

COMMENTARY

Cancer Survivorship and Employment: Intersection of Oral Agents, Changing Workforce Dynamics, and Employers' Perspectives

Cathy J. Bradley, Kelsey L. Brown, Michelle Haan, Russell E. Glasgow, Lee S. Newman, Borsika Rabin, Debra P. Ritzwoller, Liliana Tenney

See the Notes section for the full list of authors' affiliations.

Correspondence to: Cathy J. Bradley, MPA, PhD, Department of Health Systems, Management and Policy and the Associate Director, University of Colorado Cancer Center, University of Colorado, Aurora, CO (e-mail: cathy.bradley@ucdenver.edu).

Abstract

The ability to continue employment during and following cancer diagnosis and treatment is critical to working-age cancer survivors. Prolonged survival combined with concerns of the financial burden associated with high-cost therapies makes the mitigation of work-related consequences all the more relevant, particularly in light of recent workforce trends and evolving employment dynamics. Research that integrates the needs of survivors, employers, and the workforce is required so that advancements are made to support employed cancer survivors. In this commentary, we present four priorities for research to advance what is known about the employment effects of cancer: 1) data needed to understand the impact of emerging treatments and their influence on employment and job performance; 2) cancer survivors in the changing work environment with respect to contractual arrangements and employment in small and medium-sized firms; 3) employers' perspectives and approaches to implementing workplace policies for cancer survivors; and 4) the development of feasible, scalable, and sustainable workplace interventions that can be implemented to address these issues. The confluence of these factors makes a strong argument for research to advance what is known and what can be done about the employment consequences of cancer.

The population of cancer survivors exceeds 15 million, approximately one-half of whom are working age, and is steadily growing as new treatments hold promise for prolongation of life (1). The impetus to address the needs of employed cancer survivors is ever more pressing. Concerns about work and financial viability are a top priority for patients and their family members (2–4). Moreover, a shift from conventional chemotherapy to oral outpatient therapy has led to long-term treatment that continues until disease progression, and with outpatient treatment comes the expectation that work continues uninterrupted. Yet, while some toxicities and side-effects are well understood (5), the accumulated impact of these treatments on patients' ability to work is unknown.

Prolonged survival, combined with concerns of the financial burden associated with high-cost therapies (6,7), makes the mitigation of work-related consequences all the more relevant, particularly in light of recent workforce trends and new employment dynamics. Americans are working nearly four more weeks per year (46.8 weeks) compared with weeks worked in 1980 (43 weeks) (8). Additionally, the employment rate for adults age 65 years and older has increased from 12% to 19% and more adults age 55 to 64 years remain in the workforce (62%), increasing the likelihood of a cancer diagnosis while employed (8,9). Employment arrangements have also changed over time. In 2015, approximately 24 million workers (15.8% of the workforce) held nontraditional jobs with alternative

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employment arrangements such as contract labor compared with 15 million workers (10.7% of the workforce) in 2005 (8).

We conceptualized that within the spectrum of employment arrangements, including full-time, part-time, contract, and salaried or hourly workers, exists a hierarchy of vulnerabilities and protections (Figure 1). Some workers are at more risk than others, have fewer legal protections and benefits, and may experience barriers to self-care in the workplace. Employers have a central role in protecting employee well-being and promoting better health outcomes for their employees. In the absence of sweeping policies to protect all employed cancer survivors, employers are the key to developing and implementing more equitable solutions that mitigate cancer's consequences in the workplace (10,11).

Research that integrates the needs of survivors, employers, and the changing workforce and changing treatment approaches is required so that advancements are made to support cancer survivors and their employers. The published literature clearly establishes a relationship between cancer and lower employment (12,13). Various studies linked poor symptom control (13,14) and treatments such as chemotherapy (14,15) to poor work outcomes. Absent from this research are data on emerging oral antineoplastic agents. In addition to patient experiences with treatment and symptoms, prior research identified the role of the employer, particularly with regard to the absence of discrimination (16) and availability of accommodations as important predictors in return to work (17,18).

