University of Dayton

eCommons

Physical Therapy Faculty Publications

Department of Physical Therapy

3-29-2022

Knowledge Regarding Cancer-Related Fatigue: A Survey of Physical Therapists and Individuals Diagnosed with Cancer

Shana Harrington Creighton University

Mary Insana Fisher University of Dayton, mary.fisher@udayton.edu

Jeannette Lee University of California - San Francisco

Joy C. Cohn University of Pennsylvania Health System

Daniel Malone University of Colorado

Follow this and additional works at: https://ecommons.udayton.edu/dpt_fac_pub

Part of the Biomechanics Commons, Musculoskeletal System Commons, Orthopedics Commons, and the Therapeutics Commons

eCommons Citation

Harrington, Shana; Fisher, Mary Insana; Lee, Jeannette; Cohn, Joy C.; and Malone, Daniel, "Knowledge Regarding Cancer-Related Fatigue: A Survey of Physical Therapists and Individuals Diagnosed with Cancer" (2022). *Physical Therapy Faculty Publications*. 108. https://ecommons.udayton.edu/dpt_fac_pub/108

This Article is brought to you for free and open access by the Department of Physical Therapy at eCommons. It has been accepted for inclusion in Physical Therapy Faculty Publications by an authorized administrator of eCommons. For more information, please contact mschlangen1@udayton.edu, ecommons@udayton.edu.

Knowledge Regarding Cancer-related Fatigue: A Survey of Physical Therapists and Individuals Diagnosed with Cancer

Shana E Harrington, PT, PhD,¹ Mary I Fisher, PT, PhD,² Jeannette Q. Lee, PT, PhD,³ Joy Cohn, PT,⁴ Daniel Malone, PT, PhD⁵

¹Department of Exercise Science, Physical Therapy Program, University of South Carolina, 1300
 ¹Wheat Street, Blatt PE Center, Columbia, SC 29208. ORCID:0000-0002-3713-3371
 ²Department of Physical Therapy, University of Dayton, 300 College Park, Dayton, OH 45469
 ³Graduate Program in Physical Therapy, University of California San Francisco/San Francisco
 State University, SFSU Campus, 1600 Holloway Avenue, San Francisco, CA 94132
 ⁴Good Shepherd Penn Partners, 1800 Lombard Street, Philadelphia, PA 19147
 ⁵Physical Therapy Program, University of Colorado – Anschutz Medical Campus, 13121 East
 17th Avenue, Aurora, CO 80045

Corresponding author: Shana E Harrington, Department of Exercise Science, Physical Therapy Program, University of South Carolina, 1300 Wheat Street, Blatt PE Center, Columbia, SC 29208, USA. Phone: 803-777-9112, Fax: 803-777-8422, Email: <u>heel1998@aol.com</u>

Abstract

Background: Cancer-related fatigue (CRF) is a common side effect and remains underdiagnosed. Screening of CRF by physical therapists (PTs) and patient perspectives of their experiences has not been comprehensively examined.

Purpose: To survey PTs to understand the frequency of CRF screening, and to assess the knowledge and experiences of survivors as it relates to CRF.

Methods: Two separate electronic surveys developed by the authors were distributed. One targeted oncology PTs, the other for adult survivors of cancer.

Results: Of the 199 PT respondents, 36% reported screening for CRF at every encounter. Screening included interviews (46%) and/or standardized questionnaires (37%). The most common barriers to receiving treatment for CRF was lack of physician referrals and time constraints. Of patient responses (n=61), 84% reported CRF as an important ongoing issue; 77% reported that they initiated the discussion about CRF with their provider, and 23% reported being told there were treatment options for CRF.

Conclusion: CRF is common among cancer survivors. However consistent screening by PTs is lacking. Patients with CRF frequently initiated the conversation with their providers because of symptoms and many patients were not told of treatment options. These findings represent a substantial gap in clinical practice regarding CRF screening and management.

Keywords: Oncology, fatigue, patient reported outcomes, and rehabilitation

Funding details: This work is part of the development of a clinical practice guideline funded in part by the American Physical Therapy Association.

Disclosure Statement: All authors report no conflict of interest

Data availability statement: The data that support the findings of this study are available from the corresponding author, [SEH], upon reasonable request.

Manuscript word count: 3710 including references and headings.

Introduction

In 2020, there were an estimated 18.1 million new cancer cases (excluding nonmelanoma skin cancer) globally (Sung et al, 2021). According to the World Health Organization (WHO), cancer is the leading cause of death worldwide, accounting for nearly 10 million deaths (Sung et al, 2021; World Health Organization, 2021). Despite these increasing numbers, mortality rates have decreased significantly over the past three decades among the most prevalent cancer types (JM Jones et al, 2016). As cancer survival rates improve, focus on survivorship issues has gained more attention, leading to efforts to help identify and manage a variety of treatment-related side effects (Alfano et al, 2019; Geerse et al, 2018). Many survivors deal with long-term physical effects of treatment as well as psychological and socioeconomic sequelae (Miller et al, 2019). One of the most common difficult symptoms among individuals treated for cancer is cancer-related fatigue (CRF) (JM Jones et al, 2016).

Cancer-related fatigue (CRF) is defined by the National Comprehensive Cancer Network (NCCN) as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or treatment that is not proportional to recent activity and interferes with usual functioning" (Berger et al, 2020). This fatigue is considered multidimensional, impacting physical, cognitive and emotional constructs, and is not generally relieved by rest (Bower, 2014). Prevalence estimates of CRF vary between 19% and 82% (Cheville, 2020; CB Harrington et al, 2010; JM Jones et al, 2016) depending on the definition of CRF, measures used to examine CRF, types of cancer studied, and timing such as when during or after treatment CRF was examined (JM Jones et al, 2016). A recent study found that approximately one-third of those who had a diagnosis of cancer reported CRF up to six years post-treatment; these individuals also reported that their CRF was associated with high levels of disability (JM Jones et al, 2016). Additionally, CRF is reported frequently in the literature as highly distressing, negatively impacting quality of life, and interferes with a variety of daily activities (Baker, Denniston, Smith, and West, 2005; Lawrence et al, 2004; Longman, Braden, and Mishel, 1999).

