

Cancer-Related Impairments and Functional Limitations Among Long-Term Cancer Survivors: Gaps and Opportunities for Clinical Practice

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INTRODUCTION

In 2021, an estimated 1.9 million new cases of cancer were diagnosed in the United States, and approximately 608,000 patients with cancer died of the disease.¹ Today, there are approximately 17 million cancer survivors (defined as anyone with a history of cancer from the time of diagnosis until death), a number that is expected to continue increasing over the next several decades.² This trend reflects improvements in cancer detection and treatment. However, despite the advances being made in increasing the number of survivors, many experience substantial physical and psychosocial late and long-term effects related to cancer and/or its treatment. Numerous studies have described the diverse functional limitations that affect survivors' ability to work both during treatment and after treatment has been completed.^{3,4} Although many survivors do not experience work-related consequences of cancer, working-age survivors have reported changes in their employment status as a result of their diagnosis, including taking extended leave from work (paid/unpaid), changing their work schedule, changing to a less demanding job, and moving from full-time to part-time employment.^{5,6} Functional limitations have detrimental employment effects on individuals and their families and lead to a substantial economic burden and loss of productivity.⁷ In the United States, cancer-related impairments and resultant functional limitations that negatively affect work ability may lead survivors to apply for Social Security Administration (SSA) disability financial assistance. A recent consensus study report from the National Academies of Science, Engineering, and Medicine entitled *Diagnosing and Treating Adult Cancers and Associated Impairments*,⁸ requested by the SSA, provides an overview of the current status of the diagnosis, treatment, and prognosis of adult-onset cancers and the relative levels of functional limitations associated with these cancers and treatments. In this commentary, we aim to raise awareness in the clinical workforce by offering a concise overview of the epidemiology of cancer survivorship and work, common impairments and functional limitations faced by cancer survivors, and available evidence-based interventions for improving function. We describe the US SSA disability claims process, its eligibility requirements, and barriers for long-term survivors in securing approval for disability claims and offer insights for practicing clinicians in addressing and managing cancer-related impairments and functional limitations in practice.

EPIDEMIOLOGY OF CANCER SURVIVORSHIP AND WORK

Cancer survival rates are improving, and the number of survivors is expected to grow. Although many cancer types are associated with older age, an estimated 40% to 50% of cancer diagnoses worldwide occur in people 65 years old or younger, who are potentially part of the labor force.⁹ Work is an important indicator of health for cancer survivors,¹⁰ and returning to work is often seen as an indicator of full recovery.¹¹ In addition to providing economic

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TABLE 1. Functional Impairments, Their Causes, and When They Might Occur

Impairment	Causes		Occurrence ^a		
	Disease Process	Cancer Treatment	Acute	Long-Term	Late-Onset
Pain	•	•	•	•	
Cancer-related fatigue	•	•	•	•	
Chemotherapy-induced peripheral neuropathy		•	•	•	
Lymphedema		•		•	•
Cachexia	•		•		
Cardiotoxicity		•	•	•	•
Cognitive impairments	•	•	•	•	•
Depression and anxiety	•	•	•	•	
Gastrointestinal impairments	•	•	•	•	•
Graft-vs-host disease		•	•	•	
Musculoskeletal impairments	•	•	•	•	•
Pulmonary toxicity		•	•	•	•
Sleep disturbances	•	•	•	•	

Other sensory impairments have not been included in the table because they are so diverse. Reproduced with permission from the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC.⁸

^aAcute refers to impairments that may occur during or immediately after treatment; long-term refers to impairments that may begin during or immediately after treatment but persist for an extended period of time; and late-onset impairments are those that may occur months or years after treatment is complete.

and financial stability, work has been associated with emotional well-being and enhanced quality of life in cancer survivors.^{11,12} In the United States, the proportion returning to work is quite high in comparison with other countries, with up to 93% of cancer survivors returning to work within 12 months of their diagnosis.¹³ However, working cancer survivors often exhibit increased absenteeism, poorer work ability, and less productivity in comparison with workers without a history of cancer.¹⁴ In a cohort of cancer survivors, de Moor and colleagues⁵ found that employment changes were made by 41.3% of cancer survivors; 75.4% of those survivors took extended paid time off, and 46.1% made other changes, including switching to part-time work or to a less demanding job. Younger survivors, female survivors, non-White or multiracial/ethnic survivors, and those survivors with less than 20 years since their last cancer treatment were more likely to make employment changes. Moreover, cancer survivors are at greater risk for job loss than the general population and often face ongoing symptoms and functional limitations that prevent full employment.¹³