Most interventions to address the challenges faced by employed cancer survivors focus on the survivor and to a much lesser extent on employers (19–21). In this commentary, we present four priorities for research regarding the employment effects of cancer. These suggested priorities focus on the data needed to understand the impact of emerging treatments and their influence on employment and job performance; cancer survivors in the changing work environment; employers' perspectives and approaches to implementing workplace policies for cancer survivors; and the development of feasible, scalable, and sustainable workplace interventions.

Emerging Treatments, Their Impact on Work, and the Need for Data

Cancer treatment is evolving from outpatient infusion therapy to oral agents. These agents, which are prescribed in the outpatient setting and may be taken until evidence of disease progression, represent an advancement in cancer treatment. In the last five years, 15 oral agents were approved for breast, lung, and colorectal cancer (22). With patients taking medications at home comes the optimistic assumption that there is little interference with work. Moreover, employed patients may preferentially select these treatments because they minimize work disruption. However, many oral agents cause side effects such as fatigue, headache, nausea and vomiting, and diarrhea, and predispose patients to more serious side effects, including vision problems, arrhythmias, or life-threatening infection and inflammation (23) that are also impediments to work (13,24,25). Because these treatments may be preferred by employed survivors, it is important that symptoms and adverse effects are better understood in the context of work and one's ability to perform job tasks. In addition, upon hearing that an employee is taking oral medications for cancer treatment, an employer may assume that work will continue as usual without time off or side effects that disrupt work. Data that support a better

understanding of how a treatment interferes with work can help patients and their employers set realistic expectations.

Ideally, outcomes related to employment, along with efficacy and effectiveness, would be collected in the clinical trial setting for all new treatment approaches prior to regulatory approval. Absenteeism, job changes, and transitions to non-employment or early retirement are objective measures of work interference that could be placed in context with job type and responsibilities (26). Even without clinical trial data, there remains an opportunity for post marketing surveillance programs and cancer registries to monitor adverse events that interfere with work ability. Electronic medical records provide an opportunity to record, in a structured format, work loss and diminished work ability so that this information is available on a physician, facility, or health system level for future research or as a possible quality measure for those who treat working-age adults. Insurers may also have a role in data collection on work ability. Many of their customers are large- and medium-sized employer groups with a keen interest in maintaining a healthy and stable workforce. Large insurers also have the ability to tap into sophisticated electronic medical records and claims data where tracking a basic set of employment outcomes and symptom interference is feasible. Insurers may also have the ability to engage patients around treatments and symptom management approaches that minimize work interference.

Broadly categorized information on work ability can be used to design workplace accommodations and policies because in practice, a thorough investigation of all new therapeutic options is not feasible. Given the typical side effect profile of powerful drugs, it would be surprising if there were not untoward occupational impacts. Examples of how these symptoms can be accommodated at the workplace include a flexible work schedule for those who experience fatigue or job restructuring for those who experience moderate to severe peripheral neuropathy. The combination of workplace policy and practice approaches and data on work ability can proactively match accommodations to needs and mitigate unintentional consequences of treatment.

The oncology care team can play a pivotal role in helping patients get the accommodations they need—not only for patients who are prescribed oral agents but for any treatment that interferes with work performance. Physicians typically communicate to the employer and although they are prohibited from disclosing a diagnosis, physicians are responsible for sharing information about patients' need for work restrictions that lead to workplace accommodations, including time and space to take medications, work release for treatment, and needs to limit specific physical activities. In addition to physicians, oncology nurses, physician assistants, patient navigators, and social workers can help identify and meet patients' work-related needs. These professionals often spend the most time with patients and can identify risks for employment consequences early in the treatment process. They can connect patients to services for rehabilitation (eg, physical, occupational, speech). The palliative care team can also focus some of their attention on managing symptoms that directly interfere with work ability without further complicating work disruption (eg, avoiding treating insomnia with drugs that interfere with daytime performance). Together, the oncology team can lessen the overall impact of treatment on patients' work by understanding the physical and cognitive demands of a patient's job identification of potential problems, referrals to specialists, symptom management, and by serving as the bridge between patients and their employers.

