

Impact of Cancer on Employment

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INTRODUCTION

Employment provides important psychological and financial benefits for patients in terms of both income and health care benefits. For patients diagnosed with cancer, ongoing employment and return to work can promote a sense of normalcy and control during an emotionally challenging time.^{1,2} Job loss has been correlated with both short- and long-term financial distress among cancer survivors.^{3,4} Financial toxicity, which results from decreased earning and increased spending after a cancer diagnosis, is linked to increased symptom burden and emotional distress and to decreased quality of life and treatment adherence.⁵⁻¹¹ Advanced financial toxicity (ie, bankruptcy) is associated with nearly double the risk of death among cancer survivors (odds ratio [OR], 1.79).¹²

This article describes work outcome trends among cancer survivors; job retention barriers, facilitators, and socioeconomic disparities; current US policy that affects cancer and work; and possible approaches to improving work outcomes, including policy and patient-facing interventions. Much of the work outcomes literature emanates from outside of the United States, although the US literature is growing. The different national work and illness policies limit the degree to which we can extrapolate from non-US studies, but they can serve as an example and, therefore, are included here when appropriate.

SCOPE OF THE PROBLEM

Approximately 45% of people diagnosed with cancer in the United States are ages 20 to 64 years, the traditional working age.¹³ Employed individuals who are diagnosed with cancer can have a variety of postdiagnosis employment trajectories.¹⁴ Just 54% of working-age cancer survivors report that they are working full time.¹⁵ Cancer survivors may work fewer hours, take off from work for prolonged periods (often at the cost of lost wages), and suffer long-term cancer-associated job loss.^{14,16} While some choose to retire early or change career paths after a reassessment of priorities, for many, the negative impact of cancer on work is unwanted and problematic and has profound consequences for the financial and psychological well-being of survivors and their families.

The reported magnitude of the impact of cancer on employment varies by study. In a 2009 meta-analysis

and meta-regression of 36 studies (14 based in the United States), de Boer et al¹⁷ found that cancer survivors were more likely to not work compared with healthy controls (33.8% v 15.2%; pooled relative risk, 1.37; 95% CI, 1.21 to 1.55). In US studies, researchers have also uncovered stark differences between cancer survivors and controls, which persist for years after diagnosis.^{16,18} Yabroff et al¹⁶ compared work outcomes between cancer survivors and controls without cancer in a population-based sample. Cancer survivors were more likely to report that they were unable to work and/or were limited in the amount or type of work they could do because of health problems; 15.3% of survivors v 7.5% of controls said that they could not work because of health problems in the first year postdiagnosis ($P < .005$), and 19.1% of survivors v 11.3% of controls reported the same after ≥ 11 years ($P < .005$). In addition, ≥ 11 years postdiagnosis, survivors reported nearly double the number of work absence days within the preceding year versus controls (53.8 v 27.5; $P < .005$).¹⁶

In their seminal paper outlining the domains that contribute to work outcomes, Steiner et al. describe the relationship between cancer and quality of life, and how these factors, along with characteristics of the individual, the social network, and the work environment all contribute to work outcomes.^{19,20} Here we identify different types of interventions that target these factors and can be implemented at the level of the patient, clinician, workplace, and federal/state policy to improve work outcomes.

WORK OUTCOMES IN SURVIVORS OF COMMON CANCERS

Although meta-analyses have suggested subtle differences in employment outcomes by cancer type, individual diagnosis-specific studies have had relatively consistent findings. Various studies indicated that approximately 70% to 80% of US breast cancer survivors return to work during the first year postdiagnosis, although low-income and minority survivors are less likely to do so.^{3,21-24} Blinder et al²³ showed that 4 months after (neo)adjuvant treatment completion, 81% of a diverse sample of prediagnosis-employed breast cancer survivors had retained their jobs. Long-term employment rates are not substantially different from those found

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immediately post-treatment. Jagsi et al²⁵ showed that 4 years after diagnosis, only 70% of prediagnosis-employed survivors continued to work.