The loss or reduction of employment not only financially harms the individual cancer survivor^{15,16}; this loss of productivity also has societal implications. Although there have been protections put in place to support cancer survivors (eg, the Americans with Disabilities Act and the Family and Medical Leave Act), small businesses are exempt from these laws. Furthermore, these protections fail to address the increasing number of individuals who work in some form of independent or freelance position.

Researchers have found that the financial toxicity associated with cancer and cancer treatment can be devastating, leaving survivors in financial ruin and contributing to the overwhelming health care debt in the United States.¹⁷

CANCER-RELATED IMPAIRMENTS AND FUNCTIONAL LIMITATIONS

Cancer survivors are at risk for impairments that arise from the cancer itself or as a consequence of cancer treatments, such as surgery, chemotherapy, and radiation therapy, and/or the interaction of these factors with comorbid medical conditions. Functional limitations related to cancer treatment may arise shortly after treatment initiation (acute toxicities); some acute toxicities resolve at treatment completion, but others may last for years (long-term effects). Additionally, some functional limitations may first arise months or years after treatment is completed (late effects). Regardless of onset, functional limitations may affect 1 or more organ systems, including musculoskeletal, cardiovascular, pulmonary, and psychological systems, and may include additional symptoms such as pain, fatigue, peripheral neuropathy, and sleep disturbances (Table 1).

Cancer-related impairments can lead to functional limitations, which can in turn result in changes in a person’s ability to fulfill his or her work role.¹⁸ The assessment of functional status among cancer survivors is, therefore, critical so that limitations can be identified and treatments can be appropriately targeted to restore and/or maximize function. Functional status assessments may be performed in the clinical setting, which may include

primary care and/or oncology practices, through the history and physical examination and through the administration of selected validated assessment tools that identify specific impairments. Screening for potential treatment-related symptoms and conditions requires asking specific questions (guided by treatment exposures), which are followed by more specific inquiry. Functional status measurements, including patient-reported outcomes and objective performance measures based on normed parameters, can assist in understanding and identifying impairments and functional limitations that place cancer survivors at risk for disability. For example, screening for peripheral neuropathy would include asking cancer survivors at risk for this condition about the presence and severity of burning pain or numbness and tingling, gait changes, and related limitations that may affect activities of daily living (eg, dressing and eating) and administering a brief bedside sensory test using graduated monofilaments to objectively measure nerve sensation.¹⁹ If the neuropathy screening is positive, a referral to an appropriate specialist such as a neurologist or physiatrist is indicated for the management of the mobility impairments that can result from neuropathy. Because of the varied onset and duration of acute toxicities, long-term effects, and late effects noted previously, health care providers caring for cancer survivors, including primary care providers, oncologists, and other specialists, should regularly screen for changes in functional capacity. Screenings and more detailed assessments for selected, commonly reported cancer- and treatment-related impairments are shown in Table 2.

INTERVENING IN CANCER-RELATED IMPAIRMENTS AND FUNCTIONAL LIMITATIONS

Once they are identified, the management of cancer-related functional limitations is critical. Management strategies may include pharmacological and nonpharmacological interventions. Understanding the prevalence, etiology, and risk factors and then performing targeted screenings and assessments provide the best opportunity for intervening to attenuate or reverse these effects. Interventions that support employment productivity, including continuing to work, avoiding reduced hours, and/or returning to work, are crucial to mitigating the impact of acute, long-term, and late effects on functional status and well-being. In addition to effects that cause direct acute, late, and long-term effects, cancer survivors often incur a cluster of co-occurring symptoms that may

be cancer-related or due to other chronic medical conditions, such as fatigue, sleep disturbance, and depression.⁴⁰ Emotional symptom clusters may aggravate one another and often interact to exacerbate functional limitations from co-occurring impairments.⁴¹ The proper identification and treatment of one symptom in a cluster (eg, pain, anxiety, or depression) may help to resolve others and promote functional well-being. Pharmacological and nonpharmacological interventions and treatments focus on eliminating the etiology of a specific symptom or side effect. Nonpharmacological interventions may also focus on the underlying etiology while also providing education, information, and support to mitigate a symptom's impact. Evidence for specific nonpharmacological interventions may vary. Examples of effective multimodal interventions that can be used to address functional limitations in those affected by cancer include rehabilitation services, physical therapy, exercise, and psychological interventions. Furthermore, vocational retraining may be useful to help unemployed survivors to attain gainful employment through counseling, job search assistance, and placement programs.⁴² Such services may be accessed through state-based programs.

