

NCCN Policy Summit: Cancer Care in the Workplace: Building a 21st Century Workplace for Patients, Survivors, and Caretakers

Victoria Hood, MPP¹; Lindsey Bandini, MPH¹; Taneal Carter, MS, MPA¹; Alyssa Schatz, MSW¹; John Sweetenham, MD²; Warren Smedley, DSc, MSHA, MSHQS³; Joanna Fawzy Morales, Esq⁴; Rebecca V. Nellis, MPP⁵; Randy A. Jones, PhD, RN⁶; Lynn Zonakis, BSN⁷; and Robert W. Carlson, MD¹

ABSTRACT

Survival rates for people with cancer and quality of life for survivors have increased significantly as a result of innovations in cancer treatment, improvements in early detection, and improved healthcare access. In the United States, 1 in 2 men and 1 in 3 women will be diagnosed with cancer in their lifetime. As more cancer survivors and patients remain in the workforce, employers must evaluate how they can adjust workplace policies to meet employee and business needs. Unfortunately, many people still encounter barriers to remaining in the workplace following a cancer diagnosis for themselves or a loved one. In an effort to explore the impacts of contemporary employment policies on patients with cancer, cancer survivors, and caregivers, NCCN hosted the Policy Summit “Cancer Care in the Workplace: Building a 21st Century Workplace for Cancer Patients, Survivors, and Caretakers” on June 17, 2022. This hybrid event, through keynotes and multistakeholder panel discussions, explored issues regarding employer benefit design, policy solutions, current best and promising practices for return to work, and how these issues impact treatment, survivorship, and caregiving in the cancer community.

J Natl Compr Canc Netw 2023;21(5):459–464
doi: 10.6004/jnccn.2023.7007

Innovations in cancer treatment, advancements in early detection, and expanded healthcare access have significantly improved both survival rates for patients with cancer and quality of life for survivors.¹ National Cancer Institute projections estimate that the number of cancer survivors in the United States will exceed 26 million by 2040.^{2,3} In the United States, 1 in 2 men and 1 in 3 women will be diagnosed with cancer in their lifetime.⁴ As more cancer survivors and patients remain in the workforce, employers must evaluate how they can adjust workplace policies to meet employee and business needs. The COVID-19 pandemic has also elevated the need to reconsider office accommodations for immunocompromised patients to work safely. Unfortunately, many people still encounter barriers to remaining in the workplace following a cancer diagnosis for themselves or a loved one. In an effort to explore the impacts of contemporary employment policies on patients, survivors, and caretakers, NCCN hosted the Policy Summit “Cancer Care in the Workplace: Building a 21st Century Workplace for Cancer Patients, Survivors, and Caretakers” on June 17, 2022. This hybrid event, through keynotes and multistakeholder panel discussions, examined contemporary benefit design, policy barriers to accommodating workplaces, and innovative approaches in the workplace to support those impacted by a cancer diagnosis.

Building a 21st Century Workplace: Employer Strategy Today and a Look Ahead

Employers often struggle to balance meeting the needs of their employees to support a healthy workforce with managing the costs associated with employee benefit plans. To explore this issue further, Lynn Zonakis, BSN, an independent healthcare consultant who had previously served as the Managing Director for Health Strategy and Resources for Delta Air Lines, explored best practices for developing benefits plans that are beneficial to employees impacted by cancer. Ms. Zonakis provided an overview of Delta’s

¹National Comprehensive Cancer Network, Plymouth Meeting, Pennsylvania; ²Southwestern Simmons Comprehensive Cancer Center, Dallas, Texas; ³The Kinetix Group Oncology, New York, New York; ⁴Triage Cancer, Chicago, Illinois; ⁵Cancer and Careers; ⁶University of Virginia School of Nursing, Charlottesville, Virginia; and ⁷Zonakis Consulting, Sedona, Arizona.

approach to ensuring employee access to high-quality cancer care. She noted key challenges faced by Delta when re-designing its benefit program, including high costs of the existing benefit package, underutilization of benefits by employees, and the need for a policy providing flexible work accommodations or leave due to disability. To address these needs, Ms. Zonakis and her leadership team pursued creative solutions to facilitate access for employees while also pursuing strategies to reduce cost.

