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## A Review Of Screening Processes For Physical Distress And Appropriate Outcome Measures For Outpatient Rehabilitation Referral In Cancer Survivorship

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# A Review Of Screening Processes For Physical Distress And Appropriate Outcome Measures For Outpatient Rehabilitation Referral In Cancer Survivorship

## Abstract

The goal of this project is to determine which physical distress screening tools are most appropriate to trigger a wellness or rehabilitation referral when it is warranted for a survivor. The use of effective screening tools will assist in directing cancer survivors, who experience physical and emotional burdens caused by the disease and subsequent treatment, to access services that will continue to improve their overall quality of life upon completion of cancer treatment or in a setting of ongoing palliative care. These measures should focus on functional mobility, balance, fatigue, and distress. Additionally, there are many common tests used to quantify the subjective burden of pain, confidence, and difficulty with daily tasks. Outcome measures such as these should be implemented throughout the course of treatment, with consistency, for patients with cancer to promote early recognition of impairments. Improved education for patients and healthcare providers alike on the services available, possible benefits of such referrals, and the importance of carefully selected measures to monitor functional change has the potential to begin to bridge the current gap between medical oncology treatment and the network of other rehabilitative healthcare services, as well as to improve the quality of life for our surviving family, friends, neighbors, coworkers, and colleagues.

## Disciplines

Oncology | Physical Therapy | Public Health Education and Promotion

## Comments

This work was supported by The Northern New England Clinical Oncology Society Student-Led Project Grant and undertaken in collaboration with the Patrick Dempsey Center for Cancer Hope and Healing as well as the Rehabilitation Services and the Cancer Center at Central Maine Medical Center (CMMC).

The presentation given to stakeholders regarding implementation of this paper's recommendations can be found here:

[http://dune.une.edu/dphp\\_resources/2/](http://dune.une.edu/dphp_resources/2/)

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# **A Review of Screening Processes for Physical Distress and Appropriate Outcome Measures for Outpatient Rehabilitation Referral in Cancer Survivorship**

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## **Section 1: Review of Literature to Identify Rehabilitation Need in Cancer Survivors**

Several studies support the need for additional wellness services for cancer survivors but there is a discrepancy between the literature and current healthcare practice. This literature review was conducted using the following search engines: CINAHL and Medline-PubMed. Key words used in the search included the following combinations of the words and terms: “physical distress,” “screening,” “cancer,” “rehabilitation,” and “wellness services.” Only scholarly journal articles were included, and the following restrictions were imposed on the search: human studies only and English language only. There were a total of 22 articles identified in CINAHL and Medline-PubMed that were related to physical distress screening in patients who have cancer. The following narrative is based on the inclusion of 11 articles published between 1997 and 2015 that are reflective of the current body of evidence related to the incidence and need for physical distress screening in cancer populations. These articles were chosen because they displayed evidence that there is a lack of referral to additional wellness services for patients who have cancer despite a documented need in this population.

More than 1.5 million people are diagnosed with cancer annually, and there are more than 14.2 million cancer survivors in this country.<sup>1</sup> With five-year survival rate estimates at an all-time high and the number of survivors growing, the need to address issues facing cancer survivors has also grown in recognition. In Maine, approximately 8,810 individuals will be diagnosed with cancer in 2015.<sup>1</sup> Each cancer survivor has a unique set of risk factors, disease presentation, course of treatment, and cancer treatment-related side effects requiring individualized, patient-centered care. Cancer is both an acute and chronic disease that requires attention from an interprofessional healthcare team.

People undergoing medical treatment for cancer are at high risk for severe and persistent symptoms of physical distress including fatigue, pain, loss of appetite, shortness of breath, numbness and tingling, cognitive and sexual dysfunction, constipation, muscle weakness, and gait disturbances that impair post-treatment function and may limit participation in rehabilitation programs.<sup>2,3</sup> Despite the need to identify and intervene with patients experiencing physical distress, there is a lack of referrals for additional wellness services.<sup>4</sup> Many healthcare professionals do not view cancer as a chronic condition,<sup>5</sup> even though cancer survivors can endure physical distress symptoms for up to ten years following treatment.<sup>6</sup> Moreover, many healthcare professionals continue to view decreased quality of life in this population as an unavoidable outcome that accompanies the cancer diagnosis and treatment.<sup>6</sup> Many clinicians focus solely on the cancer and not the presence of associated functional problems or residual impairments from intensive medical intervention.<sup>2</sup> Oncologists may falsely assume that the patient is higher functioning than they actually are due to a lack of expertise to perform a full physical assessment.<sup>7</sup> Physical and occupational therapists may also lack knowledge about disease progression in advanced cancer survivors. Functional losses are typically a slow and gradual process and may be unintentionally overlooked by members of the healthcare team.<sup>7</sup>

Pre-rehabilitation and rehabilitation can reduce physical distress and improve quality of life as well as physical and social functioning in cancer survivors.<sup>8,9</sup> Pre-rehabilitation is especially important because it focuses on strengthening and conditioning prior to treatment in order to minimize damage to the body and mind.<sup>10</sup> Identifying the need for these rehabilitation interventions can be a challenge for both oncology and non-oncology healthcare providers alike. Developing systems to both identify and treat physical symptoms in oncology will be transformational for our growing cancer survivor patient population in need.

A study using population-based data from the Michigan Prostate Cancer Survivor Study (n=2,449) was performed to help determine the relationship between long-term prostate cancer survivors' symptom burden and information needs.<sup>9</sup> The results demonstrated a high symptom burden among all domains studied with over 56% of respondents reporting they needed more information regarding recurrence of disease, sexual relationships, and long-term effects.<sup>9</sup> With the increasing population of long-term cancer survivors, addressing symptom burden is essential to ensure that each patient receives the appropriate healthcare services following diagnosis, as well as the proper patient education regarding symptom burden and management.

Impairment and disability are interrelated terms, though they can hold entirely different implications for each individual cancer survivor. For example, a mild impairment can cause a severe disability, while a severe impairment may cause a mild disability.<sup>8</sup> For this reason, screening for early identification of impairments and how they directly relate to a patient's current function may aide in the prevention of serious lifelong disabilities. The greatest source of emotional distress in cancer survivors is physical disability.<sup>11</sup> The risk of psychological stress in individuals with cancer relates much more strongly to their level of disability than it does to the cancer diagnosis itself.<sup>11</sup> Psychological distress screening in addition to physical screening is an important part of cancer care and whole-person treatment. Routine screenings and follow-up to encourage survivors to implement techniques and skills learned in their rehabilitative program may enhance an individual's perspective on their quality of life.