Despite evidence for effectiveness, these interventions are often not provided to patients who would benefit from them. Examples of barriers to implementing these interventions include a lack of clinician knowledge about the benefits and availability, a lack of reimbursement for these programs, and a cancer care system that seldom includes professionals specializing in addressing functional limitations (eg, rehabilitation providers or exercise specialists).⁴³ Overall, cancer survivors are at greater risk for disability due to barriers to the implementation of evidence-based interventions (ie, no systemic assessment of need or referral for established effective services) or the paucity of well-researched interventions for many impairments.

US SSA DISABILITY PROCESS

Functional limitations due to cancer, its treatment, and concomitant chronic medical conditions may not be amenable or responsive to interventions. In these situations, cancer survivors may be unable to return to work and thus may apply for disability benefits. Disability benefits in the United States are provided by the SSA through 2 programs: Social Security Disability Insurance, which provides monthly disability payments to eligible adults (less than the full retirement age) who have paid sufficient taxes through their employment, and Supplemental Security Income, which

TABLE 2. Functional Impairments, Screenings, and Assessments

Symptom or Impairment	Recommended Screening and Assessment Instruments ^a	Appropriate Settings and Professionals
Pain	(S/A) 0-10 numeric pain scale (0 = no pain; 10 = worst pain imaginable) ²⁰	(S/A) Oncology, primary care
Cancer-related fatigue	(S/A) 0-10 numeric fatigue scale (0 = no fatigue; 10 = worst fatigue imaginable) ²¹	(S/A) Oncology, primary care
Chemotherapy-induced peripheral neuropathy	(S) PRO-CTCAE ²² (A) Quantitative sensory testing to include thermal detection, pain, mechanical threshold, vibration detection thresholds ²³	(S) Oncology, primary care (A) Trained neurodiagnostic technician, neurologist
Lymphedema	(S/A) Circumferential measurements of affected and unaffected limbs ^{b24}	(S/A) Oncology, primary care (S) Oncology, primary care, lymphedema-trained physical therapist
Cachexia	(S/A) Weight loss > 5% or BMI < 20 kg/m ² with weight loss > 2% or sarcopenia with weight loss > 2% ²⁵	(S/A) Oncology, primary care
Cardiotoxicity	(S) Clinical history, including treatment exposure(s), physical examination ²⁶ (A) Clinical history, including treatment exposure(s), physical examination, electrocardiogram, exercise stress testing, radionuclide imaging, echocardiography, magnetic resonance imaging ²⁷	(S) Oncology, primary care (A) Cardiologist, exercise physiologist, rehabilitation specialist
Cognitive impairment	(S) FACT-Cognitive Function, MoCA ²⁸ (A) Objective neuropsychological testing, especially for executive function and psychomotor processing speed domains ²⁹	(S) Oncology, primary care (A) Neuropsychologist
Depression and anxiety	(S) PHQ-9, GAD-7 ³⁰ (A) Comprehensive psychosocial assessment ³⁰	(S) Oncology, primary care (A) Behavioral health specialist (eg, psychologist, psychiatrist, therapist)
Gastrointestinal impairments	(S) Clinical history, including treatment exposure(s), physical examination (A) Thorough history of associated causes (eg, opioid use or conditions associated with GI symptoms); assessment of diet, bowel patterns; digital rectal examination; fecal occult blood testing; additional evaluation as needed ³¹	(S) Oncology, primary care (A) Primary care, gastroenterologist, trained pelvic floor physical therapist
Chronic graft-vs-host disease	(S/A) cGVHD Symptom Scale ³²	(S) Oncology or primary " (A) Oncology, primary care, disease-based specialists (eg, pulmonologist, gastroenterologist, dermatologist)
Musculoskeletal impairments	(S) Osteoporosis: history, risk factors, and treatment exposures ³³ (S) Arthralgias: patient report of joint pain (eg, wrist, knees) ³⁴ (S) Muscular issues: the most common clinical measurements are range of motion, strength, and a visual analogue scale for pain (0-10, with 10 being the worst pain possible). ⁸ (A) Osteoporosis: diagnosed through DEXA of hip and lumbar spine or quantitative ultrasonography of calcaneus ^{33,35}	(S) Oncology or primary care (A)Oncology, primary care, endocrinologist, physical therapist, physiatrist
Pulmonary toxicities	(S) Symptoms (cough, dyspnea, fatigue); decreased oxygen saturation ³⁶ (A) Pulmonary function tests, computed tomography imaging, bronchoscopy, thoracentesis, or lung biopsy ³⁷	(S) Oncology or primary care (A) Pulmonologist
Sleep disturbances	(S) PROMIS Sleep Disturbance and Sleep-Related Impairments item banks ³⁸ (A) Detailed sleep history, 2-wk sleep log; psychosocial and medication history. Some sleep disorders may also require an objective evaluation using actigraphy or polysomnography. ³⁹	(S) Oncology or primary care (A) Sleep specialists (eg, pulmonologist, psychiatrist, neurologist)