To address employee underutilization of benefits, her team launched an aggressive communication campaign for the existing Centers of Excellence program that included access to treatment at academic centers paired with coverage of associated costs, including travel and lodging expenses. Ms. Zonakis remarked that they received significant positive feedback from employees about this program and the quality of care they received from these Centers of Excellence. To improve utilization of benefits, Delta facilitated a process to inform employees of other programs of potential relevance when applying for related benefits. For example, if an employee applied for leave under the Family and Medical Leave Act (FMLA) to support their spouse with cancer, they would also be informed of other available resources, such as Employee Assistance Program (EAP) benefits and care management benefits. By implementing programs to reduce cost to the employee and increasing communications and awareness surrounding benefits offered, Delta was able to increase utilization of preventive services by 20%. Additionally, employees reported being more satisfied with their cancer management programs. Delta also implemented policies to make disability leave benefits more flexible by allowing for intermittent leave. Ms. Zonakis also noted that benefit programs must account for survivorship and offer appropriate coverage and flexibility to support employees through their continued healthcare journey.

Currently, employers still face challenges in creating competitive benefit plans, ensuring utilization of offered programs, and managing cancer in the workplace. The adage of “build it and they will come” is no longer enough; employers must also ensure proper marketing and education surrounding the navigation of benefits programs to increase access and utilization. Ms. Zonakis noted that employers experiencing difficulty in this area may begin by using existing resources, such as the NCCN Employer Toolkit. In 2021, NCCN published the Employer Toolkit to help employers make the best decisions possible when it comes to cancer care for their employees. This free resource comprises 6 Guiding Principles, each of which includes several corresponding strategies and tactics, complete with links to resources, to eliminate uncertainty while choosing a health plan that will deliver high-quality cancer care.⁵

Contemporary Barriers and Solutions to Achieving Inclusive Workplaces

People receiving treatment for cancer or who are in survivorship may be able to continue to work as a result of advancements in treatment options. It is estimated that approximately 45% of people diagnosed with cancer in the United States are between age 20 and 64 years.⁶ Employees with cancer often find themselves continuing to work through a cancer diagnosis and treatment for myriad reasons, such as meeting financial needs, promoting a sense of normalcy and control, and retaining employer-sponsored health benefits.⁶ Employers face a challenging but unique opportunity to assess and improve the ways their workplaces support employees impacted by cancer. To further explore innovative approaches in benefit design to support those affected by cancer, NCCN assembled a multistakeholder panel to explore these topics (Table 1).

Panel members explored the challenges faced, the role and importance of workplace culture, patient rights and disclosures, and the way the COVID-19 pandemic has helped to envision the way we are able to work. Angela Mysliwiec, MD, from WellMed noted that because work can be such an essential part of someone’s life, when it comes to creating a patient’s treatment plan, conversations regarding work expectations should start early and continue often. Understanding how a patient perceives their career can guide how they and the care team approach various treatment options, keeping in mind time commitments needed for treatment and recovery and different ways treatment can impact one’s ability to work. Randy A. Jones, PhD, RN, of the University of Virginia, also noted the importance that nurses and navigators can play during this time for patients. Knowing the work needs of a patient and the potential issues there may be with disclosure can inform nurses and navigators of what options and resources

Table 1. Summit Participants

• Robert W. Carlson, MD , National Comprehensive Cancer Network
• Lynn Zonakis, BSN , Zonakis Consulting
• Clifford Goodman, PhD , The Lewin Group
• Randy A. Jones, PhD, RN, FAAN , University of Virginia School of Nursing
• Angela Mysliwiec, MD , WellMed
• Rebecca V. Nellis, MPP , Cancer and Careers
• Joanna Fawzy Morales, Esq. , Triage Cancer
• Fran Castellow, MEd , Patient Advocate Foundation
• Warren Smedley, DSc, MSHA, MSHQS , The Kinetic Group
• John Sweetenham, MD, FRCP, FACP, FASCO , UT Southwestern Simmons Comprehensive Cancer Center
• Debbie Weir, MSW , Cancer Support Community
• Wui-Jin Koh, MD , National Comprehensive Cancer Network

can be presented to a patient to help them. From an employer perspective, Ms. Zonakis pointed out that, “It’s not just about the traditional clinical outcomes; it’s about function, the ability to show up at work.” She stressed that there must be conversations occurring in which employers ask questions such as: When are people able to work? What benefits are available to them? Can they continue to perform their essential job functions? Are there opportunities for this employee to work in a different capacity if they cannot perform their job duties?

