located in a teaching hospital in the Midwest. Although indigent patients are also treated at this clinic, the sample included few minority subjects. This limits the generalizability of these findings to non-Latino, white patients receiving radiation treatment for cancer.

The cross-sectional, descriptive design of the study is appropriate for the scope of this study, which was an introductory test of the CTRFRep instrument. However, this design limits the ability to state any causal relationships between variables related to changes over time. When compared to other studies, the use of a model incorporating logistic regression and a mediation model to test construct validity is a more robust method than comparison of Pearson correlation coefficients.

The results of this study show that depression is highly correlated with the outcome variable of CTRF distress. This limited the scope of the logistic regressions to controlling for negative affect alone, rather than the plan to control for negative affect and depression. The small sample size limited the use of independent variables in the logistic regression to three per analysis. This resulted in the use of multiple comparisons, which is problematic because it effectively increases the p-value. With more variables in the logistic regression, there may have been fewer CTRFRep variables that were significant mediators of the relationship between CTRF intensity and CTRF distress.

In summary, preliminary testing with this small sample size shows some support for the relationships hypothesized in Figure 1. The CTRFRep has four subscales that appear to be reliable and valid (Identity, Acute vs. Chronic Timeline, Consequences, and Emotional Representation). The Cause subscale appears to function well but will need to be tested using factor analysis before any relationships between it and the other constructs in the model can be tested. Two subscales failed reliability testing in this sample, (Treatment Control and Cyclical Timeline). Answers as to whether this is an issue with sample size or the underlying constructs as they related to cancer treatment-related fatigue will need to await further testing.

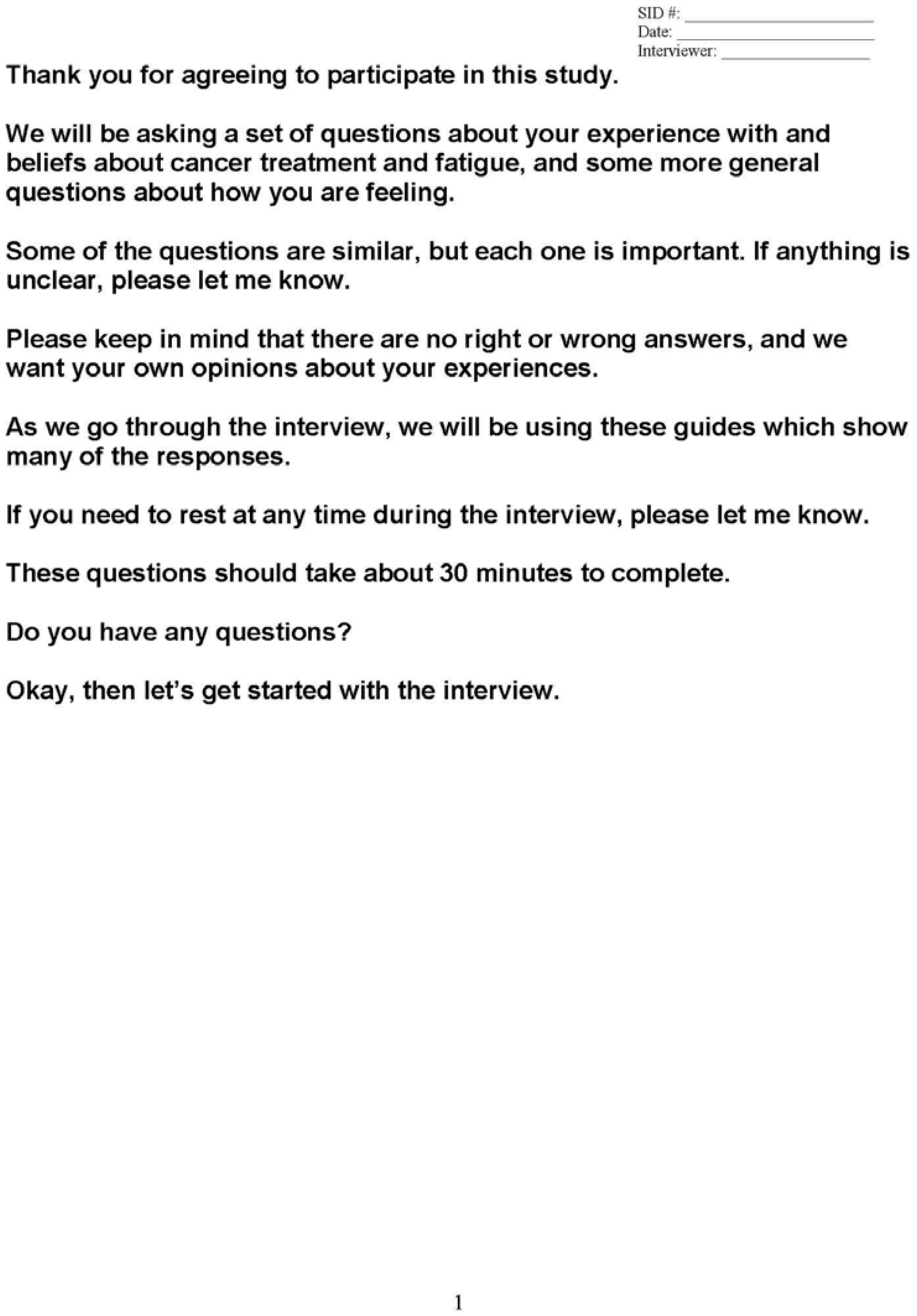
Directions for Future Research

The results of this study hold direct implications for further research in the area of CTRF and for the CTRFRep instrument. In the immediate term, data collection should continue in order to obtain a sample size adequate for factor analysis. The continuing goal is to develop a parsimonious, theoretically consistent instrument to measure CTRF representation. The methodology of the current study is labor intensive, and future research should take this into account and attempt to develop a simpler means of conducting the research.

Plans for future research include testing the CTRFRep in other populations of cancer patients in order to understand the differences in CTRF representational beliefs across other types of cancer treatment. Further development and testing of the relationships hypothesized in Figure 1 is necessary so that healthcare providers can have a better understanding of patients’ beliefs thoughts and emotions surrounding the experience of CTRF. This information, once acquired, can be used to drive tailored interventions for particular beliefs about CTRF in order to improve patient outcomes.

APPENDICES

Appendix A: Instrument Packet



SID #: ____________________
Date: ______________________
Interviewer: _______________

Thank you for agreeing to participate in this study.

We will be asking a set of questions about your experience with and beliefs about cancer treatment and fatigue, and some more general questions about how you are feeling.

Some of the questions are similar, but each one is important. If anything is unclear, please let me know.

Please keep in mind that there are no right or wrong answers, and we want your own opinions about your experiences.

As we go through the interview, we will be using these guides which show many of the responses.

If you need to rest at any time during the interview, please let me know.

These questions should take about 30 minutes to complete.

Do you have any questions?

Okay, then let's get started with the interview.

SID #: ____________________
Date: ____________________
Interviewer: ________________

MFI-20

In the first set of questions, we would like to find out how you have been feeling during the past two weeks, including today. I will read statements to you. For each statement, please tell me how true the statement is for you.

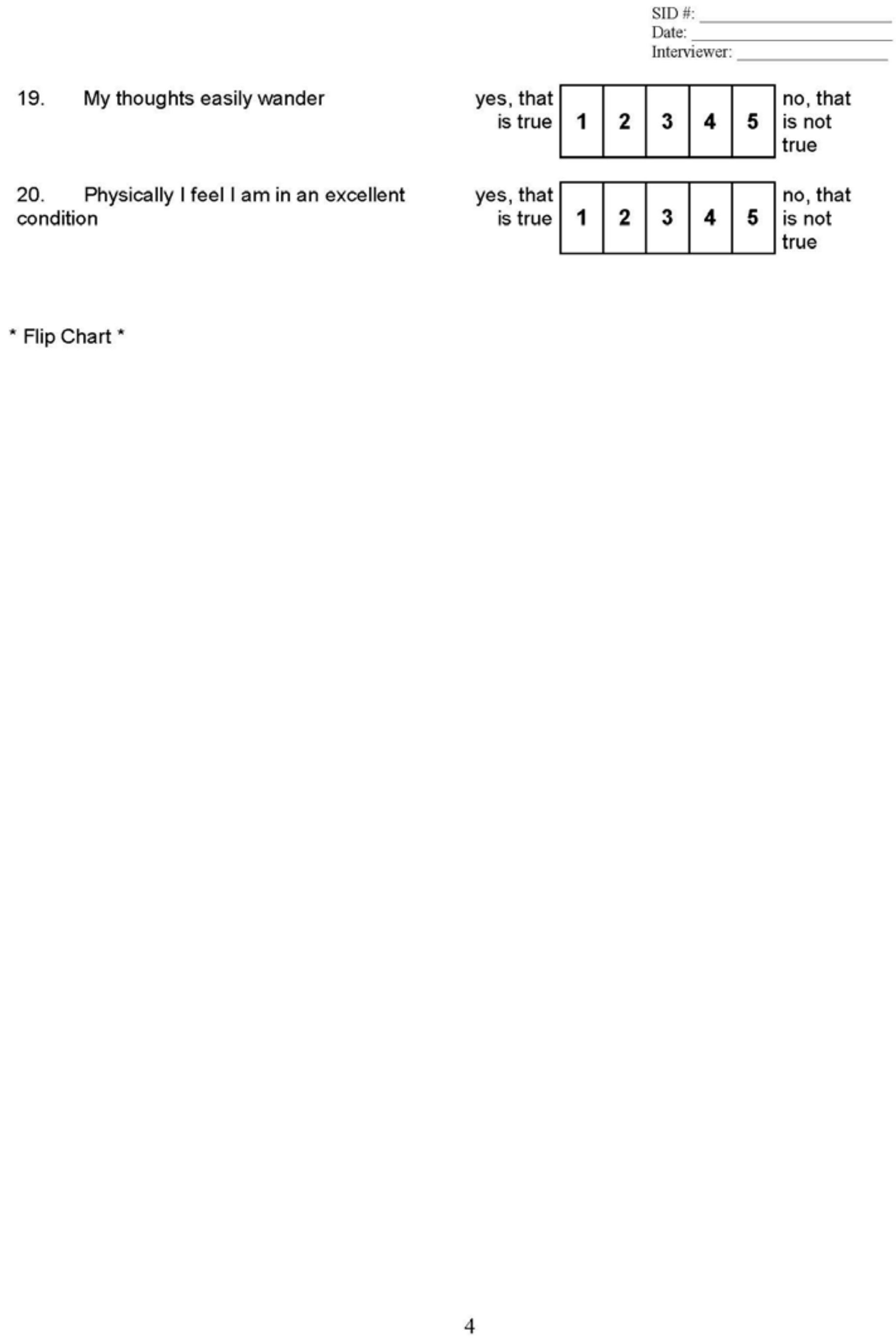
Your response will be a number from 1 to 5 where 1 means “Yes, that is true” and 5 means “No, that is not true” for me over the past two weeks, including today.

For example, if I read the statement "I FEEL RELAXED" and you think this is entirely true, that you have been feeling relaxed over the past two weeks, including today, your answer would be 1. If you think it is not at all true, your answer would be 5.

1.	I feel fit	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
2.	Physically I feel only able to do a little	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
3.	I feel very active	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
4.	I feel like doing all sorts of nice things	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
5.	I feel tired	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
6.	I think I do a lot in a day	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
7.	When I am doing something, I can keep my thoughts on it	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true

SID #: ____________________
Date: ____________________
Interviewer: ________________

8.	Physically I can take on a lot	yes, that is true	1	2	3	4	5	no, that is not true
9.	I dread having to do things	yes, that is true	1	2	3	4	5	no, that is not true
10.	I think I do very little in a day	yes, that is true	1	2	3	4	5	no, that is not true
11.	I can concentrate well	yes, that is true	1	2	3	4	5	no, that is not true
12.	I am rested	yes, that is true	1	2	3	4	5	no, that is not true
13.	It takes a lot of effort to concentrate on things	yes, that is true	1	2	3	4	5	no, that is not true
14.	Physically I feel I am in a bad condition	yes, that is true	1	2	3	4	5	no, that is not true
15.	I have a lot of plans	yes, that is true	1	2	3	4	5	no, that is not true
16.	I tire easily	yes, that is true	1	2	3	4	5	no, that is not true
17.	I get little done	yes, that is true	1	2	3	4	5	no, that is not true
18.	I don't feel like doing anything	yes, that is true	1	2	3	4	5	no, that is not true



SID #: ____________________
Date: ____________________
Interviewer: ________________

19. My thoughts easily wander	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true
20. Physically I feel I am in an excellent condition	yes, that is true	**1**	**2**	**3**	**4**	**5**	no, that is not true

* Flip Chart *

SID #: ______________________
Date: ________________________
Interviewer: __________________

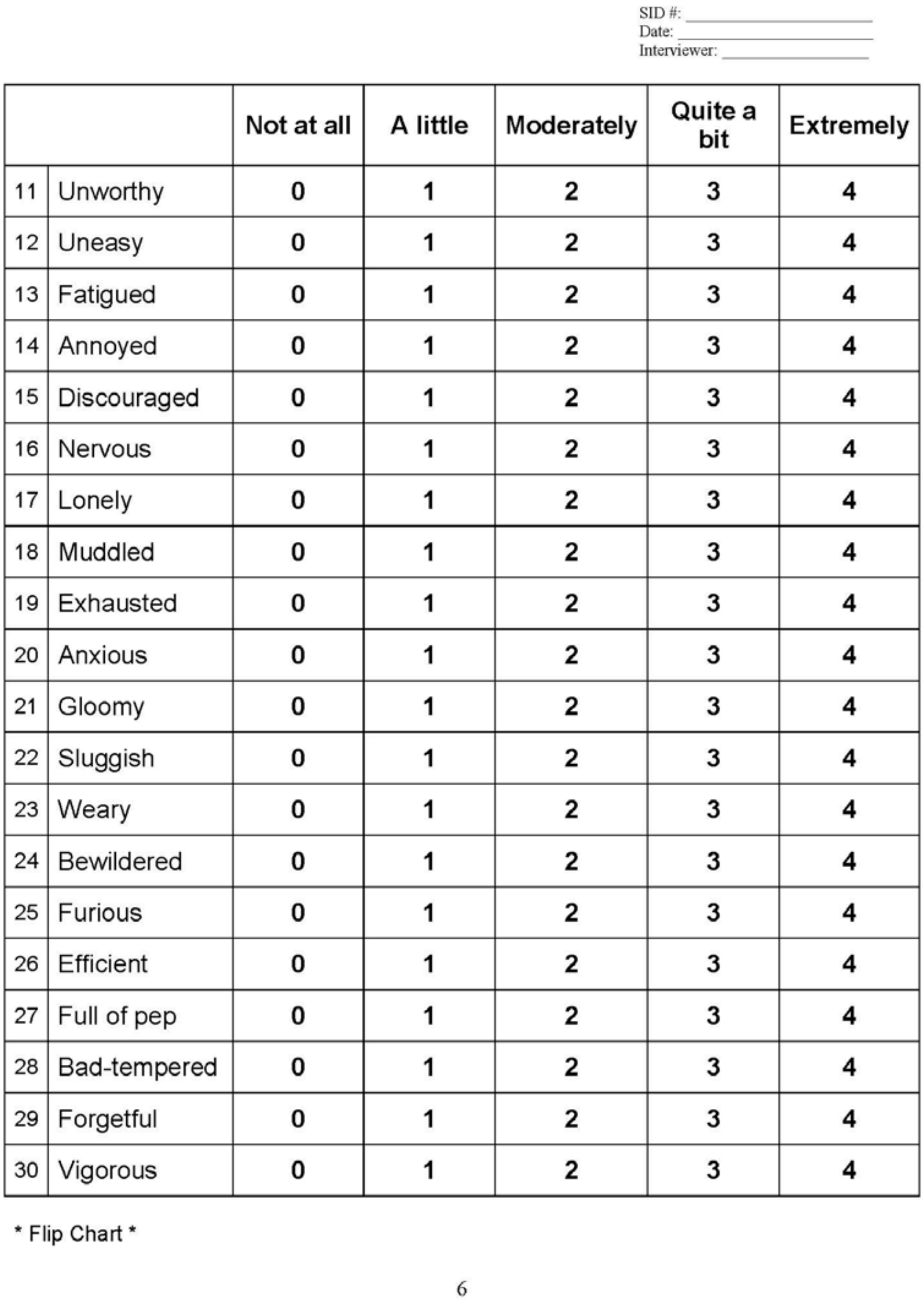
PROFILE OF MOOD STATES-Short form

For the next set of questions, I will read a list of words that describe feelings that people have. After I read each word, please tell me the number that best describes how you have been feeling during the past two weeks, including today.

