

COMMENTARY

Recommendations for Research and Practice to Improve Work Outcomes Among Cancer Survivors

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Abstract

Major knowledge gaps limit the development and implementation of interventions to improve employment outcomes among people with cancer. To identify research priorities to improve employment outcomes after cancer, the National Cancer Institute sponsored the meeting “Evidence-Based Approaches for Optimizing Employment Outcomes among Cancer Survivors.” This article describes research recommendations stemming from the meeting. At the patient level, longitudinal studies are needed to better understand how patient sociodemographic and clinical characteristics and their experiences at work shape employment outcomes. Interventions that mitigate the impact of cancer and its treatment on employment are critical. At the provider-level, future research is needed to characterize the extent to which physicians and other healthcare providers talk to their patients about employment concerns and how that information is used to inform care. Additionally, there is a need to test models of care delivery that support routine screening of employment concerns, the capture of employment outcomes in electronic health records, and the effective use of this information to improve care. At the employer level, evidence-based training programs are needed to prepare supervisors, managers, human resources staff, and occupational health professionals to address health issues in the workplace; and future interventions are needed to improve patient – employer communication and facilitate workplace accommodations. Importantly, research is needed that reflects the perspectives and priorities of patients and their families, providers and healthcare systems, and employers. Transdisciplinary partnerships and stakeholder engagement are essential to ensure that employment-focused interventions and policies are developed, implemented, and sustained in real-world healthcare delivery and workplace settings.

Cancer and its treatment frequently lead to symptoms that interfere with the ability to work, placing cancer survivors and their families at risk for financial hardship and psychosocial distress (1–6). Common side effects such as fatigue, lymphedema, and cognitive limitations can lead to poor work outcomes, such as prolonged sick leave, schedule and role changes, and job loss (7–12). Additionally, the time demands associated with cancer treatment may also make it difficult to sustain employment, forcing some survivors to work less, take a leave of absence, or withdraw from the labor force entirely (13–15).

Approximately two-thirds of people diagnosed with cancer return to work at some point after diagnosis (7). However, work

outcomes vary widely by disease and treatment, sociodemographic, and workplace characteristics. Survivors diagnosed with advanced disease and who receive intensive treatment are more likely to take extended sick leave, report loss of productivity if they remain at work, and non employment if they are no longer able to work. For adolescent and young adult (AYA) cancer survivors, cancer can be particularly disruptive because their diagnosis often coincides with entering or preparing for the work force (16,17). Additionally, survivors with lower socioeconomic status, racial and ethnic minority survivors, survivors employed in demanding jobs, and those who lack accommodating employers are more likely to report poor work outcomes

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(7,18–21). It is also widely accepted that a survivor's job performance, satisfaction, and engagement prior to cancer diagnosis are important drivers of work outcomes after cancer (22). However, few studies have examined these relationships and their impact on employment and job performance.

Minimizing work-related consequences is not generally a focus of cancer treatment, and few interventions exist to help people with cancer maintain their engagement and precancer job performance at work. Major knowledge gaps limit the ability to develop and implement interventions to improve cancer-related employment outcomes. Among populations where employment outcomes are not well documented, descriptive work is needed to better understand the scope and predictors of different employment outcomes. Among populations where employment outcomes are better understood, research is needed to identify effective interventions and to implement those interventions into practice.

In response to persistent gaps in the literature, the National Cancer Institute's Division of Cancer Control and Population Sciences convened a 1.5-day meeting to develop a research agenda focused on optimizing work outcomes among cancer survivors. A select group of 29 oncologists, occupational therapists, rehabilitation practitioners, employment representatives, researchers, and research funders were convened for the meeting, "Evidence-Based Approaches for Optimizing Employment Outcomes among Cancer Survivors," held August 11–12, 2016, to examine the problem of cancer-related work limitations from multiple perspectives. For the purposes of the discussion, cancer survivors were defined as anyone who had been diagnosed with cancer, including individuals who were currently receiving treatment. Work outcomes included returning to work (RTW) as well as job retention (ie, working during treatment and recovery), absenteeism, presenteeism (ie, functional limitations interfering with productivity), opportunities for promotion and advancement, and job satisfaction. Additional information about the meeting and the participants can be found at: <https://healthcare-delivery.cancer.gov/employment/approaches.html>. This article describes the research needs identified from the meeting, which have been further elaborated through subsequent discussions among meeting participants and collaborators.