Disclosure of a cancer diagnosis or cancer survivorship to an employer also presents complex challenges and considerations for many people impacted by cancer. Trust in an employer as well as the culture of the workplace often drives whether an employee feels comfortable disclosing their cancer diagnosis. As Rebecca V. Nellis, MPP, from Cancer and Careers noted, not only is it necessary for patients to have a discussion with their care team about why they are working and what their job entails, but also patients need to consider whether they are comfortable disclosing their diagnosis at work. Although some people are able to work through active treatment without any major changes to their schedule or work environment, many individuals—if eligible—can benefit from workplace accommodations that can involve a wide range of changes, including schedule flexibility and time off from work. However, these accommodations require sharing enough information to show why an employee is eligible. In one research study, it was found that if a disclosure was made, some of the reasons included “a supportive workplace, a desire to be open with coworkers, and a need to request supports and manage expectations.”⁷

Survivors face unique challenges when returning to work. A meta-analysis done by De Boer et al⁸ found that the risk of unemployment among cancer survivors is higher compared with healthy control participants. Ms. Zonakis pointed out that employees who have finished cancer treatment may return back to a company where they are embraced, or face the difficulty of finding new employment if they chose to or had to leave their job as they underwent treatment. In 2016, a study of survey results found that only 54% of cancer survivors aged 18 to 64 years were working.⁹ Research in one study found that survivors who had been interviewed perceived cancer as something that was highly stigmatized in their work place, including “misperceptions regarding impacts on the workplace, including survivors’ abilities, productivity, reliability, the costs associated with their continued employment (eg, workplace accommodations) and future impacts on the workplace related to cancer recurrence.”⁷

Panelists agreed that workplaces need to ensure a culture that would foster support during treatment, survivorship, and for caretakers through a cancer diagnosis. Just as survivors have faced difficulties in the workplace,

Dr. Jones pointed out that those in caretaker positions are also often left out of conversations and lack the knowledge of resources and benefits that are available to them. According to one survey, cancer caregivers spend an average of 32.9 hours per week caring for a loved one with cancer.¹⁰ Given the time that caregivers spend caring for their loved ones, it’s vital for them to also have access to benefits like flexible accommodations and leave time.

The COVID-19 pandemic has made remote work options and hybrid schedules more common, which may reduce barriers to accessing them as a reasonable accommodation for people living with cancer and in survivorship. Although caregivers are not entitled to reasonable accommodations under the law, these kinds of work arrangements becoming more familiar offer those responsible for a loved one’s care greater ease in requesting them. However, disparities in the workplace can be intensified due to a variety of demographic and socioeconomic factors of different workers. Just as this was apparent throughout the COVID-19 pandemic, it is also true for those dealing with cancer. Lack of support in accommodations and flexibility when going through treatment are most likely to be experienced by low-income and minority workers.⁶ This can further exacerbate the negative effects of cancer treatment and has wide-ranging implications, such as increased distress, poor quality of life, reduced ability to adhere to treatment recommendations, potential for job loss, and financial toxicity.⁶ Dr. Jones pointed out that disclosure is particularly difficult for workers in these situations, and reiterates the importance of navigators and treatment teams finding ways to really support patients who are in situations where they have less flexibility and their risk of job loss is higher.

Policy Landscape to Support Patients, Survivors, and Caregivers at Work

For many Americans, cancer and the workplace are intrinsically linked through employer-sponsored health insurance and replacing lost wages through disability insurance. According to Triage Cancer, an employer’s influence in a person’s experience with cancer is great, as “The number one way to mitigate financial toxicity is having adequate health insurance coverage.” This places patients with cancer in a vulnerable position, because they are heavily reliant on workplace benefits at a time when they are facing additional stressors outside the workplace. Therefore, it is important that both employers and employees understand the legal protections in place for employees impacted by cancer.