Despite international guidelines and publications highlighting CRF prevalence and its negative impact on the quality of life, CRF remains significantly underestimated and inconsistently assessed and managed by health care practitioners (Abdalrahim, Herzallah, Zeilani, and Alhalaiqa, 2014; Pearson, Morris, and McKinstry, 2015, 2017). The NCCN published its first clinical practice guideline for the screening, assessment, and management of fatigue in 2000, aimed specifically at physicians treating individuals with cancer (Mock et al, 2000). The NCCN guideline is updated at least annually in terms of practical implementation, with the most current one (as of this writing) published in December 2020 (Berger et al, 2020), but remains focused on physician management with only broad recommendations regarding screening and assessment nor does it identify tools that are appropriate at specific points during the cancer care continuum (Mock et al, 2000). A pan-Canadian clinical practice guideline on the screening, assessment, and supportive care of those with cancer-related fatigue was published in 2013 (Howell et al, 2013). An American Society of Clinical Oncology (ASCO) publication in 2014 promoting the use of a clinical practice guideline for the screening, assessment, and management of cancer-related fatigue utilizes existing clinical practice guidelines (NCCN and pan-Canadian) to derive a recommended pathway (Bower et al, 2014). Neither one of these guidelines provides recommendations for specific screening and assessment based on available evidence. Clinical practice guidelines from the European Society for Medical Oncology (ESMO) for CRF were recently published in 2020 (Fabi et al, 2020). Although the authors

outline general principles of care including screening and physical exercise, there are no specific recommendations related to non-pharmacologic interventions such as physical therapy (Fabi et al, 2020). The most recent NCCN guidelines for CRF, provides nonpharmacologic interventions for patients on active treatment, post-treatment and at the end of life (Berger et al, 2020). Although the aforementioned clinical practice guidelines have great value for appropriately managing CRF, health care providers other than physicians, such as PTs, who have an important role treating individuals with cancer may not be aware of or utilize these recommendations.

A significant challenge physical therapists (PTs) face is deciding which tool or outcome measure should be administered as multiple options exist for screening and assessment of CRF. A recent review of the literature resulted in 55 different published methods to screen or assess CRF (MI Fisher et al, 2020). The NCCN guidelines Version 2.2020 Cancer-Related Fatigue recommends 14 tools to screen and/or assess CRF (Mock et al, 2000). Researchers have sought to study clinical practices related to screening and assessment of CRF. One study aimed to identify the current practices of health professionals in the assessment and treatment of CRF using an electronic survey to a variety of oncology health care providers (Pearson et al, 2015). The study authors concluded there is a need for further education in CRF management for a range of oncology health disciplines, and additional resources to facilitate translation of CRF guidelines into practice (Pearson et al, 2015). Unfortunately, this study included a small sample size (n=125) and a limited number of respondents representing PT (8.5%) (Pearson et al, 2015). A more recent study examined patient's knowledge and perceptions regarding CRF (Schmidt, Bergbold, Hermann, and Steindorf, 2021). Although this study provided valuable information regarding patients reporting feeling uninformed about fatigue, there was no information regarding treatment including rehabilitation intervention (Schmidt et al, 2021). As the practice of healthcare moves toward person-centered care, understanding the patient perspective regarding CRF and rehabilitation is critical to delivery of quality care. Therefore, the purpose of this study was to survey PTs to understand the frequency of CRF screening, and to assess the knowledge and experiences of survivors of cancer as it relates to CRF.

Methods

Design and Participants

This was a cross-sectional study that followed the STROBE checklist. Information from two separate stakeholder groups was collected: 1) adults, 18 years or older, with a current or previous diagnosis of cancer, and 2) healthcare providers (i.e., oncologists, nurse managers, physical therapists, occupational therapists, and speech language pathologists) who either work in cancer centers or treat a caseload of individuals with cancer. Survey participants were recruited via emails sent out to cancer support groups, APTA Oncology - an Academy of the American Physical Therapy Association listserv, and by word of mouth. Cancer support groups were nurse navigator or patient-led and included a variety of cancer diagnoses and disease stages including but not limited to breast, gynecological, mixed diagnoses. A recruitment flyer was created and distributed to cancer centers in Pennsylvania, Ohio, and Northern California. The study was approved by the University of South Carolina Institutional Review Board (Pro00078586) and received exempt status. Participants were not incentivized or remunerated for their contributions.

Two separate surveys – one for survivors of cancer and one for healthcare providers – were developed through an iterative process by the authors. Pilot testing for both versions was performed via expert evaluation and/or by asking three rehabilitation providers who regularly treat patients with cancer and two patients who had a history of cancer to answer and provide

feedback about the survey before the survey was launched. REDCap® version 7.6.0 (Vanderbilt University, Nashville, TN) electronic capture tools hosted at the University of South Carolina were used to host and distribute the survey. Branching logic was used to create a variety of questions in the surveys. If a respondent answered "no" to one question, the logic would take them to the next appropriate question. Modifications were completed based on the clinicians' and patients' suggestions resulting in the final version of the survey. These modifications were minor and related to how questions were asked to help with clarity. The patient version of the survey was comprised of 25 questions about demographics (age, gender, ethnicity, type of cancer), confirmation of diagnosed CRF, who made the diagnosis, who initiated the topic of fatigue, how CRF was diagnosed, whether treatment options for CRF were discussed, what CRF treatments options received (if any), whether CRF is an important issue and how they would describe their CRF (physical, cognitive/mental &/or emotional). (Appendix 1) The PTs survey consisted of 21 questions about profession, specialty, frequency of screening for CRF, examples of how screening took place, follow up for positive screen, barriers to patient treatment for CRF, identification of tools used to screen and/or assess for CRF, patient access to PT services for CRF, and the setting they typically referred patients for treatment. (Appendix 2)

Data Analysis

All analyses were descriptive. Demographics are presented as means and standard deviations, and survey results are presented as numbers (frequencies/counts) and percentages. All percentages were calculated using the total number of included participants for each survey.

