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Making cancer rehabilitation services *work* for cancer patients: Recommendations for research and practice to improve employment outcomes

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Abstract

Cancer and its treatment can result in impairments that limit physical, psychosocial, and cognitive functioning, interfering with patients' ability to perform work-related functions. Given these work limitations can carry significant personal and societal costs, there is a timely need to identify and refer patients to cancer rehabilitation services to manage adverse consequences of treatment and preserve employment. Coordinated efforts in three key areas will better connect patients to rehabilitation interventions that will help optimize employment. These include planning for the impact of cancer on the ability to work, implementing routine screening for impairments and facilitating referrals to cancer rehabilitation specialists, and focusing rehabilitation interventions on preserving employment. Coordinated strategies are presented to achieve these three goals including practice change to implement screening for impairments; working with oncology providers and patients to better understand the benefits of cancer rehabilitation to facilitate referrals and uptake; training more cancer rehabilitation providers to handle the increased need; better coordinating care across providers and with employers; and filling research gaps needed to proactively anticipate how cancer treatment would affect work for a given patient and deploy personalized interventions to preserve the ability to work.

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Keywords

cancer; oncology; survivorship; toxicity; employment; rehabilitation

Background

The number of Americans who carry a history of cancer is growing, from a current estimate of 15.5 million to 20 million in the next decade.¹ In 2016, almost half of those newly diagnosed were of working age, conservatively defined as age 20–64². In addition, older adults are increasingly working full or part-time well past the age of 65. A cancer diagnosis and subsequent treatment can lead to a range of short-term, long-term and late-onset symptoms. In particular, common adverse consequences of cancer treatment can include fatigue, pain, lymphedema, neuropathies, balance problems, mobility issues, bladder and bowel problems, dysphonia and other communication difficulties, dysphagia, cardiopulmonary function declines, sexual dysfunction, and cognitive and psychosocial problems, among others.^{3,4} The resulting limitations in physical functioning, emotional and psychosocial concerns and cognitive dysfunction can interfere with patients' ability to be functional at work.^{5–8}

In aggregate, 64% of patients return to work at some point after diagnosis.⁶ However, people with a history of cancer are 1.37 times more likely to be unemployed than healthy controls (34% versus 15%).⁹ Cancer-related work limitations can carry personal and societal costs. For individuals, work limitations can lead to reduced income, financial hardship, and the loss of employer-sponsored health insurance and gaps in coverage, each of which has implications for the continuity of care. Furthermore, for many patients, occupation represents an important social role and serves as a source of self-worth; thus, work limitations can negatively impact social connectedness, and access to meaningful activity. The societal cost of lost-productivity is also substantial. National estimates of annual net productivity loss among those with a history of cancer are \$9.6 to \$16 billion for individual ages 18–64 and \$8.2 to \$10.6 billion for those ages 65 or older.¹⁰

The impact of cancer on employment depends on treatment side effects and job demands. Estimates of rates of return to work range from 24–94%, depending on cancer type and stage at diagnosis, which underscores the heterogeneity of work outcomes and the need for intervention.⁶ Given the importance of work for individuals and society, the potential for cancer-related work limitations should be identified and managed throughout the treatment trajectory.

Prevention and improved management of adverse consequences of treatment requires early identification of impairments and timely referrals to cancer rehabilitation providers.^{4,11–15} Cancer rehabilitation is medical care, ideally integrated with oncology and survivorship care through and beyond cancer treatment, delivered by a multidisciplinary team of rehabilitation professionals who are trained to diagnose and treat patients' physical, psychological, and cognitive impairments with a goal of maintaining or restoring function, reducing symptom burden, maximizing independence, and improving quality of life.¹³ Cancer rehabilitation interventions including physical, occupational, or speech therapy; exercise; psychiatry-

directed diagnostic imaging, injections and pharmacologic symptom management; and psychosocial and cognitive interventions have the potential to treat many impairments from cancer treatment, thereby improving functioning and quality of life^{3,4,16,17}. Unfortunately, cancer rehabilitation services are currently under-utilized with referral rates as low as 1–2%¹⁸.