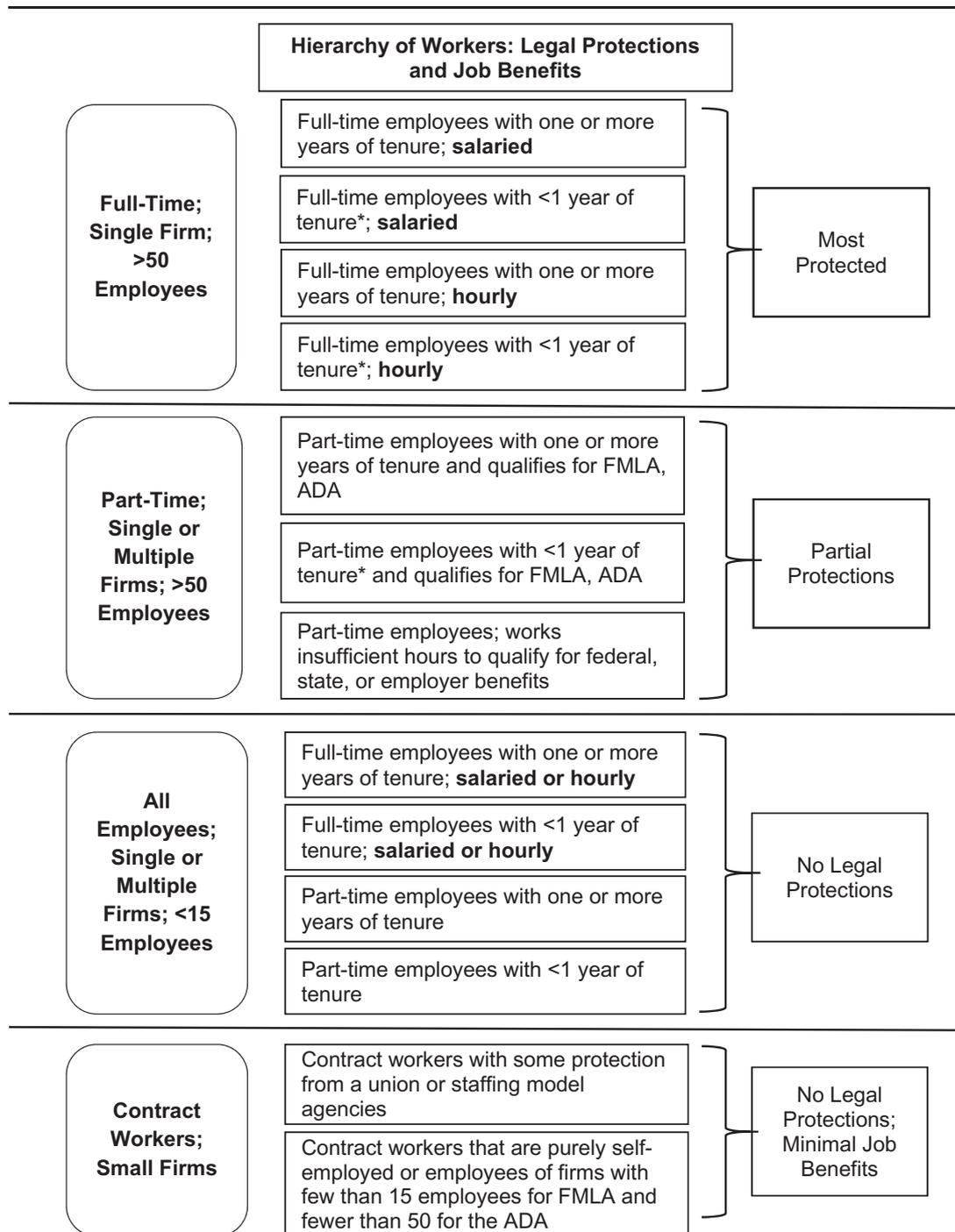


Figure 1. Vulnerabilities and protections by work arrangements (10). * Protections for full- and part-time employees with less than one year of tenure vary and may not exceed those for contract workers. ADA = Americans with Disabilities; FMLA = Family Medical Leave Act.