Studies of other common cancers have found relatively similar nonemployment trends. Earle et al²⁶ found that 15 months postdiagnosis of nonmetastatic lung or colorectal cancer, 17% of prediagnosis-employed survivors had departed the workforce for cancer-related reasons. Survivors diagnosed with cancer at a more-advanced stage (who often receive more intensive treatment) were more likely to stop working than those with earlier-stage disease. Indeed, in another study conducted exclusively among patients with stage III colorectal cancer, only 55% were still employed 8 months postdiagnosis.²⁷

Prostate cancer survivors have shown similar employment outcomes. In a 2019 systematic review of English-language studies, 80% of prostate cancer survivors had returned to work (range, 60% to 90%).²⁸ Of note, receipt of chemotherapy and the presence of adverse effects (eg, fatigue, urinary incontinence) had a negative impact on work.²⁸

WORK OUTCOMES AND CANCER TREATMENT

Systemic Therapy

Chemotherapy receipt is an important predictor of both short- and long-term job loss.^{3,29-31} In a socioeconomically diverse sample of breast cancer survivors, Blinder et al³² showed that receipt of (neo)adjuvant chemotherapy was associated with more than double the odds of not working 4 months after treatment completion. Jagsi et al²⁵ showed that 4 years postdiagnosis, breast cancer survivors treated with (neo)adjuvant chemotherapy had 1.42 times the odds of nonemployment (95% CI, 1.03 to 1.98). The long-term impact of chemotherapy likely results from the persistence of symptoms, as suggested by a French study in which ongoing chemotherapy-induced peripheral neuropathy was associated with lower employment 5 years postdiagnosis (70% v 87% among those without neuropathy; $P < .001$).³³ However, lack of work accommodations during treatment also contribute to the negative effect of chemotherapy on work. Patients who lack accommodations may be unable to work during treatment, and if they lack sick leave, they may be replaced if they take time off.^{23,30,34}

Less is known about whether work outcomes are affected by other systemic therapies, including endocrine and targeted therapies and immunotherapy. In light of the adverse effects and long duration of some of these treatments in the adjuvant setting, this area requires additional research. In the setting of advanced cancer, recent advances in systemic therapy have led to improved overall survival. Limited research on the resulting effect on work outcomes has suggested that these treatments may lead to increased productivity and return to work.³⁵

Surgery and Radiation Therapy

Oncologic surgery and radiation are each associated with important and sometimes long-term adverse effects that generally affect the treated site (eg, lymphedema, contracture). Radiation therapy has not been consistently associated with decreased employment in cancer survivors.^{31,34} On the other hand, type of surgery has been associated with work outcomes. Jagsi et al³¹ showed that 7 months postdiagnosis, breast cancer survivors who had undergone a mastectomy were more likely to have stopped working (OR, 2.3; 95% CI, 1.2 to 4.5 v lumpectomy). Survivors who undergo radical prostatectomy with or without radiation therapy are also at risk for employment decline, particularly if they experience treatment-related symptoms (eg, incontinence).^{36,37}

ADULT SURVIVORS OF CHILDHOOD CANCER

Adult survivors of childhood cancer also suffer long-term diagnosis-associated nonemployment. A systematic review and meta-analysis by de Boer et al³⁸ found that childhood cancer survivors had almost twice the odds of not being employed compared with healthy controls (OR, 1.85; 95% CI, 1.27 to 2.69). For US survivors, the risk was threefold (OR, 3.24; 95% CI, 2.16 to 4.86). The risk was highest for survivors of CNS tumors (OR, 4.74; 95% CI, 1.21 to 18.65) most likely because of the high morbidity burden associated with treatment of these tumors, including potential long-term neurocognitive effects.³⁸ Additional risk factors for nonemployment included female sex, younger age at the time of the study, younger age at diagnosis, lower education level, lower intelligence quotient, radiation therapy, and the presence of motor impairment and/or a seizure disorder.³⁸ No corresponding risk was found among European survivors overall (OR, 1.00; 95% CI, 0.58 to 1.70). de Boer et al³⁸ suggested that the difference may be due to the prevalence of cancer-related discrimination in the United States. Insufficiently robust US policies on work accommodations may also contribute to this difference in outcomes.