The answer choices are:
0= Not at all
1= A little
2= Moderately
3= Quite a bit
4= Extremely

During the last two weeks, including today, how much have you felt:

		Not at all	A little	Moderately	Quite a bit	Extremely
1	Tense	**0**	**1**	**2**	**3**	**4**
2	Angry	**0**	**1**	**2**	**3**	**4**
3	Worn out	**0**	**1**	**2**	**3**	**4**
4	Lively	**0**	**1**	**2**	**3**	**4**
5	Confused	**0**	**1**	**2**	**3**	**4**
6	Shaky	**0**	**1**	**2**	**3**	**4**
7	Sad	**0**	**1**	**2**	**3**	**4**
8	Active	**0**	**1**	**2**	**3**	**4**
9	Grouchy	**0**	**1**	**2**	**3**	**4**
10	Energetic	**0**	**1**	**2**	**3**	**4**

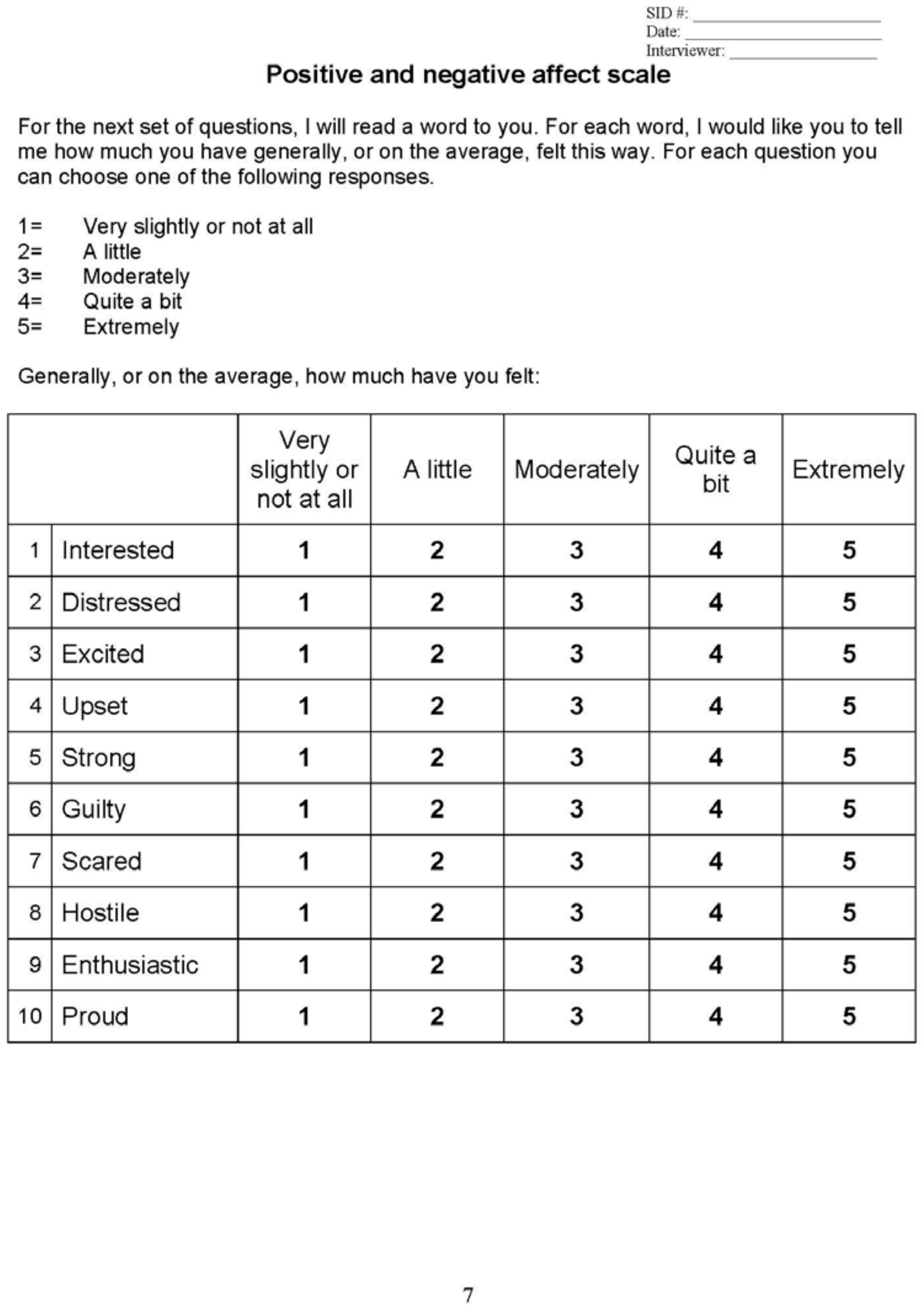


SID #: ____________________
Date: ____________________
Interviewer: ________________

		Not at all	A little	Moderately	Quite a bit	Extremely
11	Unworthy	0	1	2	3	4
12	Uneasy	0	1	2	3	4
13	Fatigued	0	1	2	3	4
14	Annoyed	0	1	2	3	4
15	Discouraged	0	1	2	3	4
16	Nervous	0	1	2	3	4
17	Lonely	0	1	2	3	4
18	Muddled	0	1	2	3	4
19	Exhausted	0	1	2	3	4
20	Anxious	0	1	2	3	4
21	Gloomy	0	1	2	3	4
22	Sluggish	0	1	2	3	4
23	Weary	0	1	2	3	4
24	Bewildered	0	1	2	3	4
25	Furious	0	1	2	3	4
26	Efficient	0	1	2	3	4
27	Full of pep	0	1	2	3	4
28	Bad-tempered	0	1	2	3	4
29	Forgetful	0	1	2	3	4
30	Vigorous	0	1	2	3	4

* Flip Chart *

6



SID #: ____________________
Date: ____________________
Interviewer: ________________

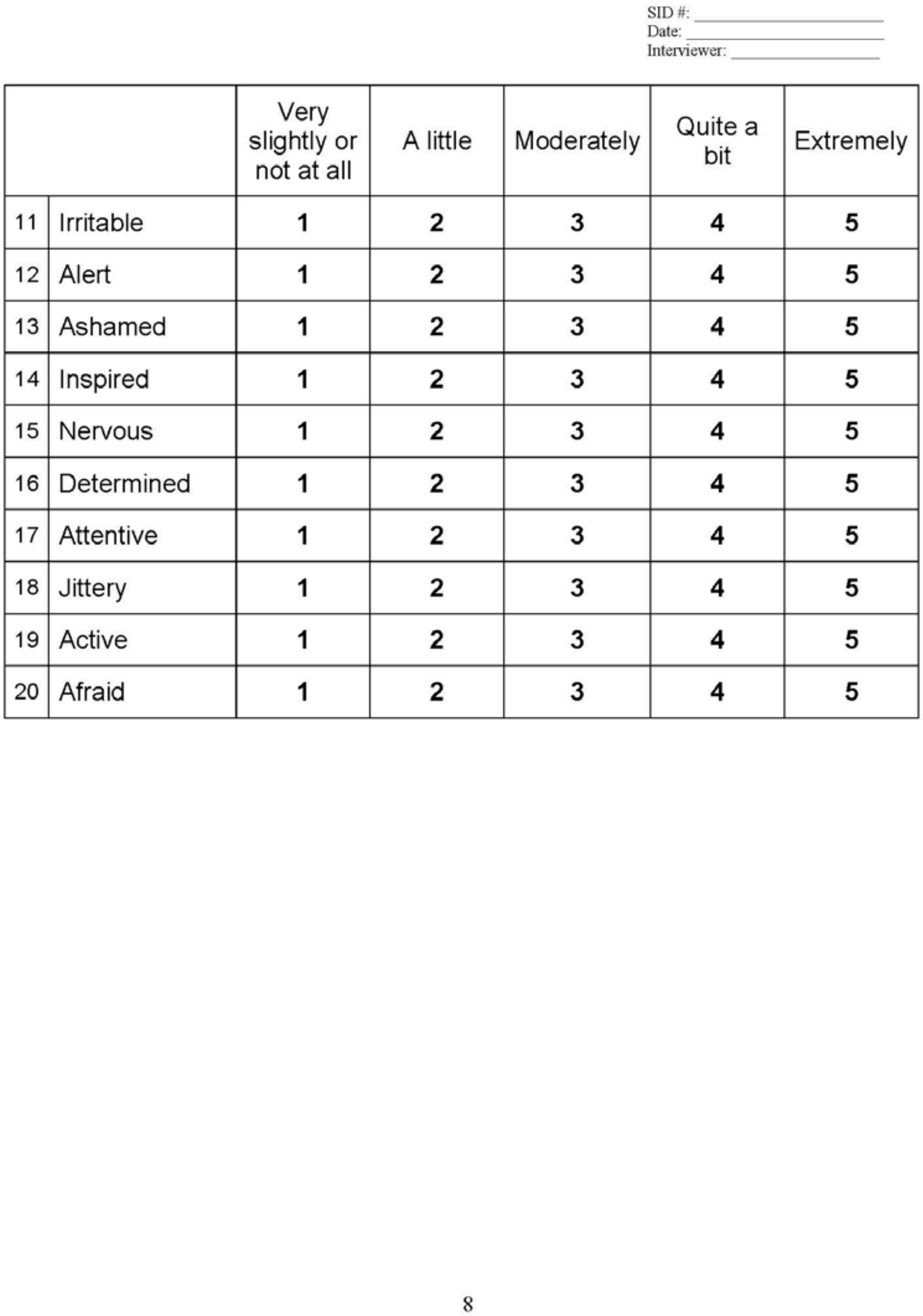
Positive and negative affect scale

For the next set of questions, I will read a word to you. For each word, I would like you to tell me how much you have generally, or on the average, felt this way. For each question you can choose one of the following responses.

1= Very slightly or not at all
2= A little
3= Moderately
4= Quite a bit
5= Extremely

Generally, or on the average, how much have you felt:

		Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
1	Interested	**1**	**2**	**3**	**4**	**5**
2	Distressed	**1**	**2**	**3**	**4**	**5**
3	Excited	**1**	**2**	**3**	**4**	**5**
4	Upset	**1**	**2**	**3**	**4**	**5**
5	Strong	**1**	**2**	**3**	**4**	**5**
6	Guilty	**1**	**2**	**3**	**4**	**5**
7	Scared	**1**	**2**	**3**	**4**	**5**
8	Hostile	**1**	**2**	**3**	**4**	**5**
9	Enthusiastic	**1**	**2**	**3**	**4**	**5**
10	Proud	**1**	**2**	**3**	**4**	**5**



SID #: ______________________

Date: ______________________

Interviewer: __________________

		Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
11	Irritable	**1**	**2**	**3**	**4**	**5**
12	Alert	**1**	**2**	**3**	**4**	**5**
13	Ashamed	**1**	**2**	**3**	**4**	**5**
14	Inspired	**1**	**2**	**3**	**4**	**5**
15	Nervous	**1**	**2**	**3**	**4**	**5**
16	Determined	**1**	**2**	**3**	**4**	**5**
17	Attentive	**1**	**2**	**3**	**4**	**5**
18	Jittery	**1**	**2**	**3**	**4**	**5**
19	Active	**1**	**2**	**3**	**4**	**5**
20	Afraid	**1**	**2**	**3**	**4**	**5**

8

SID #: ____________________
Date: ______________________
Interviewer: ________________

CTRFRep

Based on your answers so far, you have had some fatigue since starting your cancer treatment.

We are defining fatigue as overwhelming tiredness that is:
A) not relieved by rest, and
B) not necessarily related to your activity level.

Fatigue is a symptom that some people have before they are diagnosed or treated for cancer. I need to ask you a few questions about your fatigue to understand it better.

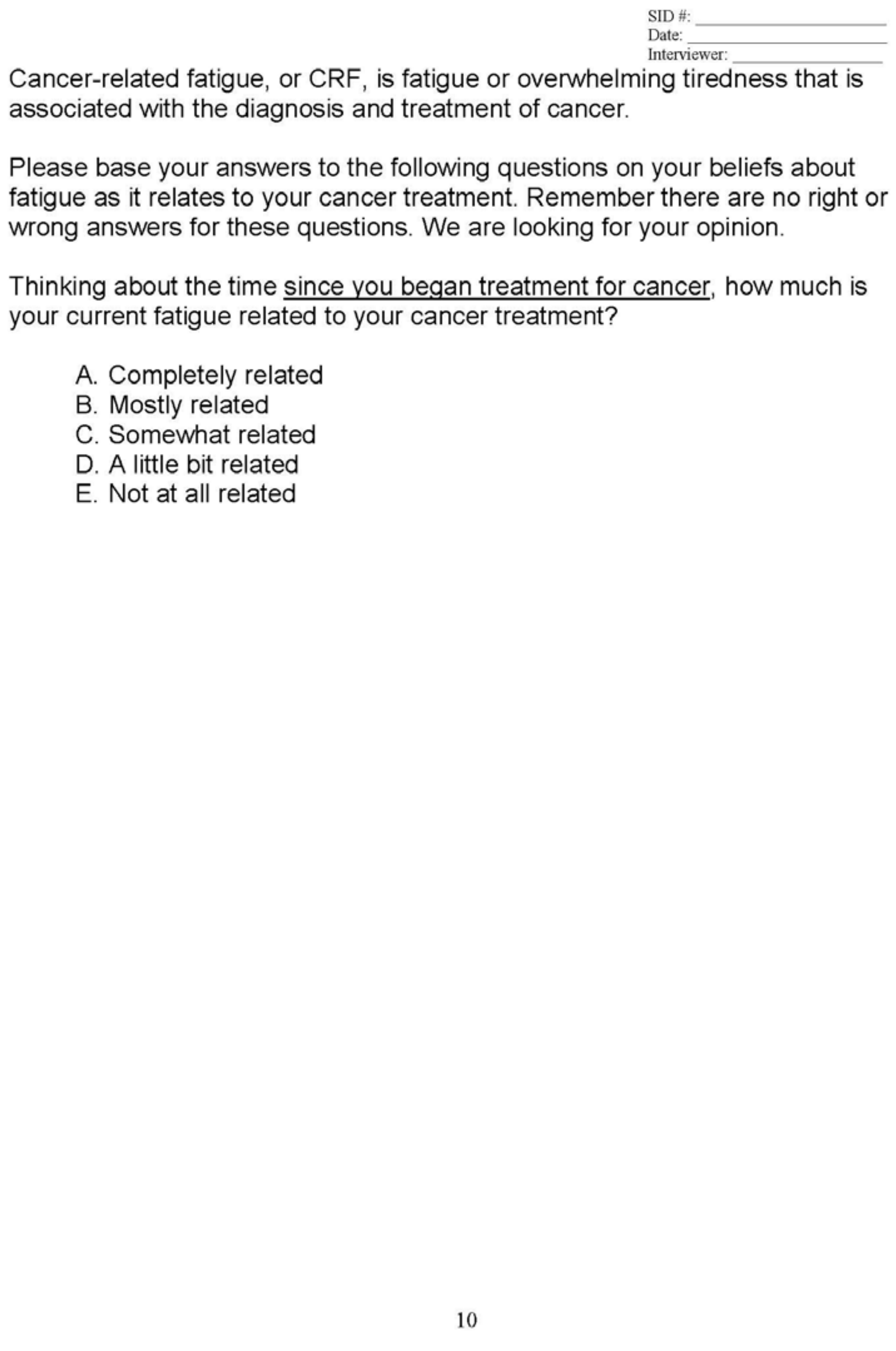
Thinking about the time <u>before you were diagnosed</u> with cancer, did you have fatigue on a regular basis?

YES NO

Now, thinking about the time <u>between when you were diagnosed with cancer and began treatment</u>, did you have fatigue that was different from the fatigue you have had since you began cancer treatment?

YES NO

Thank you for answering these questions about fatigue you may have had before your cancer treatment. The rest of the questions in this section deal with your cancer related fatigue, or CRF.



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Cancer-related fatigue, or CRF, is fatigue or overwhelming tiredness that is associated with the diagnosis and treatment of cancer.

Please base your answers to the following questions on your beliefs about fatigue as it relates to your cancer treatment. Remember there are no right or wrong answers for these questions. We are looking for your opinion.

Thinking about the time since you began treatment for cancer, how much is your current fatigue related to your cancer treatment?

A. Completely related
B. Mostly related
C. Somewhat related
D. A little bit related
E. Not at all related

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YOUR VIEWS ABOUT YOUR CRF

For the next set of questions, I will read a list of symptoms that you may or may not have experienced since you began having cancer-related fatigue (CRF). For each symptom, you will respond YES if you have experienced the symptom since you began having cancer-related fatigue, and NO if you have not.

If you have experienced the symptom, I will ask if you believe this symptom is related to or contributes to your cancer-related fatigue. You will answer these questions with Yes or No.

	I have experienced this symptom since I began having CRF		This symptom is related to or contributes to my CRF	
1. Pain	Yes	No	Yes	No
2. Nausea	Yes	No	Yes	No
3. Breathlessness	Yes	No	Yes	No
4. Weight loss	Yes	No	Yes	No
5. Stiff joints	Yes	No	Yes	No
6. Wheeziness	Yes	No	Yes	No
7. Headaches	Yes	No	Yes	No
8. Upset stomach	Yes	No	Yes	No
9. Difficulty falling asleep	Yes	No	Yes	No
10. Difficulty staying asleep	Yes	No	Yes	No
11. Difficulty waking up	Yes	No	Yes	No
12. Dizziness	Yes	No	Yes	No
13. Loss of strength	Yes	No	Yes	No
14. Muscle soreness	Yes	No	Yes	No
15. Loss of appetite	Yes	No	Yes	No

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	I have experienced this symptom since I began having CRF		This symptom is related to or contributes to my CRF	
16. Poor concentration	Yes	No	Yes	No
17. Short attention span	Yes	No	Yes	No
18. Muscle weakness	Yes	No	Yes	No
19. Sadness	Yes	No	Yes	No
20. Lack of energy	Yes	No	Yes	No
21. Difficulty moving	Yes	No	Yes	No
22. Low endurance	Yes	No	Yes	No
23. Numbness/tingling sensations	Yes	No	Yes	No
24. Feeling blue	Yes	No	Yes	No
25. No desire to move	Yes	No	Yes	No
26. Heavy limbs	Yes	No	Yes	No

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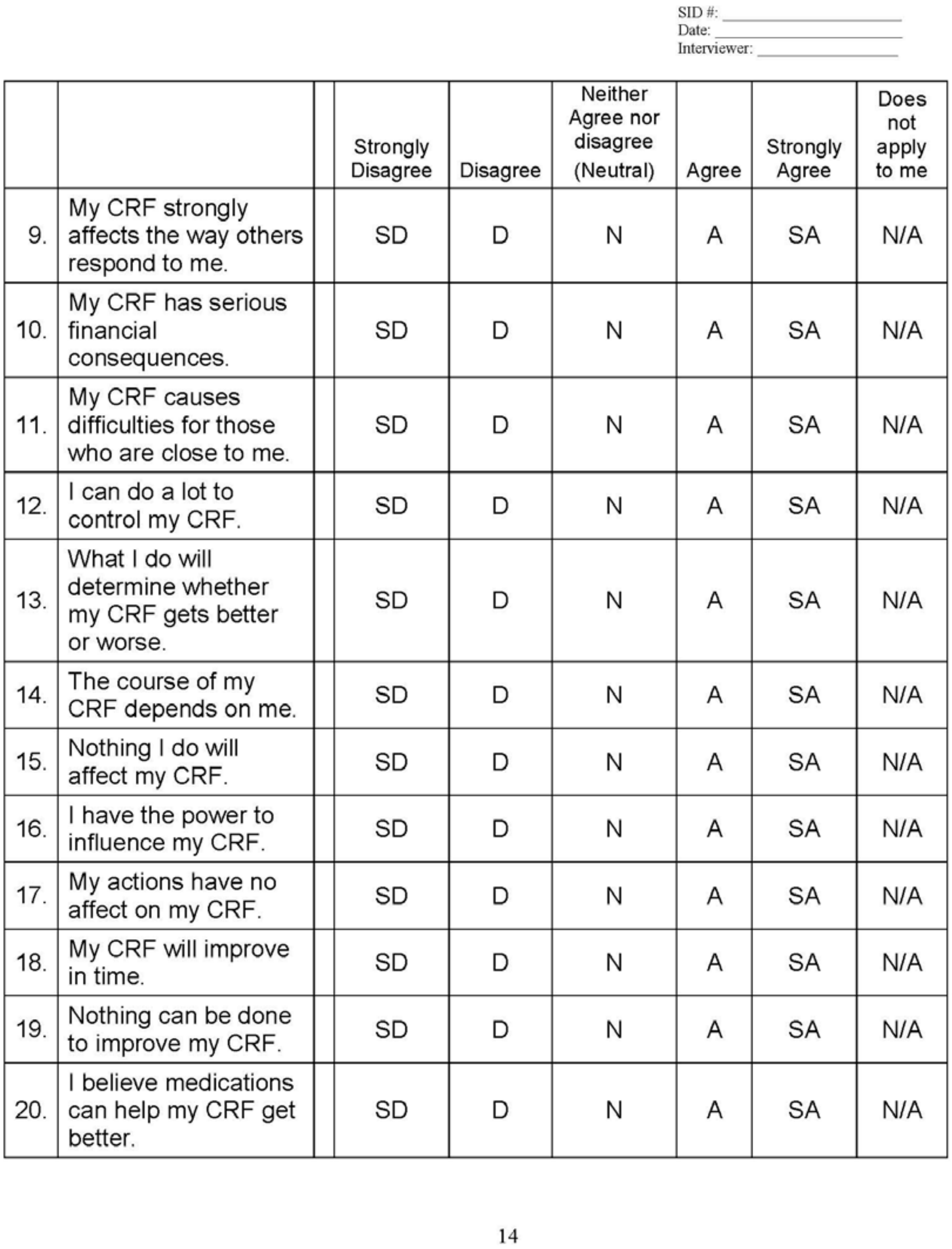
People have many different thoughts about cancer-related fatigue (CRF). We would like to know what you think about your cancer-related fatigue (CRF). For the next set of questions, I will read a statement to you. For each statement, please tell me how much you agree or disagree with the statement. Your response choices are:

Strongly Disagree	Disagree	Neither Agree nor Disagree (Neutral)	Agree	Strongly Agree

Please remember that there are no right or wrong answers, and we are looking for your opinion on each question.