Patient-Level Research Gaps and Recommendations (Box 1)

Gap 1: There are limited data about the unique effect of cancer and its treatment on employment and the mechanisms through which cancer impacts different work outcomes over time.

Most studies of cancer-related work limitations have been cross-sectional assessments of patients at different points in their treatment (10,13,15,23). Although informative, these studies likely underestimate the magnitude of work limitations. As suggested by a few longitudinal studies, the impact of cancer on employment may be greatest in the period immediately following diagnosis, and the likelihood of being employed and the impact of cancer on work ability, hours worked, and income is inversely associated with time since diagnosis and treatment (24–26). However, cancer's impact on employment can persist years after the end of treatment, becoming cumulative and long-lasting (27). Furthermore, the trajectory of work limitations may change with the expanded use of targeted therapies, which can have different side-effect profiles than nontargeted therapies and are frequently given over a long period of time (28,29). Caregivers of cancer survivors also frequently take leave from

Box 1. Research recommendations to improve patient-level assessment of cancer-related work outcomes and implementation of effective interventions

1. Employment outcomes should be included in cohort studies of cancer survivors to characterize how patient sociodemographic characteristics, behaviors, cancer type, treatment, and toxicities affect cancer-related work outcomes.
2. Longitudinal studies should evaluate facilitators and barriers to employment over time and identify modifiable risk factors for different employment outcomes. Studies should recruit diverse clinical and sociodemographic samples and capture the experiences of survivors who may be at high risk for poor employment outcomes.
3. Future studies should test multidisciplinary rehabilitation interventions in the United States using larger samples and experimental designs as well as identify other interventions that mitigate the impact of cancer and its treatment on employment outcomes.
4. Strategies should be tested to help cancer survivors and their families understand their legal rights pertaining to leave, job protection, and insurance coverage and to facilitate their access to state, municipal, and community-level programs and policies that are relevant for their needs.

work and have decreased productivity because of their caretaking responsibilities (30–34).

Future research should build upon the findings of previous studies to better understand work limitations experienced by cancer survivors and their caregivers, and to gather the data necessary to develop and evaluate interventions to improve RTW, job retention, and other employment outcomes. Self-reported employment outcomes and experiences should be included in cohort studies of adult and AYA cancer survivors to understand how patient sociodemographic characteristics, behaviors, cancer type, treatment, and toxicities affect different employment outcomes. Additionally, employment-focused longitudinal studies are needed that begin prior to cancer treatment and continue posttreatment and assess patterns of employment and modifiable predictors of employment outcomes. Detailed data should be collected about cancer survivors' disease, treatment and sociodemographic characteristics as well as their industry, occupation, and job demands. Additionally, data should be collected about modifiable predictors of employment outcomes at the level of providers and healthcare systems and employers to inform future interventions. It will be especially important to capture the experiences of survivors who may be at high risk for poor employment outcomes such as survivors diagnosed with advanced disease and who experience treatment toxicities that limit functioning as well as survivors who are self-employed, temporary and contract workers, and those employed in positions without paid sick leave or options for flexible scheduling or remote work. Furthermore, future research should characterize disparities in work outcomes by race and ethnicity, socioeconomic status, and other patient characteristics to identify possible modifiable targets for intervention.

Gap 2: Interventions are needed to address cancer-related work limitations and concerns throughout cancer treatment and recovery.

For cancer survivors who are motivated to work, interventions are needed to support a timely RTW, job retention, and

work ability. Depending on the individual, a range of interventions may be needed to successfully navigate cancer treatment and work. Over the last 30 years, a few interventions have been developed and tested to improve cancer-related employment outcomes, ranging from psychoeducation, physical training, rehabilitation and symptom management, and communication skills programs to help patients talk to their employers (35–39). Results from these studies are mixed and suggest that multidisciplinary rehabilitation programs, typically comprising a combination of functional restoration, physical training, psychosocial support, and patient education, are associated with improved work outcomes (37), a finding that aligns with the complex nature of cancer-related work limitations (40). There is also some evidence that targeted education coupled with group discussion and high-intensity physical activity improve work outcomes (41,42).