PATIENTS TREATED IN THE PALLIATIVE SETTING

Although most studies of employment outcomes in cancer survivors focus on patients treated with curative intent, limited data suggest that patients treated in the palliative setting face similar problems. Tevaarwerk et al³⁹ found that 58% of patients with metastatic cancer reported an illness-related change in employment. Patients with a higher symptom burden were less likely to work.³⁹ Glare et al² surveyed a convenience sample of 105 palliative care clinic patients and found that 80% had been employed at diagnosis but that only 42% were employed a median of 2 years later. Of note, 40% of those working at the time of the survey said that they would like to work more hours than they were working, and 56% of those not working reported that they would like to work.² The majority of participants

said that working helped or would have helped them to feel normal, was or would have been an important part of their identity, and/or helped or would have helped them to feel like they were beating the cancer.²

SOCIOECONOMIC DETERMINANTS OF EMPLOYMENT OUTCOMES

Disparities in employment outcomes and their financial sequelae are prevalent. Mehnert⁴⁰ found a link between survivors' nonemployment and an unsupportive work environment (including perceived discrimination), manual work, low income, older age, lower education levels, and being female. Ekenga et al²² found that African American breast cancer survivors and those who have public insurance or are uninsured are less likely to be working 2 years postdiagnosis. Earle et al²⁶ found that lower education and income levels were associated with nonemployment among US colorectal and lung cancer survivors. McLennan et al²⁸ found that prostate cancer survivors with low-wage jobs and/or jobs that involve physical labor were less likely to return to work.

Workplace accommodations, such as schedule flexibility or sick leave, can attenuate the negative effect of cancer and its treatment on job retention.^{23,34} However, low-income and minority workers are less likely to work in accommodating environments.^{23,34} Therefore, it is not surprising that treatments such as chemotherapy exert a disparate negative impact on demographic groups who lack access to accommodations.^{3,34}

For example, Blinder et al²³ showed that among breast cancer survivors treated with curative intent, having an accommodating employer was associated with 2.5 times the odds of post-treatment job retention, even after controlling for age, income, ethnicity, and health insurance. Survivors from low-income households were less likely to report that their employers were accommodating (45%, 60%, and 68% for survivors with a household income of < 200%, 200% to 400%, and > 400% of the Federal Poverty Level, respectively; $P < .007$), and low-income survivors had lower rates of job retention 4 months after treatment completion (57%, 90%, and 95% for survivors with a household income of < 200%, 200% to 400%, and > 400% of the Federal Poverty Level, respectively; $P < .001$).²³ Job retention also differed by race and ethnicity. Only 68% of Chinese, 73% of Korean, 78% of Latina, and 85% of black survivors reported that they still had jobs 4 months after treatment completion compared with 98% of non-Latina whites ($P < .005$).²³

In the United States, only 21% of low-wage workers have access to paid sick leave.⁴¹ Cancer survivors who intend to stop working temporarily during treatment but lack sick leave have no guarantee that their positions will be held and are at risk for permanent job loss. Without support, those who need to maintain employment struggle to do so, which

results in higher job loss and financial distress rates, potentially with long-term or permanent consequences.^{1,3,34,42}