How much do you agree or disagree with these statements?

			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
1.	My CRF will last a short time.		SD	D	N	A	SA	N/A
2.	My CRF is likely to be permanent.		SD	D	N	A	SA	N/A
3.	My CRF will last for a long time.		SD	D	N	A	SA	N/A
4.	My CRF will pass quickly.		SD	D	N	A	SA	N/A
5.	I expect to have CRF for the rest of my life.		SD	D	N	A	SA	N/A
6.	My CRF is a serious symptom.		SD	D	N	A	SA	N/A
7.	My CRF has major consequences on my life.		SD	D	N	A	SA	N/A
8.	My CRF does not have much effect on my life.		SD	D	N	A	SA	N/A



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			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
9.	My CRF strongly affects the way others respond to me.		SD	D	N	A	SA	N/A
10.	My CRF has serious financial consequences.		SD	D	N	A	SA	N/A
11.	My CRF causes difficulties for those who are close to me.		SD	D	N	A	SA	N/A
12.	I can do a lot to control my CRF.		SD	D	N	A	SA	N/A
13.	What I do will determine whether my CRF gets better or worse.		SD	D	N	A	SA	N/A
14.	The course of my CRF depends on me.		SD	D	N	A	SA	N/A
15.	Nothing I do will affect my CRF.		SD	D	N	A	SA	N/A
16.	I have the power to influence my CRF.		SD	D	N	A	SA	N/A
17.	My actions have no affect on my CRF.		SD	D	N	A	SA	N/A
18.	My CRF will improve in time.		SD	D	N	A	SA	N/A
19.	Nothing can be done to improve my CRF.		SD	D	N	A	SA	N/A
20.	I believe medications can help my CRF get better.		SD	D	N	A	SA	N/A

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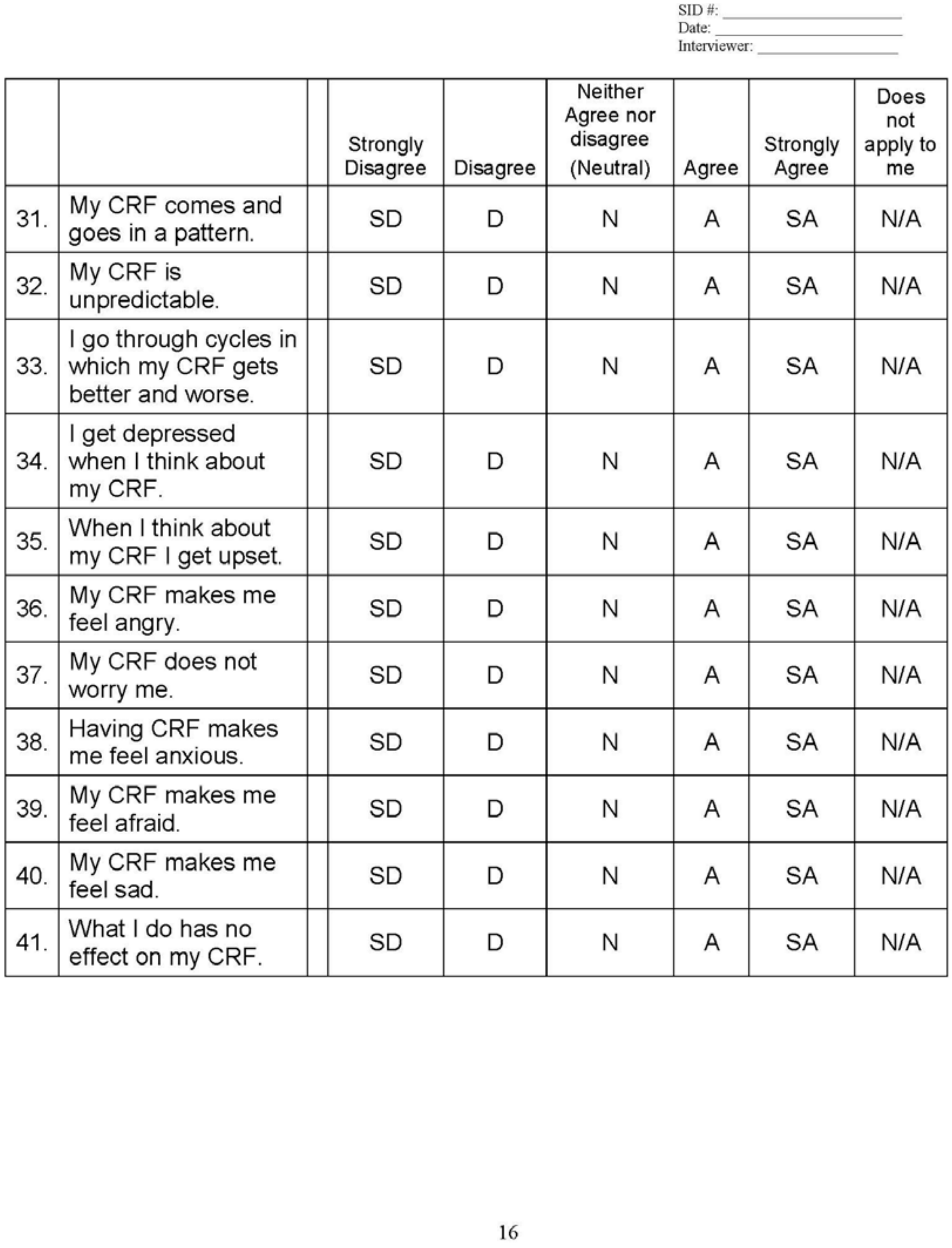
			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
21.	The negative effects of my CRF can be prevented or avoided.		SD	D	N	A	SA	N/A
22.	I believe that eating a healthy diet will help my CRF.		SD	D	N	A	SA	N/A
23.	There is nothing which can help my CRF.		SD	D	N	A	SA	N/A
24.	My CRF is puzzling to me.		SD	D	N	A	SA	N/A
25.	My CRF is a mystery to me.		SD	D	N	A	SA	N/A
26.	I don’t understand my CRF.		SD	D	N	A	SA	N/A
27.	My CRF doesn’t make any sense to me		SD	D	N	A	SA	N/A
28.	I have a clear picture or understanding of my CRF.		SD	D	N	A	SA	N/A
29.	I know why I have CRF.		SD	D	N	A	SA	N/A
30.	My CRF changes a great deal from day to day.		SD	D	N	A	SA	N/A



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			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
31.	My CRF comes and goes in a pattern.		SD	D	N	A	SA	N/A
32.	My CRF is unpredictable.		SD	D	N	A	SA	N/A
33.	I go through cycles in which my CRF gets better and worse.		SD	D	N	A	SA	N/A
34.	I get depressed when I think about my CRF.		SD	D	N	A	SA	N/A
35.	When I think about my CRF I get upset.		SD	D	N	A	SA	N/A
36.	My CRF makes me feel angry.		SD	D	N	A	SA	N/A
37.	My CRF does not worry me.		SD	D	N	A	SA	N/A
38.	Having CRF makes me feel anxious.		SD	D	N	A	SA	N/A
39.	My CRF makes me feel afraid.		SD	D	N	A	SA	N/A
40.	My CRF makes me feel sad.		SD	D	N	A	SA	N/A
41.	What I do has no effect on my CRF.		SD	D	N	A	SA	N/A

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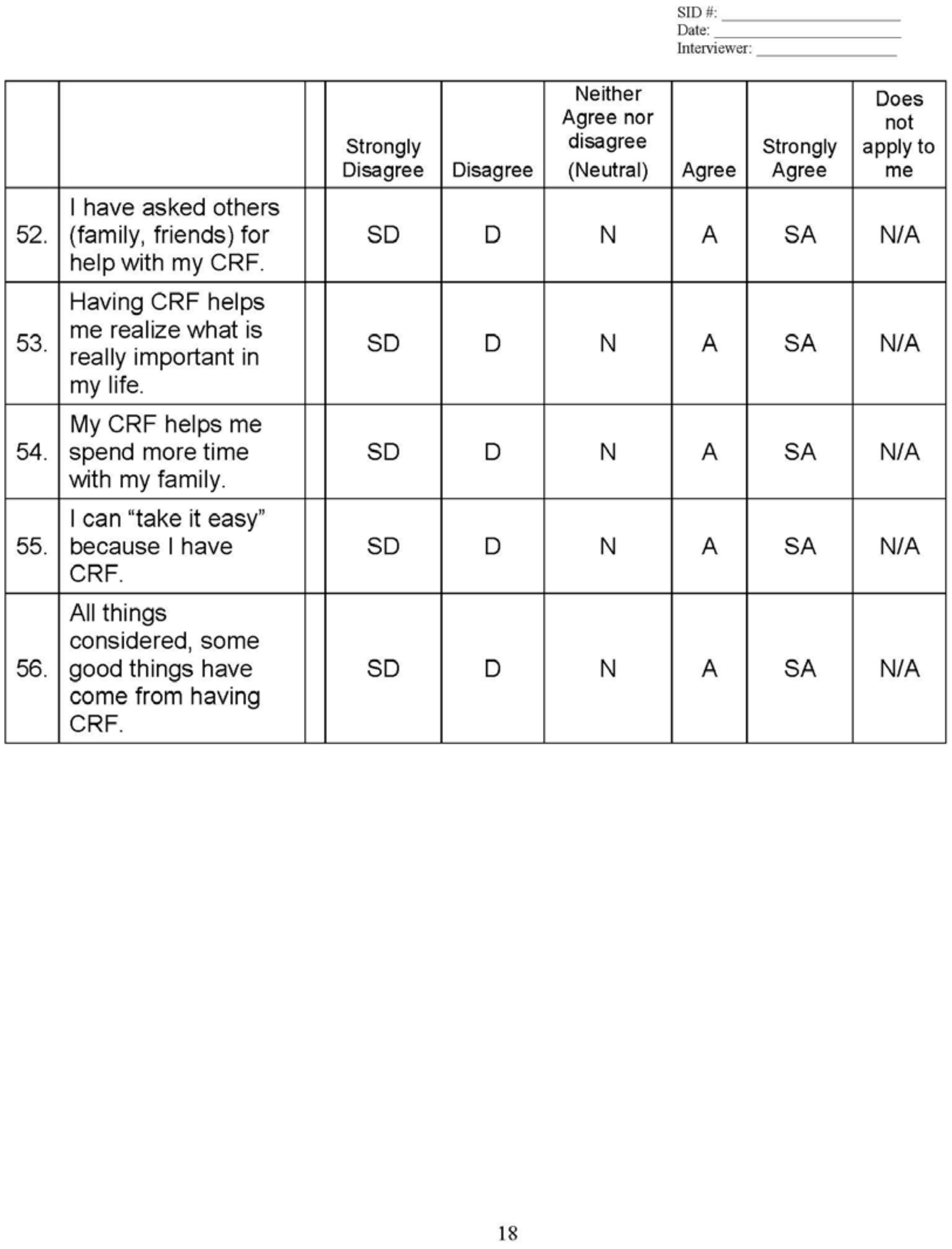
			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
42.	If I could sleep more, my CRF would get better.		SD	D	N	A	SA	N/A
43.	I take naps during the day for my CRF.		SD	D	N	A	SA	N/A
44.	I make sure I sleep at least 8 hours every night		SD	D	N	A	SA	N/A
45.	My doctor knows that I have CRF.		SD	D	N	A	SA	N/A
46.	Eating well balanced meals helps my CRF.		SD	D	N	A	SA	N/A
47.	I ignore my CRF as much as I can.		SD	D	N	A	SA	N/A
48.	I wish my CRF would just go away.		SD	D	N	A	SA	N/A
49.	I asked my doctor if there are any medicines or treatments for my CRF.		SD	D	N	A	SA	N/A
50.	There are things I can do to make my CRF better.		SD	D	N	A	SA	N/A
51.	There is nothing I can do to make my CRF better.		SD	D	N	A	SA	N/A



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Interviewer: __________________

			Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
52.	I have asked others (family, friends) for help with my CRF.		SD	D	N	A	SA	N/A
53.	Having CRF helps me realize what is really important in my life.		SD	D	N	A	SA	N/A
54.	My CRF helps me spend more time with my family.		SD	D	N	A	SA	N/A
55.	I can “take it easy” because I have CRF.		SD	D	N	A	SA	N/A
56.	All things considered, some good things have come from having CRF.		SD	D	N	A	SA	N/A

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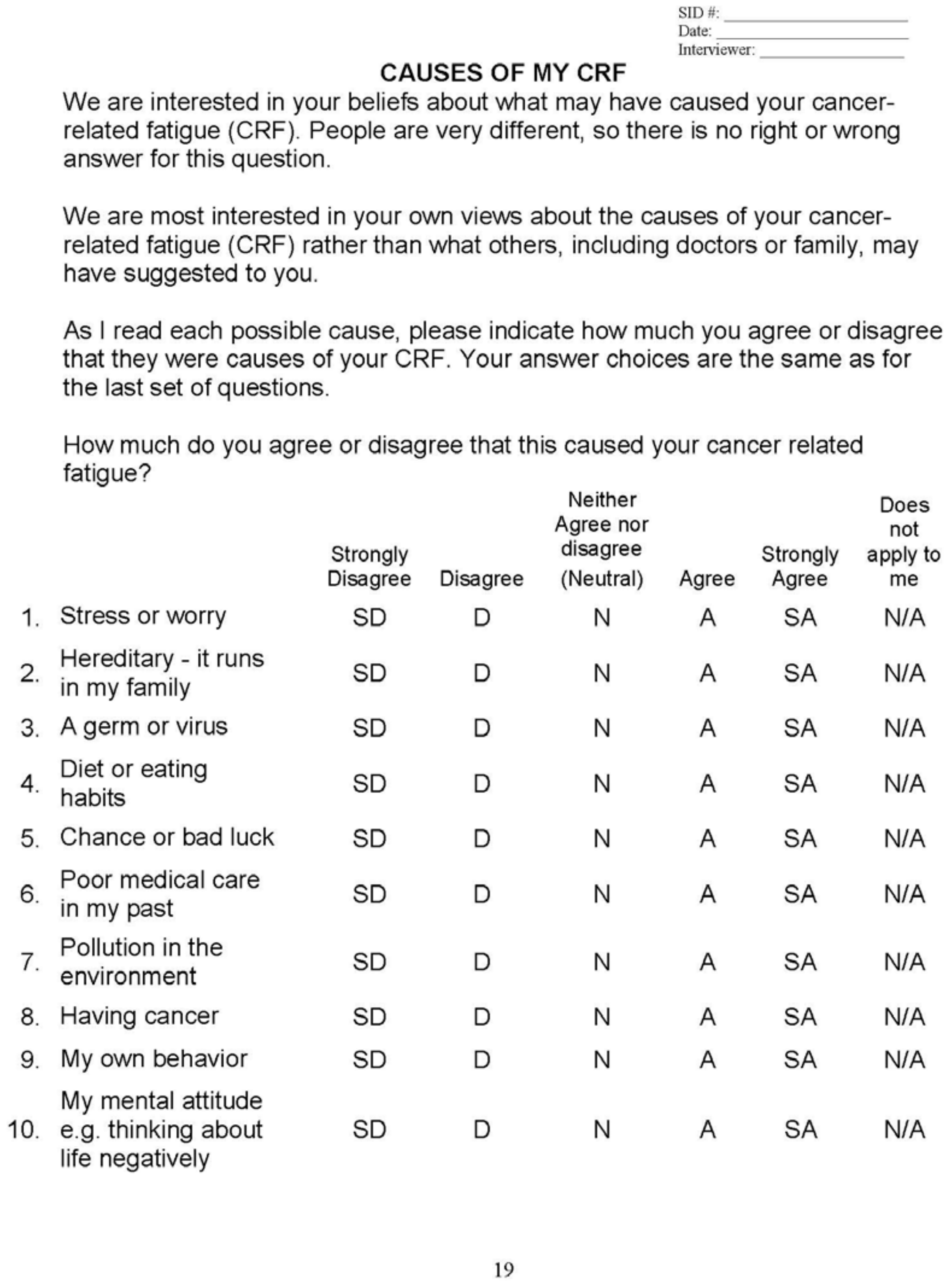

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CAUSES OF MY CRF

We are interested in your beliefs about what may have caused your cancer-related fatigue (CRF). People are very different, so there is no right or wrong answer for this question.

We are most interested in your own views about the causes of your cancer-related fatigue (CRF) rather than what others, including doctors or family, may have suggested to you.

As I read each possible cause, please indicate how much you agree or disagree that they were causes of your CRF. Your answer choices are the same as for the last set of questions.

How much do you agree or disagree that this caused your cancer related fatigue?

		Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
1.	Stress or worry	SD	D	N	A	SA	N/A
2.	Hereditary - it runs in my family	SD	D	N	A	SA	N/A
3.	A germ or virus	SD	D	N	A	SA	N/A
4.	Diet or eating habits	SD	D	N	A	SA	N/A
5.	Chance or bad luck	SD	D	N	A	SA	N/A
6.	Poor medical care in my past	SD	D	N	A	SA	N/A
7.	Pollution in the environment	SD	D	N	A	SA	N/A
8.	Having cancer	SD	D	N	A	SA	N/A
9.	My own behavior	SD	D	N	A	SA	N/A
10.	My mental attitude e.g. thinking about life negatively	SD	D	N	A	SA	N/A

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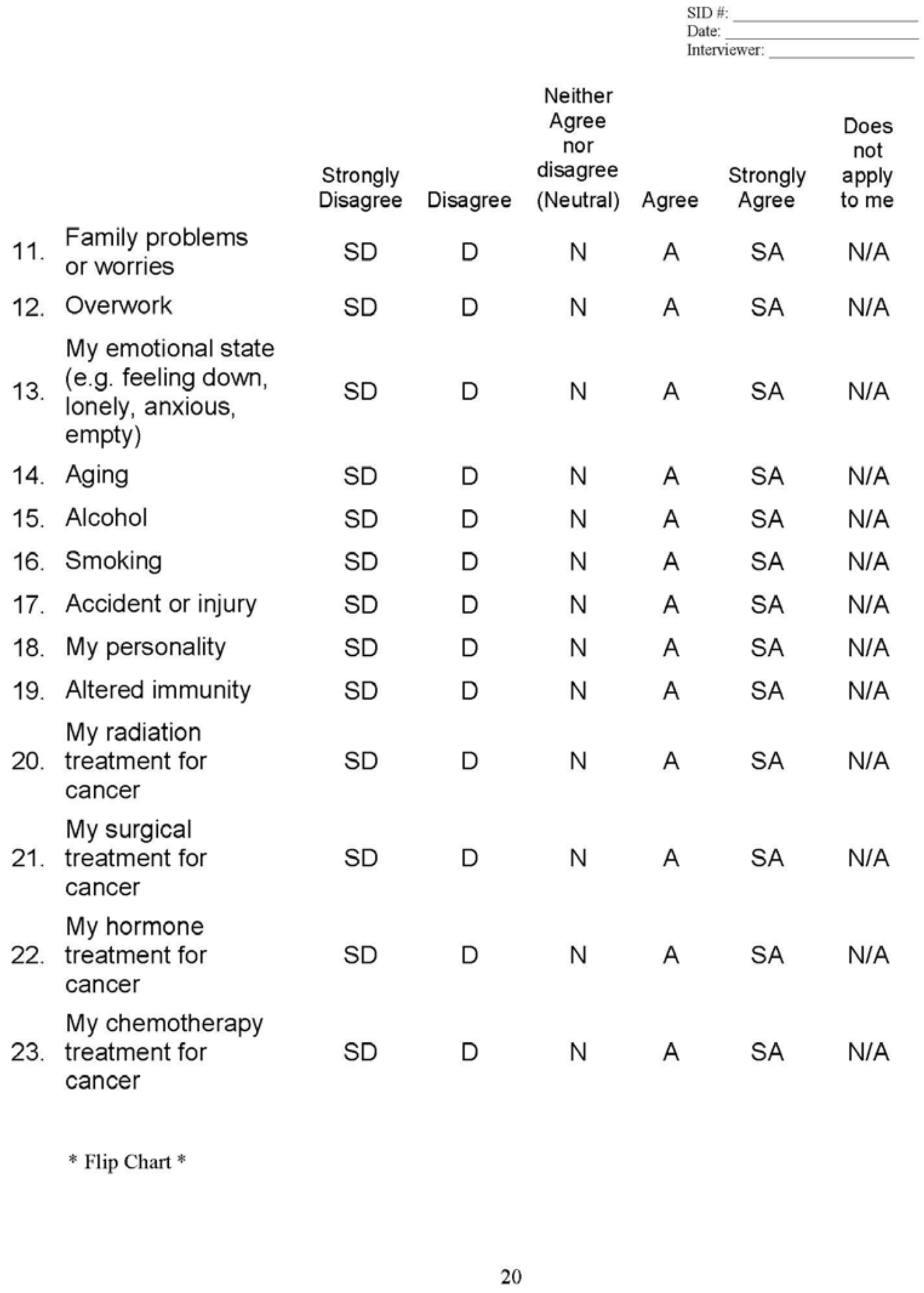

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		Strongly Disagree	Disagree	Neither Agree nor disagree (Neutral)	Agree	Strongly Agree	Does not apply to me
11.	Family problems or worries	SD	D	N	A	SA	N/A
12.	Overwork	SD	D	N	A	SA	N/A
13.	My emotional state (e.g. feeling down, lonely, anxious, empty)	SD	D	N	A	SA	N/A
14.	Aging	SD	D	N	A	SA	N/A
15.	Alcohol	SD	D	N	A	SA	N/A
16.	Smoking	SD	D	N	A	SA	N/A
17.	Accident or injury	SD	D	N	A	SA	N/A
18.	My personality	SD	D	N	A	SA	N/A
19.	Altered immunity	SD	D	N	A	SA	N/A
20.	My radiation treatment for cancer	SD	D	N	A	SA	N/A
21.	My surgical treatment for cancer	SD	D	N	A	SA	N/A
22.	My hormone treatment for cancer	SD	D	N	A	SA	N/A
23.	My chemotherapy treatment for cancer	SD	D	N	A	SA	N/A

* Flip Chart *

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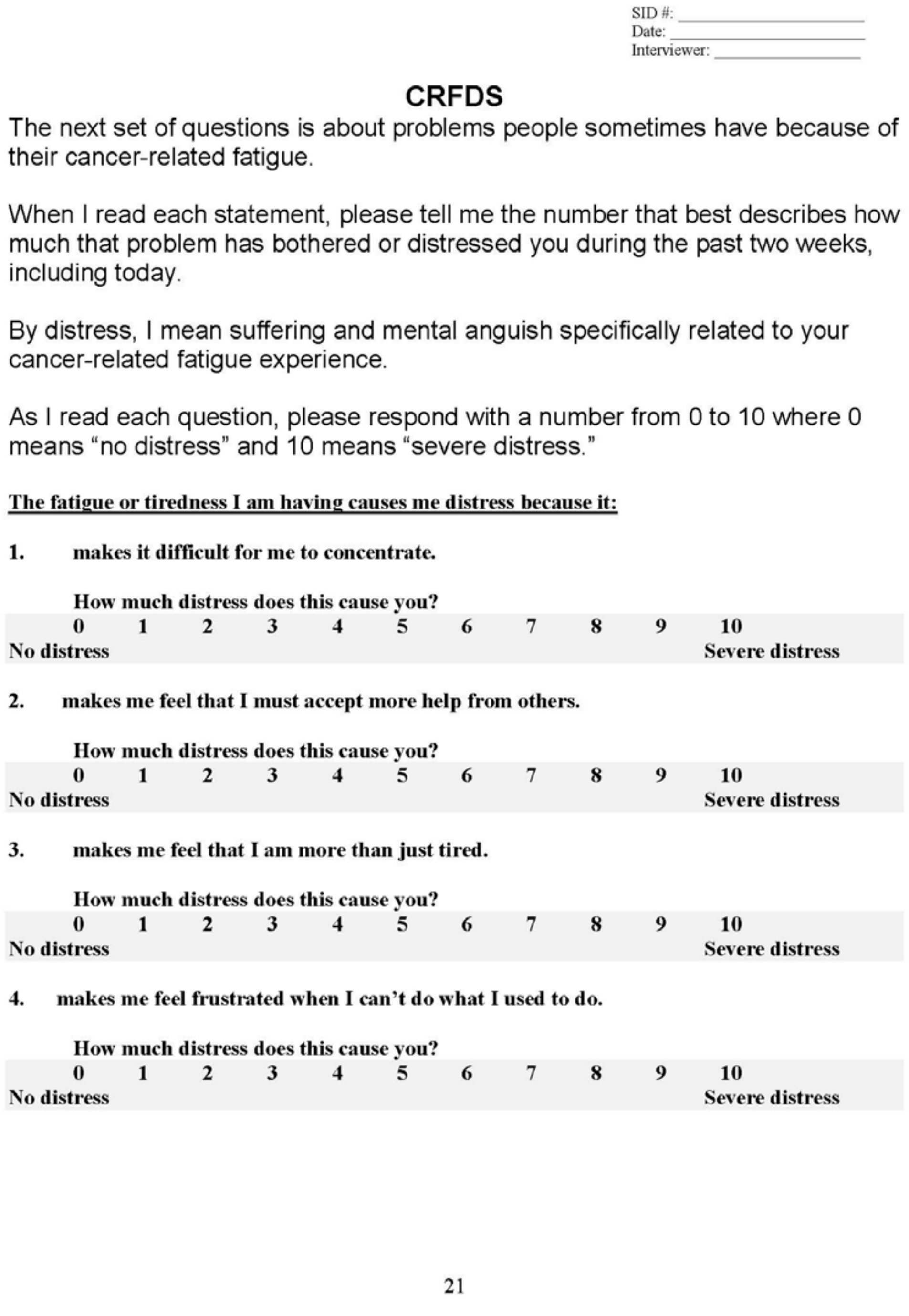

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CRFDS

The next set of questions is about problems people sometimes have because of their cancer-related fatigue.

When I read each statement, please tell me the number that best describes how much that problem has bothered or distressed you during the past two weeks, including today.

By distress, I mean suffering and mental anguish specifically related to your cancer-related fatigue experience.

As I read each question, please respond with a number from 0 to 10 where 0 means "no distress" and 10 means "severe distress."

The fatigue or tiredness I am having causes me distress because it:

1. makes it difficult for me to concentrate.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10
No distress Severe distress

2. makes me feel that I must accept more help from others.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10
No distress Severe distress

3. makes me feel that I am more than just tired.

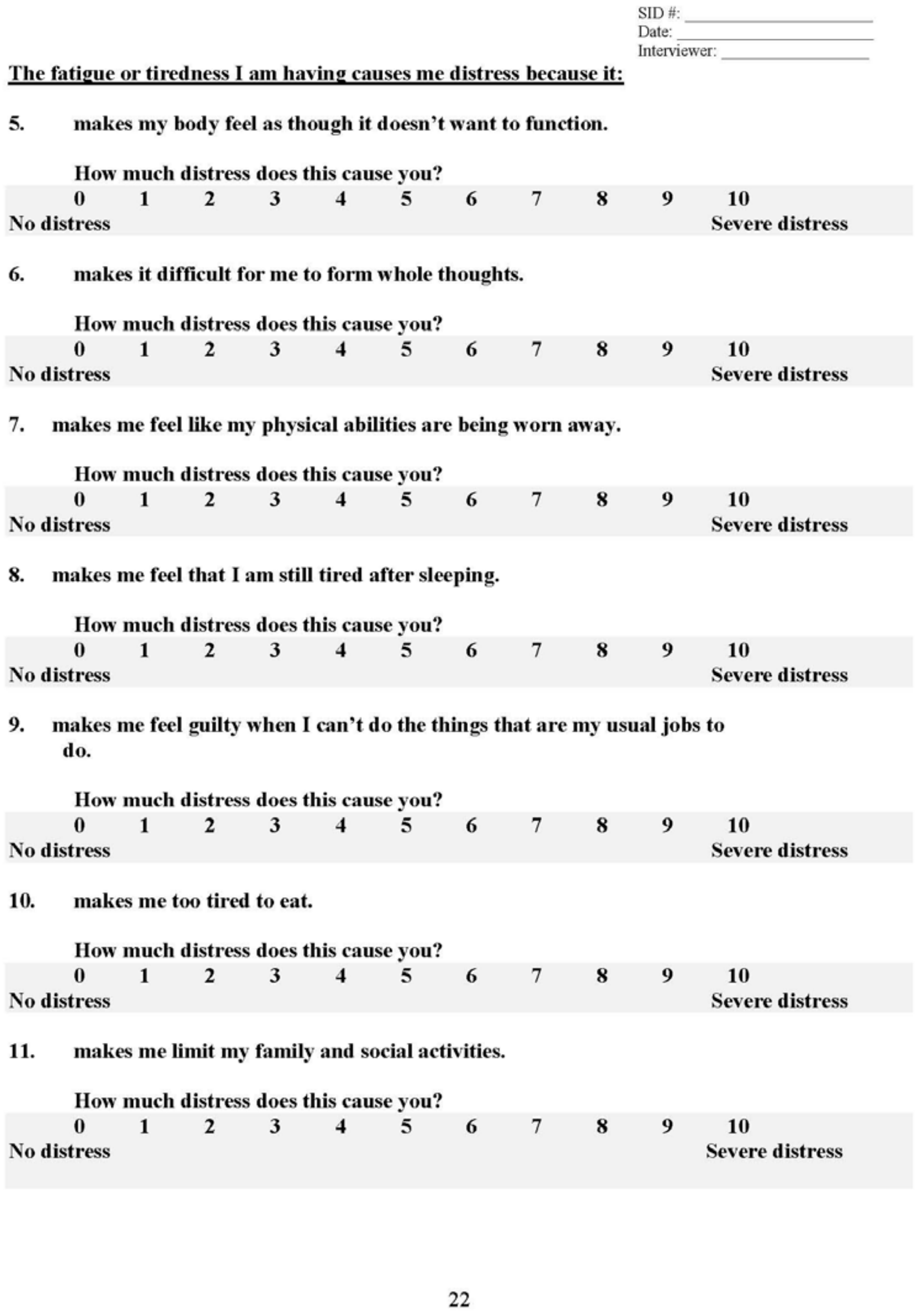
How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10
No distress Severe distress

4. makes me feel frustrated when I can't do what I used to do.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10
No distress Severe distress



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The fatigue or tiredness I am having causes me distress because it:

5. makes my body feel as though it doesn't want to function.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

6. makes it difficult for me to form whole thoughts.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

7. makes me feel like my physical abilities are being worn away.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

8. makes me feel that I am still tired after sleeping.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

9. makes me feel guilty when I can't do the things that are my usual jobs to do.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

10. makes me too tired to eat.

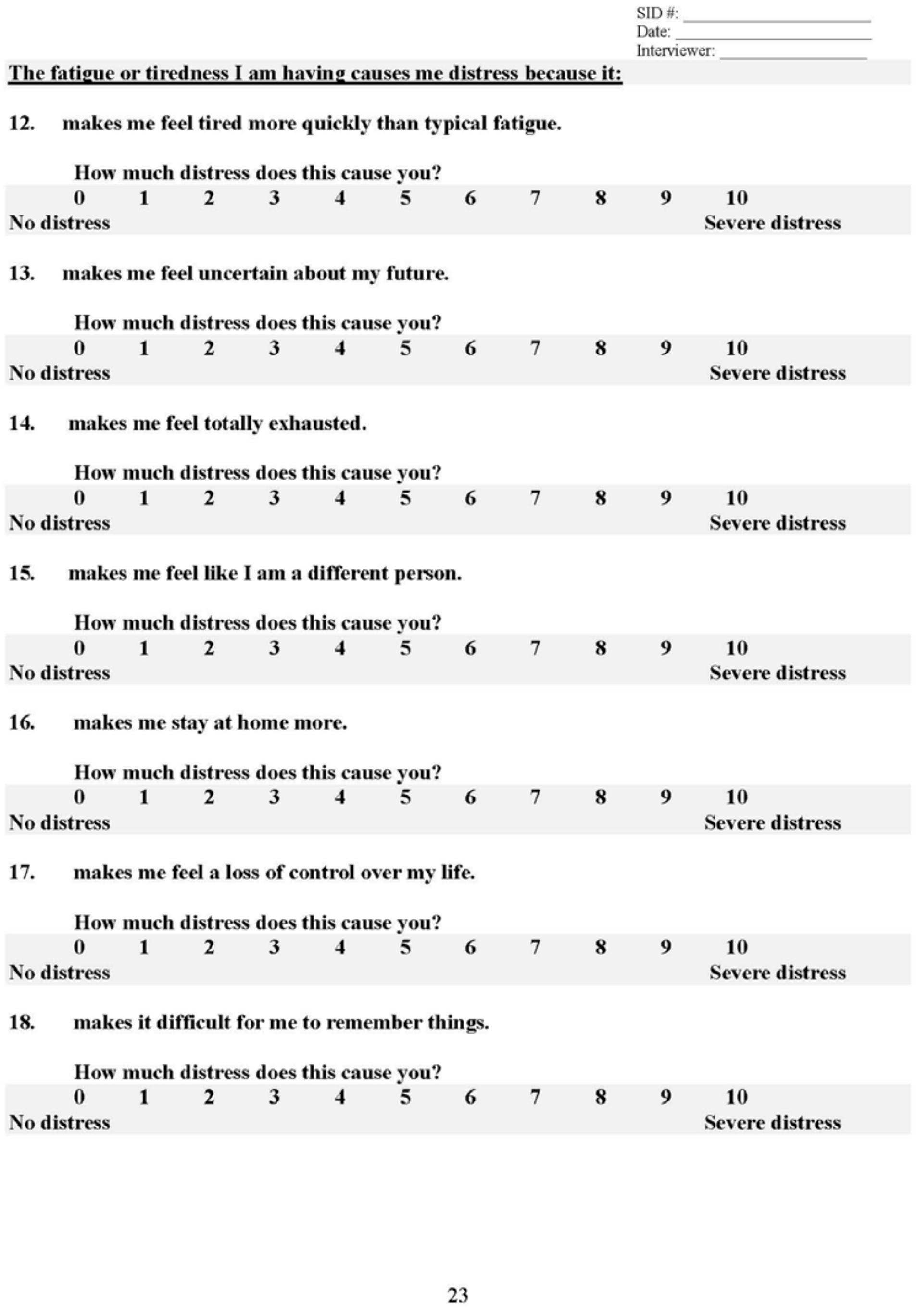
How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress

11. makes me limit my family and social activities.

How much distress does this cause you?

0	1	2	3	4	5	6	7	8	9	10
No distress										Severe distress



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The fatigue or tiredness I am having causes me distress because it:

12. makes me feel tired more quickly than typical fatigue.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

13. makes me feel uncertain about my future.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

14. makes me feel totally exhausted.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

15. makes me feel like I am a different person.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

16. makes me stay at home more.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

17. makes me feel a loss of control over my life.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

18. makes it difficult for me to remember things.

How much distress does this cause you?

0 1 2 3 4 5 6 7 8 9 10

No distress **Severe distress**

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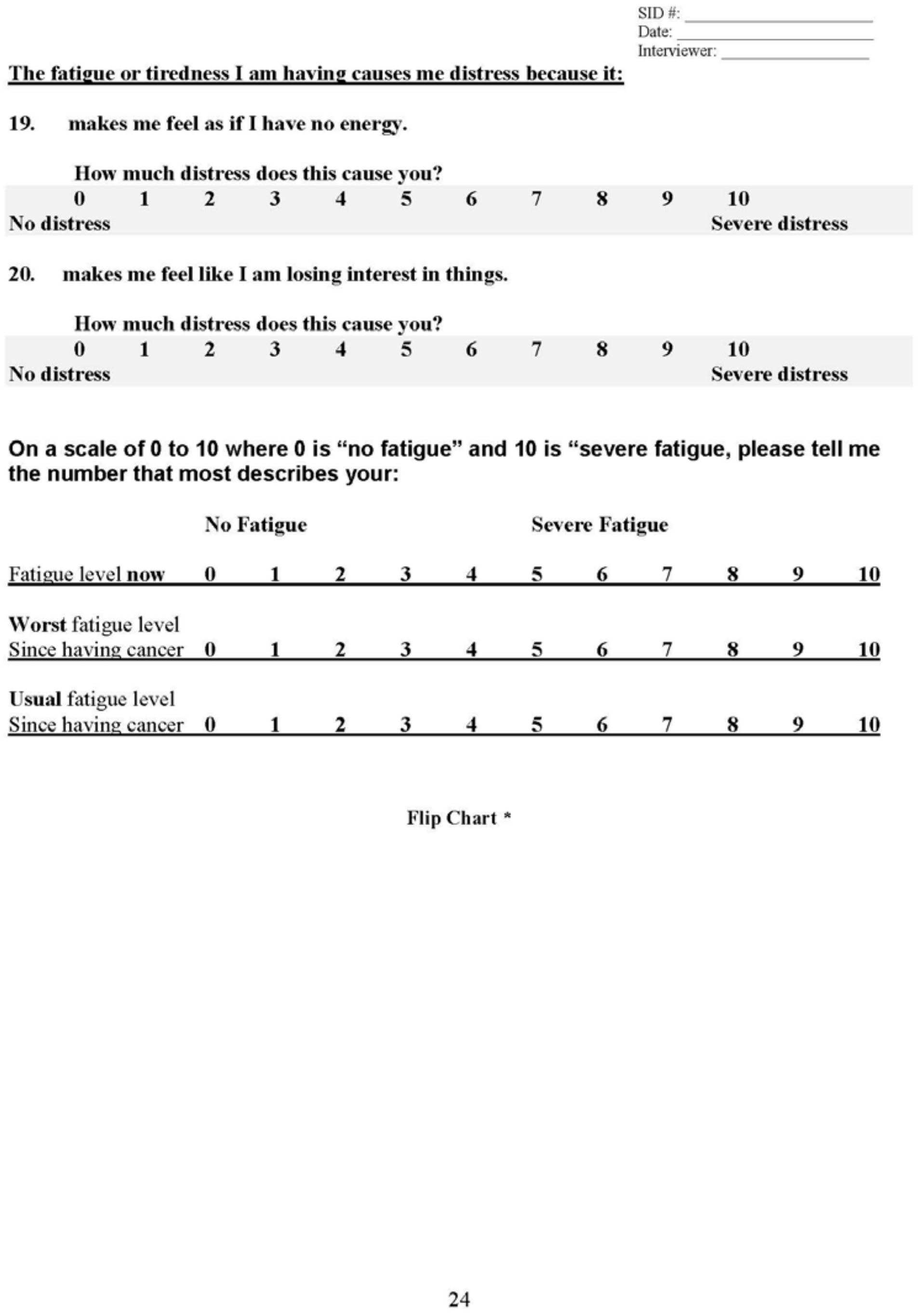

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The fatigue or tiredness I am having causes me distress because it:

19. makes me feel as if I have no energy.

