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Greater support and resources needed for cancer survivors returning to work

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Key Points

Cancer survivors face a myriad of challenges in the workplace, including the side effects of treatment, misconceptions about their disease, and the potential for its recurrence.

Some survivors said they avoided disclosing their illness because they were afraid it might cost them their job or jeopardize advancement opportunities.

Although nearly 90% of survivors said their companies were supportive, that was mostly true for employees at large companies.

A new Canadian study published in *Psychooncology* (2019;28:792-798. doi:[10.1002/pon.5021](https://doi.org/10.1002/pon.5021)) reports that cancer survivors face a range of problems in the workplace, including stigma and misperceptions about their abilities; a higher risk of losing their job compared with healthy controls; a lack of understanding regarding their work abilities, productivity, and reliability; and costs associated with their continued employment.

According to the lead author of the study, Margaret Fitch, PhD, adjunct professor of the faculty of nursing at the University of Toronto in Toronto, Ontario, Canada, the research was designed to paint a fuller picture of the challenges survivors and caregivers face in reentering the workforce. Dr. Fitch and her colleagues were funded by the nonprofit Canadian Partnership

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Against Cancer, which intends to use the findings of the study to develop a national action plan for supporting cancer survivors.

Although the study is based on Canadian data, the observations and conclusions would not differ significantly from a similar study based in the United States, says Catherine Alfano, PhD, vice president of survivorship at the American Cancer Society in Atlanta, Georgia. “While issues like paid time off and accessing FMLA (the Family and Medical Leave Act) might differ in the US versus Canada, I think the majority of the findings and recommendations from the report are relevant to the US survivor, caregiver, and employer population.”

Study Details

To better understand the challenges of returning to work after cancer, researchers organized online surveys, in-person interviews, and focus groups with cancer survivors, their caregivers, and workplace representatives, such as employers, union leaders, and managers.



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“It’s one thing to acknowledge that patients are having difficulty and give them help to prepare to go back,” Dr. Fitch says. “But if we don’t do anything about the work environment, and we

don't try to help some of the coworkers and the employers...we could be preparing people to go back to an environment that is not ready for them, or is not capable of necessarily supporting them." The broad participation in the study, she adds, "should allow for the development of an intervention to improve employment for survivors and caregivers that actually works."

Cancer Survivors

The surveys were completed by 410 cancer survivors. The majority of the survivors were female and ranged in age from 25 to 64 years. Nearly 46% were diagnosed with breast cancer, whereas 13% were diagnosed with colorectal cancer and 7% were diagnosed with prostate cancer. Greater than 80% of the respondents had undergone surgery, greater than 62% had been treated with chemotherapy, and nearly 53% had received radiation treatment.

Respondents generally believed that their communications with employers had been positive during treatment and recovery and 88%, most of whom were employees of large companies, reported receiving accommodations. However, some said they avoided disclosing their illness because they were afraid it might cost them their job, lead to reduced responsibilities, or jeopardize advancement opportunities.

Of the 73% of respondents who experienced side effects, greater than 50% reported being unable to resume their work schedule, said they needed flexibility with regard to work hours and workload, or said they needed time off for appointments.

Approximately one-half of respondents were troubled by a lack of control over key areas, such as when they should return to work, changes in their job duties, and to whom they reported.

Caregivers

The online survey was completed by 60 caregivers, 85% of whom were well-educated workers. The majority had cared for an immediate family member or close friend who was likely diagnosed with advanced cancer, and they typically resumed full-time work when their loved one's treatment ended.

Almost all of the caregiver respondents said they provided emotional support (98%) and home management (93%). In addition, approximately 83% provided transportation to and from medical appointments, and 55% said they provided support with activities of daily living. Although most said they had received support from their employers, they also reported a loss of concentration and productivity, stress, and a lack of support from coworkers.

Workplace Representatives

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Of the 68 employer representatives who participated, 41 were interviewed individually and 27 participated in focus groups. Key issues this group considered to be important included:

Managing the survivor's workload and productivity;

Accommodating the survivor's restrictions and diminished capacity;

Managers' lack of education, training, and experience with cancer survivors;

Costs incurred when an employee's capacity to work is diminished; and

Assessing an employee's readiness to return to work.

In general, they agreed that a better understanding of the survivor's situation was needed, as well as stronger communication between stakeholders and a greater awareness of options and strategies available for managing the situation.

Study Implications

According to Dr. Fitch, there was a broad overlap among recommendations from cancer survivors, caregivers, and employers. Each stakeholder group cited the need for greater education regarding workplace accommodation, improved communication, and a clearer understanding of the roles that patients, employers, insurers, and the medical team play. They also acknowledged a need for more community resources.

According to Dr. Alfano, a better understanding of how interventions such as cancer rehabilitation help patients and caregivers to be more productive and participate fully in work might spur legislation that either requires these benefits to be covered by health insurance plans and/or reimburses these services with lower cost sharing for patients. "This is important since so many survivors and families are financially strapped trying to cover their cancer therapy bills. They simply cannot afford to pay co-pays for services that will help them re-engage to/participate fully in work." As another alternative, she says, employers "might consider providing for these services fully so survivors and caregivers can fully return to work."

In addition, Dr. Fitch notes that there is a key consideration for patients with cancer who wish to reenter the workforce or reclaim their job. "First and foremost, cancer patients and survivors who want to go back to work and carry on with their lives must face the reality that some of the long-term effects of their illness, such as fatigue and cognitive changes, might interfere with their abilities to resume their work...we need patients themselves to understand that, along with family members, the health care professions, and employers."

Barbara Hoffman, JD, assistant clinical professor at the Rutgers Law School in Newark, New Jersey, and founding chair of the National Coalition for Cancer Survivorship, has been following

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this issue for several decades, both as a cancer survivor and specialist in disability law. She says that before the 1970s, it was common for cancer survivors to face “blatant employment discrimination with little legal recourse, a paucity of support services, and limited medical options for curative treatment.” Since then, survivors have benefited from the passage of antidiscrimination laws and more open attitudes about cancer. Ms. Hoffman notes that regulations to the Americans with Disabilities Act were modified in 2011, which “...improve the chance that a cancer survivor could prove he or she was ‘an individual with a disability’ as defined by the ADA.” She also explains that most employment situations are best addressed without a formal legal response. Educational and advocacy resources, such as medical-legal partnerships, patient navigators, and cancer support organizations, can help survivors obtain reasonable accommodations and other employment-related assistance.

The ACS website (cancer.org/treatment/survivorship-during-and-after-treatment/staying-active/working-during-and-after-treatment.html) provides information regarding working during and after cancer treatment. This resource page also includes tip sheets concerning employment and cancer for a variety of stakeholders, including supervisors and coworkers, and was created in partnership with the National Business Group on Health.

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