Joanna Fawzy Morales, Esq, Chief Executive Officer of Triage Cancer and a cancer rights attorney, provided a keynote presentation to help patients, caregivers, healthcare professionals, and employers understand legal rights of relevance to employees impacted by cancer. Ms. Fawzy Morales noted that relevant laws exist at both the federal and state levels, and fall into 2 categories: fair employment

laws and workplace leave laws. Fair employment laws protect individuals from discrimination based on a disability and provide access to reasonable accommodations. One such example highlighted by Ms. Fawzy Morales is Title I of the Americans with Disabilities Act (ADA).¹¹ Although it is limited to private employers with ≥ 15 employees, it does offer wide protections from discrimination, based on both real and perceived limitations, for patients with cancer, cancer survivors, and caregivers. Title I applies broadly across all phases of employment, including within the application process, and requires workplaces to offer any reasonable accommodation to people with cancer or in survivorship who can perform essential job functions. She also highlighted these accommodations as a key to balancing a cancer diagnosis with a career, and stressed the importance of creativity and customization when designing accommodations. She also noted that accommodations are often inexpensive, with most costing $\leq \$500$.¹² Other policies impacting employees with cancer include the Rehabilitation Act of 1973, FMLA, and a variety of state laws.^{13–15}

Many employers extend benefits to patients with cancer beyond what is required by law, often through their benefit design. Health insurance is the most obvious example, but disability insurance can also offer critical financial support to replace some lost wages associated with time off work due to a medical condition. However, disability insurance often doesn't cover the beneficiary's full salary, the impact of which may be exacerbated by heightened medical expenses. Ms. Fawzy Morales noted that disability benefits are subject to medical underwriting. Therefore, individuals with cancer may be denied disability insurance, as well as life or long-term care insurance. Federal disability insurance, either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), are onerous to access, with lengthy wait times and burdensome paperwork. Another high-impact opportunity proposed by Ms. Fawzy Morales is creating a federal standard for paid sick leave. She noted that in addition to benefiting employees in active cancer treatment, paid sick time can enable employees to seek screening and preventive services.

To date, the most notable national policy impacting employee access to cancer care occurred when the Affordable Care Act (ACA) was signed into law in 2010 by former President Barack Obama. The aim of this health insurance reform legislation was to help make prevention affordable and accessible by requiring health plans to cover recommended preventive services without charging a deductible, copayment, or coinsurance. Approximately 137 million Americans with private health coverage have received better preventive services coverage as a result.¹⁶ The ACA has transformed the coverage landscape in the United States, and through its provision to expand

Medicaid in the states it has significantly improved the early detection of cancer.^{17–19}

High-Value Care for Employers: Innovation in an Evolving Benefit Package

Cancer treatment is often accompanied by greater cost burdens for employers compared with other common health conditions, with cancer drugs comprising 9 of the 10 costliest injectable drugs in 2020.²⁰ According to some studies, it is estimated that the total cost of treating cancer will likely exceed \$246 billion in the United States by 2030.²¹ Benefit design is one mechanism employers can use to manage health spending.²² The summit's second panel discussion featured stakeholders from patient advocacy organizations, payers, and providers, and explored ways employers are responding to pursue high-value cancer benefit design.

Panelists noted that ensuring employer benefit design is aligned with guideline concordance is one simple way to reduce costs while maintaining quality. Warren Smedley, DSc, MSHA, MSHQS, from The Kinetix Group, pointed out that cancer care is complicated, but cost-effective solutions can be achieved when the right therapy is delivered at the right time for a patient. He noted that resources such as clinical guidelines can help ensure patients are getting the best care, while also managing costs. From a clinical perspective, John Sweetenham, MD, of UT Southwestern Simmons Comprehensive Cancer Center, agreed, stating, "I think that the literature is very clear, that when you're delivering guideline- and pathway-concordant care, it reduces variation in treatment, it improves the quality of care, and it reduces costs."