The goal of this project, in collaboration with the Patrick Dempsey Center for Cancer Hope and Healing as well as the Rehabilitation Services and the Cancer Center at Central Maine Medical Center (CMMC), is to determine which physical distress screening tools are most appropriate to trigger a wellness or rehabilitation referral when it is warranted for a survivor. The use of effective screening tools will assist in directing cancer survivors, who experiencing physical and emotional burdens that are caused by the disease and subsequent treatment, to access services that will continue to improve their overall quality of life upon completion of cancer treatment or in a setting of ongoing palliative care.<sup>2</sup> These measures should focus on functional mobility, balance, fatigue, and distress. Additionally, there are many common tests used to quantify the subjective burden of pain, confidence, and difficulty with daily tasks. Outcome measures such as these should be implemented throughout the course of treatment, with consistency, for patients with cancer to promote early recognition of impairments. Improved education for patients and healthcare providers alike on the services available, possible benefits of such referrals, and the importance of carefully selected measures to monitor functional change has the potential to begin to bridge the current gap between medical oncology treatment and the network of other rehabilitative healthcare services, as well as to improve the quality of life for our surviving family, friends, neighbors, coworkers, and colleagues.

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## **Section 2: Review of Oncology Physical Distress Screening Tools and Outcome Measures**

This literature review was conducted using the following search engines: CINAHL, Medline-PubMed, and EBSCO. Key words used in the search included the following combinations of the words and terms “physical distress,” “screening,” “cancer,” “rehabilitation,” “wellness services,” “eastern cooperative oncology group scale,” “patient specific functional scale,” “fatigue,” “weakness,” “peripheral neuropathy,” “quality of life,” and “pain.” Only scholarly journal articles were included, and the following restrictions were imposed on the search: human studies only and English language only. There were 12 articles identified in EBSCO, CINAHL, and Medline-PubMed that were related to physical distress screening in patients who have cancer. Information was also included from websites such as the National Comprehensive Cancer Network (NCCN) and Rehab Measures. Additional articles were also identified through the reference lists of other articles and websites. The following narrative is based on the inclusion of 18 articles published between 1990 and 2015 that are reflective of the current body of evidence related to outcome measures and physical distress screening tools for cancer survivors.

The need for referrals to additional wellness and rehabilitative services among cancer survivors is well documented in the literature, but there is currently no consensus on which screening tools and/or outcome measures should be used to help identify those who are in need of services. Cancer agencies, such as the NCCN and the American Cancer Society provide guidelines for cancer care as it relates to specific diagnoses and symptoms, such as quality of life, fatigue, pain, distress, and survivorship. However, there is little guidance on which tools should be used to detect physical distress and the role physical therapy can play in a survivor’s plan of care.

### **Current Practice at Central Maine Medical Cancer Center**

Central Maine Medical Center (CMMC) currently utilizes the Eastern Cooperative Oncology Group Scale of Performance Status (ECOG), the Patient Specific Functional Scale (PSFS), and the National Comprehensive Cancer Network (NCCN) distress thermometer to assess physical and emotional distress and function in patients with cancer. The following describes those tools.

The tool reportedly used most often by the oncology team at CMMC to assess function of patients is the ECOG (See Appendix 1). This scale is commonly used around the country in research settings when determining which patient population to include in trials of a new treatment method.<sup>1</sup> However, our stakeholders at CMMC reported this is the primary tool for detecting change in a patient’s self-reported status and function. The ECOG was found to have fair interrater reliability (Kappa values greater than 0.40) between three oncologists with a population of 100 patients. All three oncologists were in complete agreement of a patient’s score for only 44 patients.<sup>2</sup> This tool also encompasses a wide range of function, where 0 indicates no impairment and full activity and 5 indicates death. This tool is administered for each patient at CMMC when they check-in for appointments. Due to the multitude of abilities and disabilities a person may encounter as a result of their cancer treatment, a more sensitive tool may be beneficial to detect more subtle changes in patient status. As our technology and treatment methods develop, so should the standard of our functional assessment. The need for increased referrals to address quality of life issues in this patient population has been discussed previously, and a more detailed performance scale will assist in ameliorating this gap.



The PSFS is a tool that is reportedly used during the initial patient visit following a cancer diagnosis, but is inconsistently administered at subsequent visits (See Appendix 2). This tool asks the patient to identify up to five activities they are having difficulty performing and rate the difficulty on a 0 to 10 scale, where 0 indicates they are unable to perform and 10 indicates they are able to perform at the same level as prior to their diagnosis. The PSFS is recommended to be re-administered at each subsequent visit to track changes in function specific to those activities. Despite excellent reliability (0.91), the PSFS has been primarily studied for patients with musculoskeletal injuries and the psychometric properties were determined as compared to other musculoskeletal outcome measures.<sup>4</sup> No specific psychometric properties were found for the PSFS as it relates to impairments from cancer treatments. Many cancer survivors have musculoskeletal complaints, so the PSFS may still be an appropriate tool to use with this population. However, to keep the reliability of this measure relevant to the ever-fluctuating physical condition of this patient population, it must be administered on a more consistent and structured basis.

The distress thermometer is recommended by the NCCN to screen for emotional, psychological, and physical distress (See Appendix 3).<sup>5</sup> It includes a thermometer for the patient to rate their overall distress from 0 to 10, where 0 indicates no distress and 10 indicates extreme distress. It also includes a list of possible practical, family, emotional, spiritual/religious, and physical problems the patient could experience. The patient is asked to check yes if it is a problem or no if it is not a problem. Though this tool has good internal consistency (0.86)<sup>6</sup> it does not provide specific questions as to the nature of the patient's problems or how often it interferes with their everyday life. This tool is currently being administered at CMMC upon initial diagnosis as well as at subsequent visits. It is reviewed by a licensed social worker, and is then sent to a doctor to generate referrals to other specialties, including rehabilitation, that the patient may need.

### **Additional Outcome Measures**

Upon searching the literature, multitudes of screening tools and outcome measures exist that pertain to symptoms and impairments a cancer survivor may endure. The following are additional outcome measures that can be utilized once a symptom is identified on one of the pre-existing screening tools (i.e. ECOG, PSFS, and/or the distress thermometer). These outcome measures may serve as a method to further determine a patient's level of impairment with a given symptom and to better direct referrals to appropriate services..

### ***Quality of Life***

A commonly used tool to assess quality of life in adult cancer survivors, specifically breast cancer survivors, is The Quality of Life in Adult Cancer Survivors scale (QLACS) (See Appendix 4). The QLACS scale is a psychometrically sound Quality of Life (QoL) instrument that assesses both acute and long-term concerns of cancer survivors. The QLACS scale was developed for long-term cancer survivors in response to limitations of QoL scales that focused mostly on acute diagnostic and treatment-related effects in cancer survivors.<sup>7</sup> The QLACS scale has 47 items which comprise 12 domains. Seven of the domains include QoL components that reflect issues of importance to cancer survivors such as fatigue and cognitive and sexual problems, but purposely do not mention cancer to allow for comparison between survivors and the general population.<sup>7</sup> The remaining five domains are cancer-specific and refer to cancer-related concerns such as financial problems, family-related distress, recurrence-related distress,

and appearance concerns. A review of QoL instruments for long-term breast cancer survivors noted the QLACS scale had high internal consistency, high validity, and good responsiveness as well as test-retest reliability when compared to other QoL instruments used in this population.<sup>7</sup> This data suggests the QLACS scale is a promising comprehensive measure of QoL for early post-treatment breast cancer survivors.<sup>7</sup>

The Reintegration to Normal Living Index (RNLI) is a patient reported outcome that aims to quantify the degree to which a patient has declined from their typical lifestyle and/or the degree to which they have been able to reintegrate into normal daily life, depending on where they are in the course of treatment (See Appendix 5).<sup>8</sup> It consists of 11 declarative items, 8 items for activities of daily living and the remaining 3 items for self-perception.<sup>8</sup> The RNLI has been found to have excellent concurrent validity (0.72) when used with Spitzer's Quality of Life Index among patients with cancer.<sup>9</sup> Though there is an opportunity for more research to be conducted on the reliability and validity of the RNLI for cancer patients, it has been shown to have good validity and reliability in assessing the community reintegration of adults living with subsequent impairments from chronic health conditions.<sup>9</sup> From a healthcare system perspective, this test is inexpensive, quickly administered, and easily understood across disciplines and diverse patient demographics.