Changing Workforce Dynamics and the Cancer Survivor

Legal protections and insurance options for employed cancer survivors have not kept pace with the evolving workforce trends. Notable examples include the Americans with Disabilities Act (27) and the Family Medical Leave Act. Cancer is a specified condition for which employers cannot dismiss an employee and for whom they must offer reasonable accommodations, but the Americans with Disabilities Act applies only to

employers with more than 50 employees. Likewise, the Family Medical Leave Act protects employees to take unpaid leave for a period of 12 weeks and return to their job if they meet the specific criteria for hours worked and tenure but does not apply to employers with 25 or fewer employees. With regard to health insurance, the Consolidated Omnibus Budget Reconciliation Act health benefit provisions of 1986 allows employees to purchase employer-based health insurance coverage for a period of up to 18 months following employment termination, but former employees pay the full cost of coverage, which is often

unaffordable. With the passage of the Affordable Care Act, some lower wage employees qualified for expanded Medicaid and subsidized health insurance exchange market plans, providing options for health insurance outside of employer-based coverage. However, the future of the Affordable Care Act is uncertain with ongoing policy debates and administrative actions that weaken its provisions. Taken together, these policies leave gaps in coverage for employed cancer survivors.

Although the legal protections described above offer a financial and healthcare lifeline for many cancer survivors, some of these protections are in danger of elimination and others are not applicable to a large and growing segment of the workforce. In 2014, 57.9 million US workers, representing 48% of the workforce, were employed by small businesses, with the majority having fewer than 50 employees (28). Small businesses have a low adoption of work benefits and health promotion programs and a limited understanding of the effectiveness and sustainability of accommodation policies and strategies (Kelsey L. Brown, Lee S. Newman, Cathy J. Bradley, unpublished data).

Up to 20% to 30% of the working-age population engages in some form of independent or freelance work (29). The evidence demonstrates trends toward nonstandard and longer working hours in conjunction with precarious contracts and job insecurity (30–32). Many of these workers are employed by large firms that offer benefits to their standing workforce. In addition, data from the United States Bureau of Labor Statistics in 2017 suggest that roughly 2% to 4% of all workers comprise the “gig economy” (33). A “gig” refers to a single project or task for which a worker is hired to work on demand. Vulnerable workers also exist in traditional work settings that employ individuals as hourly or temporary workers, often exempting them from employer benefits. As a result of these trends, a growing sector of the American workforce no longer has access to traditional benefits acquired through employed positions. As we show in Figure 1, these individuals are especially vulnerable and at risk for catastrophic health, well-being, and financial harms following serious illness, including a diagnosis of cancer. They also commonly do not receive paid annual leave or sick leave. For them, no work means no pay. Evidence suggests that these work arrangements at the time of cancer diagnosis are negatively correlated with work ability (34).

Emerging workforce trends require more attention from the research and policy community. Although legislation affords some protections to ill workers, policies have not kept up with trends toward contract and part-time work (often at multiple jobs), leaving millions of workers vulnerable when diagnosed with cancer. The impact on cancer survivors employed in the growing number of jobs without protections and policies is not understood and may require new approaches and policies to mitigate unintentional adverse effects of what otherwise might be considered as advances in treatment (such as oral agents) and work arrangements like those that allow for more flexibility. The approaches and policies may address priority areas such as paid sick leave, accommodations, and insurance to apply to a broader range of employers or have options for employees without benefits and protections to purchase coverage at an affordable price.