Abbreviations: A, assessment; BMI, body mass index; cGVHD, chronic graft-vs-host disease; DEXA, dual-energy x-ray absorptiometry; FACT, Functional Assessment of Cancer Therapy; GAD-7, Generalized Anxiety Disorder-7 item scale; GI, gastrointestinal; MoCA, Montreal Cognitive Assessment; PHQ-9, Patient Health Questionnaire-9 item scale; PRO-CTCAE, Patient-Reported Outcome-Common Toxicity Criteria for Adverse Events; PROMIS, Patient-Reported Outcomes Measurement Information System; S, screening.

^aReference citations for the tools are included.

^bNot useful for detecting head, neck, or torso lymphedema.

pays benefits on the basis of financial need. Those eligible for Social Security Disability Insurance may also be eligible for Medicare health insurance coverage after a 2-year waiting period, whereas those eligible for Supplemental Security Income may be eligible for Medicaid health insurance.

The SSA has a 5-step disability determination process (Table 3), which considers listings of medical impairments (“listings”), including malignant neoplastic disease (cancer), that are deemed severe enough to interfere with a person’s ability to engage in gainful employment or to result in death. SSA’s current listings of impairments for adult cancers (Table 3) focus predominantly on the acute treatment phases of cancer and/or the presence of metastatic cancer and, for the most part, do not include allowances for long-term impairments and functional limitations that may result from cancer treatments. If other conditions are present, individuals are referred to a condition-specific listing of impairments in other body systems. A notable exception is the listing for lymphedema, which is noted for breast cancer but not for other cancers with which lymphedema may occur, such as head and neck cancer, gynecological cancer, or melanoma. Disability allowance listings for recipients of stem cell transplants also recognize long-term effects such as graft-vs-host disease, immunosuppressant therapy, frequent infections, and significant deterioration of other organ systems. Other late-onset impairments that were not present at the time of the cancer diagnosis are often not taken into consideration.

Between 2015 and 2019, the total disability claims awarded by the SSA for any disability decreased from 2,220,153 to 1,849,027 (a 17% decrease overall). During this time, the number of awards for which cancer was given as the primary impairment also decreased from 125,904 to 114,187 (a 9% decrease overall); claims for a primary diagnosis of cancer made up approximately 6% of all disability claims in 2019.⁸ The most common cancer-based disability claims were for breast, lung, colorectal, head and neck, pancreatic, nervous system, blood and bone marrow (ie, leukemia and lymphoma), liver/biliary tract, and ovarian cancers.⁸ The highest numbers of claims received were for lung, breast, and colorectal cancers, with the largest percentages of denials reported for breast cancer and lymphoma (with denial rates for both cancers being greater than 50%). The majority of these denials occurred because the SSA found that the claimant’s impairment or combination of impairments was not severe enough to limit his or her ability to perform any basic work activities, had not lasted or was unlikely to last at least 12 months, or was not expected to result in death; these denials occurred at step 2 of the disability determination process.⁸

TABLE 3. Social Security Administration Disability Determination Process

Step 1. Are you working (with predefined maximum earnings)?