How much distress does this cause you?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No distress										**Severe distress**

20. makes me feel like I am losing interest in things.

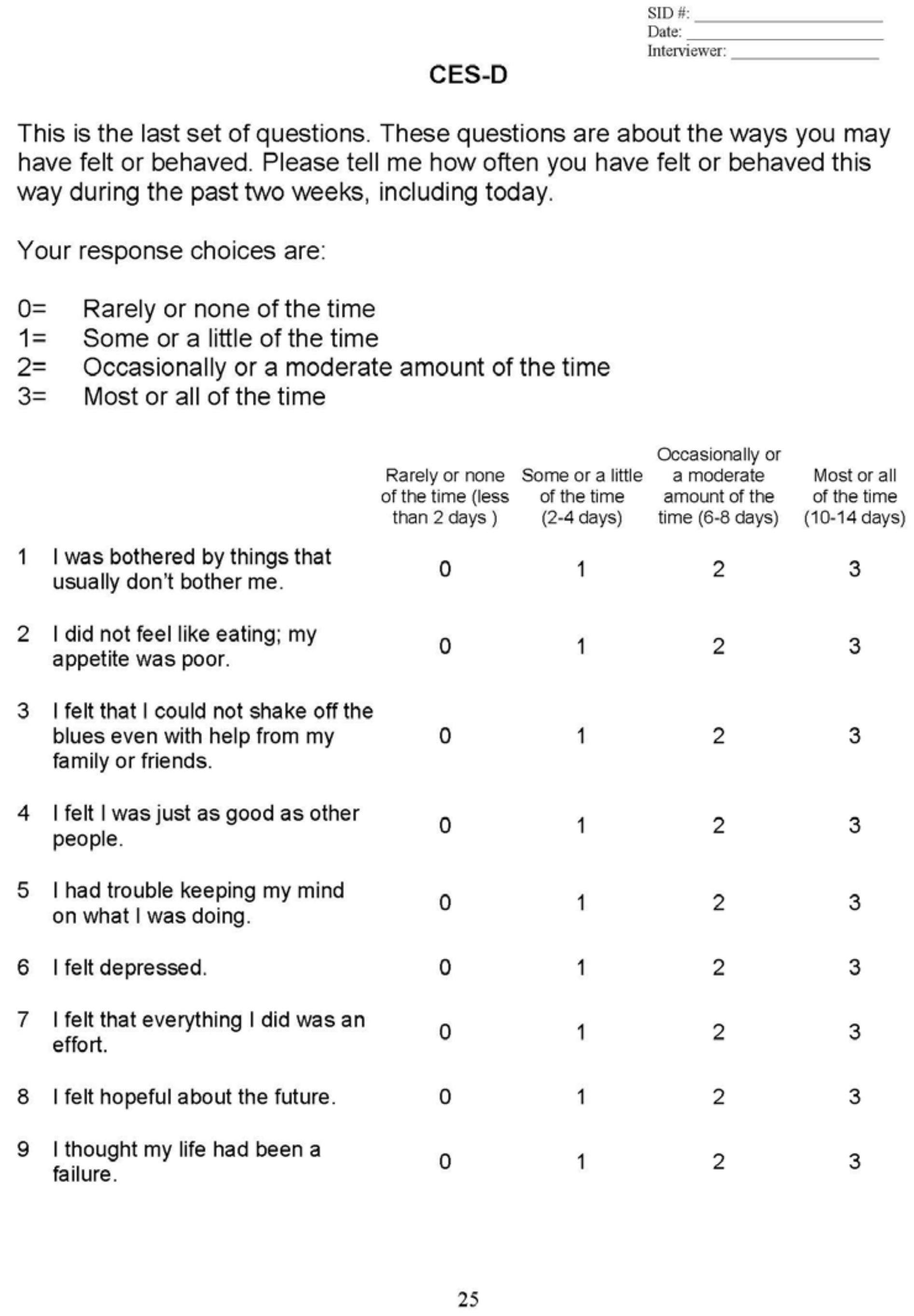
How much distress does this cause you?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No distress										**Severe distress**

On a scale of 0 to 10 where 0 is "no fatigue" and 10 is "severe fatigue, please tell me the number that most describes your:

	No Fatigue					**Severe Fatigue**					
Fatigue level **now**	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Worst fatigue level Since having cancer	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Usual fatigue level Since having cancer	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

Flip Chart *



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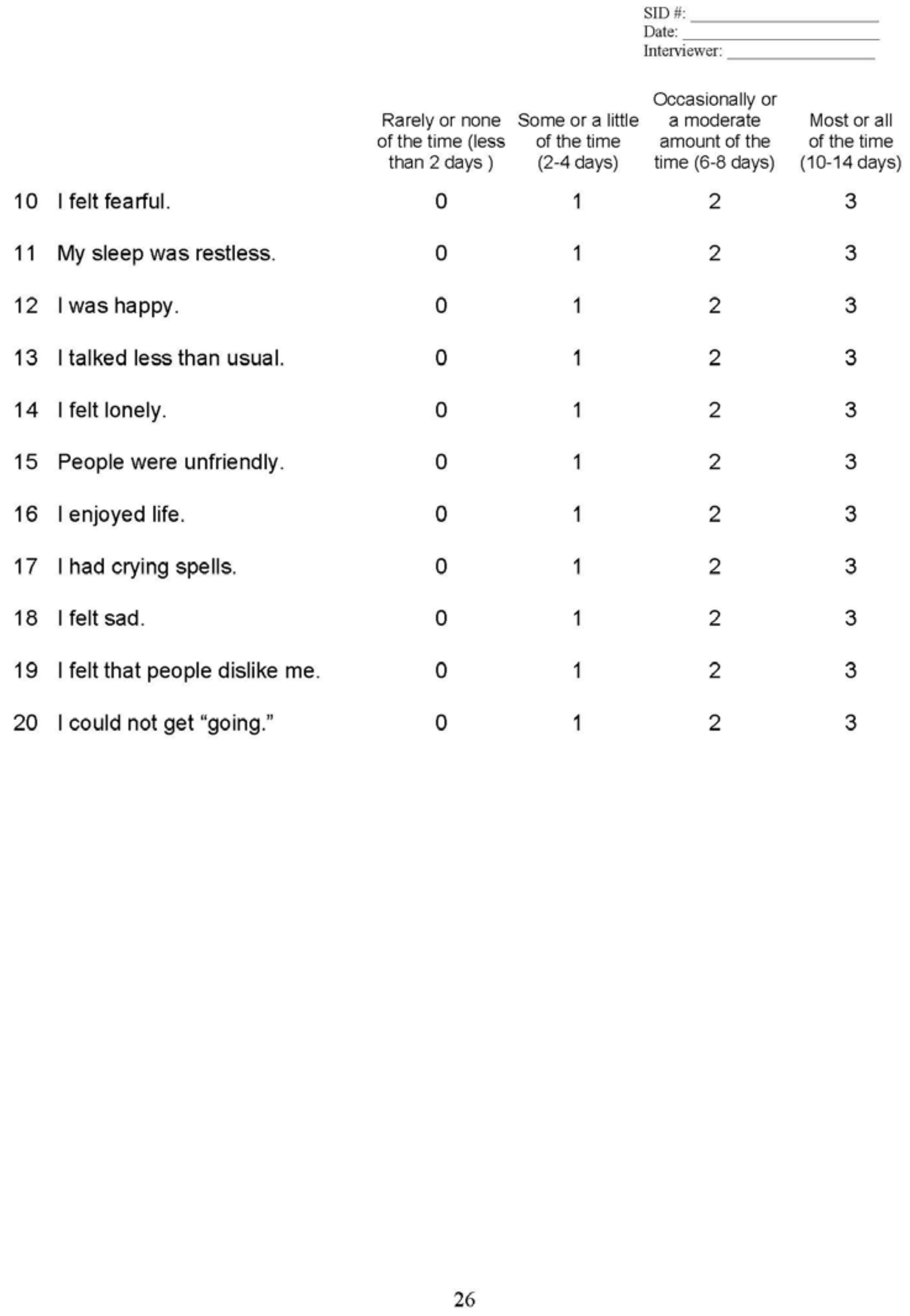
CES-D

This is the last set of questions. These questions are about the ways you may have felt or behaved. Please tell me how often you have felt or behaved this way during the past two weeks, including today.

Your response choices are:

0= Rarely or none of the time
1= Some or a little of the time
2= Occasionally or a moderate amount of the time
3= Most or all of the time

		Rarely or none of the time (less than 2 days)	Some or a little of the time (2-4 days)	Occasionally or a moderate amount of the time (6-8 days)	Most or all of the time (10-14 days)
1	I was bothered by things that usually don't bother me.	0	1	2	3
2	I did not feel like eating; my appetite was poor.	0	1	2	3
3	I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4	I felt I was just as good as other people.	0	1	2	3
5	I had trouble keeping my mind on what I was doing.	0	1	2	3
6	I felt depressed.	0	1	2	3
7	I felt that everything I did was an effort.	0	1	2	3
8	I felt hopeful about the future.	0	1	2	3
9	I thought my life had been a failure.	0	1	2	3



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		Rarely or none of the time (less than 2 days)	Some or a little of the time (2-4 days)	Occasionally or a moderate amount of the time (6-8 days)	Most or all of the time (10-14 days)
10	I felt fearful.	0	1	2	3
11	My sleep was restless.	0	1	2	3
12	I was happy.	0	1	2	3
13	I talked less than usual.	0	1	2	3
14	I felt lonely.	0	1	2	3
15	People were unfriendly.	0	1	2	3
16	I enjoyed life.	0	1	2	3
17	I had crying spells.	0	1	2	3
18	I felt sad.	0	1	2	3
19	I felt that people dislike me.	0	1	2	3
20	I could not get “going.”	0	1	2	3

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Interviewer: _______________

That ends the questions I have for you. Do you have any other thoughts you would like to share about your fatigue?

Thank you very much for agreeing to participate in this study.

Appendix B: Illness Perception Questionnaire-Revised

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name……………………………… *Date…………………………………*

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom *since my illness*			**This symptom is *related to my illness***	
Pain	**Yes**	**No**		**Yes**	**No**
Sore Throat	**Yes**	**No**		**Yes**	**No**
Nausea	**Yes**	**No**		**Yes**	**No**
Breathlessness	**Yes**	**No**		**Yes**	**No**
Weight Loss	**Yes**	**No**		**Yes**	**No**
Fatigue	**Yes**	**No**		**Yes**	**No**
Stiff Joints	**Yes**	**No**		**Yes**	**No**
Sore Eyes	**Yes**	**No**		**Yes**	**No**
Wheeziness	**Yes**	**No**		**Yes**	**No**
Headaches	**Yes**	**No**		**Yes**	**No**
Upset Stomach	**Yes**	**No**		**Yes**	**No**
Sleep Difficulties	**Yes**	**No**		**Yes**	**No**
Dizziness	**Yes**	**No**		**Yes**	**No**
Loss of Strength	**Yes**	**No**		**Yes**	**No**

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1*	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4*	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

IP7	My illness has major consequences on my life					
IP8*	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15*	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17*	My actions will have no affect on the outcome of my illness					
IP18*	My illness will improve in time					
IP19*	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36*	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

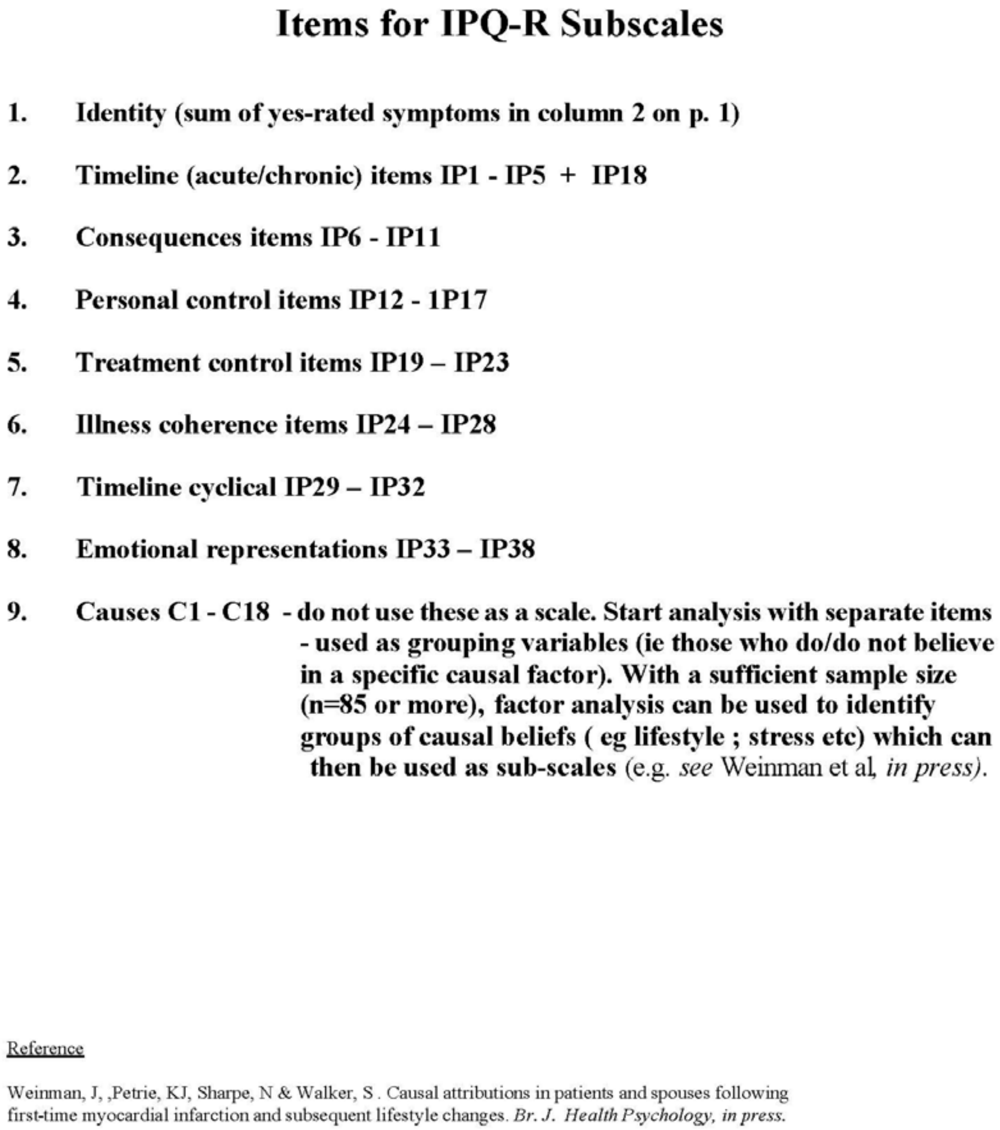
In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. ____

2. ____

3. ____



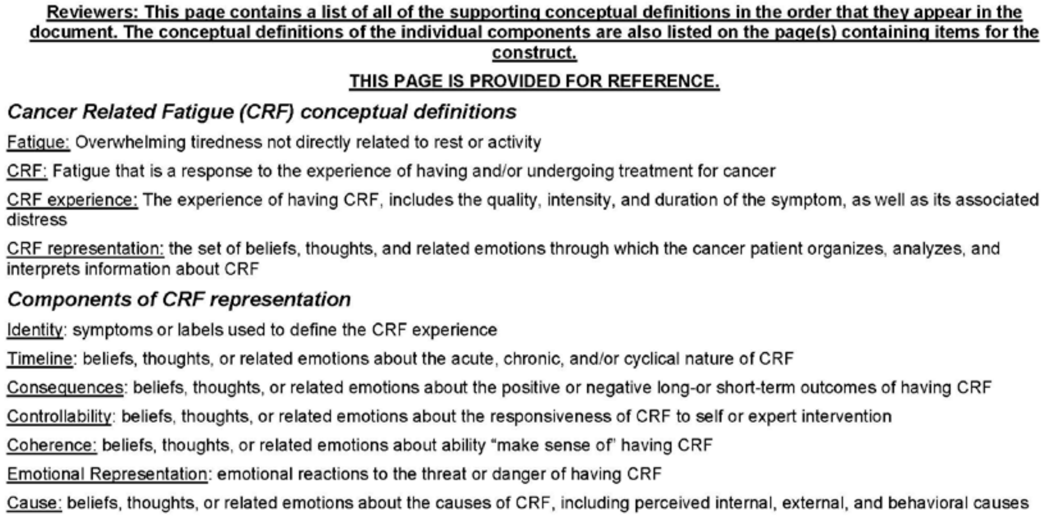
Items for IPQ-R Subscales

1. **Identity (sum of yes-rated symptoms in column 2 on p. 1)**
2. **Timeline (acute/chronic) items IP1 - IP5 + IP18**
3. **Consequences items IP6 - IP11**
4. **Personal control items IP12 - 1P17**
5. **Treatment control items IP19 – IP23**
6. **Illness coherence items IP24 – IP28**
7. **Timeline cyclical IP29 – IP32**
8. **Emotional representations IP33 – IP38**
9. **Causes C1 - C18 - do not use these as a scale. Start analysis with separate items - used as grouping variables (ie those who do/do not believe in a specific causal factor). With a sufficient sample size (n=85 or more), factor analysis can be used to identify groups of causal beliefs (eg lifestyle ; stress etc) which can then be used as sub-scales** (e.g. *see* Weinman et al, *in press).*

Reference

Weinman, J, ,Petrie, KJ, Sharpe, N & Walker, S . Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle changes. *Br. J. Health Psychology, in press.*

Appendix C: Content Validity Survey



Reviewers: This page contains a list of all of the supporting conceptual definitions in the order that they appear in the document. The conceptual definitions of the individual components are also listed on the page(s) containing items for the construct.