### ***Fatigue***

The NCCN recommends using a single item 0 to 10 point patient-report scale to document changes in fatigue (See Appendix 6).<sup>10</sup> A score from 0 to 3 indicates none to mild fatigue, a score 4 to 6 indicates moderate fatigue, and a score 7 to 10 indicates severe fatigue. Per NCCN guidelines, a more focused assessment should be performed for patients who report a score of 4 or higher and education on fatigue management strategies should be provided to all patients. Our group was unable to find any information on reported psychometric properties for this tool.

The Brief Fatigue Inventory (BFI) is a reliable self-report measure developed to quickly assess the severity of fatigue in individuals with cancer (See Appendix 7). Fatigue is rated on a 0 to 10 numeric rating scale, with 0 indicating "no fatigue" and 10 indicating "fatigue as bad as you can imagine."<sup>11</sup> (p. 1188) Six items assess the amount that fatigue has interfered with different aspects of the patient's life over the past 24 hours including: general activity, mood, walking ability, normal work (including work both inside or outside of the home), relationships with other people, and enjoyment of life.<sup>11</sup> These items are also measured on a 0 to 10 scale, with 0 indicating "does not interfere" and 10 indicating "completely interferes."<sup>11</sup> (p. 1188) The use of simple single word designations for severity of fatigue levels and functional domains make it easy to understand. The BFI has good psychometric properties such as good reliability (0.95), construct validity (0.81-0.92), and concurrent validity (0.84).<sup>11</sup> Overall, the BFI is an effective clinical screening tool and can be used as an outcome measure in cases where fatigue severity is a primary concern.

The Functional Assessment of Cancer Therapy - General (FACT-G) is an instrument commonly used to assess aspects of quality of life that may be impacted by cancer care, such as emotional, physical, and functional well being (See Appendix 8). There are many versions of the FACT that relate to specific cancer diagnoses, specific types of cancer treatment, and common symptoms associated with cancer and/or cancer treatment. Of the symptom-specific Functional

Assessment of Chronic Illness Therapy (FACIT) tools, the ones that relate to symptoms treatable by physical therapy include the FACIT-Fatigue (FACIT-F), FACIT-Anemia/Fatigue (FACIT-An), and the FACIT-Lymphedema (FACIT-B+4) which is used in conjunction with the FACIT-Breast Cancer. Many patients develop anemia and anemia-related symptoms with cancer or after cancer treatment.<sup>12</sup> These specific 20-item questionnaires were developed to determine how fatigue and anemia-related symptoms impact a patient's quality of life. Both FACIT-F (See Appendix 9) and FACIT-An (See Appendix 10) have strong internal consistency, 0.95 and 0.96 respectively, as well as great test-retest reliability, 0.84 and 0.90 respectively.<sup>12</sup> All versions of the FACT and FACIT questionnaires are relatively inexpensive and easy to administer. These are extremely useful tools in the healthcare system because they capitalize on the importance of the widespread problems with fatigue and anemia-related symptoms due to cancer and cancer treatment.<sup>12</sup>

### ***Pain***

The NCCN recommends utilizing the Numerical Pain Rating Scale (NPRS) in conjunction with the Faces Pain Rating Scale (FPRS) to assess for pain severity (See Appendix 11).<sup>13</sup> The NPRS is an 11-point scale where 0 indicates no pain and 10 indicates the worst pain imaginable. The NPRS and the FPRS have been found to have good to excellent reliability (0.88-0.91) for patients with chronic neurogenic pain or acute pain.<sup>14</sup> Though specific oncology populations were not assessed in this study, the results may still be applicable to oncology populations.

The Brief Pain Inventory (BPI) has a short form version, which includes nine questions, and a long form version, which includes 32 questions (See Appendix 12). Both versions also include an outline of the anterior and posterior aspects of a body so the patient can report the specific location(s) of their pain. Both versions are free for clinical use and take the patient five to ten minutes to complete depending on which version is used. Among cancer patients and people with chronic pain, the BPI has adequate to excellent test-retest reliability and excellent internal consistency, which makes it a reliable tool to document changes in a patient's pain.

### ***Neuropathy***

Neuropathy during cancer treatment is a common and debilitating side-effect often caused by chemotherapy occurring in 25% to 56% of cancer survivors receiving chemotherapy.<sup>16</sup> The Modified Total Neuropathy Score (mTNS) was developed to be a clinically feasible tool that has been shown to be a reliable and valid measure to evaluate the severity of chemotherapy-induced peripheral neuropathy (See Appendix 13). The mTNS is simple, takes approximately 10 minutes to administer, and has been shown to be correlated with the Total Neuropathy Score (TNS), TUG, and other QoL measures.<sup>16</sup>

### ***Weakness***

Manual muscle testing (MMT), as described by Kendall et al., is a method to assess a patient's muscle strength. The grades range from 0, which indicates no movement or muscle contraction, to 5, which indicates the patient can hold the test position against gravity and strong pressure. MMT has been found to have good validity as well as excellent intrarater and interrater reliability when assessed in an orthopedic population.<sup>17</sup> Though not specifically assessed in an

oncology population, this tool may still be appropriate to assess musculoskeletal impairments in cancer survivors.

Grip strength is typically assessed through use of a hand-held dynamometer. It has been found to have excellent interrater and intrarater reliability as well as excellent test-retest reliability among various patient populations.<sup>18</sup> Though psychometric properties as they pertain to oncology patient populations have not been developed, this may still be a valid tool to assess grip strength in cancer survivors. This test may be indicated for any patient with diminished grip or upper extremity strength to assess function, and it may be especially pertinent for patients with breast cancer who have had unilateral and/or bilateral axillary node dissection(s).

In summary, cancer survivors often experience far-reaching and debilitating side effects of treatment that cause physical distress. Some of these side effects are directly related to treatment modalities, such as radiation and chemotherapy, while others are the result of cancer-related surgical intervention or the tumor itself. Regardless of the source of impairment or functional limitation, healthcare professionals working with cancer survivors should be vigilant and prepared to deal with the high prevalence of physical distress in cancer survivors. A large body of evidence supports the effectiveness of screening tools to identify symptoms of physical distress. Referral to rehabilitation services, such as physical therapy, has repeatedly been shown to be effective in treating these symptoms.