Employer Perspectives on Opportunities to Reduce the Burden of Cancer

The deleterious effects of cancer on employment can be reduced by workplace accommodations and a supportive work

culture and environment. Evidence suggests that a favorable psychosocial work environment is positively correlated with overall work ability (34). Unfortunately, only 44% of American workers report that their organization supports employee well-being, while one in three workers report chronic job-associated stress (35). Specific to cancer survivors, survivors who felt discriminated against at work or had unaccommodating employers were most likely not to return to work following treatment (16). Similarly, a study of low-income, multi-ethnic women with breast cancer found that those who worked for accommodating employers were more than twice as likely to retain their jobs (18).

A business case can be made for employers to offer benefits and accommodations. Although on average the cost of providing employee benefits is approximately one-third of total employee compensation (36), the return on investment and value on investment can be positive for the employer. Return on investment considerations include “risk management” or defensive actions taken to avoid legal consequences for failure to accommodate as well as the potential to improve retention and productivity; value on investment includes less tangible rewards such as the ability to attract talented workers, worker and customer loyalty, increased productivity, and improved communication and trust between employers and employees.

Perhaps the most quantifiable benefit to offering job accommodations is employee retention. Employers may spend one-third or more of a worker’s annual salary to hire a replacement when a worker leaves (37). These costs include reduced productivity during the time with an unfilled role, the cost of hiring (eg, advertising, recruiting, interviewing), training new employees, time to peak productivity for a new employee, possible loss of engagement from others due to high turnover, business error rates, and negative workplace culture (38).

Observational research suggests that there are support services, many of which are low cost, employers can offer employees with cancer that will help them remain employed and can help optimize employment outcomes (17). Examples of support services include leave (preferably paid) to seek treatment, time to recuperate, periodic breaks, a private place to take medication, modified work schedule, permission to work at home, modified office temperature, and reassignment to a vacant position if survivors can no longer perform their assigned job. Neumark et al. (2015) reported that the accommodations most often requested by women with breast cancer were flexible schedule and fewer hours worked followed by providing women with a laptop computer so they could work from home (17). These accommodations were associated with both job retention and improved health status (17). In a qualitative study of cancer survivors, healthcare providers, and employers, Stergiou-Kita (2016) (39) reported that cancer survivors required accommodations such as a graduated return to work plan, modification of work duties and performance expectations, retraining, and modifications to the physical work space or adaptive aids. In another qualitative study, cancer survivors cited supervisor attributes such as empathy, understanding, and honesty that facilitated their ability to work (40). These survivors also noted that having less pressure and supervisors who were willing to engage in finding solutions for accommodations were helpful to them. For many employers, these accommodations are not costly in the short term and can result in positive business outcomes. These findings point toward interventions, training, and education that facilitate open conversations between employers and employees followed by creative solutions that allow survivors to continue meaningful employment.

The Equal Employment Opportunities Commission offers formal guidance on policies and suggestions for appropriate accommodations for employees with cancer (41). The Equal Employment Opportunities Commission website guidance notes that there are no “magic words” when requesting an accommodation, but the examples provided suggest that simple language clearly stating the accommodations needed are best. A family member, friend, health professional, or other representative can make a request on behalf of a person with cancer. A study by Brown et al. (2013) (42) provides situation-specific communication skills for cancer survivors when communicating with their employer, but further research is not only needed to refine and test policies and approaches in the workplace setting but also to aid survivors and their employers in initiating conversations about accommodations, specifically what is needed, when it is needed, and for how long the accommodations will be needed followed by the employer’s concrete response about what will be done.

Despite the need for employer engagement, a review of employment interventions found only 19 studies that met preestablished criteria (20). The quality of evidence was low to moderate, samples sizes were small, and the overall effect of these interventions ambivalent. To shed further light on what is needed from the employer perspective, our research team convened a focus group of eight employers to discuss cancer survivors in the workplace (unpublished data). Participants were selected from a preexisting network of businesses associated with the University of Colorado Center for Work, Health, and Environment. These businesses were located in the Denver metropolitan area and represented companies in health, government, service, and financial sectors, including small (2–10 employees, $n = 1$), mid-size (11–49 employees, $n = 4$), large (50–199 employees, $n = 1$), and very large (>199 employees, $n = 3$) employers. Through a guided discussion, the group identified benefits, accommodations, education and training, and communication and culture as areas where more information, education, and research was needed.