Step 2. If you are not working, is your condition severe, restricting your ability to do basic work-related activities, such as lifting, standing, walking, sitting, or remembering—for at least 12 months?

Step 3. Is your condition found in the list of disabling conditions?

- Musculoskeletal system
- Special senses and speech
- Respiratory disorders
- Cardiovascular system
- Digestive system
- Genitourinary disorders
- Hematological disorders
- Skin disorders
- Endocrine disorders
- Congenital disorders that affect multiple body systems
- Neurological disorders
- Mental disorders
- Cancer (malignant neoplastic diseases)
- Immune system disorders

Step 4. Can you do the work you did previously?

Step 5. Can you do any other type of work?

Cancer-related impairment listing

- All cancers except certain cancers associated with human immunodeficiency virus infection (which are also evaluated under immune system disorders). These include listings for soft tissue cancers of the head and neck, skin cancers, sarcomas, lymphoma, leukemia, multiple myeloma, salivary cancer, thyroid cancer, breast cancer, skeletal cancer, nervous system cancer, lung cancer, pleural cancer, esophageal cancer, stomach cancer, small intestine cancer, pancreatic cancer, liver cancer, bile duct cancer, large intestine cancer, kidney cancer, ureter cancer, bladder cancer, cancer of the female reproductive organs, testicular cancer, penile cancer, prostate cancer, malignant melanoma, cancer of unknown primary site, and cancers treated by bone marrow transplantation.
- Factors considered include the cancer’s origin, extent of involvement, duration, frequency, and response to anticancer therapy and the effects of any posttherapeutic residuals.
- Consideration is given to complications or adverse effects of therapy, such as persistent weakness, neurological complications, cardiovascular complications, and reactive mental disorders. The residual effects of treatment are temporary in most instances; however, on occasion, the effects may be disabling for a consecutive period of at least 12 months. Impairment may be deemed disabling beyond 12 months when medical and other evidence justifies it.
- When the impairment or impairments have been in complete remission for at least 3 years, that is, the original tumor or a recurrence (or relapse) and any metastases have not been evident for at least 3 years, the impairment or impairments will no longer meet or medically equal the criteria of a listing in this body system.

The sources for this table include <https://www.ssa.gov/disability/professionals/bluebook/13.00-NeoplasticDiseases-Malignant-Adult.htm> and <https://www.ssa.gov/disability/determination.htm>.

BARRIERS TO SUCCESSFULLY APPLYING FOR DISABILITY AMONG CANCER SURVIVORS

Long-term cancer survivors often face many barriers to applying for disability and getting the benefits approved. To help to illustrate this section, we describe a patient scenario in Table 4. Mr. C is a long-term survivor of Hodgkin lymphoma treated with multi-agent chemotherapy and radiation therapy. He began to experience late effects decades after treatment. He has a number of chronic

TABLE 4. Patient Scenario

Mr. C is a 56-year-old male with a history of Hodgkin lymphoma that was treated 40 years ago with splenectomy and mantle radiation. His posttreatment course has been complicated by late-onset, radiation-induced thyroid cancer status post thyroidectomy, restrictive lung disease, coronary artery disease, and aortic stenosis (status post a coronary artery bypass graft with aortic valve replacement in the past 10 years). Additionally, he has moderately well-controlled hypertension, hyperlipidemia, type 2 diabetes, and gout. His most recent cardiac testing showed preserved heart function and a normal stress test. However, he reports worsening functional limitations and trouble in performing his job duties. He works in the financial industry and is mainly sedentary at work. Specifically, he reports that his diuretic medication restricts his abilities at work. If he takes his medicine at work, he is frequently interrupted with trips to the bathroom. If he takes it at bedtime, he requires frequent bathroom trips that interrupt his sleep and dampen his ability to perform at his job. He also suffers from severe neck stiffness and drop neck syndrome related to prior radiation and finds it challenging to keep his head up during the day, particularly when he is using the computer. All of these issues adversely affect his mood, although he has not been diagnosed with depression and is not on medications. He applied for disability but failed to meet requirements.

medical conditions but has continued to work. He sought disability because he was having trouble with sustaining his duties at work but failed to meet requirements. Next, we discuss some of the potential barriers that cancer survivors may face in this process.