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<http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=1185> Accessed November 12, 2015

### **Section 3a: Theories of Behavior Change**

This literature review was conducted using the following search engines: CINAHL, Medline-PubMed, and EBSCO. Key words used in the search included the following combinations of the words and terms: “physical distress,” “screening,” “cancer,” “rehabilitation,” “wellness services,” “health belief model,” and “diffusion of innovation theory.” Only scholarly journal articles were included, and the following restrictions were imposed on the search: human studies only and English language only. There were 5 articles identified in EBSCO, CINAHL, and Medline-PubMed that were related to the Health Belief Model and the Diffusion of Innovation Theory. Educational websites were also utilized. The following narrative is based on the inclusion of 5 articles published between 2009 and 2015 as well as one website that are reflective of the current body of evidence related to the Health Belief Model and the Diffusion of Innovation Theory.

The Health Belief Model encompasses a person’s belief as it relates to the severity of a disease, the effectiveness or ineffectiveness of the recommended medical treatment, and willingness to overcome barriers to treatment.<sup>1</sup> Through a stakeholder meeting with members from CMMC, it was determined that many of the barriers for referral to physical therapy services came from a lack of understanding of what physical therapy can do for the patient. Stated barriers included the perception that many cancer survivors will not want wellness services, difficulty of making referrals through their computer system, and the limited availability of a physical therapist within the cancer center to discuss the benefits of a physical therapy or wellness program with patients. These barriers have impeded the generation of referrals to additional wellness and rehabilitation services.

The Diffusion of Innovation Theory is a community-level theory describing how new information is disseminated into a community.<sup>2</sup> Our recommendation of increasing the frequency of screening tool administration to help healthcare professionals provide improved care to cancer survivors living with physical distress relies on early adopters and will likely face resisters. During our meeting it became clear that while some healthcare professions are eager to fill the gap in services for cancer survivors living with physical distress, others are resistant to change. The Diffusion of Innovation Theory matches well with this dynamic, describing how new evidence will be disseminated within these two groups.

Through a review of literature, we determined which tests and measures are the most appropriate and effective to screen cancer survivors for physical distress and determine when a referral is indicated for additional wellness services (see Section 2). Several meetings have been held with our stakeholders at CMMC and the Dempsey Center, and it was determined there was a need to educate other members of the healthcare team on the benefits of rehabilitation and wellness programs to help generate an increase in referrals to those services. With the identification of a variety of outcome measures, it made it possible to focus our efforts on which tools would be most appropriate for CMMC and the most opportune time for these tools to be administered. By properly identifying those in need of rehabilitation services and making the appropriate referrals, the patient has the potential to benefit with an improved quality of life.

Adopting new screening tools in a healthcare organization with established protocols is challenging. It often takes as long as twenty years between the development of evidence-based research and implementation into clinical practice.<sup>6</sup> This means that although there is well-published evidence that cancer survivors’ symptoms of physical distress are underreported,<sup>3,4,5</sup> it may be decades before automatic referrals for cancer survivors with physical distress becomes a standard of care. The Diffusion of Innovation Theory describes innovators and early adopters as

being critical in the early stages of implementation.<sup>2</sup> These early adopters individually respond to and incorporate innovative ideas which leads to an eventual diffusion and change within the social system. This describes our situation accurately. Our group has identified innovative physical distress screening tools that will be used by rehabilitation clinicians at CMMC who are clearly motivated to lead the charge of adopting new and better ways of screening patients for physical distress. This will help lead to diffusion through the CMMC Cancer Center as people see the benefits of improved services for cancer survivors and increases in referrals.

The Health Belief Model provides a framework for understanding the viewpoints of stakeholders at the Dempsey Center and CMMC. While this theory more directly applies to individuals making decisions about personal health behaviors, it provides insight into how stakeholders may view implementing a new protocol into their healthcare system. After we present our data on how to improve screening for physical distress to stakeholders, an evaluation of perceived benefits and barriers, perceived threat, and cues to action will guide perceptions of the feasibility of implementation.

### **Section 3b: Program Delivery and Projected Impact**

A comprehensive list of screening tools has been identified as options for CMMC to use in identifying cancer survivors who would benefit most from rehabilitation services (see Section 2). These tools may be utilized to improve upon the current method of needs identification among cancer survivors. Currently the ECOG is used as a standard within treatment sessions; however, it lacks the detailed information to truly determine those who would require rehabilitative care. The distress thermometer, which is also used by CMMC, is a more specific tool that, if used on a more consistent basis, could have more of an impact on the number of referrals to rehabilitation services.

Systemic challenges we have identified with our stakeholders are that the current distress tools are not being used on a consistent basis, there is no set system to inform other healthcare professionals of the pertinent patient findings, and the ECOG is not sensitive enough to detect changes in physical distress in this patient population. This project aims to address this problem by providing other screening and outcome tool options that are more highly sensitive to common cancer treatment symptoms. A secondary challenge that arises is the lack of a person on staff who can take on the responsibility of selecting, administering, or appropriately passing forth the information gathered from these measurement tools, resulting in a necessary referral.

The feasibility of this program is dependent upon a cancer survivor's access to a healthcare professional who is trained and knowledgeable about administering the specific screening tools. In many cases, this may require that a rehabilitation professional be present in the primary cancer care setting. It is the recommendation of this group that the distress thermometer be administered to patients on a more consistent and structured basis in order to better detect changes in physical distress throughout their continuum of care. This project also identifies the long-term solutions to be the implementation and inclusion of a rehabilitation professional on the interdisciplinary oncology rehabilitation team at CMMC. This rehabilitation professional would be present within the infusion center to administer appropriate screening tools, and have conversations with patients and their families who are experiencing distress and may benefit from rehabilitation services. The projected impact of this project will be dependent on follow-through with CMMC's physical therapy department and the Cancer Center. By



incorporating a physical therapist into the routine care for cancer survivors there is potential for increased referrals to physical therapy and an improved quality of life for those patients.

## References

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#### **Section 4: Methods of Program Evaluation**

Success of this program will be dependent upon CMMC adopting policy changes to include rehabilitation professionals, such as physical therapists, occupational therapists, and speech and language pathologists, as members of the healthcare team upon initial cancer diagnosis. This will allow for early access to screen survivors for symptoms of physical distress and provide an opportunity for early education on symptom burden management. It will also provide access to rehabilitation services throughout the patient's cancer care with regular follow-ups and screening. Ultimately, success of this program will be evident by an increase in referrals to rehabilitation and wellness services, a decrease in hospital readmission rates, and, most importantly, a better overall quality of life for cancer survivors.

#### **Outputs:**

Our group performed two needs assessment meetings with stakeholders at CMMC and the Dempsey Center. These stakeholders included the director of outpatient rehabilitation services at CMMC, the nurse manager at the CMMC infusion center, two medical oncology nurse practitioners at CMMC, and the executive director of the Dempsey Center. These meetings demonstrated a need to clarify which screening tools best identify physical distress in cancer survivors. The final product for this project will be a one-hour presentation attended by approximately 10 members of our stakeholders to discuss utilization of physical distress screening tools and a pilot of implementing a physical therapist during chemotherapy infusion at the CMMC Cancer Center.