SELF-EMPLOYED CANCER SURVIVORS

Research about self-employed cancer survivors is limited to a relatively small number of European and Canadian studies. A 2019 review of European data showed that self-employed survivors were more likely to continue to work compared with those who were employees.⁴³ Self-employed workers generally work longer hours than employees, and this trend continued among cancer survivors.⁴³ Although self-employed cancer survivors reduced their work hours by a larger amount than did employees, they continued to work, on average, more hours than employee-survivors.⁴³ Self-employed workers also more commonly experienced a negative change in their personal finances, probably at least partly because of the receipt of less government-issued financial compensation for cancer-related work absence among self-employed workers versus employees.⁴³ A Canadian study of breast cancer survivors found that self-employed survivors had a higher mean percentage of wages lost in the year after diagnosis compared with employee-survivors (41% v 24% of annual wages, respectively; $P < .001$).⁴⁴ In addition, some self-employed survivors had to pay the salary of a temporary substitute worker, an uncompensated expense.⁴⁴

WORK IS CRITICAL FOR FINANCIAL STABILITY, ACCESS TO HEALTH CARE, AND PSYCHOSOCIAL WELL-BEING

Employment provides important financial benefits for patients in terms of both health care benefits and income. In 2018 in the United States, 69% of private industry workers had employer-based health insurance access.⁴⁵ Therefore, it is not surprising that even long-term cancer survivors report higher rates of job lock, or the perceived need to stay at a specific job to maintain health insurance, compared with similar workers with no cancer history.⁴⁶ The Health Insurance Portability and Accountability Act offers limited health insurance legal protections for workers diagnosed with a severe or chronic illness. Although the Affordable Care Act has improved access to health insurance not tied to employment, the future of this law remains uncertain.⁴⁶

Job loss has been correlated with both short- and long-term financial distress among cancer survivors.^{3,4} For example, Mujahid et al³ found that 9 months postdiagnosis, breast cancer survivors who reported having lost their jobs were more likely to experience difficulty with paying bills (27% v 11% of those who had not lost their jobs; $P < .001$). Banegas et al¹⁵ showed that unemployed survivors were more likely to incur debt (OR, 1.28) or file for bankruptcy (OR, 1.74) than those who were working ($P < .05$). This problem is exacerbated in low-income patients who have a lower odds of working during and after treatment.^{4,23} Among low-income breast cancer survivors, not working is correlated with not having enough money to cover

household needs for up to 5 years postdiagnosis ($P < .005$).⁴ With a lack of significant savings or unearned income (eg, investments), low-income patients are less able to absorb the financial shock of cancer-related lost wages.^{3,7,47,48}

Financial toxicity, which results from decreased earning and increased spending after a cancer diagnosis, is linked to increased symptom burden and emotional distress and decreased quality of life and treatment adherence.⁵⁻¹¹ Advanced financial toxicity (ie, bankruptcy) is associated with nearly double the risk of death among cancer survivors (OR, 1.79).¹² This is likely attributable to, at least in part, decreased treatment adherence, a well-documented maladaptive coping strategy.^{7,49,50} To save money, patients cancel cancer-related appointments or limit use of prescription medications.^{47,48,50,51} Although initially cost saving, nonadherence can have devastating consequences from inadequate treatment of adverse effects to cancer progression and premature death.

In addition, work inherently has meaning for people's engagement in society and sense of self-worth. Among long-term cancer survivors, employment is associated with increased personal growth leading to functional improvement.⁵² For patients diagnosed with cancer, including those treated in the palliative setting and those treated with curative intent, work promotes a sense of normalcy and control during and after treatment.^{1,2}

REMIEDIATING THE PROBLEM

US Policy With Regard to Cancer and Work

The United States has two key policies that protect the employment status of people diagnosed with disabling illnesses: the Americans With Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA). The ADA protects individuals with a disability, including cancer, from workplace discrimination.^{53,54} In addition, it requires employers to make reasonable accommodations to allow people with disabilities to continue to work. Examples of accommodations that might be relevant for a patient with cancer include changes in schedule or duties; working from home; or physical accommodations, such as comfortable seating.⁵⁴