Most of the existing evidence base is limited by small samples and interventions that were tested using single group or non-experimental designs. Furthermore, much of the intervention research, particularly studies of multidisciplinary rehabilitation, have occurred in European countries that have different labor market, healthcare, and health insurance systems than the United States; therefore, it is unclear how well results from these studies will generalize. However, the risk of nonemployment among cancer survivors is similar between the US and Europe (43). Thus, future studies should build on previous international studies to conduct multidisciplinary rehabilitation interventions in the US, using larger samples and experimental designs. In fact, cancer rehabilitation, a multidisciplinary suite of interventions designed to address the physical, psychosocial, and cognitive sequelae of cancer and its treatment has been recommended in the US as a strategy to improve survivors' ability to work (44). Research is needed to build the evidence base about the effectiveness of cancer rehabilitation for employment outcomes as well as expand upon past studies to identify other interventions that mitigate the impact of cancer and its treatment on employment.

Because employment outcomes are influenced by factors at the level of patients, provider/healthcare systems, and employers—as well as broader municipal, state, and federal policies, a multilevel approach to improving employment outcomes is warranted. At the patient level, research is needed to ensure that all survivors have the knowledge and skills to access federal, state, and local resources that already exist. Although a great deal of information about minimizing risks to employment is available, this information is often not centrally located, well organized, or effectively communicated. To that end, research is needed to identify the best approaches to help cancer survivors and their families understand and access the legal protections afforded by the Americans with Disability Act and the Family Medical Leave Act as well as resources offered by state and municipal-level programs and policies, the Job Accommodations Network (45), community organizations such as Cancer and Careers (46), and resources within the healthcare system. Research and intervention needs at the level of healthcare providers and delivery systems and employers are discussed in the next two sections.

Healthcare Providers and Delivery System Level Gaps and Research Recommendations (Box 2)

Gap 1: The extent to which healthcare providers address employment limitations and concerns and the impact on work outcomes is poorly understood.

Box 2. Research recommendations to improve the provider- and health system-level assessment of cancer-related work outcomes and implementation of effective interventions

1. Future research should characterize the extent to which healthcare providers talk to their patients about employment as well as the content of these conversations and the impact of these conversations on treatment decisions, care coordination, and work outcomes.
2. Patients should be systematically screened for work limitations and concerns throughout the course of treatment in a manner that aligns with clinic staffing and workflow and effectively informs care, triggers referral to rehabilitation, social work, and other services.
3. Information about employment should be assessed as part of clinical trials and routine clinical practice and captured in the electronic health record (EHR) to understand how specific treatments or doses of a given treatment impact work outcomes. These data can be used to inform the care of individual patients as well as facilitate research.

The National Academy of Medicine report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” recommends that employers, healthcare providers, and other stakeholders work to minimize the adverse effects of cancer on employment and support survivors who experience limitations in their ability to work (47). Furthermore, the American College of Surgeons Commission on Cancer mandates that accredited programs offer survivorship care plans, which may foster patient–provider communication about employment concerns and facilitate referrals to appropriate services (48). Healthcare providers—including oncologists, primary care providers, nurses, social workers, rehabilitation specialists, and occupational therapists—can be an important source of information and support for individuals who are navigating the intersection between cancer and work (49). However, despite evidence suggesting that survivors would like to receive support and information about returning to work, working during treatment, and other related issues, survivors generally receive little guidance about employment from their healthcare providers (50–53), and vocational counseling is rarely part of survivorship care planning (54). Confusion over which member of the healthcare team is responsible for addressing employment may serve as a barrier to addressing these issues as part of care delivery. There may also be differences by discipline in how providers view their role in addressing employment issues and concerns (22).