#### **Outcomes:**

##### *Short-term:*

We will measure the outcome of our program by the number of stakeholders present for our presentation, the overall professional response across disciplines, and feedback received from the attending audience to implement some or all of our recommendations. The collective information gathered at prior meetings and a literature review served as the foundation for our stakeholder presentation on December 4th, 2015 at CMMC.

##### *Medium-term:*

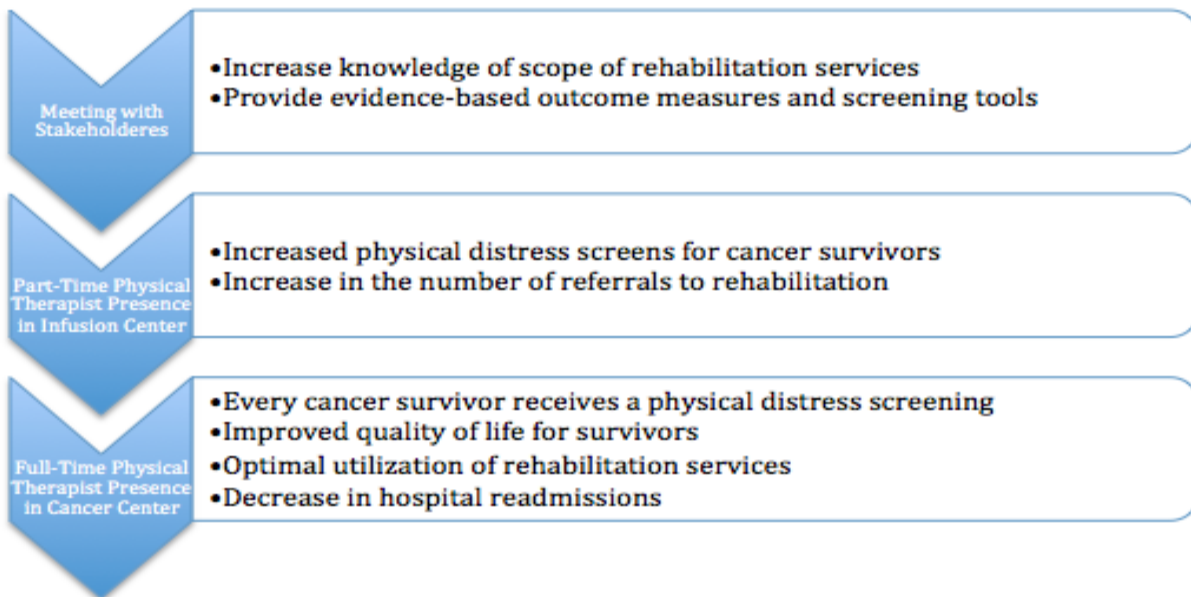
The integration of rehabilitation and wellness services will be measured by the number of referrals generated to rehabilitation services. Following the addition of a part-time physical therapist to the CMMC infusion team, our goal is to increase the number of monthly oncology referrals to rehabilitation and wellness services by 10%.

##### *Long-term:*

Long-term outcomes include employment of a full-time physical therapist in the CMMC Cancer Center where every cancer survivor is screened for signs of physical distress weekly and an increase in referrals to rehabilitative and wellness services. Standardization of rehabilitation and wellness services will be measured by reassessing baselines in 2020 for goal 14 in the Maine Cancer Control Plan. Assessments will be made through the Maine Cancer Consortium's Activity Tracker, as well as phone calls and e-mails to cancer treating hospitals, as needed. Decreased public healthcare financial burden will be measured by annual economic assessments. The quality of life of cancer survivors will be measured by annual quality of life outcome assessments.

## Logical Model

This model will encompass a basis for selection of screening tools for this population. This model is based upon the International Classification of Functioning Disability and Health (ICF) model. Components of this model are patient-centered and include the following: health condition, body function and structure, activity limitations and participation restrictions, environmental factors, and personal factors. This model will provide a framework that can be used across all disciplines in order to standardize language and concepts to improve patient quality of life. Utilizing the ICF framework can help guide rehabilitation services in choosing appropriate outcome measures that are useful in assessing patients for physical distress with an oncology diagnosis.



This model is dependent on CMMC adopting behavior change in order for rehabilitation services to become a cohesive part of the cancer care team.

## Appendix 1

### Eastern Cooperative Oncology Group Scale of Performance Status (ECOG)

GRADE	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

From: <http://ecog-acrin.org/resources/ecog-performance-status>

## Appendix 2

### Patient Specific Functional Scale (PSFS)

#### The Patient-Specific Functional Scale

This useful questionnaire can be used to quantify activity limitation and measure functional outcome for patients with any orthopaedic condition.

**Clinician to read and fill in below:** Complete at the end of the history and prior to physical examination.

#### Initial Assessment:

I am going to ask you to identify up to three important activities that you are unable to do or are having difficulty with as a result of your \_\_\_\_\_ problem. Today, are there any activities that you are unable to do or having difficulty with because of your \_\_\_\_\_ problem? (Clinician: show scale to patient and have the patient rate each activity).

#### Follow-up Assessments:

When I assessed you on (state previous assessment date), you told me that you had difficulty with (read all activities from list at a time). Today, do you still have difficulty with: (read and have patient score each item in the list)?

#### Patient-specific activity scoring scheme (Point to one number):

0      1      2      3      4      5      6      7      8      9      10

Unable to perform activity

Able to perform activity at the same level as before injury or problem

(Date and Score)

Activity	Initial					
1.						
2.						
3.						
4.						
5.						
Additional						
Additional						

Total score = sum of the activity scores/number of activities  
 Minimum detectable change (90%CI) for average score = 2 points  
 Minimum detectable change (90%CI) for single activity score = 3 points

PSFS developed by: Stratford, P., Gill, C., Westaway, M., & Binkley, J. (1995). Assessing disability and change on individual patients: a report of a patient specific measure. *Physiotherapy Canada*, 47, 258-263.

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From: [http://www.tac.vic.gov.au/data/assets/pdf\\_file/0020/27317/Patient-specific.pdf](http://www.tac.vic.gov.au/data/assets/pdf_file/0020/27317/Patient-specific.pdf)

## Appendix 3

### NCCN Distress Thermometer

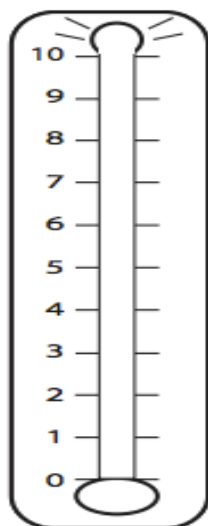


## NCCN Distress Thermometer for Patients

### SCREENING TOOLS FOR MEASURING DISTRESS

**Instructions:** First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

**Extreme distress**



**No distress**

**Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.**

**YES NO Practical Problems**

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

**Family Problems**

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

**Emotional Problems**

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

- Spiritual/religious concerns**

**Other Problems:** \_\_\_\_\_

**YES NO Physical Problems**

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines™) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines® is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use, or application, and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2013.