Employers expressed genuine concern for their employees overall but were unaware of cancer survivors’ specific needs and how to meet them. Employers were explicit in their need for education and training and resources with regard to existing policies, needs of survivors, and communication skills to facilitate mutually beneficial decisions. Employers were also aware of the impact that cancer has on workplace morale, individual and company productivity, redistribution of job duties, and other aspects of running a business. They were aware of the direct and indirect costs as well as the value of benefits offered to employees, including those benefits related to health and life insurance, leave time, and retiree benefits. Employers acknowledged the importance of workplace culture and the role of leadership to set a tone that is compassionate and supportive. This evidence suggests that employers, even those with few employees, are receptive to adopting cancer-facing policies that support survivors, but there is limited understanding of the barriers to adoption and the feasibility, costs, effectiveness and sustainability of accommodation policies and strategies in these businesses.

Following our conversation with employers, we presented a summary of employer responses to concerns about cancer survivors in the workplace with the Kaiser Permanente Colorado’s Cancer Patient Advisory Board (PAB). PABs have an increasingly important role in motivating and guiding research meaningful to patients. We sought reactions from the PAB to gauge the extent to which patients and employers shared perceptions for how cancer patients were treated in

the workplace. The PAB underscored the need for employer training, resources, and improved understanding about cancer survivors’ needs. They reiterated how well-intentioned employers often err in their approach to cancer survivors and that existing policies do not offer full protection.

Workplace Interventions: Role for Pragmatic Trials and Dissemination and Implementation Research

In a political environment where the success of passing sweeping national policies to protect workers is less certain, directly engaging and training employers to improve their corporate policies and practices may be one strategy for moving forward with solutions that ease cancer’s burden in the workplace. European organizations have taken substantial steps to address the issue of cancer in this direction. For example, one such organization, MacMillan Cancer Support (43), offers extensive information and individual consultation services such as employer support, communication, managing treatment side effects at work, self-employment, and return to work. Cancer and Careers (44) has similar information consolidated under a single website that markets resources for employees and employers. In addition, they offer conferences and workshops aimed toward employer and patient audiences.

Table 1 lists selected organizations that offer information about legal issues at work and with insurance, return to work strategies and concerns, and communication with co-workers and supervisors for cancer survivors. Relative to information available to survivors, there are few resources for employers who seek information on how to handle workplace issues specific to cancer survivors, suggesting an unmet need. Missing from these guidelines is the evidence and information specific to implementation (ie, cost, feasibility, training, effectiveness) to facilitate widespread dissemination and adoption. To our knowledge, few studies exist that measure the outcomes associated with the implementation of workplace strategies that are specific not only to cancer survivors but to employees with chronic conditions in general.

Pragmatic worksite research is an initial step toward developing an approach to conducting the research needed to reduce cancer’s burden in the workplace. There is an acute need for stakeholder-informed (eg, employers, patients, providers), actionable (eg, accommodations, leave policies), and multi-level outcome measures (eg, absenteeism, job retention, health improvements) to identify and prioritize feasible and acceptable means to ensure successful and sustainable change at the worksite (11). Pragmatic research is also needed to identify costs from the perspective of different employers, varying in size, sector, and worker skill level (45). More information is needed on the factors that influence successful implementation (eg, management endorsement, supervisor communication skills), return on investment (eg, employee retention), and scalability of programs, accommodations, and implementation strategies (46). Interventions conducted in representative employer settings are largely absent from the literature, leaving employers and patients alike unable to discern the best approach to meeting their needs in the workplace.