Several synergistic strategies are needed to better understand and address patients' work limitations that arise from cancer treatment from diagnosis forward. These include provider and patient education about rehabilitation, practice tools to facilitate identification of impairments and work limitations and generate rehabilitation referrals, and healthcare delivery research to identify best practices to prescribe the right treatment for the right patient at the right time. To support these strategies, this report will 1) review common adverse consequences of treatment and their association with aspects of work; 2) outline the potential for rehabilitation interventions to help patients maintain employment or return to work; and 3) articulate a vision for filling research gaps, training providers and educating patients, and making practice changes needed to optimize employment outcomes following a cancer diagnosis.

Review of adverse consequences of cancer treatment affecting work

Although the nature and severity of adverse consequences of treatment will vary by cancer type, treatment regimen, and individual patient characteristics, common problems include decreased physical functioning, psychosocial impacts, and impaired cognition. These symptoms can interfere with patients' ability to be fully functional at work⁷, resulting in prolonged absences, sub-optimal productivity, and decisions to drop out of the labor force entirely. This section reviews the literature describing common adverse consequences of treatment and their impact on work capacity.

Physical functioning

Fatigue—Fatigue is one of the most common side effects of cancer treatment, affecting nearly all cancer patients at some point during their treatment.¹⁹ Unlike non-cancer fatigue, cancer-related fatigue is typically not alleviated by sleep and rest. In many cases cancer-related fatigue will decrease after the conclusion of treatment; however, some patients experience chronic fatigue lasting for years after the end of treatment.²⁰ Fatigue can limit participation in activities and can exacerbate or precipitate poor physical functioning, depression, and cognitive dysfunction.^{19,21} Evidence suggests that levels of fatigue are higher among individuals with versus without a cancer history and, not surprisingly, fatigue is consistently associated with work outcomes.^{22–25} Horsboel et al demonstrated that patients with the highest scores of physical fatigue were approximately 50% less likely to return to work.²⁵ Among individuals who were working, those with a cancer history were almost twice as likely to report easy fatigability and exhaustion at work as compared to individuals without a cancer history.²³ Additionally, various aspects of work can exacerbate fatigue, including work pressure, physical workload and a lack of workplace accommodation for new activity restrictions or challenges.²⁶

Pain & Neuropathy—Pain is also a common side effect of cancer treatment, estimated at 39%–66% of patients²⁷. Pain impacts quality of life in myriad ways, with patients reporting that pain hampered concentration, interfered with normal activities, and made them dependent on others.²⁸ Pain is a consistent predictor of poor work outcomes in the general population^{28,29} and while not well documented for cancer patients specifically, there is some evidence of similar findings.¹⁰ For example, among breast cancer patients, women with arm pain and range of motion limitations are more likely to experience losses in productivity compared to women without pain.³⁰ Moreover, chemotherapy-induced peripheral neuropathy (CIPN) secondary to treatment with platinum compounds, taxanes, vinca alkaloids, thalidomide, and bortezomib can cause pain. Independent of pain, CIPN associated numbness and tingling in the hands and feet can interfere with physical functioning and has been shown to interfere with patients' ability to return to work and work performance.^{31–33}

Lymphedema—Lymphedema is a common side effect of cancer treatment, notably axillary surgery and radiation for breast cancer.³⁴ Incidence varies by cancer type and treatment, with a 5-year cumulative incidence of 42% among women with breast cancer.³⁵ Lymphedema, characterized by fluid accumulation in the affected limb, can lead to cellulitis, limited range of motion, and other conditions that result in pain and limitations in performing activities of daily living.³⁴ Lymphedema incidence and severity is associated with poor return to work, work ability and work performance.^{7,36}

Other Physical Symptoms and Limitations—Additional cancer related physical symptoms and limitations may manifest as a result of specific cancer treatments and result in employment challenges. For example, nausea and vomiting affect patients both during and after their treatment with chemotherapy^{37,38} and negatively affect the number of hours patients work.³⁹ Treatment of localized prostate cancer with radical prostatectomy results in urinary and bowel dysfunction⁴⁰ that contribute to employment difficulties for these men.⁴⁰ Prostate cancer patients also report difficulties with physical tasks such as stooping and heavy lifting (30%)⁴¹ that can affect work. Treatment for lung and head and neck cancers in particular are associated with symptoms that interfere with work outcomes. For example, dyspnea has been associated with not working.⁴² Head and neck cancer patients report treatment-related problems with social eating, social contact, and teeth, trismus, xerostomia and sticky saliva that negatively affect work.^{43,44,45} Additionally, multiple problems from cancer treatment such as limited range of motion, especially in the cervical spine, along with cognitive dysfunction, pain, and other symptoms may also limit the ability of head and neck patients to drive a car, causing an additional transportation barrier for work^{46,47}.