Future research should characterize the extent to which healthcare providers talk to their patients about their job, goals for working during treatment, and how cancer treatment may interfere with the ability to work. In particular, research is needed to better understand the frequency and content of these conversations, and which member(s) of the healthcare team are involved as well as whether the communication was effective in helping patients understand the implications of their cancer and treatment for work. Research is needed to understand how information about a person's job and work-related concerns are used to inform treatment decisions when multiple treatment options are available. Additionally, improving care coordination, such as scheduling treatment to minimize work disruption and facilitating referrals to rehabilitation, social work, or other services are also important areas for future research. Subsequently, research is needed to build upon this information to develop and

implement models of care that foster routine screening for patients' employment concerns, including clarifying and institutionalizing appropriate referral patterns into the clinic workflow.

Much of what we know about the practices of healthcare providers in the context of cancer and employment has been reported from the patient's perspective. Future studies have the opportunity to build on this research to capture the perspective of both providers as well as the systems in which care is delivered. A systematic investigation is needed of the interpersonal and institutional situations that foster the initiation of discussions about workplace issues and what resources oncologists, nurses, and other providers need to address employment issues with their patients. This information is critical to ensure that efforts to integrate interventions addressing cancer-related work limitations into care are responsive to perspectives of providers, clinical work flow, and other constraints within the healthcare system.

Gap 2: Cancer survivors are not systematically screened for employment concerns from diagnosis forward, and information about employment is not typically used to guide cancer care delivery.

Although a patient's employment status is typically captured during the initial intake visit, the nature of their job, schedule, and access to paid leave are not. Therefore, research is needed to develop a brief screen for work-related limitations and concerns. Effectively screening patients for work-related limitations and concerns can solicit input from patients and their families about their goals for work; initiate discussions about the potential impact of cancer treatment on their work lives; and identify survivors at risk for poor work outcomes. This recommendation is akin to ongoing efforts to screen cancer patients for distress (48) and to capture patient-reported symptom data at the point of care (55), activities pursued with the goal of identifying patients who are in need of additional support or intervention. The person or professions best prepared to provide screening will vary by healthcare delivery setting. However, examples of staff who may fill this role include nurses, nursing assistants, patient navigators, and social workers.

Consistent with the goals of rapid-learning systems for healthcare, information about employment should also be captured in electronic health records (EHR) to build a repository of data about how specific treatments or doses of a given treatment might impact patients' work ability and the association between symptom prevalence and severity and work outcomes. This information can inform patient care and identify clinical, rehabilitation, supportive care, and other healthcare interventions that minimize the impact of cancer on employment (56). Likewise, employment outcomes should be captured in the context of clinical trials to assess the impact of novel therapeutics on different work outcomes. As with other rapid-learning systems in oncology, the collection and use of patient data in the context of employment must be done in accordance with the Health Insurance Portability and Accountability Act (HIPAA) (57). Additionally, complementary efforts to inform and educate patients about how their data are used will help to build understanding and trust in this new era of healthcare delivery (58).

Employer-Level Gaps and Research Recommendations (Box 3)

Gap 1: The employer perspective is lacking from research on cancer-related work limitations.

Employers are uniquely knowledgeable about how specific employment situations can be modified in response to a cancer

Box 3. Research recommendations to improve the employer-level assessment of cancer-related work outcomes and implementation of effective interventions

1. Research on cancer-related work outcomes should be grounded in an understanding of employers' experiences and resources for managing employees with cancer or other health problems.
2. Research should inform the development and implementation of education for supervisors, managers, occupational health practitioners, and human resource professionals about legal issues protecting employees with health problems such as cancer and include best practices for managing health issues in the workplace.
3. Research is needed to develop tools and approaches that will improve patient-employer communication; help employers translate information about an employee's limitations into accommodations, plan for job retraining, and other assistance; and evaluate those interventions on an ongoing basis.
4. Research should inform the development and implementation of programs and policies to address the unique needs of small-scale employers and employees who do not typically have access to current programs and policies.

diagnosis, and in some cases, will have workplace-level policies governing paid sick leave, remote work, and other accommodations for employees with health problems. Although the work environment largely influences the extent to which cancer will lead to poor employment outcomes, the perspectives and experiences of employers are missing from the scientific literature. Further, the extent to which work outcomes differ by industry/occupation, employer size, benefits, and other workplace features is unknown. The few studies of employer perspectives have been conducted outside the US. These studies suggest that employers are often uncertain about the best way to manage an employee with cancer. However, clear communication, support, and return to work policies can all be helpful in supporting an employee with cancer (59). Given the protracted nature of cancer treatment, there are multiple events that need to be navigated related to initial disclosure, employment changes during treatment, and planning for work posttreatment (60). When employers are absent from research, individual studies may fail to account for "real-world" considerations involved in managing employees with cancer and chronic health problems. Likewise, researchers may be less likely to collect data that is meaningful and actionable for employers, thereby limiting the utility of the findings.