First, as noted previously, the cancer category mainly focuses on the likelihood of death, the treatment outlook, and acute toxicities. The cancer-related impairment listings typically do not extend to long-term complications of cancer treatment and do not permit the use of this cancer category for late-onset manifestations of cancer treatment, particularly when they are interacting with co-occurring medical conditions. Second, although numerous other listings exist, cancer survivors may not have the level of severity required to achieve a disability claim under those other listings. Rather, functional limitations may result from multiple impairments subsumed under distinct listings (symptom clusters), but with each individual symptom at a mild to moderate level. Third, once patients decide to proceed with filing a disability claim, they may be faced with logistical barriers in getting approval. Patient-level factors may include patients not discussing their symptoms and/or functional limitations with their health care providers. Alternatively, clinicians may fail to ask about or adequately document symptoms and/or functional limitations in the medical record. Clinician factors include a lack of awareness of late and long-term effects and a holistic approach to the evaluation and management of limitations. System factors may include a lack of care coordination, particularly when patients receive care from a variety of health care providers who

operate in different facilities, among other factors. In summary, as exemplified in the case scenario, Mr. C was denied disability benefits. With the current process, it is often difficult for cancer survivors to substantiate that the level of impairment or combination of impairments is severe enough to limit their ability to perform work activities. Mr. C has multiple morbidities, across several listings of disabling conditions, affecting his function; these co-occurring in themselves may not be sufficient to claim disability, but they are likely additive and progressive, and all are occurring decades after his cancer treatment. A lack of sufficient supporting medical record documentation likely contributed to the inability to substantiate the level of functional limitations and attribute them to an active disease process.

CLINICIAN ROLE IN PATIENT-CENTERED APPROACH TO ADDRESSING FUNCTIONAL IMPAIRMENTS

The clinician plays a critical role in supporting patients with cancer-related impairments and functional limitations. First, all clinicians, including primary care providers, oncologists, and other medical and allied health care professionals, have an important role in assessing patients for late and long-term effects and resultant functional limitations. Furthermore, the ability to work should be assessed regularly in all cancer survivors to detect emerging difficulties that may portend the need for an evaluation of the impairments and potentially a disability assessment. Validated tools for the determination of SSA disability may be used in clinical practice.^{44,45} Documentation in the electronic health record of the assessment and reassessment is critical; the use of standard patient-reported outcomes that are embedded in the electronic health record facilitates documentation and longitudinal monitoring. Once an impairment is identified, appropriate specialist referrals can be made (eg, pulmonary, cardiac, and neurologic evaluations as well as rehabilitation medicine specialists). Lastly, it is important for patients and clinicians to keep track and engage with all those caring for the patients and to encourage cross-specialty communication, care coordination, and facilitated access to medical records.

SUMMARY

Cancer survivors may experience a myriad of acute toxicities as well as late and long-term effects as a result of cancer itself, its treatment, and/or concomitant comorbid medical conditions. These effects may have major

consequences for their functioning and ability to work and result in a loss of productivity, increased financial toxicity, and poorer quality of life. Pharmacological and non-pharmacological interventions can be effective for some of the impairments commonly experienced by cancer survivors. When treatments are not effective at alleviating functional limitations and gainful employment is not possible, the US SSA provides a process for cancer survivors to file for disability. However, many barriers prevent long-term survivors from securing approval of their disability claims. Clinicians play a pivotal role in supporting cancer survivors by assessing for and documenting functional limitations in the medical record. This ongoing assessment should also include referring cancer survivors to specialists who can address and manage the complicated symptoms, side effects, impairments, and functional limitations often faced by cancer survivors. Such assessments and documentation will facilitate the disability application if it is needed. Survivors should be educated about the availability of community-based resources, including vocational retraining and, if needed, SSA disability. The use of standardized tools to assess disability by the SSA that take into account the multisystem impairments common among cancer survivors may promote successful applications by those in need. Clinicians are also poised to be at the forefront in educating and promoting policy that supports the enhancement of disability criteria to promote the overall well-being of survivors and their families.

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