Emotional and psychosocial functioning

A bidirectional relationship underlies employment and emotional/psychosocial functioning. Individuals experiencing distress are more likely to be unemployed or have adverse work outcomes. In addition, unemployed patients report higher rates of psychosocial distress. Those already in stressful jobs are likely to experience greater challenges returning to

work.⁴⁸ The need for new work routines or restrictions put in place upon return to work can also present challenges for many patients.⁴⁹

Depression—Work can provide structure to the day and prevent social isolation often experienced by patients, thus mitigating triggers for depression⁷. However, depression is considered one of the main impediments to return to work among those with breast⁸, hematological⁵⁰, and head and neck cancers.⁵¹ Depression is a commonly reported side effect of chemotherapy that often co-occurs with fatigue, thus synergistically hindering work-related goals. At the same time, changes to work as a result of the impact of cancer can exacerbate or lead to the onset of depression²². For example, higher work pressure, physical workload, and fewer workplace accommodations are associated with increased fatigue and depression.²¹

Sociodemographic factors also may moderate the association between depression and work outcomes. While one study found being unemployed is associated with depression among older African American cancer patients,⁵² another study found lower depressive symptoms but nonetheless reduced employment among African American vs. non-Hispanic white patients, indicating the presence of intervening impediments to work in this population.⁵³

Anxiety—Anxiety is associated with lower rates of employment in patients with hematological²⁵, head and neck,⁴³ and breast cancer.⁵⁴ Anxiety often co-occurs with depression, and both are often included in studies concurrently. Patients may experience generalized anxiety disorder, but they also may experience cancer-specific anxiety. Indeed, many patients report strategies for managing fear of recurrence, which can be severe, as one of the most under-recognized unmet needs post-treatment⁵⁵.

Cognitive functioning

Cancer and its treatment can lead to impairments in multiple domains of cognitive functioning including memory, information processing speed, attention, concentration, visuospatial ability, psychomotor functioning, and executive functioning which have been collectively referred to as “chemobrain.”⁵⁶ In some cases, cognitive limitations from cancer and treatment improve over time, whereas in other cases, patients experience long-term limitations in cognitive functioning.⁵⁷ Cancer patients experience greater cognitive limitations than individuals without a cancer history^{22,58} that limit the ability to be fully functional at work.^{22,58} Indeed, patients reporting cognitive limitations are more likely to leave the workforce.⁵⁷

Gaps in the science

Although a growing body of research has begun to document the impact of adverse consequences of treatment on employment, this literature has several noteworthy limitations.^{6,7,22,59} The majority of studies have been conducted among women with breast cancer, and information about less common cancers is scant. Many studies have been based on small convenience samples, limiting generalizability. In addition, the majority of the literature is cross-sectional, and there are few large and well-designed studies on the long-term impact of cancer on aspects of employment. Also, many studies are based on

heterogeneous samples in terms of time since diagnosis, so it is difficult to disentangle the timing and trajectory of cancer symptoms and side effects and work-related limitations.