Results

Patient Survey

A total of 61 individuals living with or beyond cancer completed the survey. Only completed surveys were analyzed (i.e.: surveys in which respondents went to the last page of the survey and clicked "submit"). Ninety percent of respondents were female, 90% were Caucasian, 59.7% were diagnosed with breast cancer, and the mean age was 57.2 ± 12.9 years. (Table 1) Forty-two percent of patient respondents reported being diagnosed with CRF and 22.6% were unsure. A majority (76.0%) reported being the first to bring up the topic of CRF, followed by the medical doctor or nurse (both at 12.0%). A diagnosis of CRF was most often made by the medical doctor (80.8%), predominantly by the medical oncologist (76.2%). Respondents reported diagnosis occurred primarily via an interview (65.4%), and only 20.0% were told there were treatments for CRF. Of those diagnosed with CRF (n=25), 16% reported receiving treatment for their fatigue, whereas 20% reported being unsure. The three most common treatments for CRF were: independent exercise (22%), medications (44%), and education (34%). Of those who answered either "no" or "unsure" about whether they were diagnosed with CRF, a large percentage (77.8%) believed they did have CRF. Those who were either diagnosed or believed to have fatigue described it as physical (96.3%); cognitive/mental (63%); and/or emotional (46.3%), with many (77%) describing their fatigue as a combination of these. These findings are consistent with the multidimensional nature of CRF. Nearly 84% of respondents reported CRF as an important issue.

Physical Therapist Survey

A total of 248 healthcare providers completed the survey. For the present study, however, we only report data for PTs (n=199) due to the low response rate of other healthcare providers. Only completed surveys were analyzed (i.e.: surveys in which respondents went to the last page of the survey and clicked "submit"). Seventy-eight percent of the rehabilitation provider respondents

reported screening for CRF although 36% of those reporting screening at every visit. Forty-nine percent of respondents reported patient barriers to receive treatment for CRF. Lack of time, access, insurance, and lack of referrals from physicians were listed as the most common barriers. For respondents who reported using a screening or assessment tool, the top three tools used were: visual analog scale/numeric fatigue rating scale (44%), Brief Fatigue Inventory (34%), and Functional Assessment of Cancer Therapy – Fatigue (FACIT-F) (33%) with several respondents reporting using at least two of these three tools in combination. Additional PT provider characteristics can be viewed in Table 2.

Discussion

This study investigated knowledge about CRF from the perspective of individuals living with and beyond cancer and PT provider information related to screening, assessment and treatment of CRF. The findings indicate according to their recollection, patients are typically the first to bring up the topic of CRF to their healthcare provider, and that PT respondents in this study do not consistently screen at every visit for CRF. Further, the results showed that many patients were not told about treatment options for CRF.

Our study is one of the first to focus on CRF screening and assessment for oncology PTs. Our sample size of 199 is greater than past reports surveying nurses (n=81)(Abdalrahim et al, 2014), various healthcare providers in Australia (n=112) of which only 8.5% were PTs, (Pearson et al, 2015) as well as an earlier survey distributed at a pediatric oncology conference in Australia (n=56) (Gibson, Edwards, Sepion, and Richardson, 2006). Our larger sample, and focus on oncology PTs, provides contemporary information about the understanding and implementation recommendations for screening and assessment of CRF. Consistent with the study by Pearson and colleagues, our results indicate an in-depth assessment of CRF among patients with cancer is deficient (Pearson et al, 2015). The absence of consistent screening and assessment, in addition to the unique perspective of those living with and beyond cancer, present several opportunities to improve care related to CRF: awareness and education, consistent screening and assessment, and intervention.

Opportunity: Awareness and Education

The survey results reveal that the majority of individuals with a cancer diagnosis recalled bringing up the topic of CRF with their healthcare provider. This begs the question: why do healthcare providers not discuss CRF with their patients, especially when it is a common side effect of cancer and its treatment? One possible explanation is that the current understanding of the etiology of CRF is poor (Bennett et al, 2016). Healthcare providers may not be aware of, or minimize the prevalence of CRF, or may overlook screening because CRF does not always manifest as an "obvious" or visible impairment. A lack of awareness could explain why PTs in this study listed a lack of physician referrals as a barrier to patients receiving treatment for CRF. Indeed, studies related to the management of CRF highlight that healthcare providers' lack of understanding and education are primary barriers to implementation of clinical practice guidelines for CRF or management of CRF (Abdalrahim et al, 2014; Pearson et al, 2015). If healthcare providers lack understanding, there may be minimal patient education about the topic.