THIS PAGE IS PROVIDED FOR REFERENCE.

Cancer Related Fatigue (CRF) conceptual definitions

Fatigue: Overwhelming tiredness not directly related to rest or activity

CRF: Fatigue that is a response to the experience of having and/or undergoing treatment for cancer

CRF experience: The experience of having CRF, includes the quality, intensity, and duration of the symptom, as well as its associated distress

CRF representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF

Components of CRF representation

Identity: symptoms or labels used to define the CRF experience

Timeline: beliefs, thoughts, or related emotions about the acute, chronic, and/or cyclical nature of CRF

Consequences: beliefs, thoughts, or related emotions about the positive or negative long-or short-term outcomes of having CRF

Controllability: beliefs, thoughts, or related emotions about the responsiveness of CRF to self or expert intervention

Coherence: beliefs, thoughts, or related emotions about ability “make sense of’ having CRF

Emotional Representation: emotional reactions to the threat or danger of having CRF

Cause: beliefs, thoughts, or related emotions about the causes of CRF, including perceived internal, external, and behavioral causes

Reviewer: The following instructions and questions will be given in order to get a sense of the participant's prior experience or history of fatigue. Please read the script and answer the questions that follow at the bottom of this page.

START:
Fatigue, or overwhelming tiredness not directly related to rest or activity, is a symptom that some people have before they are diagnosed with or treated for cancer. To better understand your cancer fatigue, I need to ask you a few questions about it.

1. Thinking about the time before you were diagnosed with cancer, did you usually have fatigue on a regular basis? (Y/N)
    a. If No: Thinking about the time between when you were diagnosed with cancer and began treatment, did you have fatigue that was different from the fatigue you have had since you began cancer treatment? (Y/N)

Thank you for answering these questions about fatigue you may have had before your cancer treatment. The rest of the questions in this section deal with your cancer related fatigue, or CRF. Please base your answers on your beliefs about fatigue as it relates to your cancer treatment. Remember there are no right or wrong answers for these questions. We are looking for your opinion.

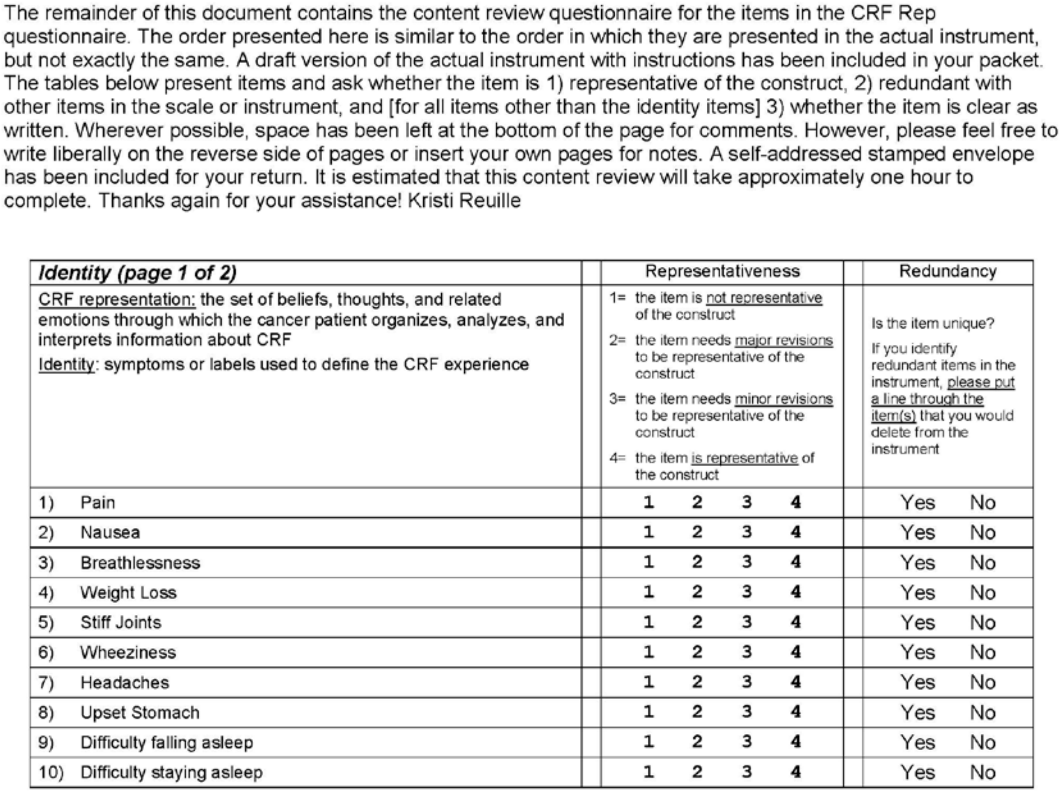
2. Thinking about the time since you began treatment for cancer, how much is your current fatigue related to your cancer treatment?

A. Completely related B. Mostly related C. Somewhat related D. A little bit related E. Not at all related

END

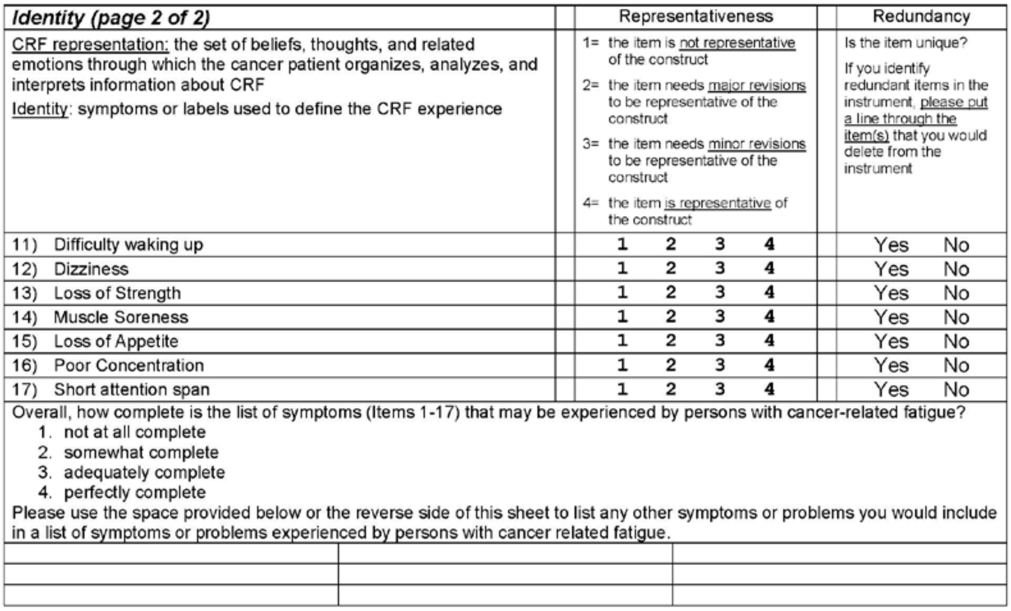
Reviewer Questions:

1. The objective of this set of instructions and questions is to understand the participant's prior history with fatigue, and it's relationship to current cancer-related fatigue. How well is this objective met by the instructions and questions?
    a. completely meets the objective
    b. adequately meets the objective
    c. somewhat meets the objective
    d. does not meet the objective
2. How clear or understandable is the set of questions?
    a. completely clear
    b. adequately clear
    c. somewhat clear
    d. not at all clear
3. Please use the space provided or the reverse side of this sheet to provide comments or edits on the instructions and/or questions.



The remainder of this document contains the content review questionnaire for the items in the CRF Rep questionnaire. The order presented here is similar to the order in which they are presented in the actual instrument, but not exactly the same. A draft version of the actual instrument with instructions has been included in your packet. The tables below present items and ask whether the item is 1) representative of the construct, 2) redundant with other items in the scale or instrument, and [for all items other than the identity items] 3) whether the item is clear as written. Wherever possible, space has been left at the bottom of the page for comments. However, please feel free to write liberally on the reverse side of pages or insert your own pages for notes. A self-addressed stamped envelope has been included for your return. It is estimated that this content review will take approximately one hour to complete. Thanks again for your assistance! Kristi Reuille

Identity (page 1 of 2)	Representativeness	Redundancy
CRF representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Identity: symptoms or labels used to define the CRF experience	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct	Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument
1) Pain	1 2 3 4	Yes No
2) Nausea	1 2 3 4	Yes No
3) Breathlessness	1 2 3 4	Yes No
4) Weight Loss	1 2 3 4	Yes No
5) Stiff Joints	1 2 3 4	Yes No
6) Wheeziness	1 2 3 4	Yes No
7) Headaches	1 2 3 4	Yes No
8) Upset Stomach	1 2 3 4	Yes No
9) Difficulty falling asleep	1 2 3 4	Yes No
10) Difficulty staying asleep	1 2 3 4	Yes No

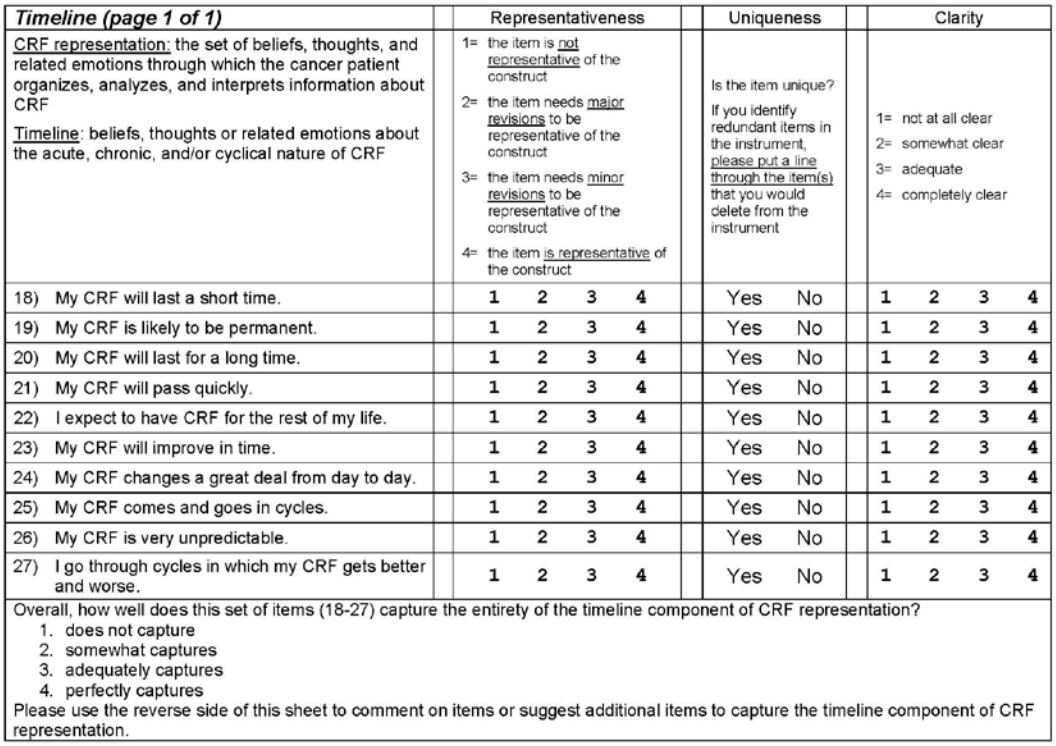


Identity (page 2 of 2)		Representativeness		Redundancy
CRF representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Identity: symptoms or labels used to define the CRF experience		1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct		Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument
11) Difficulty waking up		1 2 3 4		Yes No
12) Dizziness		1 2 3 4		Yes No
13) Loss of Strength		1 2 3 4		Yes No
14) Muscle Soreness		1 2 3 4		Yes No
15) Loss of Appetite		1 2 3 4		Yes No
16) Poor Concentration		1 2 3 4		Yes No
17) Short attention span		1 2 3 4		Yes No

Overall, how complete is the list of symptoms (Items 1-17) that may be experienced by persons with cancer-related fatigue?

1. not at all complete
2. somewhat complete
3. adequately complete
4. perfectly complete

Please use the space provided below or the reverse side of this sheet to list any other symptoms or problems you would include in a list of symptoms or problems experienced by persons with cancer related fatigue.

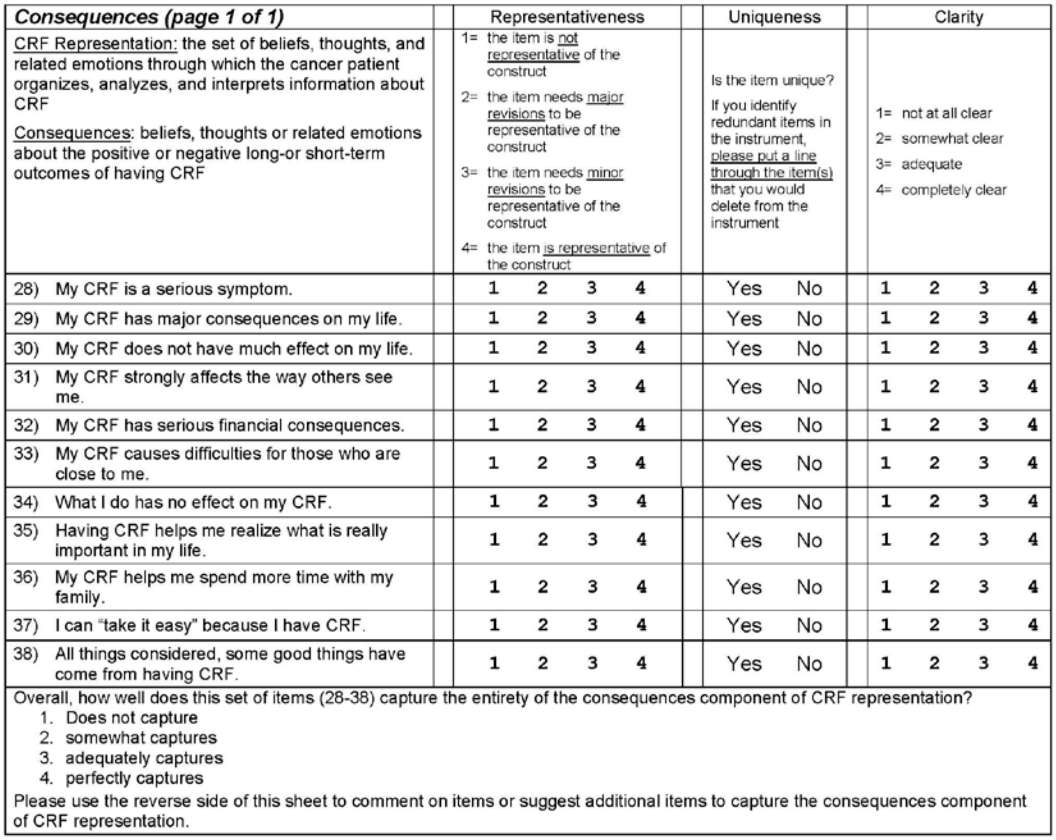


Timeline (page 1 of 1)	Representativeness	Uniqueness	Clarity
CRF representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Timeline: beliefs, thoughts or related emotions about the acute, chronic, and/or cyclical nature of CRF	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct	Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument	1= not at all clear 2= somewhat clear 3= adequate 4= completely clear
18) My CRF will last a short time.	1 2 3 4	Yes No	1 2 3 4
19) My CRF is likely to be permanent.	1 2 3 4	Yes No	1 2 3 4
20) My CRF will last for a long time.	1 2 3 4	Yes No	1 2 3 4
21) My CRF will pass quickly.	1 2 3 4	Yes No	1 2 3 4
22) I expect to have CRF for the rest of my life.	1 2 3 4	Yes No	1 2 3 4
23) My CRF will improve in time.	1 2 3 4	Yes No	1 2 3 4
24) My CRF changes a great deal from day to day.	1 2 3 4	Yes No	1 2 3 4
25) My CRF comes and goes in cycles.	1 2 3 4	Yes No	1 2 3 4
26) My CRF is very unpredictable.	1 2 3 4	Yes No	1 2 3 4
27) I go through cycles in which my CRF gets better and worse.	1 2 3 4	Yes No	1 2 3 4

Overall, how well does this set of items (18-27) capture the entirety of the timeline component of CRF representation?

1. does not capture
2. somewhat captures
3. adequately captures
4. perfectly captures

Please use the reverse side of this sheet to comment on items or suggest additional items to capture the timeline component of CRF representation.