The Role of Cancer Rehabilitation in Improving Patient Employment Outcomes

As discussed earlier, evidence supports that cancer rehabilitation interventions can successfully treat many symptoms and impairments from cancer therapy while improving functioning and quality of life^{3,4,16,17}. While improvements in these impairments and in functioning *should* result in improved ability to work during treatment or to return to work after treatment, very few studies testing cancer rehabilitation interventions have included employment status. A recent Cochrane review evaluated the 15 randomized clinical trials testing varied components of rehabilitation and other interventions to enhance return to work for cancer patients⁶⁰. The evaluated trials tested medical (e.g., function-conserving treatments) and pharmacologic interventions, psycho-educational or psychological counseling, and physical exercise interventions alone or in combination (i.e., multi-disciplinary approaches combining psycho-educational, physical, and medical components along with vocational counseling) vs. usual care. The results of this review underscore the importance of rehabilitation and specifically support the multidisciplinary rehabilitation approach: the review found moderate evidence that interventions including physical rehabilitation, psycho-educational, and vocational counseling components enhanced return to work compared to usual care (RR=1.11, 95% CI: 1.03–1.06) but that single modality interventions were less successful⁶⁰. The review concluded that the most effective interventions for patients with cancer are likely those that include graded activity along with counseling to address illness perceptions and build self-efficacy for work.⁶⁰ This conclusion makes rehabilitation of cancer patients similar to rehabilitation of patients with low back pain where multidisciplinary interventions result in improved return to work⁶¹. However, future research must further test the efficacy of these multi-disciplinary rehabilitation interventions on the ability to work through and beyond cancer treatment.

Coordinated Efforts to Facilitate Practice Changes Needed to Optimize Patient Employment

Given the personal and societal costs of adverse consequences of treatment that limit employment through and beyond cancer therapy and the growing population of individuals with a cancer history, there is a timely need to develop a better clinical pathway to identify and treat these problems to optimize employment for individuals treated for cancer. Coordinated efforts in three priority areas will better connect patients to interventions that will help optimize employment.

Priority 1: Planning for cancer's effects on the ability to work

The first step in improving employment outcomes for patients involves helping to facilitate a better initial conversation about work between the oncology team and patient. As described in the Institute of Medicine's 2011 report on patient-centered cancer treatment planning⁶², this conversation should include expectations for how treatment will progress, including

anticipating expected adverse consequences of treatment, what the patient does for work, including the cognitive and physical demands of work, and how treatments might affect work capacities. In this context, the oncology team can proactively discuss how referrals to cancer rehabilitation providers can help treat these issues and preserve the ability to work. This conversation also allows the patient to anticipate and plan for how to discuss potential problems with their employer and ask for workplace accommodations they need to continue successfully doing their job or to reenter their job if they need to take leave during treatment. While the increased push for shared decision-making provides opportunities to discuss the inclusion of work as a patient-centered goal, overall these conversations are infrequent⁶² and few delve into employment problems and needs.

Priority 2: Implement routine screening for Impairments and Referrals to Cancer Rehabilitation

Patients experience symptoms throughout treatment and beyond that can interfere with work and decrease quality of life. However, in the absence of a system to routinely screen and monitor patients these problems will often go unidentified and unaddressed.¹⁸ Thus, routine screening for cancer-related impairments and referral to rehabilitation services should be implemented across oncology settings. A brief patient questionnaire included as part of oncology visits can be used to facilitate a more productive conversation between the provider and the patient about the patient's symptoms, allowing the provider to make the right referrals to meet the patient's symptom management needs. To the extent that symptom reporting data are integrated into the patient's electronic health record, the provider and patient can monitor trends in symptoms over time.

Data from studies that have tested electronic symptom reporting in oncology show this process results in improved patient-provider communication about needs, improved patient satisfaction, and the identification of unrecognized problems⁶³. However, there is only modest evidence symptom reporting results in better patient outcomes⁶³, likely because symptom reporting is not resulting in adequate referral to rehabilitation providers who can treat the problems. Several groups have called for implementation of routine screening of patient impairments and symptoms in oncology to identify impairments early and facilitate referrals to cancer rehabilitation for treatment^{11,13,64,65}. To be maximally effective to patients and providers, screening instruments should be both dynamic and interactive, and should incorporate both patient-reported and objective measurement in electronic formats, which allow for monitoring change over time and facilitate feedback on symptom needs and trends for both patients and providers¹⁵. Screening for symptoms and impairments should start before treatment to identify any pre-existing problems and to allow for referrals for rehabilitation interventions to prevent these problems where possible^{15,64}.