Partnerships between researchers and individual employers or employer associations are needed to engender bidirectional sharing of information and expertise to optimize work outcomes among cancer survivors. Additionally, these partnerships could stimulate research on tangible benefits to employers, such as retaining valuable employees and saving on the cost of retraining new staff (61). To this end, researchers are encouraged to include employers or employer representatives on the external advisory panels for their studies, along with patients and providers, to ensure that relevant data are collected and that findings are disseminated to workplace policy-makers. Relatedly, studies designed to understand the employer perspective on the challenges of managing employees with health problems and best practices for supporting these

individuals at work would provide valuable context for employment-focused interventions.

Gap 2: Employers' needs for managing cancer survivors in the workplace are not well documented.

Cancer is an umbrella term that encompasses diverse diagnoses, treatments, symptomatology, and prognoses. Given the limited communication between providers and employers, patients are typically responsible for translating complex medical information for their supervisor or manager. This information may include how long and to what extent cancer will affect the essential functions of their job as well as how specific accommodations could help them remain productive during and following cancer treatment. Supervisors and managers are instrumental in implementing an organization's policies and programs and are typically the first point of contact for employees with cancer or another health problem (62). However, individual supervisors and managers as well as human resources and occupational health staff may vary in their level of understanding and capacity to accommodate an employee's needs, a problem not unique to cancer. They may also overestimate the negative impact of cancer on a person's ability to work (63). Future research should inform the development and implementation of evidence-based programs for supervisors, managers, occupational health practitioners, and human resource professionals that include education about legal protections afforded to employees with cancer as well as strategies to prevent workplace discrimination and implement supportive accommodations. Additionally, research is needed to develop tools and strategies that will improve patient–employer communication and help employers translate information about a cancer survivor's limitations into accommodations such as gradual return to work, flexible scheduling, modified performance expectations, retraining, and physical changes to the workplace (49). The importance of paid sick leave has also been repeatedly documented (64,65). Future research should identify the specific accommodations that are most helpful under different circumstances and inform their implementation and evaluation. Additionally, research is needed to inform reasonable accommodations for small-scale employers and across different work environments. This research can build on existing findings about employer needs, patient–employer communication, and best practices for managing health issues in the workplace in other disease areas to develop cancer-specific guidance (66,67).

Gap 3: Worksite wellness programs and policies are not universally available.

A robust evidence base is needed to inform the development of workplace wellness programs and policies and employer benefit that are tailored to different types of employers. For example, 200 private, nonprofit and government employers have earned Cancer CEO Gold Standard accreditation in recognition of the provision of programs to their employees that include high-quality care and survivorship (68). Select employers have also contracted with third-party programs, such as the Johns Hopkins Managing Cancer at Work program, to support their employees with cancer (69). Several evidence-based toolkits, such as the Workplace Transitions for people touched by cancer toolkit, have been developed to help employers manage employees with cancer (70). Many employers, particularly large-scale employers, have also implemented evidence-based policies and programs to support employee health more generally (71). Future research should identify the models of workplace wellness programs that are available across different industries and assess the factors driving employers' interest in supporting these programs. In particular, research is needed to inform the development of

resources that are tailored to the unique needs of small-scale employers and employees who do not typically have access to many of the resources described previously, such as workers employed in low-skilled occupations, seasonal and part-time workers, and temporary or contract workers. Finally, dissemination and implementation research and evaluation studies are needed to understand how best to expand and integrate available evidence-based interventions, programs, and policies into everyday operations in a larger number of employment settings.

Cross-Cutting Recommendations (Box 4)

In addition to the recommendations presented above for improving research and intervention at the patient, provider/healthcare system, and employer levels, the meeting also highlighted additional cross-cutting recommendations to advance research that addresses work outcomes after a cancer diagnosis.