The Equal Employment Opportunities Commission coordinates with the Department of Justice to enforce the ADA, which applies to all employers of ≥ 15 employees.⁵³ Overall, approximately 86% of people employed by private firms receive protection under the ADA.⁵⁵ The 17 million people who work for companies with < 15 employees do not receive this federal protection, although some states extend similar protections to employees of smaller businesses.⁵⁴⁻⁵⁶

The FMLA, enforced by the Department of Labor's Wages and Hours Division, grants eligible employees up to 12 weeks of unpaid leave over a 12-month period without

the risk of losing their job or health insurance if they are ill or are caring for a dependent who is ill.^{54,57} The time can be taken all at once or in increments as small as 1 hour.^{54,57} An employee with a serious health condition that makes it impossible for them to perform the essential functions of their job may qualify for leave under the FMLA.⁵⁷ The employee must have worked for his or her employer for at least 1,250 hours in the preceding 12 months (approximately 24 hours/week) to be eligible.⁵⁴ Private employers with ≥ 50 employees (and most federal employers) are covered, but overall 27% of US workers lack access to paid sick leave.^{45,57} Although disclosure of the diagnosis is not required, the employer must be informed that the leave is due to an FMLA-covered condition. The employer can request that the employee provide medical certification of their need for time off, and the employee may be responsible for the cost of obtaining the certification.

Of note, 40% of low-wage workers are employed by small businesses compared with 20% of all workers, so low-income workers are disproportionately excluded from ADA (and FMLA) protections.⁵⁸ Household employees and those who work in the informal sector (ie, off the books) are also unprotected.

Patients with cancer who cannot work may qualify for federal disability benefits administered by the Social Security Administration. To be eligible for Social Security Disability Income (SSDI), an applicant must be unable to work because of a medical condition that is expected to last for at least 1 year or to result in death.⁵⁹ The disability must be total and prevent the individual from doing the work that he or she did previously or from changing to a different job.⁵⁹ Therefore, many patients with cancer who undergo adjuvant therapy may not qualify. The amount that is paid, which is based on the applicant's age and prior payroll contributions, may be small.⁵⁹ The average monthly SSDI at the beginning of 2019 was \$1,234, which was barely enough to keep a recipient above the 2018 poverty level.⁵⁹ Not only is the amount of SSDI often inadequate but also the structure of this benefit discourages workforce re-engagement. SSDI benefits cease if an individual engages in a substantial gainful activity. The 2019 substantial gainful activity monthly income threshold was only \$1,220.⁵⁹ Individuals who seek to re-enter the workforce must be sure that they will be able to work since once they return to work, their SSDI is forfeited.

Policy Solutions From Abroad That Could Be Considered in the United States

The Organization for Economic Cooperation and Development is an international body that works with governments and policymakers to establish international norms, including workplace standards. Although the United States is a member, US policies lag those of several other members that aim to change behavior at the employer level to recruit or retain sick/disabled workers.⁶⁰ For example,

Australia, Denmark, Norway, Sweden, and the United Kingdom provide financial incentives to employers to provide accommodations, such as building adaptations, equipment, and support workers (eg, sign language interpreters).⁶⁰⁻⁶⁴ A 2012 systematic review evaluated the effectiveness of government policies in place from 1990 to 2008 in Canada, Denmark, Norway, Sweden, and the United Kingdom to change employer behavior with regard to return to work.⁶¹ The most successful policies included financial incentives for employers to hire people with disabilities; flexibility and adaptations in the work environment, particularly with flexible schedules and giving employees more control over work demands; and programs that involved employers in return-to-work planning.⁶¹

In many European countries, individuals with disabilities who are unable to work receive a disability income, which varies across countries but is generally more robust than SSDI in the United States.⁶⁵ These benefits often are coupled with return-to-work initiatives through which those who are considered potentially capable of working are offered subsidized or adapted jobs as a pathway back to full-time work.⁶⁵ In contrast to US policy, individuals with disabilities may engage in limited work activities and earn an income without losing their disability income.⁶⁵