Individuals who are diagnosed with cancer often receive an education component around the time of diagnosis regarding the side effects of cancer and its treatment. A common example is the lymphedema education many women receive when diagnosed with breast cancer (Borman, Yaman, Yasrebi, and Özdemir, 2017). This pre-treatment education would be an opportune time to begin sharing information about CRF. Counseling strategies aims to teach patients how to manage and understand adverse effects of cancer treatments including CRF. This education greatly benefits patients with breast cancer (Wanchai, Armer, and Stewart, 2011). Educational components can be delivered in a variety of ways including in person, in a group setting, online and/or via telephone (Wanchai et al, 2011). An opportunity exists to incorporate an educational component about CRF at the time of a new cancer diagnosis, including but not limited to: NCCN definition, cancer treatments that are associated with developing CRF, what healthcare providers should screen and/or assess for CRF and common interventions. Additional components of CRF education could include stress management, psychoeducation, and physical activity guidelines, all of which have been shown to improve quality of life in those diagnosed with CRF (Wanchai et al, 2011).

Opportunity: Consistent Screening and Assessment

While almost three-quarters of the PTs reported screening for CRF, just over one-third reported doing so at every visit. Although NCCN guidelines recommend screening at regular intervals, there is no specificity with regards to what "regular" means (Berger et al, 2020). Due to the prevalence of individuals with cancer who report fatigue, a recommendation to screen every visit is warranted. Additionally, CRF may be experienced during cancer treatment or at any stage of the disease trajectory (Bennett et al, 2016). Several studies have reported a pattern of increasing fatigue during treatment that often improves after the treatment completion (Jacobsen et al, 1999; Smets et al, 1998). However, for some, fatigue may continue for longer periods (Bower, 2006; Smets et al, 1998). Due to the high prevalence and variability of when fatigue is experienced as well as its duration, it is recommended that healthcare providers screen for CRF at every visit (M Fisher et al, 2020). This is consistent with NCCN recommendations for CRF (Berger et al, 2020). A screening tool should be quick, easy to administer, easy to interpret, and can be

answered with a simple "yes" or "no" (S Harrington and Fisher, 2018). Valid and reliable CRF screening tools reported in the literature include: the one-item fatigue scale, Distress Thermometer/Problem List and the European Organisation for Research and Treatment of Cancer-Quality of Life Questions-Cancer 30 (EORTC-QLQ-C30) (M Fisher et al, 2020).

The survey results demonstrated PT variability regarding screening and assessment of CRF, whether by interview, patient-reported outcome, or structured questions. This variability may be due to a lack of consensus on screening or assessment methods. (M Fisher, Davies, Lacy, and Doherty, 2018). Recommended screening and assessment tools for CRF should be based on strong psychometric properties (S Harrington and Fisher, 2018). The Academy of Oncologic Physical Therapy of the American Physical Therapy Association began work on the Evaluation Database to Guide Effectiveness (EDGE) in 2010 to establish a framework to facilitate the evaluation of outcome measures in the cancer population and to assist in promoting the use of a core set (Levangie and Fisher, 2013). In 2018, an EDGE working group reported on measures of CRF through a systematic review and provided recommendations on optimal measures for screening and assessment. However, the EDGE recommendations are not without limitations. The systematic reviews, while comprehensively surveying and summarizing the literature, did not assess the quality of the evidence in reporting the psychometric strength of screening and assessment methods (M Fisher et al, 2018). Because of these limitations, an opportunity exists to develop a clinical practice guideline that describes the best means to screen for and assess CRF.

Opportunity: Management of CRF

Only 23% of the patient respondents who were diagnosed with CRF were told there are treatment options for their fatigue. Management of CRF is often hindered by a lack of knowledge about its etiology although attempts have been made to develop interventions considering the

multiple factors that may contribute to it (Bennett et al, 2016). The NCCN developed guidelines recommending medically treatable factors such as pain, emotional distress, activity level, sleep disturbance, anemia, and co-morbidities that may contribute to fatigue (Berger et al, 2020). Rehabilitation providers are in the unique position to educate those with CRF regarding management options. Among the individuals diagnosed with cancer who completed this survey, 77% reported their fatigue impacted more than one domain (physical, cognitive, emotional), reflecting the multidimensional nature of CRF. NCCN recommendations include education and counseling, general strategies for the management of fatigue such as energy conservation and distraction, and pharmacological and non-pharmacological interventions throughout the cancer continuum from initial diagnosis to end of life (Berger et al, 2020). Based on the multidimensional manifestation of CRF reported by the survey respondents, rehabilitation providers are able to direct intervention options based on NCCN recommendations and individual clinical presentation to comprehensively address CRF among this population.

The effectiveness of pharmacologic therapies alone has not been sufficient in the management of CRF and combining pharmacological with nonpharmacologic interventions is recommended (Wanchai et al, 2011). Exercise training is safe for those living with and beyond a cancer diagnosis and helps to improve physical fitness, restore physical functioning, enhance quality of life, and mitigate CRF (Schmitz et al, 2010). The American College of Sports Medicine (ACSM) recently conducted a multidisciplinary roundtable to advance exercise recommendations beyond public health guidelines and toward prescriptive programs specific to cancer type, treatments, and/or outcomes (Campbell, Winters-Stone, Wiskemann, et al, 2019). These recommendations state that exercise training and testing are generally safe for those living with and beyond cancer and that inactivity should be avoided (Campbell, Winters-Stone,

Wiskemann, et al, 2019). Furthermore, an exercise prescription for moderate-intensity aerobic and/or resistance exercise at least 3 times per week, 30 minutes/sessions, for at least 8-12 weeks may consistently improve common treatment-related symptoms and side effects (Campbell, Winters-Stone, Patel, et al, 2019). Specific to CRF, the evidence illustrates that programs lasting at least 12 weeks, with moderate-intensity aerobic training three times per week can significantly ameliorate CRF both during and after treatment (Meneses-Echávez, González-Jiménez, and Ramírez-Vélez, 2015; Tomlinson, Diorio, Beyene, and Sung, 2014; Van Vulpen et al, 2016). Physical therapists are professionally prepared to address CRF through non-pharmaceutical means.