Summary

Although considerable advances have been made in what is known about cancer and its treatment’s impact on the work

Table 1. Selected organizations that provide services and resources for employed cancer survivors

Organization	URL	Summary
Legal concerns and the workplace Cancer and Careers	https://www.cancerandcareers.org/en/at-work/legal-and-financial	Workplace rights, health insurance navigation, and workplace accommodations
American Society for Clinical Oncology	https://www.cancer.net/blog/2017-02/when-cancer-leads-workplace-discrimination	Legal protections against discrimination; preventing and addressing workplace discrimination
Survivorship from A-Z	https://www.survivorshipatoz.org/cancer	Financial, legal, and practical information
National Cancer Legal Services Network	https://www.nclsn.org/	Legal services for employment and insurance issues
Triage Cancer	http://triagecancer.org/statelaws	Laws related to employment, disability insurance, health insurance, and other cancer-related state laws
Americans with Disabilities Act	https://www.ada.gov	Answers to ADA-related questions, offers free ADA materials, information about filing a complaint
U.S. Equal Employment Opportunity Commission	https://www.eeoc.gov/laws/types/cancer.cfm	Rights and the laws that apply to each state within the US, including filing charges for discrimination. Page dedicated to "Questions and Answers About Cancer in the Workplace and the Americans with Disabilities Act"
Cancer Care	https://www.cancercare.org/tagged/legal_assistance	Resources and support for managing workplace and insurance legal issues
National Institute for Occupational Safety and Health	https://www.cdc.gov/niosh/	Resources and education on current research and recommendations for the prevention of work-related injury and illness
International Agency for Research on Cancer	https://www.iarc.fr/	Resources and cancer database focused on the causes and occurrences of cancer globally
International Labour Organization	https://www.ilo.org	Information on global labor standards, social protection, and employment opportunities world-wide
Returning to work Macmillan Cancer Support	https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/information-for-employees/going-back-to-work.html#44765	Return to work plan
Cancer Legal Resource Center	http://cancerlegalresources.org/about/	Action plan development, legal and insurance issues
Cancer and Careers	https://www.cancerandcareers.org/en/at-work/back-to-work-after-cancer	Recasting oneself after a diagnosis, addressing comments from co-workers and supervisors, setting professional boundaries, relieving stress, and traveling with cancer
	https://www.cancerandcareers.org/en/at-work/where-to-start/managing-treatment-side-effects	Information on working with chemo brain, balancing a treatment plan and work, what to wear, makeup, skincare, exercise, and nutrition
Workplace Transitions	http://workplacetransitions.org/for-employees	Resources on returning to work, setting professional boundaries, and working with chemo brain
Macmillan Cancer Support	https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/information-for-employees/coping-with-side-effects.html#161500	Coping with treatment side effects at work
Job Accommodation Network	https://askjan.org/media/Cancer.html	Job accommodations for people with limitations, accommodation ideas

(continued)

Table 1. (continued)

Organization	URL	Summary
Communication about cancer at work Cancer and Careers	https://www.cancerandcareers.org/en/at-work/where-to-start/sharing-the-news	Sharing a cancer diagnosis with co-workers
Job Accommodation Network	https://askjan.org/media/Cancer.html	Tips on how to ask for accommodations
Macmillan Cancer Support	https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/information-for-employees/talking-to-your-employer.html#44714	Talking to employer and co-workers about cancer diagnosis
Resources for employers Macmillan Cancer Support	https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/if-youre-an-employer/policies-and-resources.html	Resources for employers to assist employees in the workplace

ability of cancer survivors, gaps in our knowledge exist. Survivorship research with respect to employment outcomes has not kept pace in four important areas: 1) data needed to understand the impact of emerging treatments and their influence on employment and job performance; 2) cancer survivors in the changing work environment with respect to contractual arrangements and employment in small- and medium-sized firms; 3) employers' perspectives and approaches to implementing workplace policies for cancer survivors; and 4) the development of feasible, scalable, and sustainable workplace interventions that can be implemented to address these issues. The confluence of these factors makes a strong argument for research to advance what is known and what can be done about the employment consequences of cancer.

Notes

Affiliations of authors: University of Colorado Cancer Center (CJB, KLB); Center for Health, Work, and Environment (MH, LSN, LT) and Department of Family Medicine (REG), University of Colorado; University of California San Diego (BR); Kaiser Permanente Colorado (DPR).

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