From: [http://www.nccn.org/patients/resources/life\\_with\\_cancer/pdf/nccn\\_distress\\_thermometer.pdf](http://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf)

## Appendix 4

### The Quality of Life in Adult Cancer Survivors scale (QLACS)

INSTRUCTIONS: We'd like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer each one. Below is a scale ranging from "never" to "always". Please indicate how often each of these statements has been true for you in the past four weeks. [Choose one answer for each question]

1 = never    2 = seldom    3 = sometimes    4 = about as often as not    5 = frequently  
6 = very often    7 = always

In the past 4 weeks ...

1. You had the energy to do the things you wanted to do.
2. You had difficulty doing activities that require concentrating.
3. You were bothered by having a short attention span.
4. You had trouble remembering things.
5. You felt fatigued.
6. You felt happy.
7. You felt blue or depressed.
8. You enjoyed life.
9. You worried about little things.
10. You were bothered by being unable to function sexually.
11. You didn't have energy to do the things you wanted to do.
12. You were dissatisfied with your sex life.
13. You were bothered by pain that kept you from doing the things you wanted to do.
14. You felt tired a lot.
15. You were reluctant to start new relationships.
16. You lacked interest in sex.
17. Your mood was disrupted by pain or its treatment.
18. You avoided social gatherings.
19. You were bothered by mood swings.
20. You avoided your friends.
21. You had aches or pains.
22. You had a positive outlook on life.
23. You were bothered by forgetting what you started to do.
24. You felt anxious.
25. You were reluctant to meet new people.
26. You avoided sexual activity.
27. Pain or its treatment interfered with your social activities.
28. You were content with your life.

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.



29. You appreciated life more because of having had cancer.
30. You had financial problems because of the cost of cancer surgery or treatment.
31. You worried that your family members were at risk of getting cancer.
32. You realized that having had cancer helps you cope better with problems now.
33. You were self-conscious about the way you look because of your cancer or its treatment.
34. You worried about whether your family members might have cancer-causing genes.
35. You felt unattractive because of your cancer or its treatment.
36. You worried about dying from cancer.
37. You had problems with insurance because of cancer.
38. You were bothered by hair loss from cancer treatment.
39. You worried about cancer coming back.
40. You felt that cancer helped you to recognize what is important in life.
41. You felt better able to deal with stress because of having had cancer.
42. You worried about whether your family members should have genetic tests for cancer.
43. You had money problems that arose because you had cancer.
44. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.
45. You had financial problems due to a loss of income as a result of cancer.
46. Whenever you felt a pain, you worried that it might be cancer again.
47. You were preoccupied with concerns about cancer.

Scales are computed as follows:

Negative feelings, items 7, 9, 19, and 24  
Positive feelings, items 6, 8, 22, and 28  
Cognitive Problems, items 2, 3, 4, and 23  
Pain, items 13, 17, 21, and 27  
Sexual Interest, items 16 and 26  
Energy/Fatigue, items 1 (reversed), 5, 11, and 14  
Sexual Function, items 10 and 12  
Social Avoidance, items 15, 18, 20, and 25  
Financial Problems, items 30, 37, 43, and 45  
Benefits, items 29, 32, 40, and 41  
Distress-Family, items 31, 34, and 42  
Appearance, items 33, 35, 38, and 44  
Distress-Recurrence, items 36, 39, 46, and 47

From: <http://www.psy.miami.edu/faculty/ccarver/sclQLACS.html>

## Appendix 5

### Reintegration to Normal Living Index (RNLI)

1. I move around my living quarters as I feel is necessary (Wheelchairs, other equipment or resources may be used.)
2. I move around my community as I feel is necessary. (Wheelchairs, other equipment or resources may be used.)
3. I am able to take trips out of town as I feel are necessary. (Wheelchairs, other equipment or resources may be used.)
4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met. (Adaptive equipment, supervision and/or assistance may be used.)
5. I spend most of my days occupied in a work activity that is necessary or important to me. (Work activity could be paid employment, housework, volunteer work, school, etc. Adaptive equipment, supervision and/or assistance may be used.)
6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to. (Adaptive equipment, supervision and/or assistance may be used.)
7. I participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to. (Adaptive equipment, supervision and/or assistance may be used.)
8. I assume a role in my family which meets my needs and those of other family members. (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis. Adaptive equipment, supervision and/or assistance may be used.)
9. In general, I am comfortable with my personal relationships.
10. In general, I am comfortable with myself when I am in the company of others.
11. I feel that I can deal with life events as they happen.

From: <http://www.strokengine.ca/pdf/rnli.pdf>

## **Appendix 6**

### **NCCN-Recommended Fatigue Patient-Report Scale**

“How would you rate your fatigue on a scale of 0-10 over the past 7 days?”

Adults >12 years old:

0 = No fatigue

1-3 = Mild fatigue

4-6 = Moderate fatigue

7-10 = Severe fatigue where 10 = the worst fatigue you can imagine

Children 7-12 years old:

1 = No fatigue

5 = Worst

Children 5-6 years old:

Tired or Not tired

From: [http://www.nccn.org/professionals/physician\\_gls/pdf/fatigue.pdf](http://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf)

**Appendix 7**  
**Brief Fatigue Inventory (BFI)**

<b>Brief Fatigue Inventory</b>										
STUDY ID# _____	HOSPITAL # _____									
Date: ____/____/____	Time: _____									
Name: _____										
Last	First Middle Initial									
<p>Throughout our lives, most of us have times when we feel very tired or fatigued. Have you felt unusually tired or fatigued in the last week? Yes <input type="checkbox"/> No <input type="checkbox"/></p>										
<p><b>1. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right NOW.</b></p>										
0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine
<p><b>2. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your USUAL level of fatigue during past 24 hours.</b></p>										
0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine
<p><b>3. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during past 24 hours.</b></p>										
0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine
<p><b>4. Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your:</b></p>										
<b>A. General activity</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<b>B. Mood</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<b>C. Walking ability</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<b>D. Normal work (includes both work outside the home and daily chores)</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<b>E. Relations with other people</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<b>F. Enjoyment of life</b>										
0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes
<small>Copyright 1997  The University of Texas M. D. Anderson Cancer Center  All rights reserved.</small>										

From: [http://www.npcrc.org/files/news/brief\\_fatigue\\_inventory.pdf](http://www.npcrc.org/files/news/brief_fatigue_inventory.pdf)