Priority 3: Focus rehabilitation efforts on employment as an outcome

After patients are referred for rehabilitation, either following initial conversations about anticipated consequences of treatment on work or the emergence of physical, emotional, psychosocial or cognitive symptoms, rehabilitation providers should perform a comprehensive work assessment to capture whether someone is working and work history, their physical, cognitive, and interpersonal job demands, their role within the organization,

degree of flexibility on the job, access to paid sick leave, and goals for working both during and following cancer treatment. The goal of the comprehensive work assessment is to gather sufficient information to anticipate how cancer and treatment will impact work life if the patient is being seen prior to treatment or to understand the current problems that limit work if the patient is being seen once problems develop. Rehabilitation providers then work with the patient to craft a tailored plan to help the patient manage expected or current challenges. This includes rehabilitation interventions to address the patient's work-related limitations and concerns and periodic reassessment to determine ongoing needs. Silver and colleagues have proposed a set of questions about work for use by rehabilitation providers.⁶⁶ There are also self-report measures of work limitations that can be used to better understand certain topics or to monitor limitations on an ongoing basis.⁶⁷ Results from the comprehensive work assessment and follow up should be shared with the oncologist and other members of care team to inform decision about treatment, supportive care, and survivorship care planning.

Although the rehabilitation efforts will vary depending upon the type of cancer someone has, the consequences of treatment they are likely to experience, and the job that someone does; in most cases, the tailored work management plan will include: 1. *symptom assessment and mitigation*: identifying symptoms that are likely to interfere with the essential functions of a person's job and prescribing preventive or early rehabilitation as appropriate to mitigate those symptoms; and 2) *patient education and empowerment*: educating patients about their legal protections offered in the United States (U.S.) under the Americans With Disabilities Act⁶⁸ and the Family Medical Leave Act,⁶⁹ connecting the patient to outside resources such as the U.S. Department of Labor Office of Disability Employment Policy Job Accommodations Network or community resources such as Cancer and Careers⁷⁰, and providing patients with the necessary tools to talk with their employer.

Coordinating Research, Healthcare Innovation, and Education and Training Strategies to Achieve These Three Priority Goals

To achieve the three priority goals: planning for cancer's effects on the ability to work, implementing routine screening for impairments and referrals to cancer rehabilitation, and focusing rehabilitation efforts on employment, three coordinated strategies are needed involving targeted research, practice innovation, and provider training and patient education.

Strategy #1: Research

An optimal healthcare system would proactively anticipate how cancer treatment would affect work for a given patient and deploy interventions to preserve the ability to work. To facilitate this care, epidemiological research is needed articulating how the varied cancer treatments affect different areas of functioning needed for diverse types of jobs and how this varies by factors (e.g. comorbidity) in a given patient, and randomized trials are needed to determine the optimal personalized rehabilitation interventions for given problems.

The research on cancer and employment thus far has included studies documenting the prevalence of work limitations, risk factors for work limitations and patient subgroups who are vulnerable to poor work outcomes^{6,9,22} as well as household population surveys that

provide data about employment patterns of cancer patients compared to the general population. Research is needed now that follows work outcomes over time among patients and develops tailored interventions for managing work limitations following a cancer diagnosis. To understand the trajectory and determinants of cancer-related work limitations, including how particular treatments impact domains of functioning, data on employment should be captured throughout treatment and survivorship care. As new drugs are developed, it is critical to understand their adverse consequences and how those problems interfere with patients' functioning at work. Thus, employment information should be captured as part of clinical trials to document the impact of new drugs on domains of functioning and work outcomes.

Likewise, rehabilitation interventions designed to improve physical, psychosocial or cognitive functioning should be evaluated for their potential impact on employment. Data from new trials are needed to demonstrate the most effective interventions for patients with different impairments and needs. Reviews of the limited number of studies on cancer rehabilitation interventions and employment concluded that future trials should focus on an overall increase in quality including larger trials, adequate control groups, and extended follow-up periods^{7,59}. Additionally, much of the existing research providing early findings has been conducted with breast cancer populations⁷¹, investigators should expand their work to include other cancer groups^{7,59}. Finally, most intervention research has focused only on the patient. Future research should test multilevel interventions that engage oncology providers to facilitate referrals, patients to engage them in their care, and cancer rehabilitation providers to focus their interventions on work outcomes.