Other non-pharmacologic interventions have shown promise in reducing CRF. Using a Bayesian approach, a recent systematic review incorporating an indirect-comparisons metaanalysis found that during cancer treatment, relaxation, cognitive-behavioral therapy combined with physical activity, massage, aerobic and resistance training (alone or combined) and yoga were able to reduce CRF (Hilfiker et al, 2018). After cancer treatment, relaxation seems no longer the most suitable choice, rather yoga, combined aerobic and resistance training, CBT or combined with physical activity, Tai-Chi, aerobic or resistance training help to mitigate CRF (Hilfiker et al, 2018). Non-pharmacologic interventions are not without limitations; side effects of cancer-related treatment and preexisting health conditions often make it difficult for individuals to engage in exercise (LW Jones et al, 2012; Petrick, Foraker, et al, 2014; Petrick, Reeve, et al, 2014). Additional barriers include environmental constraints, concerns about safety, and motivation (Bauman et al, 2012; Giles-Corti and Donovan, 2002; Thraen-Borowski, Gennuso, and Cadmus-Bertram, 2017).

Limitations

Survey data provided by cross-sectional studies such as this one has a variety of limitations. One possible limitation is sampling bias, as those who responded to the survey may have had a particular interest in CRF. Although we had a large sample size, all PT and patient respondents were from the United States. This may limit generalizability to PTs and individuals with cancer in other countries due to differences in health care systems and delivery as well as training and education for PTs. Additionally, our sample size of patient respondents was limited, preventing analysis according to cancer types, stage, or experience. Recall of events specific to medical treatment by patients could be faulty (Jansen et al, 2008; Kessels, 2003). Therefore, results must be interpreted with caution. Future research should include a larger sample of PTs from various countries to better understand their knowledge related to CRF as well as a larger patient sample with various types of cancer across the lifespan and information on the time between health care appointments and completion of the survey.

Conclusions

Cancer-related fatigue is the most common side effect of all cancer treatments, extending from the acute treatment phase through survivorship. It is essential that it be addressed proactively at the time of cancer diagnosis and beyond. This study highlights the need for improving awareness and education about CRF, the importance of consistent screening and assessment to detect and therefore address CRF, and the significance of PT intervention in improving overall function and quality of life for those diagnosed with cancer. Acknowledgements – n/a

Declaration of interest statement - The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- Abdalrahim MS, Herzallah MS, Zeilani RS, Alhalaiqa F 2014 Jordanian nurses' knowledge and attitudes toward cancer-related fatigue as a barrier of fatigue management. Journal of American Science 10: 191-197.
- Alfano CM, Mayer DK, Bhatia S, Maher J, Scott JM, Nekhlyudov L, Merrill JK, Henderson TO
 2019 Implementing personalized pathways for cancer follow-up care in the United States:
 Proceedings from an American Cancer Society–American Society of Clinical Oncology
 summit. CA: A Cancer Journal for Clinicians 69: 234-247.
- Baker F, Denniston M, Smith T, West MM 2005 Adult cancer survivors: how are they faring? Cancer 104: 2565-2576.
- Bauman AE, Reis RS, Sallis JF, Wells JC, Loos RJ, Martin BW, Lancet Physical Activity Series Working Group 2012 Correlates of physical activity: why are some people physically active and others not? Lancet 380: 258-271.
- Bennett S, Pigott A, Beller EM, Haines T, Meredith P, Delaney C 2016 Educational interventions for the management of cancer-related fatigue in adults. Cochrane Database of Systematic Reviews 11.
- Berger AM, Mooney K, Banerjee C, Breitbart W, Carpenter K, Chang Y, Cleeland C, Davis E,
 Dest V, DuBenske LL, et al 2020 NCCN Clinical Practice Guideilnes in Oncology
 (NCCN Guidelines) Cancer-Related Fatigue Version 1.2021. NCCN.org.
- Borman P, Yaman A, Yasrebi S, Özdemir O 2017 The importance of awareness and education in patients with breast cancer-related lymphedema. Journal of Cancer Education 32: 629-633.

- Bower JE 2006 Management of cancer-related fatigue. Clinical Advances in Hematology and Oncology 4: 828-829.
- Bower JE 2014 Cancer-related fatigue—mechanisms, risk factors, and treatments. Nature Reviews Clinical Oncology 11: 597.
- Bower JE, Bak K, Berger A, Breitbart W, Escalante CP, Ganz PA, Schnipper HH, Lacchetti C, Ligibel JA, Lyman GH et al. 2014 Screening, assessment, and management of fatigue in adult survivors of cancer: an American Society of Clinical oncology clinical practice guideline adaptation. Journal of Clinical Oncology 32: 1840.
- Campbell KL, Winters-Stone KM, Patel AV, Gerber LH, Matthews CE, May AM, Stuiver MM, Stout NL, Schmitz KH, Morris, GS et al. 2019 An executive summary of reports from an international multidisciplinary roundtable on exercise and cancer: Evidence, guidelines, and implementation. Rehabilitation Oncology 37: 144-152.
- Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, Zucker DS, Matthews CE, Ligibel JA, Gerber LH et al. 2019 Exercise guidelines for cancer survivors: consensus statement from international multidisciplinary roundtable. Medicine & Science in Sports & Exercise 51: 2375-2390.
- Cheville A 2020 Cancer-related fatigue. In Frontera WR, Silver JK, Rizzo TD (Eds) Essentials of Physical Medicine and Rehabilitation (4th ed), p. 684-688. Philadelphia, PA: Elsevier.
- Fabi A, Bhargava R, Fatigoni S, Guglielmo M, Horneber M, Roila F, Weis J, Jordan K, Ripamonti C 2020 Cancer-related fatigue: ESMO clinical practice guidelines for diagnosis and treatment. Annals of Oncology 31: 713-723.