## Appendix 8

### Functional Assessment of Cancer Therapy - General (FACT-G)

#### FACT-G (Version 4)

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

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
0P1	I have a lack of energy .....	0	1	2	3	4
0P2	I have nausea .....	0	1	2	3	4
0P3	Because of my physical condition, I have trouble meeting the needs of my family .....	0	1	2	3	4
0P4	I have pain .....	0	1	2	3	4
0P5	I am bothered by side effects of treatment .....	0	1	2	3	4
0P6	I feel ill .....	0	1	2	3	4
0P7	I am forced to spend time in bed .....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
001	I feel close to my friends .....	0	1	2	3	4
002	I get emotional support from my family .....	0	1	2	3	4
003	I get support from my friends .....	0	1	2	3	4
004	My family has accepted my illness .....	0	1	2	3	4
005	I am satisfied with family communication about my illness .....	0	1	2	3	4
006	I feel close to my partner (or the person who is my main support) .....	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
007	I am satisfied with my sex life .....	0	1	2	3	4

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

<b><u>EMOTIONAL WELL-BEING</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
080	I feel sad .....	0	1	2	3	4
082	I am satisfied with how I am coping with my illness .....	0	1	2	3	4
083	I am losing hope in the fight against my illness .....	0	1	2	3	4
084	I feel nervous .....	0	1	2	3	4
085	I worry about dying .....	0	1	2	3	4
086	I worry that my condition will get worse .....	0	1	2	3	4

<b><u>FUNCTIONAL WELL-BEING</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
091	I am able to work (include work at home) .....	0	1	2	3	4
092	My work (include work at home) is fulfilling .....	0	1	2	3	4
093	I am able to enjoy life .....	0	1	2	3	4
094	I have accepted my illness .....	0	1	2	3	4
095	I am sleeping well .....	0	1	2	3	4
096	I am enjoying the things I usually do for fun .....	0	1	2	3	4
097	I am content with the quality of my life right now .....	0	1	2	3	4

From: <http://www.facit.org/FACITOrg/Questionnaires>

## Appendix 9

### Functional Assessment of Chronic Illness Therapy - Fatigue (FACIT-F)

#### FACIT-F (Version 4)

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

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
001	I have a lack of energy .....	0	1	2	3	4
002	I have nausea .....	0	1	2	3	4
003	Because of my physical condition, I have trouble meeting the needs of my family .....	0	1	2	3	4
004	I have pain .....	0	1	2	3	4
005	I am bothered by side effects of treatment .....	0	1	2	3	4
006	I feel ill .....	0	1	2	3	4
007	I am forced to spend time in bed .....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
001	I feel close to my friends .....	0	1	2	3	4
002	I get emotional support from my family .....	0	1	2	3	4
003	I get support from my friends .....	0	1	2	3	4
004	My family has accepted my illness .....	0	1	2	3	4
005	I am satisfied with family communication about my illness .....	0	1	2	3	4
006	I feel close to my partner (or the person who is my main support) .....	0	1	2	3	4
01	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
007	I am satisfied with my sex life .....	0	1	2	3	4

## FACTIT-F (Version 4)

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

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
080	I feel sad .....	0	1	2	3	4
080	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
080	I am losing hope in the fight against my illness.....	0	1	2	3	4
080	I feel nervous.....	0	1	2	3	4
080	I worry about dying.....	0	1	2	3	4
080	I worry that my condition will get worse.....	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
091	I am able to work (include work at home).....	0	1	2	3	4
092	My work (include work at home) is fulfilling.....	0	1	2	3	4
093	I am able to enjoy life.....	0	1	2	3	4
094	I have accepted my illness.....	0	1	2	3	4
095	I am sleeping well .....	0	1	2	3	4
096	I am enjoying the things I usually do for fun.....	0	1	2	3	4
097	I am content with the quality of my life right now.....	0	1	2	3	4



## FACIT-F (Version 4)

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

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
K11	I feel fatigued .....	0	1	2	3	4
K12	I feel weak all over .....	0	1	2	3	4
A11	I feel listless ("washed out") .....	0	1	2	3	4
A12	I feel tired .....	0	1	2	3	4
A13	I have trouble <u>starting</u> things because I am tired.....	0	1	2	3	4
A14	I have trouble <u>finishing</u> things because I am tired .....	0	1	2	3	4
A15	I have energy .....	0	1	2	3	4
A17	I am able to do my usual activities.....	0	1	2	3	4
A18	I need to sleep during the day .....	0	1	2	3	4
A19	I am too tired to eat .....	0	1	2	3	4
A14	I need help doing my usual activities.....	0	1	2	3	4
A15	I am frustrated by being too tired to do the things I want to do.....	0	1	2	3	4
A16	I have to limit my social activity because I am tired.....	0	1	2	3	4

From: <http://www.facit.org/FACITOrg/Questionnaires>

## Appendix 10

### Functional Assessment of Chronic Illness Therapy - Anemia/Fatigue (FACIT-An)

#### FACT-An (Version 4)

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

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
0P1	I have a lack of energy .....	0	1	2	3	4
0P2	I have nausea .....	0	1	2	3	4
0P3	Because of my physical condition, I have trouble meeting the needs of my family .....	0	1	2	3	4
0P4	I have pain .....	0	1	2	3	4
0P5	I am bothered by side effects of treatment .....	0	1	2	3	4
0P6	I feel ill .....	0	1	2	3	4
0P7	I am forced to spend time in bed .....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
0S1	I feel close to my friends .....	0	1	2	3	4
0S2	I get emotional support from my family .....	0	1	2	3	4
0S3	I get support from my friends .....	0	1	2	3	4
0S4	My family has accepted my illness .....	0	1	2	3	4
0S5	I am satisfied with family communication about my illness .....	0	1	2	3	4
0S6	I feel close to my partner (or the person who is my main support) .....	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
0S7	I am satisfied with my sex life .....	0	1	2	3	4

## FACT-An (Version 4)

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

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
000	I feel sad .....	0	1	2	3	4
000	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
000	I am losing hope in the fight against my illness.....	0	1	2	3	4
000	I feel nervous.....	0	1	2	3	4
000	I worry about dying.....	0	1	2	3	4
000	I worry that my condition will get worse.....	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
001	I am able to work (include work at home).....	0	1	2	3	4
002	My work (include work at home) is fulfilling.....	0	1	2	3	4
003	I am able to enjoy life.....	0	1	2	3	4
004	I have accepted my illness.....	0	1	2	3	4
005	I am sleeping well .....	0	1	2	3	4
006	I am enjoying the things I usually do for fun.....	0	1	2	3	4
007	I am content with the quality of my life right now.....	0	1	2	3	4

## FACT-An (Version 4)

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

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
N07	I feel fatigued .....	0	1	2	3	4
N02	I feel weak all over .....	0	1	2	3	4
A01	I feel listless ("washed out") .....	0	1	2	3	4
A02	I feel tired .....	0	1	2	3	4
A03	I have trouble <u>starting</u> things because I am tired .....	0	1	2	3	4
A04	I have trouble <u>finishing</u> things because I am tired .....	0	1	2	3	4
A05	I have energy .....	0	1	2	3	4
A06	I have trouble walking .....	0	1	2	3	4
A07	I am able to do my usual activities .....	0	1	2	3	4
A08	I need to sleep during the day .....	0	1	2	3	4
A09	I feel lightheaded (dizzy) .....	0	1	2	3	4
A010	I get headaches .....	0	1	2	3	4
N1	I have been short of breath .....	0	1	2	3	4
A011	I have pain in my chest .....	0	1	2	3	4
A012	I am too tired to eat .....	0	1	2	3	4
N04	I am interested in sex .....	0	1	2	3	4
A013	I am motivated to do my usual activities .....	0	1	2	3	4
A014	I need help doing my usual activities .....	0	1	2	3	4
A015	I am frustrated by being too tired to do the things I want to do .....	0	1	2	3	4
A016	I have to limit my social activity because I am tired .....	0	1	2	3	4