Patient-Oriented Interventions

Patient-focused interventions are needed to tackle the factors that affect cancer survivors' ability to work during and/or after treatment.⁶⁶ In a 2015 review and meta-analysis, de Boer et al⁶⁷ evaluated data from randomized controlled trials that involved four types of interventions: psycho-educational, exercise or functional training, medical (that compared oncologic treatments with various associated toxicities), and multidisciplinary interventions. Only the multidisciplinary interventions were found to be effective. Specifically, multidisciplinary interventions that involve physical training, psycho-educational, and/or vocational components were associated with higher return-to-work rates compared with usual care (risk ratio, 1.11; 95% CI, 1.03 to 1.16; 450 patients).⁶⁷

A more recent trial that evaluated a multidisciplinary intervention in the Netherlands provided additional evidence to support this approach. An oncology occupational physician provided counseling on work-related issues, and prediagnosis-employed patients engaged in supervised physical exercise during (neo)adjuvant chemotherapy.⁶⁸ Participants experienced a significant increase in perceived importance of work, work ability, and self-efficacy with regard to returning to work, and return to work was 59%, 86%, and 83% at 6, 12, and 18 months, respectively.

Additional support for a multidisciplinary approach is found in the noncancer disabilities literature. A review of return-to-work and work maintenance interventions for people with chronic diseases (excluding cancer) found that

multidisciplinary approaches that involve various health and work professionals are the most helpful.⁶⁹ At the 2019 Work Disability Prevention and Integration Conference, Cullen et al⁷⁰ presented a systematic review of interventions to improve return to work after an absence related to musculoskeletal pain/injury or mental health condition. They found strong evidence that multidisciplinary interventions are effective in improving return to work and moderate to strong evidence that most single-component interventions are ineffective.

DISCUSSION

A cancer diagnosis puts people at risk for poor employment outcomes, including job loss with its attendant financial toxicity and related consequences, such as bankruptcy, poor symptom control, impaired quality of life, treatment nonadherence, and premature death. Poor employment outcomes can be mitigated by patient-directed, employer, and government policies and interventions, including multifaceted patient interventions that combine education, training, and vocational rehabilitation approaches; employer accommodations incentivized and mandated by government policy; and local and national laws that provide financial stability to bridge a potential income gap without compromising the physical and psychological well-being of the patient and family. Some of these could be modeled on the basis of existing policies in parts of Europe, Australia, and Canada.

Additional research is needed to model and determine the impact of employment practices and policies on patient outcomes. Differences in local US worker protections could be used to compare outcomes in otherwise similar populations. Collaborations between labor economists and clinical researchers could lead to more comprehensive analyses of work outcomes and provide the necessary information to invoke large-scale policy change. Clinical trialists also play an important role in this arena. In an era of patient-reported outcomes, therapeutic clinical trials should include an assessment of the impact of treatment on employment. A dearth of regimen-specific data exists on employment outcomes, yet every oncologist knows that patients ask about it almost without fail when learning about the schedule and anticipated adverse effects of a proposed treatment.

In the absence of significant US policy change, researchers and clinicians must focus on patient-facing interventions and build upon what has already been established in a growing and robust field of interdisciplinary research. The bulk of the literature in this area comes from abroad, which limits its applicability to US patients but provides researchers with a solid foundation upon which to develop, adapt, and test appropriate interventions.

Finally, clinicians must work with their patients to ensure that their work-related concerns are addressed. As a matter

of course, we monitor our patients for the physical and psychological adverse effects of the treatments we administer. Similarly, we must also address their work-related needs vis-à-vis these treatments by accommodating scheduling requests to the best of our ability, offering

assistance in the form of a letter or other documentation when work accommodations are needed (with the patient in control of the degree of illness-related disclosure included), and asking patients about their jobs before and throughout the treatment trajectory.

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