Recommendation 1. Develop enhanced partnerships and stakeholder engagement to tackle the recommendations outlined in this report.

A coordinated approach to addressing cancer-related work limitations across multiple sectors requires enhanced partnerships and stakeholder engagement. These engaged partnerships will ensure that interventions, programs, and policies for mitigating the impact of cancer on employment are based on an understanding of the specific problems and challenges encountered by employers, providers, and patients. Meeting participants suggested the creation of a cancer and work network as one strategy for supporting enhanced partnerships and stakeholder engagement. A formal cancer and work network could facilitate collaboration among a cadre of researchers, practitioners, employers and representatives from employer groups, community organizations, and patient advocates. Such a network could also foster information sharing and the dissemination of best practices for optimizing cancer-related employment outcomes as well as provide central coordination for the activities outlined in this report.

Recommendation 2. Identify and develop standardized metrics of work outcomes.

To build the evidence base for optimizing work outcomes after cancer, it is essential to identify and develop standardized measures of employment outcomes. A set of standardized measures would drive consistency in research and foster research syntheses and meta-analyses, which are important for informing policy. Standardized measures could support employment-focused research as well as the integration of employment outcomes into behavioral, psychosocial, and clinical research. Brief validated screening tools to capture information about employment status and work-relevant limitations could also inform care coordination and treatment decisions. Furthermore, capturing and storing data on employment outcomes in the EHR, in a retrievable way, would support the generation of an evidence base about the impact of specific treatment regimens on cancer survivors' employment outcomes as well as develop the basis for evaluating how aspects of clinical care impact employment.

Recommendation 3. Leverage implementation science to ensure that evidence-based, employment-focused interventions are developed, evaluated, implemented, and sustained in real-world healthcare delivery and employer-based settings.

Implementation science offers guidance for how to develop and test employment-focused interventions to increase the

Box 4. Cross-cutting research recommendations to improve cancer-related employment outcomes

1. Develop a community of practice involving researchers, practitioners, employers, and representatives from employer groups, community organizations, and patient advocates to address the recommendations outlined in this report.
2. Identify and develop standardized measures of work outcomes and risk factors for employment outcomes and integrate these measures into research and practice.
3. Leverage implementation science to identify how best to integrate evidence-based, employment-focused interventions into healthcare delivery and employer settings to maximize impact and improve patient outcomes.

likelihood of their subsequent adoption and appropriate use in real-world healthcare delivery and employer settings (72). Employment interventions should be conceptualized and developed with input from multistakeholder groups, including patients, caregivers, providers, managers, employer groups, community organizations, and payers. Multistakeholder input can ensure that interventions reflect the considerations and priorities of relevant groups, which is particularly important for the complex nature of cancer-related employment outcomes (73). Additionally, interventions should be designed with practicality in mind; interventions that are too costly, labor intensive, cumbersome, and unappealing are less likely to be adopted in real-world settings, even if they are effective in research studies. Studies to evaluate interventions should be designed to resemble real-world settings as much as possible; pragmatic trials may be particularly appropriate for such evaluations (74,75). Additionally publishing process evaluations and data on intervention feasibility can help build the evidence base to inform future intervention development and tailoring (76).

Research is also needed to identify effective strategies for integrating employment-focused interventions into routine settings after an evidence base has been established. Strategies may include traditional dissemination outlets, such as publications and use of social media to target end-users, but will likely require more intensive efforts to reach full integration into healthcare delivery and employer-based settings (77).

Summary

Over the past 25 years, a growing number of studies have documented the scope and severity of cancer-related work limitations. However, many unanswered questions remain about the trajectory and long-term impact of cancer on employment as well as effective strategies for improving work outcomes. For people diagnosed with cancer, the ability to work is central to their quality of life and is associated with multifaceted psychological, social, and economic benefits. Thus, cancer survivors' concerns about work limitations and goals related to work should be addressed throughout the course of care. The research agenda outlined in this report is intended to drive multilevel solutions, at the level of patients, providers, and employers, to optimizing work outcomes for people who are diagnosed with cancer.

Notes

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