- Fisher M, Cohn J, Harrington SE, MaloneD, Lee J 2020 Cancer-Related Fatigue Clinical Practice Guideline. Paper presented at: American Physical Therapy Association Combined Sections Meeting, Denver, CO.
- Fisher M, Davies C, Lacy H, Doherty D 2018 Oncology section EDGE task force on cancer: Measures of cancer-related fatigue—A systematic review. Rehabilitation Oncology 36: 93-105.
- Fisher MI, Harrington SE, Cohn JC, Lee J, Malone D 2020 A Clinical Practice Guideline for the Screening and Assessment of Cancer-Related Fatigue for Healthcare Providers. Paper presented at: American Congress of Rehabilitation Medicine, Virtual.
- Geerse OP, Lakin JR, Berendsen AJ, Alfano CM, Nekhlyudov L 2018 Cancer survivorship and palliative care: Shared progress, challenges, and opportunities. Cancer 124: 4435-4441.
- Gibson F, Edwards J, Sepion B, Richardson A (2006) Cancer-related fatigue in children and young people: Survey of healthcare professionals' knowledge and attitudes. European Journal of Oncology Nursing 10: 311-316.
- Giles-Corti B, Donovan RJ 2002 The relative influence of individual, social and physical environment determinants of physical activity. Social Science & Medicine 54: 1793-1812.
- Harrington CB, Hansen JA, Moskowitz M, Todd BL, Feuerstein M 2010 It's not over when it's over: long-term symptoms in cancer survivors—a systematic review. International Journal of Psychiatry in Medicine 40: 163-181.
- Harrington S, Fisher MI 2018 Screening and assessment for cancer rehabilitation. Rehabilitation Oncology 36: 141-142.

- Hilfiker R, Meichtry A, Eicher M, Balfe LN, Knols RH, Verra ML, Taeymans J 2018 Exercise and other non-pharmaceutical interventions for cancer-related fatigue in patients during or after cancer treatment: a systematic review incorporating an indirect-comparisons meta-analysis. British Journal of Sports Medicine 52: 651-658.
- Howell D, Keller–Olaman S, Oliver T, Hack T, Broadfield L, Biggs K, Chung J, Gravelle D, Green E, Hamel M 2013 A pan-Canadian practice guideline and algorithm: screening, assessment, and supportive care of adults with cancer-related fatigue. Current Oncology 20: e233.
- Jacobsen PB, Hann DM, Azzarello LM, Horton J, Balducci L, Lyman GH 1999 Fatigue in women receiving adjuvant chemotherapy for breast cancer: characteristics, course, and correlates. Journal of Pain and Symptom Management 18: 233-242.
- Jansen J, Butow PN, Van Weert JC, Van Dulmen S, Devine RJ, Heeren TJ, Bensing JM, Tattersall MH 2008 Does age really matter? Recall of information presented to newly referred patients with cancer. Journal of Clinical Oncology 26: 5450-5457.
- Jones JM, Olson K, Catton P, Catton CN, Fleshner NE, Krzyzanowska MK, McCready DR, Wong RKS, Jiang H, Howell D 2016 Cancer-related fatigue and associated disability in post-treatment cancer survivors. Journal of Cancer Survivorship 10: 51-61.
- Jones LW, Courneya KS, Mackey JR, Muss HB, Pituskin EN, Scott JM, Hornsby WE, Coan AD, Herndon JE, Douglas PS 2012 Cardiopulmonary function and age-related decline across the breast cancer survivorship continuum. Journal of Clinical Oncology 30: 2530.
- Kessels RP 2003 Patients' memory for medical information. Journal of the Royal Society of Medicine 96: 219-222.

- Lawrence DP, Kupelnick B, Miller K, Devine D, Lau J 2004 Evidence report on the occurrence, assessment, and treatment of fatigue in cancer patients. Journal of the National Cancer Institute. Monographs 2004: 40-50.
- Levangie PK, Fisher MI 2013 Oncology Section Task Force on Breast Cancer Outcomes: an introduction to the EDGE Task Force and clinical measures of upper extremity function. Rehabilitation Oncology 31: 6-10.
- Longman AJ, Braden CJ, Mishel MH 1999 Side-Effects Burden, Psychological Adjustment, and Life Quality in Women with Breast Cancer: Pattern of Association Over Time. Paper presented at: Oncology Nursing Forum.
- Meneses-Echávez JF, González-Jiménez E, Ramírez-Vélez R 2015 Effects of supervised multimodal exercise interventions on cancer-related fatigue: systematic review and metaanalysis of randomized controlled trials. BioMed Research International.
- Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, Jemal A, Kramer JL, Siegel RL 2019 Cancer treatment and survivorship statistics, 2019. CA: A Cancer Journal for Clinicians 69: 363-385.
- Mock V, Atkinson A, Barsevick A, Cella D, Cimprich B, Cleeland C, Donnelly J, Eisenberger
 MA, Escalenate C, Hinds P 2000 NCCN Practice guidelines for cancer-related fatigue.
 Oncology (Williston Park, NY), 14: 151-161.
- Pearson EJ, Morris ME, McKinstry CE 2015 Cancer-related fatigue: a survey of health practitioner knowledge and practice. Supportive Care in Cancer 23: 3521-3529.
- Pearson EJ, Morris, ME, McKinstry CE 2017 Cancer related fatigue: implementing guidelines for optimal management. BMC Health Services Research 17: 1-11.