From: <http://www.facit.org/FACITOrg/Questionnaires>

## Appendix 11

### Numerical Pain Rating Scale (NPRS)

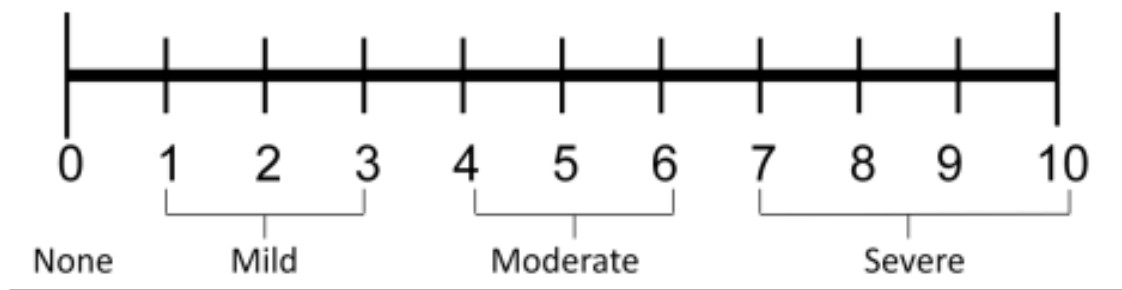
#### The Numeric Pain Rating Scale Instructions

##### General Information:

- The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours.
- The average of the 3 ratings was used to represent the patient's level of pain over the previous 24 hours.

##### Patient Instructions (adopted from (McCaffery, Beebe et al. 1989):

*"Please indicate the intensity of current, best, and worst pain levels over the past 24 hours on a scale of 0 (no pain) to 10 (worst pain imaginable)"*



From:

<http://www.rehabmeasures.org/PDF%20Library/Numeric%20Pain%20Rating%20Scale%20Instructions.pdf>

## Appendix 12

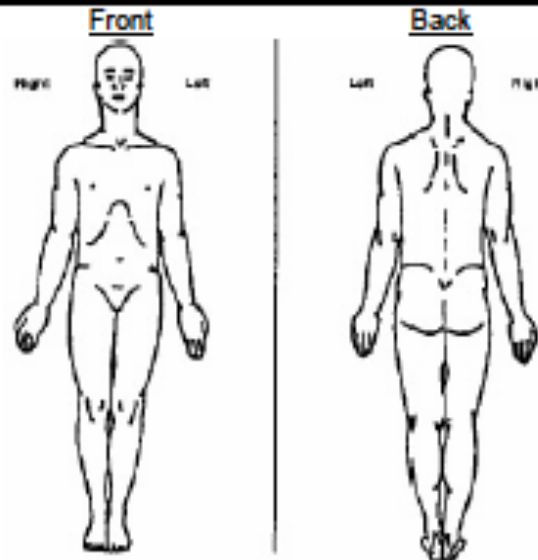
### Brief Pain Inventory Short Form (BPI)

#### Brief Pain Inventory (Short Form)

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

Yes  No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by marking the box beside the number that best describes your pain at its **worst** in the last 24 hours.

0  1  2  3  4  5  6  7  8  9  10  
No Pain Pain As Bad As You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its **least** in the last 24 hours.

0  1  2  3  4  5  6  7  8  9  10  
No Pain Pain As Bad As You Can Imagine

5. Please rate your pain by marking the box beside the number that best describes your pain on the **average**.

0  1  2  3  4  5  6  7  8  9  10  
No Pain Pain As Bad As You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have **right now**.

0  1  2  3  4  5  6  7  8  9  10  
No Pain Pain As Bad As You Can Imagine

**7. What treatments or medications are you receiving for your pain?**


**8. In the last 24 hours, how much relief have pain treatments or medications provided? Please mark the box below the percentage that most shows how much relief you have received.**

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No Relief										Complete Relief

**9. Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:**

**A. General Activity**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**B. Mood**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**C. Walking ability**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**D. Normal Work (includes both work outside the home and housework)**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**E. Relations with other people**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**F. Sleep**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

**G. Enjoyment of life**

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

From: [http://www.npcrc.org/files/news/briefpain\\_short.pdf](http://www.npcrc.org/files/news/briefpain_short.pdf)

## Appendix 13

### Modified Total Neuropathy Score (mTNS)

Parameter	Score				
	0	1	2	3	4
Sensory symptoms	None	Symptoms limited to fingers or toes	Symptoms extend to ankle or wrist	Symptoms extend to knee or elbow	Symptoms above knees or elbows, or functionally disabling
Motor symptoms	None	Slight difficulty	Moderate difficulty	Require help or assistance	Paralysis
Number of autonomic symptoms	None	One	Two	Three	Four or five
Pin sensibility	Normal	Reduced in fingers and/or toes	Reduced up to wrist and/or ankle	Reduced up to elbow and/or knee	Reduced above elbow and/or knee
Vibration sensibility	Normal	Reduced in fingers and/or toes	Reduced up to wrist and/or ankle	Reduced up to elbow and/or knee	Reduced above elbow and/or knee
Strength	Normal	Mild weakness	Moderate weakness	Severe weakness	Paralysis
Tendon reflex	Normal	Ankle reflex reduced	Ankle reflex absent	Ankle reflex absent, others reduced	All reflexes absent

From: <http://joannabriggslibrary.org/index.php/jbisrir/article/view/1486/1976>



**Appendix 14**  
Manual Muscle Testing (MMT)

**MANUAL MUSCLE TESTING PROCEDURES**  
**Key to Muscle Grading**

	Function of the Muscle	Grade		
<b>No Movement</b>	No contractions felt in the muscle	0	0	Zero
	Tendon becomes prominent or feeble contraction felt in the muscle, but no visible movement of the part	T	1	Trace
<b>Test Movement</b>	<b>MOVEMENT IN HORIZONTAL PLANE</b>			
	Moves through partial range of motion	1	2-	Poor-
	Moves through complete range of motion	2	2	Poor
	<b>ANTIGRAVITY POSITION</b>			
	Moves through partial range of motion	3	2+	
<b>Test Position</b>	<i>Gradual</i> release from test position	4	3-	Fair-
	Holds test position (no added pressure)	5	3	Fair
	Holds test position against slight pressure	6	3+	Fair+
	Holds test position against slight to moderate pressure	7	4-	Good-
	Holds test position against moderate pressure	8	4	Good
	Holds test position against moderate to strong pressure	9	4+	Good+
	Holds test position against strong pressure	10	5	Normal

From: <http://www.prohealthcareproducts.com/blog/manual-muscle-testing-grading-chart-florence-kendall/>