Strategy #2: Healthcare Innovation

The field must build on existing efforts to develop a screening assessment for impairments and build referral pathways to get patients from oncology to cancer rehabilitation. This effort can leverage the efforts clinical systems are already pursuing to develop methods for screening patients for psychosocial distress to meet the American College of Surgeons Commission on Cancer accreditation standard for distress screening and referral⁷². The American Cancer Society and numerous clinical groups are currently partnering with the National Cancer Institute's Grid Enabled Measures (GEM) team to crowd-source consensus around the best comprehensive screening assessment(s) (distress, functional impairments, and other symptoms) for nation-wide use. For maximum impact on patient functioning and clinic efficiency, the assessment will be used to facilitate referrals to cancer rehabilitation, palliative care, and psychosocial care, depending on patient need. As a next step, efforts will be needed to develop, launch, and test a platform for electronic administration of the screening instrument(s) and methods to incorporate these data into an individual hospital or clinic's electronic health record in such a way to trigger appropriate referrals. Referral pathways will need to be built to make it easier for oncologists to make timely referrals to cancer rehabilitation. Strategies to integrate rehabilitation with other care the patient is receiving will also be needed to reduce patient burden.

To keep patients functioning at work as optimally as possible, efforts will also be needed to better partner with occupational medicine providers⁵⁹ and with a patient's employer to help

facilitate making workplace accommodations for patients who need them due to ongoing problems. Historically, the mode of communication between healthcare providers and employers has been through the administration of paperwork. The oncologist or other healthcare provider documents the existence of a health-limiting disability or work limitation, which is used to verify patients' eligibility for disability benefits and time off, and sends this to the employer. However, for individuals who want to keep working or return to work, rehabilitation providers can expand this interaction by providing documentation of patients' abilities and specific recommended work accommodations (informed by the comprehensive work assessment). This document can serve as an important communication tool, helping patients to initiate conversations with their employer about cancer and a return to work or work sustainability plan. Additionally, since employers are increasingly offering programs to help patients at the worksite, better communication between providers and employers can help coordinate work-based programs with cancer rehabilitation for optimal effectiveness.

Strategy #3: Education and Training

Facilitating timely referrals to cancer rehabilitation also will entail training oncology providers, helping them incorporate employment needs into their treatment planning discussions with patients, educating them about rehabilitation, and helping them to use the screening assessment to understand which clinical services are ideally suited to treat a given problem. Additionally, efforts to educate patients about the efficacy of rehabilitation interventions in improving the problems that limit their work functioning are needed. More than 90% of NCI-Designated Comprehensive Cancer Centers do not have patient-focused information on cancer rehabilitation services on their websites⁷³. Currently, even when patients with high levels of disability are offered rehabilitation, only 32% of them are interested in receiving that care due to perceptions of limited benefit⁷⁴. Thus, strategies that engage patients in their care, educate them about the benefits of cancer rehabilitation and activate them to follow-up on rehabilitation referrals are key.

To handle the increased referrals to cancer rehabilitation from the new screening efforts, more rehabilitation providers must be trained about the special needs of people living with and beyond cancer¹⁵. Currently, there are not enough rehabilitation providers with specialty training in cancer from occupational, physical, speech, or other therapy disciplines, nor do physical medicine and rehabilitation physicians receive adequate cancer-specific training⁷⁵. For new providers, the curricula of medical and allied health rehabilitation training programs should be supplemented with cancer-specific offerings so that newly trained rehabilitation providers across rehabilitation disciplines recognize cancer as a specialty and have basic skills for working with this population. To train existing rehabilitation providers about the needs of people living with and beyond cancer, continuing medical education curricula and educational courses should be developed that include information about the identification and management of cancer-related work limitations.

Conclusions

The personal and societal costs of untreated physical, psychosocial, and cognitive functioning problems that limit employment for people with cancer are modifiable burdens. There is a timely need to better identify these issues early and refer patients to cancer rehabilitation and related interventions so that adverse complications of treatment are successfully managed and employment is preserved. Implementing the strategies delineated here including innovating practice changes to implement screening for impairments, helping oncology providers and patients to better understand the benefits of cancer rehabilitation, training more cancer rehabilitation providers to handle the increased need, better coordinating care across providers and with employers, and filling research gaps to deploy personalized preventive interventions will go far in preserving the ability to work. It is time for our cancer treatment system to evolve to help patients stay healthy, functional, and employed by making rehabilitation services *work* for cancer patients.

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