- Petrick JL, Foraker RE, Kucharska-Newton AM, Reeve BB, Platz EA, Stearns SC, Han X, Windham BG, Irwin DE 2014 Trajectory of overall health from self-report and factors contributing to health declines among cancer survivors. Cancer Causes & Control 25: 1179-1186.
- Petrick JL, Reeve BB, Kucharska-Newton AM, Foraker RE, Platz EA, Stearns SC, Han X, Windham BG, Irwin DE 2014 Functional status declines among cancer survivors: trajectory and contributing factors. Journal of Geriatric Oncology 5: 359-367.
- Schmidt ME, Bergbold S, Hermann S, Steindorf K 2021 Knowledge, perceptions, and management of cancer-related fatigue: the patients' perspective. Supportive Care in Cancer 29: 2063-2071.
- Schmitz KH, Courneya KS, Matthews C, Demark-Wahnefried W, Galvão DA, Pinto BM, Irwin ML, Wolin KY, Segal RJ, Lucia A 2010 American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. Medicine & Science in Sports & Exercise 42: 1409-1426.
- Smets E, Visser M, Willems-Groot A, Garssen B, Oldenburger F, Van Tienhoven G, De Haes J 1998 Fatigue and radiotherapy: (A) experience in patients undergoing treatment. British Journal of Cancer 78: 899-906.
- Smets E, Visser M, Willems-Groot A, Garssen B, Schuster-Uitterhoeve A, De Haes J 1998Fatigue and radiotherapy: (B) experience in patients 9 months following treatment.British Journal of Cancer 78: 907-912.
- Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, Bray F 2021 Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA: A Cancer Journal for Clinicians 71: 209-249.

- Thraen-Borowski KM, Gennuso KP, Cadmus-Bertram L 2017 Accelerometer-derived physical activity and sedentary time by cancer type in the United States. PloS One 12.
- Tomlinson D, Diorio C, Beyene J, Sung L 2014 Effect of exercise on cancer-related fatigue: a meta-analysis. American Journal of Physical Medicine & Rehabilitation 93: 675-686.
- Van Vulpen JK, Peeters PH, Velthuis MJ, Van Der Wall E, May AM 2016 Effects of physical exercise during adjuvant breast cancer treatment on physical and psychosocial dimensions of cancer-related fatigue: a meta-analysis. Maturitas 85: 104-111.
- Wanchai A, Armer JM, Stewart BR 2011 Nonpharmacologic supportive strategies to promote quality of life in patients experiencing cancer-related fatigue. Clinical Journal of Oncology Nursing 15.
- World Health Organization 2021 Cancer. <u>https://www.who.int/news-room/fact-sheets/detail/cancer</u>.

Appendix 1 **CPG Healthcare Provider**

Please complete the survey below.

Thank you!

Please specify which of the following profession applies to you:	Medical Doctor Nurse Physician Assistant Physical Therapist Occupational Therapist Speech-language Pathologist Other Rehabilitation Professional Other
Please provide your specialty:	
Please provide your credentials:	
Please describe your rehabilitation profession:	
Please specify which other profession applies to you:	
Do you SCREEN for cancer-related fatigue in your	O Yes
patients?	
Do you SCREEN at every visit with patients?	⊖ Yes ⊖ No
How do you SCREEN?	Interview Structured/key questions Standardized test/questionnaire
	⊖ Other
Please provide an example of the structured/key	
questions you use for SCREENING:	
Which standardized test/questionnaire do you use for	
SCREENING?	
Please specify "other" ways you SCREEN for cancer-related fatigue:	
If the SCREEN is positive, what is your next step?	Laboratory tests such as bloodwork Physical Examination Issue a cancer-related fatigue questionnaire Interview the patient for further information Refer to another healthcare provider Wait and see if fatigue persists or worsens Other

REDCap

Page 2 of 2

Who do you refer to (ie: type of provider)?	
Please describe your "other" next step if a SCREEN is positive:	
Are there barriers to your patients getting treatment for cancer-related fatigue?	 ○ Yes ○ No ○ Unsure
Please describe these barriers:	
Which of the following tools, if any, do you use in screening or assessing cancer-related fatigue?	 Brief Fatigue Inventory European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) Fatigue Questionnaire Visual Analog/Numeric Fatigue Rating Scale Fatigue Symptom Inventory Functional Assessment of Cancer Therapy - Fatigue (FACT-F) Multidimensional Fatigue Inventory - 20 (MFI-20) Multidimensional Fatigue Symptom Inventory (MFSI) Piper Fatigue Score - 12 Schwartz Cancer Fatigue Scale - Revised Other
Which "other" tool do you use in screening or assessing cancer-related fatigue?	
Do patients you have access to physical therapy treatment for cancer-related fatigue at your site?	 Yes No I am unaware of what is available
If no/unaware of what is available do you refer elsewhere?	⊖ Yes ⊖ No
Where do you refer?	



......

Appendix 2

CPG patient

Please complete the survey below.

Thank you!

Have you ever been diagnosed with cancer related fatigue?	O Yes O No O Unsure
Who first brought up the topic of fatigue?	You (the patient) Medical doctor Nurse or other navigator Physical therapist Occupational therapist Speech-language pathologist Other rehabilitation professional Other provider
Please specify other	
Who diagnosed you with fatigue?	 Medical doctor Other health car provider Rehabilitation professional
Please specify type of medical doctor	 Surgeon Medical Oncologist Radiation Oncologist Other medical doctor
Please specify other medical doctor	
Please specify other health care provider	 Nurse/nurse practitioner Physician assistant Other
Please specify other type of healthcare provider	
Please specify type of Rehabilitation professional	 Physical therapist Occupational therapist Speech-language pathologist Other
Please specify other type of rehabilitation professional	
How were vou diagnosed	Caboratory tests such as blood work Physical examination by healthcare provider Completed a questionnaire Interview with healthcare provider Other

Confidential

projectredcap.org

Page 2 of 2

Please specify other method of diagnosis	
Were you told there is a treatment option for cancer-related fatigue?	O Yes O No
Did you receive treatment for cancer-related fatigue?	O Yes O No O Unsure
lf yes, what treatment(s) did you receive? Check all that apply	 Medications Supervised exercise Exercise on my own Education Yoga Acupuncture Other
Please specify other type of treatment received	
If you answered no or unsure, do you think you have fatigue?	O Yes O No O Unsure
How would you describe your fatigue? (check all that apply)	☐ Physical ☐ Cognitive/mental ☐ Emotional
Do you think cancer-related fatigue is an important issue for you?	O Yes No Unsure
What is your age (years)?	
What type of cancer were you diagnosed with?	