Although larger employers may be well-resourced to develop competitive and cost-effective benefit design, Fran Castellow, MEd, of Patient Advocate Foundation, notes that most businesses in this country are small businesses. This means they will have little to no control over what's being covered, what guidelines are used in coverage determination, or what networks will even look like given that they are unable to provide tailored benefit packages to their employees. Patient navigation and health literacy were also discussed. Debbie Weir, MSW, from Cancer Support Community, agreed that navigation and support are critical, because benefits are often difficult for individuals to understand and navigate.

Panelists also emphasized the importance of considering long-term rather than just short-term costs when considering benefit design. Ms. Weir notes that employers may elect to offer high-deductible plans to reduce cost, but it could unintentionally result in delays in screening and prevention. Dr. Sweetenham pointed out recently released data that suggested that patients who changed from low- to high-deductible plans had about a 5-month delay in diagnosis for metastatic cancer.²³ This warrants

particular attention given that US employees with high-deductible health plans has increased from 10% in 2006 to >50% as of 2016.²³ Ms. Castellow noted that other utilization management tools, including step therapy and narrow networks, can be especially problematic for patients with cancer. Dr. Smedley agreed from an administrator's perspective that utilization management tools can complicate things, stating that, "those kinds of things are put in place to try and reduce costs, but they add incredible administrative burden to organizations."

Ms. Castellow acknowledged the lack of focus on supporting employees in survivorship, noting "Survivorship is severely underrepresented in benefit design and educational materials." Survivors may experience many challenges associated with their return to work but have fewer resources at their disposal to help address them.

The impact of COVID-19 on both the workplace and the healthcare system was also discussed. Panelists noted that COVID-19 has led to an expansion of telehealth services, but access is inequitable.^{24,25} Access to broadband and technology may be limited in rural and low-income areas, and some patients may struggle with digital literacy. Clinicians must also consider equity and access issues in their practice and how they impact a patient's ability to adhere to treatment. Dr. Sweetenham noted, "We're also thinking about whether that particular patient has the support that they need in order to actually take the treatment effectively and have it be effective," such as consideration of the patient's available resources and health-related social needs.

Panelists concluded by emphasizing that as employers navigate rising costs, they consider not only short-term but also long-term implications of their benefit design. Investment in programs aimed at early detection and prevention, staff retention for employees experiencing medical challenges, and benefit design that supports access to guideline-adherent care can result in cost

savings down the line through improved employee health, retention, productivity, satisfaction, and wellness.²⁶ As Ms. Weir noted, when employers shift from focusing on short-term to long-term costs, "There is a return on investment that will be realized."

Conclusions

The Policy Summit explored employer benefit design, policy solutions, current best and promising practices for return to work, and how these impact treatment, survivorship, and caregiving in the cancer community. A cancer diagnosis presents unique challenges for a patient, their caregiver, and their employer. Although advancements in treatment have made it possible for many patients to return to work, support systems for employees impacted by cancer are still evolving. The rising costs of healthcare, and cancer care in particular, demand innovative solutions to allow employers to offer comprehensive benefits to employees while also controlling costs.

Submitted December 6, 2022; final revision received January 17, 2023; accepted for publication February 1, 2023.

Disclosures: The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors. V. Hood, L. Bandini, T. Carter, A. Schatz, and R.W. Carlson are employed by NCCN.

Sponsor: Boehringer Ingelheim Pharmaceuticals, Inc.

Supported by: Zseventy bio; ADC Therapeutics; AmerisourceBergen; Astellas; AstraZeneca, BeiGene Ltd.; Bluebird Bio; Bristol Myers Squibb; Eisai Inc.; EMD Serono; (Merck KGaA); EQRx; Exelixis; Foundation Medicine, Genentech, GlaxoSmithKline; Helsinn Healthcare; Heron; Incyte Corporation; Janssen Oncology; Kite Pharma, Lilly; Merck & Co. (Merck Sharp & Dohme); MorphoSys; Regeneron; Sanofi Genzyme; and Sun Pharma.

This activity was made possible by Pharmacyclics, an AbbVie Company.

Correspondence: Victoria Hood, MPP, National Comprehensive Cancer Network, 3025 Chemical Road, Suite 100, Plymouth Meeting, PA 19462. Email: hood@nccn.org

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