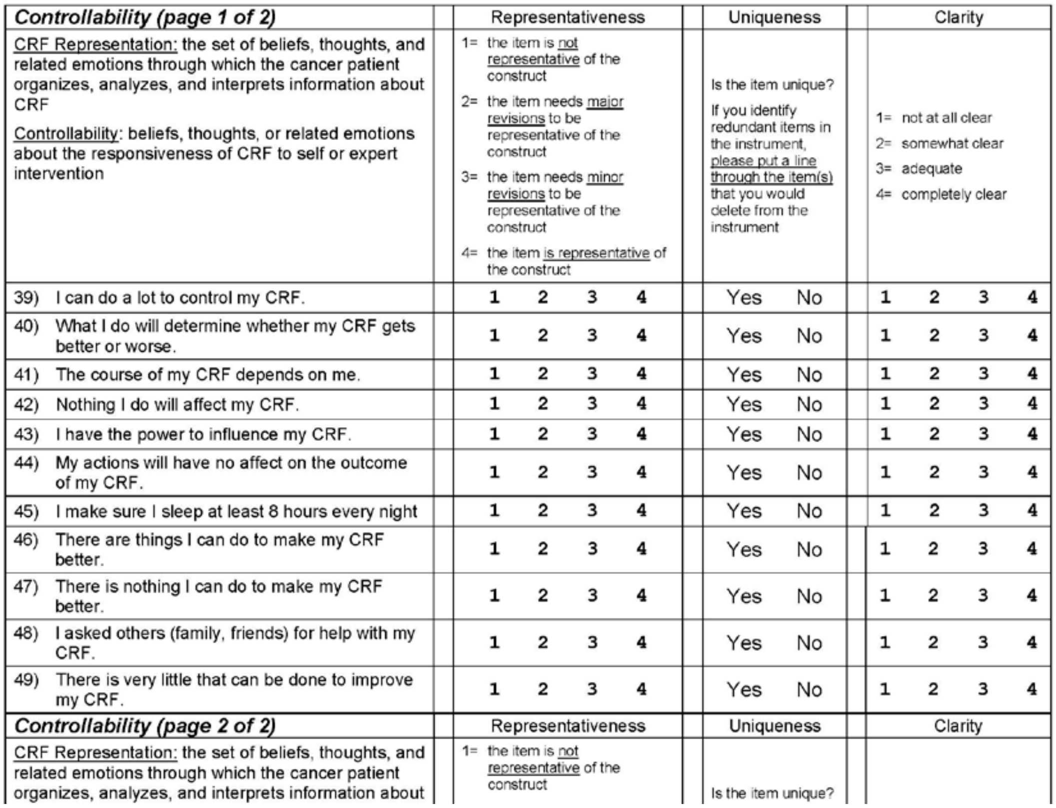


Consequences (page 1 of 1)	Representativeness				Uniqueness		Clarity			
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Consequences: beliefs, thoughts or related emotions about the positive or negative long-or short-term outcomes of having CRF	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct				Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument		1= not at all clear 2= somewhat clear 3= adequate 4= completely clear			
28) My CRF is a serious symptom.	1	2	3	4	Yes	No	1	2	3	4
29) My CRF has major consequences on my life.	1	2	3	4	Yes	No	1	2	3	4
30) My CRF does not have much effect on my life.	1	2	3	4	Yes	No	1	2	3	4
31) My CRF strongly affects the way others see me.	1	2	3	4	Yes	No	1	2	3	4
32) My CRF has serious financial consequences.	1	2	3	4	Yes	No	1	2	3	4
33) My CRF causes difficulties for those who are close to me.	1	2	3	4	Yes	No	1	2	3	4
34) What I do has no effect on my CRF.	1	2	3	4	Yes	No	1	2	3	4
35) Having CRF helps me realize what is really important in my life.	1	2	3	4	Yes	No	1	2	3	4
36) My CRF helps me spend more time with my family.	1	2	3	4	Yes	No	1	2	3	4
37) I can "take it easy" because I have CRF.	1	2	3	4	Yes	No	1	2	3	4
38) All things considered, some good things have come from having CRF.	1	2	3	4	Yes	No	1	2	3	4

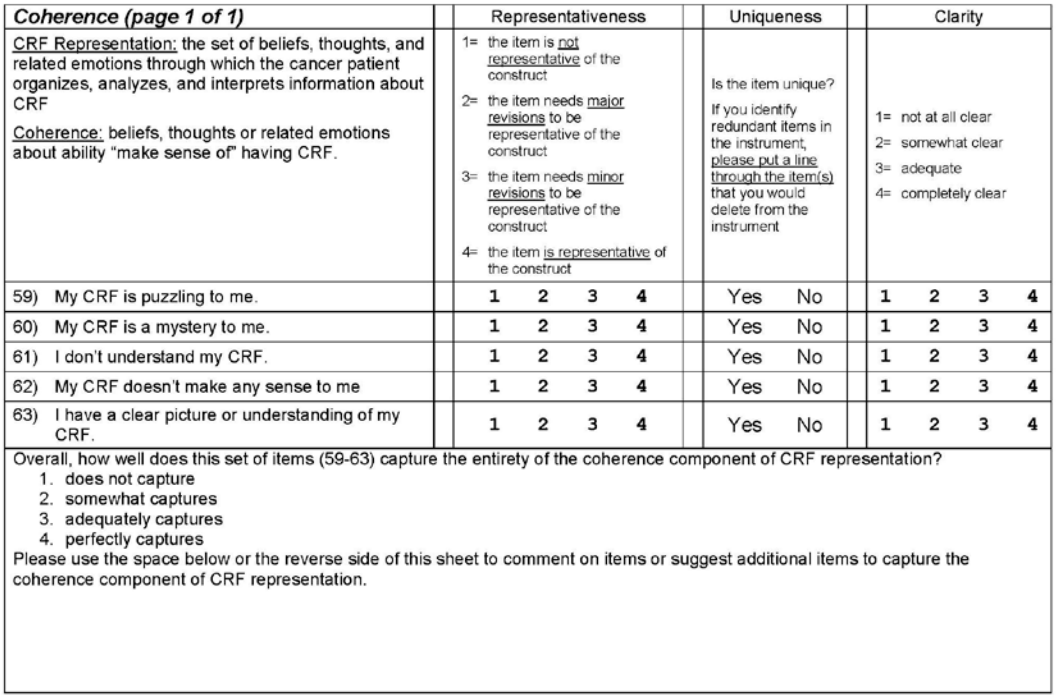
Overall, how well does this set of items (28-38) capture the entirety of the consequences component of CRF representation?

1. Does not capture
2. somewhat captures
3. adequately captures
4. perfectly captures

Please use the reverse side of this sheet to comment on items or suggest additional items to capture the consequences component of CRF representation.



Controllability (page 1 of 2)	Representativeness	Uniqueness	Clarity
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Controllability: beliefs, thoughts, or related emotions about the responsiveness of CRF to self or expert intervention	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct	Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument	1= not at all clear 2= somewhat clear 3= adequate 4= completely clear
39) I can do a lot to control my CRF.	1 2 3 4	Yes No	1 2 3 4
40) What I do will determine whether my CRF gets better or worse.	1 2 3 4	Yes No	1 2 3 4
41) The course of my CRF depends on me.	1 2 3 4	Yes No	1 2 3 4
42) Nothing I do will affect my CRF.	1 2 3 4	Yes No	1 2 3 4
43) I have the power to influence my CRF.	1 2 3 4	Yes No	1 2 3 4
44) My actions will have no affect on the outcome of my CRF.	1 2 3 4	Yes No	1 2 3 4
45) I make sure I sleep at least 8 hours every night	1 2 3 4	Yes No	1 2 3 4
46) There are things I can do to make my CRF better.	1 2 3 4	Yes No	1 2 3 4
47) There is nothing I can do to make my CRF better.	1 2 3 4	Yes No	1 2 3 4
48) I asked others (family, friends) for help with my CRF.	1 2 3 4	Yes No	1 2 3 4
49) There is very little that can be done to improve my CRF.	1 2 3 4	Yes No	1 2 3 4
Controllability (page 2 of 2)	Representativeness	Uniqueness	Clarity
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about	1= the item is not representative of the construct	Is the item unique?	

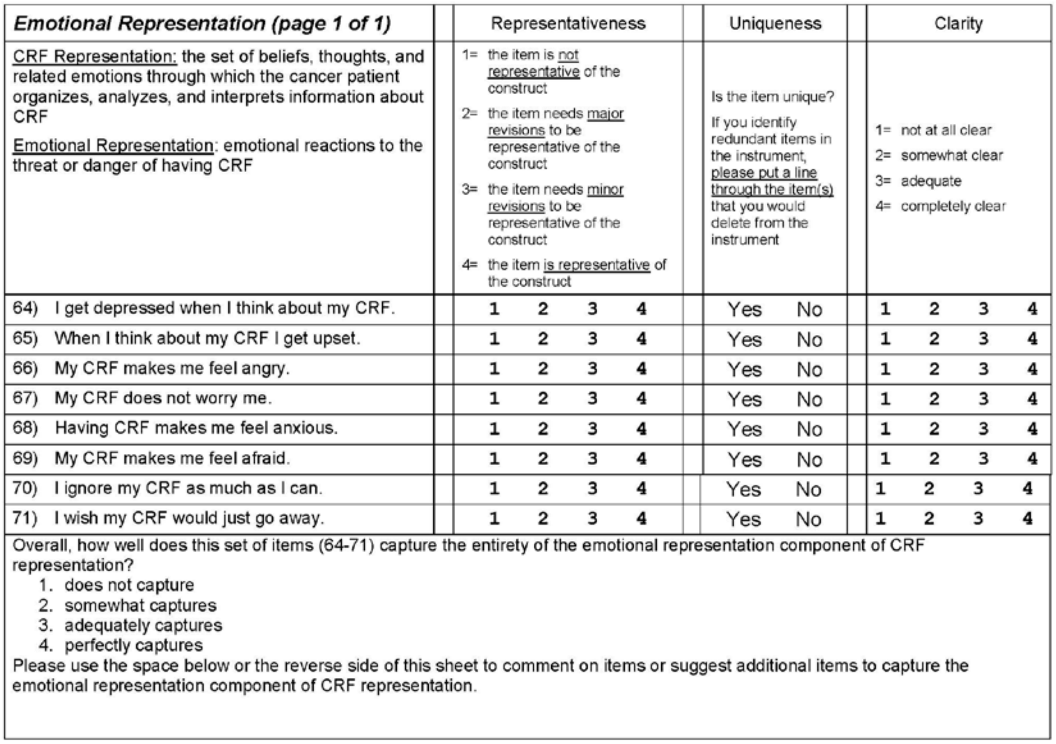


Coherence (page 1 of 1)	Representativeness				Uniqueness		Clarity			
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Coherence: beliefs, thoughts or related emotions about ability "make sense of" having CRF.	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct				Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument		1= not at all clear 2= somewhat clear 3= adequate 4= completely clear			
59) My CRF is puzzling to me.	**1**	**2**	**3**	**4**	Yes	No	**1**	**2**	**3**	**4**
60) My CRF is a mystery to me.	**1**	**2**	**3**	**4**	Yes	No	**1**	**2**	**3**	**4**
61) I don't understand my CRF.	**1**	**2**	**3**	**4**	Yes	No	**1**	**2**	**3**	**4**
62) My CRF doesn't make any sense to me	**1**	**2**	**3**	**4**	Yes	No	**1**	**2**	**3**	**4**
63) I have a clear picture or understanding of my CRF.	**1**	**2**	**3**	**4**	Yes	No	**1**	**2**	**3**	**4**

Overall, how well does this set of items (59-63) capture the entirety of the coherence component of CRF representation?

1. does not capture
2. somewhat captures
3. adequately captures
4. perfectly captures

Please use the space below or the reverse side of this sheet to comment on items or suggest additional items to capture the coherence component of CRF representation.

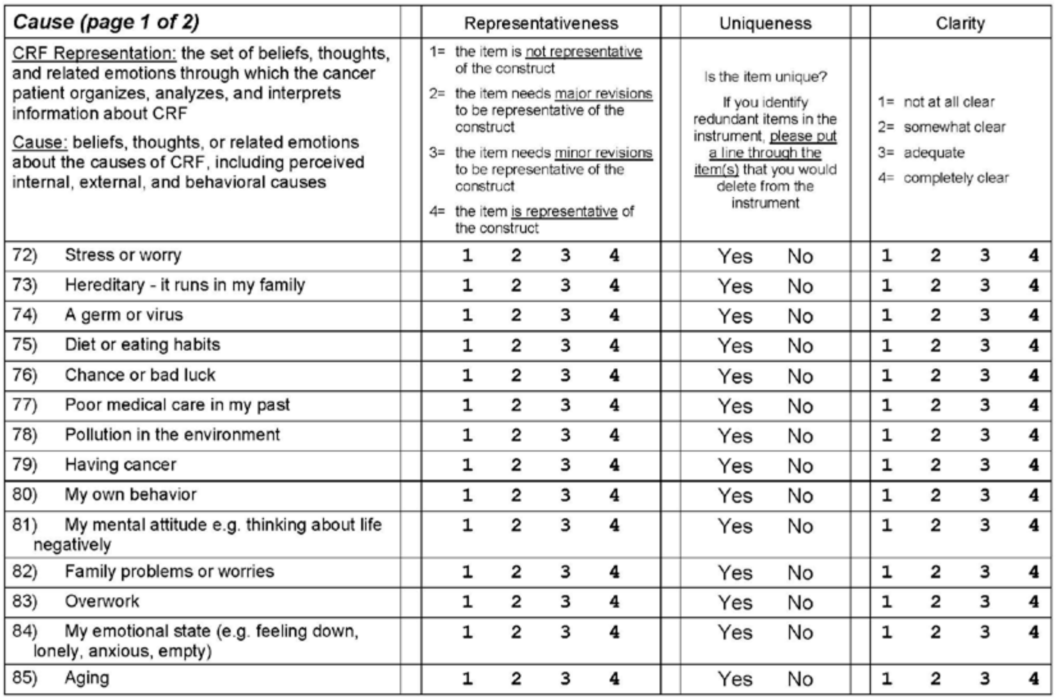


Emotional Representation (page 1 of 1)	Representativeness	Uniqueness	Clarity
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Emotional Representation: emotional reactions to the threat or danger of having CRF	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct	Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument	1= not at all clear 2= somewhat clear 3= adequate 4= completely clear
64) I get depressed when I think about my CRF.	1 2 3 4	Yes No	1 2 3 4
65) When I think about my CRF I get upset.	1 2 3 4	Yes No	1 2 3 4
66) My CRF makes me feel angry.	1 2 3 4	Yes No	1 2 3 4
67) My CRF does not worry me.	1 2 3 4	Yes No	1 2 3 4
68) Having CRF makes me feel anxious.	1 2 3 4	Yes No	1 2 3 4
69) My CRF makes me feel afraid.	1 2 3 4	Yes No	1 2 3 4
70) I ignore my CRF as much as I can.	1 2 3 4	Yes No	1 2 3 4
71) I wish my CRF would just go away.	1 2 3 4	Yes No	1 2 3 4

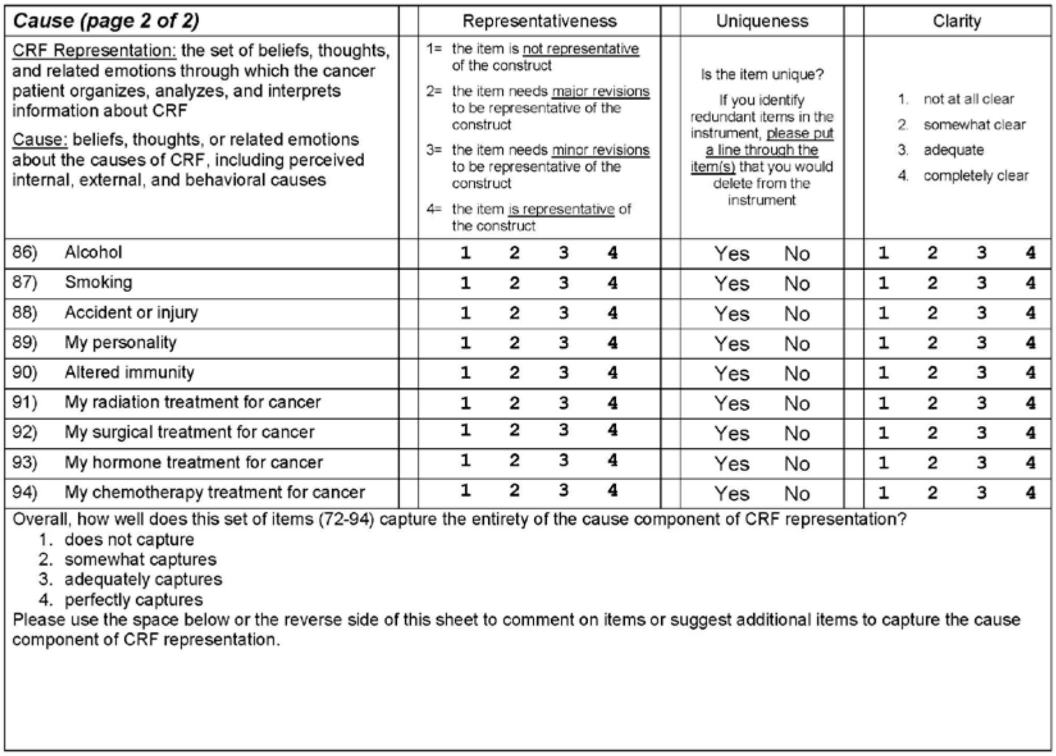
Overall, how well does this set of items (64-71) capture the entirety of the emotional representation component of CRF representation?

1. does not capture
2. somewhat captures
3. adequately captures
4. perfectly captures

Please use the space below or the reverse side of this sheet to comment on items or suggest additional items to capture the emotional representation component of CRF representation.



Cause (page 1 of 2)	Representativeness				Uniqueness		Clarity			
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Cause: beliefs, thoughts, or related emotions about the causes of CRF, including perceived internal, external, and behavioral causes	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct				Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument		1= not at all clear 2= somewhat clear 3= adequate 4= completely clear			
72) Stress or worry	1	2	3	4	Yes	No	1	2	3	4
73) Hereditary - it runs in my family	1	2	3	4	Yes	No	1	2	3	4
74) A germ or virus	1	2	3	4	Yes	No	1	2	3	4
75) Diet or eating habits	1	2	3	4	Yes	No	1	2	3	4
76) Chance or bad luck	1	2	3	4	Yes	No	1	2	3	4
77) Poor medical care in my past	1	2	3	4	Yes	No	1	2	3	4
78) Pollution in the environment	1	2	3	4	Yes	No	1	2	3	4
79) Having cancer	1	2	3	4	Yes	No	1	2	3	4
80) My own behavior	1	2	3	4	Yes	No	1	2	3	4
81) My mental attitude e.g. thinking about life negatively	1	2	3	4	Yes	No	1	2	3	4
82) Family problems or worries	1	2	3	4	Yes	No	1	2	3	4
83) Overwork	1	2	3	4	Yes	No	1	2	3	4
84) My emotional state (e.g. feeling down, lonely, anxious, empty)	1	2	3	4	Yes	No	1	2	3	4
85) Aging	1	2	3	4	Yes	No	1	2	3	4



Cause (page 2 of 2)	Representativeness	Uniqueness	Clarity
CRF Representation: the set of beliefs, thoughts, and related emotions through which the cancer patient organizes, analyzes, and interprets information about CRF Cause: beliefs, thoughts, or related emotions about the causes of CRF, including perceived internal, external, and behavioral causes	1= the item is not representative of the construct 2= the item needs major revisions to be representative of the construct 3= the item needs minor revisions to be representative of the construct 4= the item is representative of the construct	Is the item unique? If you identify redundant items in the instrument, please put a line through the item(s) that you would delete from the instrument	1. not at all clear 2. somewhat clear 3. adequate 4. completely clear
86) Alcohol	1 2 3 4	Yes No	1 2 3 4
87) Smoking	1 2 3 4	Yes No	1 2 3 4
88) Accident or injury	1 2 3 4	Yes No	1 2 3 4
89) My personality	1 2 3 4	Yes No	1 2 3 4
90) Altered immunity	1 2 3 4	Yes No	1 2 3 4
91) My radiation treatment for cancer	1 2 3 4	Yes No	1 2 3 4
92) My surgical treatment for cancer	1 2 3 4	Yes No	1 2 3 4
93) My hormone treatment for cancer	1 2 3 4	Yes No	1 2 3 4
94) My chemotherapy treatment for cancer	1 2 3 4	Yes No	1 2 3 4

Overall, how well does this set of items (72-94) capture the entirety of the cause component of CRF representation?

1. does not capture
2. somewhat captures
3. adequately captures
4. perfectly captures

Please use the space below or the reverse side of this sheet to comment on items or suggest additional items to capture the cause component of CRF representation.

Appendix D: Informed Consent Statement

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Psychometric testing of the Cancer Treatment-Related Fatigue Representation Scale (CTRFRep) in patients receiving radiation treatment for cancer

You are invited to participate in a research study that tests a survey tool for patients with cancer and fatigue. You were selected as a possible subject because you are getting radiation treatments for cancer**.** We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Janet Welch, DNS, RN, and Kristina M. Reuille, PhD(c), RN, of the Indiana University School of Nursing; and Dr. Higinia R. Cardenes, of the Department of Radiation Oncology, Indiana University School of Medicine. It is funded by the National Institute of Nursing Research through a National Research Service Award (NRSA) fellowship awarded to Ms. Reuille.