What state do you currently reside in?

What is your gender?	\bigcirc Male \bigcirc Female \bigcirc Prefer not to answer
Which of the following racial or ethnicity group(s) do you MOST identify with?	 African-American (non-Hispanic) Asian/Pacific Islanders Caucasian (non-Hispanic) Latino or Hispanic Native American or Aleut Other
Which "other" racial or ethnicity group(s) do you MOST identify with?	
PCC R	

Table 1:	Patient	Responses	(N=61)
----------	---------	-----------	--------

Characteristics	Number (%)
Have you ever been diagnosed with CRF?	
Yes	25 (40.9)
No	22 (36.0)
Unsure	14 (22.9)
If you answered no or Unsure, do you think you have fatigue?	
Yes	28 (77.8)
No	7 (19.4)
Unsure	1 (2.8)
Who first brought up the topic of fatigue?	
You (the patient)	19 (76.0)
Medical Doctor	3 (12.0)
Nurse or other navigator	3 (12.0)
Other Health Care Provider ^a	0 (0.0)
Who diagnosed you with fatigue?	
Medical Doctor	20 (80.0)
Other Health Care Provider ^b	3 912.0)
Rehabilitation Professional ^c	2 (8.0)
Please specify type of Medical doctor	
Medical Oncologist	16 (80.0)
Other Medical Doctor ^d	4 (20)
Surgeon; Radiation Oncologist	0 (0.0)
How were you diagnosed?	
Laboratory Tests (blood work)	4 (16.0)
Physical examination by a HCP	4 (16.0)
Completed a questionnaire	0 (0.0)
Interview with a HCP	16 (64.0)
Other ^e	1 (4.0)
Were you told there is a treatment option for CRF?	
Yes	5 (20.0)
No	20 (80.0)
Did you receive treatment for CRF?	
Yes	4 (16.0)
No	15 (60.0)
Unsure	5 (20.0)
No Response	1 (4.0)
If yes, what treatment(s) did you receive? ^f	
Medications	3 (75.0)
Exercise on my own	4 (100.0)
Education	2 (50.0)
Supervised Exercise; Yoga; Acupuncture; Other	0 (0.0)
How would you describe your fatigue? ^f	

Physical	51 (83.6)
Cognitive/mental	33 (54.0)
Emotional	24 (39.3)
Do you think CRF is an important issue for you?	
Yes	51 (83.6%)
No	6 (9.8%)
Unsure	4 (6.5%)
Age	
<30	2 (3.2)
30-39	4 (6.5)
40-49	9 (14.7)
50-59	20 (32.7)
60-69	15 (24.5)
≥70	11 (18)
Cancer Diagnosis ^f	
Breast	38 (62.3)
Gynecologic (ovarian, cervical, endometrial, uterine)	8 (13.1)
Male (prostate, testicular)	3 (4.9)
Lung	1 (1.6)
GI (colon,pancreatic)	2 (3.2)
Thyroid	2 (3.2)
Other (Ewing's Sarcoma, Clear Cell Carcinoma, Head and Neck,	6 (9.8)
melanoma)	
Not reported	2 (3.2)
Gender	
Female	55 (90.2)
Male	5 (8.2)
Prefer to Not Answer	1 (1.6)
Race	
African-American	3 (4.9)
Asian/Pacific Islander	2 (3.3)
Caucasian	55 (90.2)
Other (Italian)	1 (1.6)
Latino or Hispanic; Native American or Aleut	0 (0.0)

^aPhysical therapist, Occupational Therapist, Speech-Language Pathologist; ^bNurse Practitioner; ^cPhysical Therapist; ^dEndocrinologist, primary care practitioner, psychiatrist; ^emammogram; ^fable to provide more than one response

Characteristics	Number (%)	
Do you Screen for CRF?		
Yes	155 (78)	
No	44 (22)	
If YES, Do you Screen at every visit?		
Yes	56 (36)	
No	99 (64)	
If YES, How do you Screen?		
Interview	72 (46)	
Structured/Key questions	22 (14)	
Standardized Test/Questionnaire	57 (37)	
Other	4 (3)	
If Screen is positive, what is your next step? ^a		
Laboratory Tests	7 (4)	
Physical Exam	51 (33)	
Administer CRF questionnaire	38 (25)	
Interview for further information	92 (59)	
Refer to another Provider	12 (8)	
Wait and See if fatigue persists or worsens	14 (9)	
Other	24 (15)	
Are there barriers for patients getting treatment for CRF?		
Yes	97 (49)	
No	42 (21)	
Unsure	61 (30)	
Do your patients have access to physical therapy treatment for CRF?		
Yes	190 (86)	
No	14 (6)	
Unaware of what is available	18 (8)	
If unaware of what is available, do you refer elsewhere?		
Yes	2 (11)	
No	16 (89)	

Table 2: Physical Therapist Responses (N=199)

^aCheck all that apply