STUDY PURPOSE

The purpose of this study is to learn about new survey tool designed to help health care personnel understand patients' beliefs, thoughts and emotions about having cancer treatment-related fatigue, or cancer treatment-related fatigue representation. Many patients who have radiation treatment for cancer have fatigue during or after their treatment. If the new survey tool accurately measures cancer treatment-related fatigue representation, this study will help us understand more about patient's experiences with cancer treatment-related fatigue.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 100 subjects who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

- You will answer questions in a one-time survey interview that takes about 25-45 minutes to finish.
- This interview will take place in a private location at the Radiation Oncology Clinic in the Indiana University Cancer Center.
- The types of questions in the survey include: "I think I do a lot in a day;" My cancer-related fatigue changes a great deal from day to day;" and "The fatigue or tiredness I am having causes me distress because it makes me stay at home more."
- There are no right or wrong answers to the questions in the survey.

If you choose to participate in this study, the timeline of the study will be as follows:

- You will complete your radiation treatments here in the Radiation Oncology Clinic

- Near the time of your last treatment, you will schedule a follow-up appointment with your doctor.
- This follow-up appointment usually happens about four weeks after your treatment is finished.
- During this follow-up appointment you will meet with your doctor and complete the interview for this study.

RISKS OF TAKING PART IN THE STUDY:

While on the study, the risks or discomforts are:

There are no physical risks to taking part in this study.

The risks of completing the survey are being uncomfortable answering the questions. There is a risk of possible loss of confidentiality.

The following measures will be taken to minimize these risks:

While completing the survey, you can tell the interviewer that you feel uncomfortable or do not care to answer a particular question.
Every attempt will be made to protect your confidentiality and ensure that only members of the research team will be aware of your identity.

BENEFITS OF TAKING PART IN THE STUDY:

There is no direct benefit to participating in the study. The benefits to participation that are reasonable to expect are: 1) satisfaction gained from sharing your thoughts and feelings about your experience with fatigue and/or 2) cancer treatment and knowledge that your participation may help other patients like you in the future.

ALTERNATIVES TO TAKING PART IN THE STUDY:

Instead of being in the study, you have these options:

You may choose not to be in the study.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and databases where results may be stored.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, the study sponsor, the National Institute of Nursing Research, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP), and the National Institutes of Health (NIH) who may need to access your medical and/or research records.

COSTS

There are no monetary costs for subjects participating in this study. If you choose to participate in the study, the follow-up appointment may be up to 45 minutes longer than normal because you will be completing the interview at this appointment. This will not affect the scheduling of your follow-up appointment.

PAYMENT

You will not receive payment for taking part in this study

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researcher Kristina M. Reuille PhD(c), RN at 317-295-0083 or 317-439-5743 or Janet Welch, DNS, RN at 317-274-0024 or 317-294-8091. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949. After business hours, please call Ms. Reuille at 317-295-0083 or 317-439-5743.

In the event of an emergency, you may contact Ms. Reuille at 317-295-0083 or 317-439-5743.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with the Indiana University Cancer Center Radiation Oncology Clinic.

SUBJECT’S CONSENT

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject’s Printed Name:____

Subject’s Signature:____**Date**:_________________

(must be dated by the subject)

Printed Name of Person Obtaining Consent:____

Signature of Person Obtaining Consent:___________________________**Date**:________________

Appendix E: HIPAA Authorization

Introduction: You have the right to decide who may review or use your Protected Health Information ("PHI"). The type of information that may be used is described below. When you consider taking part in a research study, you must give permission for your PHI to be released from your doctors, clinics, and hospitals to the research team, for the specific purpose of this research study.

What does this authorization relate to? This authorization relates to the following study:

Janet Welch, DNS, RN	**IRB #0403-69B**
PRINCIPAL INVESTIGATOR (in charge of Research Team)	***IRB PROTOCOL #*** ***SPONSOR #*** NINR/ 1 F31 NR 008834-01 A1
NAME OF RESEARCH PARTICIPANT	***BIRTHDATE***
STREET ADDRESS	***CITY, STATE & ZIP CODE***

What information will be used for research purposes? The PHI that will be used for research purposes may include some or all of your health records. This includes, but is not limited to: information provided by you directly to the Research Team, hospital records and reports; admission histories, and physicals; X-ray films and reports; operative reports; laboratory reports; treatment and test results; immunizations; allergy reports; prescriptions; consultations; clinic notes; and any other medical or dental records needed by the Research Team.

Specific Authorizations: I understand that this release also pertains to records concerning hospitalization or treatment that may include the categories listed below. I have the right to specifically request that records NOT be released from my health care providers to the Research Team. However, I understand that if I limit access to any of the records listed below, I may not be able to be in this research study. Check limitations, if any, below:

☐ Mental health records
☐ Psychotherapy Notes
☐ HIV (AIDS)
☐ Sexually transmitted diseases
☐ Alcohol / Substance abuse
☐ Other: ______________________________

Who will be allowed to release this information?

I authorize the following persons, groups or organizations to disclose the information described in this Release of Information/Authorization for the above referenced research study:

☒ **Treating providers**
☐ **Hospitals, clinics or other places where I have received treatment**
☐ **Other:**____________________________
☒ **The Principal Investigator and the Research Staff**

Who can access your PHI for the study? The people and entities listed above may share my PHI (or the PHI of the individual(s) whom I have the authority to represent), with the following persons or groups for the research study: the Research Team, Institutional Review Board, Research Sponsor and its representatives, Research Organizations, the Department of Health & Human Services or other US or foreign government agencies as required by law, and to the Food and Drug Administration (FDA) or a person subject to the jurisdiction of the FDA in order to audit or monitor the quality, safety or effectiveness of the product or activity.

The **Research Team** includes the Principal Investigator, his/her staff, research coordinators, research technicians and other staff members who provide assistance to the Research Team. If there is a **Research Sponsor(s),** this shall include: **The National Institute of Nursing Research** and any **Research**

Organizations who provided assistance to the **Research Sponsor(s)** including, but not limited to: -______________________________.

Expiration date of this Authorization: This authorization is valid until the following date or event:

☐ Specify Date ___/___/____ ☐ End of the Study ☐ None
☐Other: **_______________________** ☐ Indefinitely, or until such time as authorized by the sponsor to destroy study documents

Efforts will be made to ensure that your PHI will not be shared with other people outside of the research study. However, your PHI may be disclosed to others as required by law and/or to individuals or organizations that oversee the conduct of research studies, and these individuals or organizations may not be held to the same legal privacy standards as are doctors and hospitals. Thus, the Research Team cannot guarantee absolute confidentiality and privacy.

I have the right:

1. To refuse to sign this form. Not signing the form will not affect my regular health care including treatment, payment, or enrollment in a health plan or eligibility for health care benefits. However, not signing the form will prevent me from participating in the research study above.

2. To review and obtain a copy of my personal health information collected during the study. However, it may be important to the success and integrity of the study that persons who participate in the study not be given access until the study is complete. The Principal Investigator has discretion to refuse to grant access to this information if it will affect the integrity of the study data during the course of the study. Therefore, my request for information may be delayed until the study is complete.

3. To cancel this release of information/authorization at any time. If I choose to cancel this release of information/authorization, I must notify the Principal Investigator for this study **in writing** at: **Janet Welch, DNS, RN at the Indiana University School of Nursing, 1111 Middle Drive, NU 407, Indianapolis, IN 46202**. However, even if I cancel this release of information/authorization, the Research Team, Research Sponsor(s) and/or the Research Organizations may still use information about me that was collected as part of the research project between the date I signed the current form and the date I cancel the authorization. This is to protect the quality of the research results. I understand that canceling this authorization may end my participation in this study.

4. To receive a copy of this form.

I have had the opportunity to review and ask questions regarding this release of information/authorization form. By signing this release of information/authorization, I am confirming that it reflects my wishes.

Printed name of Individual/Legal Representative *Date*

Signature of Individual/Legal Representative

**If signed by a legal representative; state the relationship and identify below the authority to act on behalf of the individual's behalf.*

***Individual is:** ☐ a Minor ☐ Incompetent ☐ Disabled
☐ Deceased

***Legal Authority:**

☐ Custodial Parent ☐ Legal Guardian ☐ Executor of Estate of the Deceased

☐ Power of Attorney Healthcare ☐ Authorized Legal Representative ☐ Other: ___________

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Wratten, C., Kilmurray, J., Nash, S., Seldon, M., Hamilton, C. S., & O'Brien, P. C. (2004). Fatigue during breast radiotherapy and its relationship to biological factors. *International Journal of Radiation Oncology, Biology, Physics, 59*(1), 160-167.

CURRICULUM VITAE

NAME: Kristina M. Reuille

EDUCATION:

Degree	Granting Institution	Year	Area of Study
B.S.N.	Indiana University	1994	Nursing
M.S.N.	Indiana University	2002	Adult Health CNS
Ph.D.	Indiana University	2009	Behavioral Oncology Symptom Management

CURRENT LICENSURE: Indiana

PROFESSIONAL EXPERIENCE:

Position Title	Dates	Name and Location of Employer
Graduate Nurse Registered Nurse	1994 1994-1996	Brandywine Nursing and Rehabilitation Greenfield Indiana
Staff Nurse	1996-1997	American Transitional Hospital Indianapolis, Indiana
Staff Nurse	1997-2000	Indiana University Hospital-Clarian Health Indianapolis, Indiana (Krannert Multi-Specialty Unit)
Research Assistant	1999-2000	Indiana University School of Nursing Indianapolis, Indiana
Teaching Assistant	1999-2000	Indiana University School of Nursing Indianapolis, Indiana (R505 Measurement & Data Analysis)
Project Manager Data Manager	2000-2001	Mary Margaret Walther Program Walther Cancer Institute Indiana University School of Nursing Indianapolis, Indiana
Teaching Assistant	2003 2004 2005	Indiana University School of Nursing Indianapolis, Indiana (R500 Nursing Research I)

RN/Associate Partner	2007	Indiana University Hospital-Clarian Health Indianapolis, Indiana (2 North Surgical Oncology Unit)

PROFESSIONAL SOCIETIES:

Indiana State Nurses Association	1997-present
Sigma Theta Tau International Honor Society of Nursing	1999-present
Midwest Nursing Research Society	1999-present
Gerontological Society of America	2001-2002
Oncology Nursing Society	2001-present
National Association of Clinical Nurse Specialists	
Central Indiana Affiliate	2001-present
Behavioral Cooperative Oncology Group	2001-present

SERVICE:

Extramural

Key Club	
Outstanding Student Award	1986, 1987
Distinguished Student Award	1989
Alpha Phi Omega Coeducational Service Organization	1991-1993
Brandywine Nursing and Rehabilitation-24 Karat Committee	1994-1995
Damien Center Volunteer	1995-1997
Indianapolis Women’s Chorus	
Member and Section Leader	1996-1998
All Saints Episcopal Church	
Hospitality Committee Co-Chair	1997-2001
Lector, Greeter	1997-2003
YWCA of Indianapolis–Tech Generations Volunteer Instructor	2001-2002
National Women’s Music Festival	
Cancer Prevention, Support, and Survivorship Workshop Leader	2002

University Level

Indiana University–System	
Student Health Insurance Committee Representative	2004-2005
Student Trustee Search and Screen Committee	2004-2005
University Faculty Council Graduate Student Representative	2004-2005

Indiana University Purdue University Indianapolis–Campus	
Race Relations Study Circle Participant	2001
Advocate Diversity Panel Participant	2003
Diversity Awareness Resource Team (DART)	2003-2005

National Coalition Building Institute (NCBI) Trainee	2003
Graduate Student Organization	
School of Nursing Representative	2003-2005
Secretary	2003-2004
President	2004-2005

Intramural

Graduate Student Organization	
School of Nursing Representative	2003-2005
Dean’s Council–Indiana University School of Nursing	
Graduate Student Representative	2000-2005
IU School of Nursing-Mandatory Health Insurance Planning Committee	
Graduate Student Representative	2001
IU School of Nursing Diversity Program Presenter	
Hearing our Voices–Individuals with Disabilities & Families	2001
B104 Power Up: Strategies for Academic Success Diversity Panel	2003, 2004, 2005

AWARDS:

National Honor Society	1987
John H. Noll Scholarship Award	1989-1993
Who’s Who among Students at American Colleges and Universities	2000
Graduate Nursing Scholarship, Indiana University	2001
University Graduate Fellowship	2001-2002
Indiana University-Purdue University Indianapolis	
Institutional National Research Service Award	2001-2004
Indiana University School of Nursing PHS Grant 5T32NR07066	
Graduate Scholarship Award Competition, First Place	2002
National Association of Clinical Nurse Specialists	
Emily Holmquist Award	2002
Indiana University School of Nursing Alumni Association	
Individual National Research Service Award	2004-2006
National Institute of Nursing Research–F31NR008834-01A1	
Graduate Student Poster Competition, First Place	2005
Oncology Nursing Society 8th National Conference for Cancer Nursing Research	

PUBLICATIONS:

Refereed Articles:

Reuille, K.M. (2002). Using self-regulation theory to develop an intervention for cancer related fatigue. *Clinical Nurse Specialist*. 16(6), 312-319.

Giesler, R.B. Given, B.A., Given C.W., Rawl, S.M., Monahan, P.O., Burns, D.S., Azzouz, F., **Reuille, K.M.**, Weinrich, S. Koch, M. Champion, V.L. (2005). Improving the quality of life of patients with prostate carcinoma: A randomized trial testing the efficacy of a nurse-driven intervention. *Cancer*. 104(4), 752-762.

Monahan, P.O., Champion, V., Rawl, S., Giesler, R.B., Given, B.A., Given, C.W., Burns, D.S., Bigatti, S., **Reuille, K.M.**, Azzouz, F., Wu, J., Koch, M. (2007). What contributes more strongly to prediction QoL during 1-year recovery from treatment for clinically localized prostate cancer: 4-weeks-post-treatment depressive symptoms or type of treatment? *Quality of Life Research*. 16(3), 399-411.

Champion, V.L., Williams, S.D., Miller, A., **Reuille, K.M.**, Wagler-Ziner, K, Monahan, P.O., Zhou, Q. Gershenson, D., Cella, D., Gynecologic Oncology Group. (2007). Quality of life in long-term survivors of ovarian germ cell tumors: A Gynecologic Oncology Group study. *Gynecologic Oncology*. 105(3), 687-694.

Refereed Abstracts:

Reuille, K.M., Champion, V.L., Haase, J.E. (2005). Psychometric testing of the Cancer Treatment-Related Fatigue Representation (CTRFRep) scale. Presented at the 8th National Conference on Cancer Nursing Research. *Oncology Nursing Forum*. 32(1), 197.

Reuille, K.M., Carpenter, J.S. Fatigue in breast cancer survivors: A psychometric analysis. Presented at the 8th National Conference on Cancer Nursing Research. *Oncology Nursing Forum*. 32(1), 197.

PRESENTATIONS:

Refereed:

Reuille, K.M. (2000) “Testing an Educational Intervention to Decrease Fatigue Distress and Increase Fatigue Management among Patients with Lymphoma: A Pilot Study” Poster Presentation at the 26th Annual Nursing Research Conference, Clarian Health, Indianapolis, Indiana; December 1, 2000.

Reuille, K.M., Menon, U. Champion, V. L. (2001) “Effect of Age and Race on Beliefs Regarding Mammography Screening among Non-Compliant Women Aged 51 and Older” Poster Presentation at the 6th National Conference on Cancer Nursing Research, Ponte Vedra Beach, Florida; February 8-10, 2001.

Reuille, K.M. (2001) “Testing an Intervention to Decrease Cancer-Related Fatigue among Patients with Lymphoma: A Pilot Study” Poster Presentation at the National Association of Clinical Nurse Specialists 2001 Conference: CNS 2001 VISION, Indianapolis, Indiana, March 8-10, 2001.

Reuille, K.M. (2002). “Differences in Quality of Life of Patients with Localized Prostate Cancer: The Effect of Treatment Modality and Time” Poster Presentation at the Midwest Nursing Research Society 26th Annual Research Conference: Nursing Research: International Perspectives, Chicago, Illinois, March 1-4, 2002.

Champion, V.L., Rawl, S.M., Giesler, R.B., Burns, D.S., **Reuille, K.M.**, Koch, M., Monahan, P., Given, B., & Given, C.W. (2002). Comparing the impact of baseline depression on quality of life of prostate cancer patients vs. patients’ spouses. Presented at 9th Annual Conference of the International Society for Qualify of Life Research, Orlando, FL., October, 2002.

Reuille, K.M. (2003). Variance in Psychosocial Adjustment Explained by Cancer Related Fatigue and Hope in Women with Breast Cancer. Poster Presentation at the Midwest Nursing Research Society 27th Annual Research Conference: Interdisciplinary Research: Developing Strong Partnerships, Grand Rapids, Michigan, April 4-7, 2003.

Ziner, K.W., Haase, J.E., Lewis, F.M., Stiffler, D., Farmer, T, **Reuille, K.M.** (2003). Mothers with Breast Cancer and Adolescents: Experiences of Parenting and Being Parented. Presentation at the 29th Annual Nursing Research Conference: Using Technology to Improve Healthcare Outcomes, Clarian Health Indianapolis, Indiana, December 5, 2003.

Reuille, K.M. (2004). Development and Testing of the Cancer Treatment-Related Fatigue Representation (CTRFRep) Scale. Poster Presentation at the Midwest Nursing Research Society 28th Annual Research Conference: Nursing Research: Addressing Health Disparities, St. Louis, Missouri, February 27-March 1, 2004.

Reuille, K.M., Carpenter, J.S. (2005) Fatigue in Breast Cancer Survivors: A Psychometric Analysis. Podium Presentation at the Midwest Nursing Research Society 29th Annual Research Conference: Advancing the Clinical Research Enterprise: Translation and Dissemination, Cincinnati, Ohio, April 1-4, 2005.

Non-Refereed

Reuille, K.M., Rawl, S.M., Champion, V.L., Giesler, R.B., Given, C.W., Given, B.A., “Urinary Problems Following Prostate Cancer Treatment: A Descriptive Comparison of Patient and Spouse-Partner Perspectives in the First Seven Months Post-Treatment” Poster Presentation at the Behavioral Cooperative Oncology Group Colloquium 2001, Indianapolis, Indiana, October 9, 2001.

Reuille, K.M., Champion, V.L. “The Impact of Age and Race on Health Beliefs Regarding Mammography Screening among Non-Compliant Women Aged 51 and older” Oral Presentation at the Indiana University – Purdue University Indianapolis Graduate Showcase 2001, Indianapolis, Indiana, October 26, 2001.

Invited Lectures

Indiana University School of Nursing Adult Health CNS Program: M556 Symptom Management – Theory-based interventions for fatigue in patients with cancer. Spring Semester, 2003.

Indiana University School of Nursing Adult Health CNS Program: M556 Symptom Management – Theory-based interventions for fatigue in patients with cancer. Spring Semester, 2004.

Indiana University School of Nursing Adult Health CNS Program: M556 Symptom Management – Theory-based interventions for fatigue in patients with cancer. Spring Semester, 2005.