

Issue Brief

VOLUME 16, NUMBER 2 APRIL 2021

The Financial Toxicity of Cancer

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Introduction

More than 294,300 people in Wisconsin are currently living with a cancer diagnosis.¹ Cancer is a challenging and complex disease, and it is one of the most expensive medical conditions a person can experience.²

In 2020, cancer care cost the United States an estimated 173 billion dollars.³ The average cost of treating the most common cancers is on the rise, largely because of expensive advances in technology and treatments such as targeted therapies.³ Currently, the average patient cost of initial cancer treatment can range from \$5,047 for melanoma to \$108,168 for brain

cancer.⁴ Patients incur additional and often increasing costs throughout their lifetime and at the end of life, regardless of cancer type.⁴

There is a growing recognition that the high costs of cancer care can create severe financial distress for patients and their loved ones.² This financial distress can negatively affect the physical, psychological, and behavioral well-being of patients, survivors, and families, and in some cases can lead to refusal of care or non-adherence to recommended treatments.²

This phenomenon is known as financial toxicity.

KEY POINTS

- Cancer is one of the **most expensive** illnesses a person can have.
- Cancer can cause **severe financial distress** for patients, survivors, caregivers, and families.
- Financial difficulties **can last for many years** after diagnosis.
- Increasing access to **high-quality and affordable health insurance** is an important way to reduce cancer's financial burden.



A Constellation of Costs

The financial burden for cancer survivors often begins at diagnosis and can last through end of life, regardless of disease severity or prognosis.² This burden can be caused by a constellation of direct and indirect costs, such as high out-of-pocket expenses related to treatment, as well as transportation, child care, and other expenses incurred during and after treatment.²

These costs can create hardships that reduce quality of life, threaten the ability of patients and families to meet basic daily needs (see Box 1), and negatively affect patient outcomes.² Cancer survivors who are younger, underinsured or uninsured⁵, and/or have lower incomes are more likely to experience financial hardship, as are long-term survivors of childhood cancer.⁶

Cancer patients and survivors face significantly higher out-of-pocket medical expenses than people without cancer.^{5,7} For example, according to recent studies:

- Cancer patients in active treatment spent a median of \$1,730-\$4,727 per year in out-of-pocket treatment-related expenses—about \$1,000 per year more than patients without cancer.⁷
- Cancer survivors post-treatment spent an average of \$1,000 per year in out-of-pocket medical expenses—compared to \$622 per year for people without a history of cancer.⁵

Other studies have found that 25 percent of cancer survivors reported significant problems paying medical bills, such as having to borrow money, going into debt, filing for bankruptcy, or being unable to cover their medical costs.⁵ In a 2018 study of 9.5 million people ages 50 and older who were newly diagnosed with cancer, 42.4 percent of patients had depleted their life assets two years after diagnosis.⁸ A separate study found that cancer patients were 2.65 times more likely to go bankrupt than people without cancer—a risk that increased even further among patients who were younger.⁹

Cancer patients and caregivers commonly experience lost wages, unemployment, and/or reduced hours of

work.¹⁰ A longitudinal analysis found that on average, cancer survivors earn up to 40 percent less than what they earned before their diagnosis, a disparity that appears to persist for several years.¹⁰ The same analysis found that total family income, on average, drops by more than 20 percent after a cancer diagnosis and remains for about four years.¹⁰ In 2015, Americans overall lost \$94.4 billion in earnings because of cancer, or about \$191,900 per cancer death.¹¹ The economic burden of cancer affects not only individual patients and families, but also may represent a substantial amount of lost revenue for the state and the country.

In 2015, Americans lost \$94.4 billion in earnings because of cancer — or about \$191,900 per cancer death.¹¹



Cancer survivors and their families can experience financial difficulties many years after diagnosis. People with a history of cancer often have unique medical and psychosocial needs that require ongoing management by follow-up care providers.⁶ While many survivors will outlive their cancer, they may continue to experience long-term and/or latent side effects due to cancer treatment that can affect quality of life, morbidity, and mortality.¹² Survivors also can have an increased risk of other forms of cancer or related health problems that can lead to additional financial and emotional costs.¹² For example, certain types of radiation and chemotherapy are associated with an increased risk of developing cardiovascular complications, sometimes not present until up to 20 years after cancer treatment.¹²

Fortunately, there is an increasing emphasis on improving cancer survivors' overall well-being and quality of life, often referred to as survivorship. Unfortunately, few studies address the financial costs related to the needs of long-time cancer survivors. Thus, it is difficult to determine the complete financial and psychological costs incurred by surviving cancer.

The Effects of Financial Toxicity

The financial hardships associated with a cancer diagnosis can have far-reaching effects on quality of life for patients and families. For example, the high costs of cancer can cause some survivors and families to face unmet basic needs. In a 2019 study of cancer survivors participating in the National Health and Nutrition Examination Surveys, 8 percent of 1,022 cancer survivors experienced food insecurity.¹³ Rates were higher for survivors who were uninsured, younger, parents with children at home, and Hispanic or Black.¹³ In a separate study of 9.5 million people with new cancer diagnoses between 2000-2012, 38.2 percent faced financial insolvency (when a person is no longer able to pay their bills) four years after diagnosis.⁸

Financial toxicity affects patients and families from across the socioeconomic spectrum. In an attempt to manage health care expenses and/or reduced incomes, cancer survivors and their loved ones may forego healthy eating, routine household expenses, retirement, children's activities, vacations, visiting relatives, promotions at work, childcare, or caring for other family members.¹⁴

Financial toxicity can shape patients' health care decisions in ways that jeopardize health outcomes. Cancer patients experiencing financial toxicity are more likely to report noncompliance with medication, inability to afford prescription drugs, and foregoing necessary medical care in order to afford basic household expenses.¹⁵

Financial toxicity extends beyond the direct impact on finances. Financial hardship can cause psychological distress for patients and families. Overall, surveys have found that up to 52 percent of cancer patients experience significant levels of psychological distress¹⁶, and up to 37 percent of cancer patients experience depressive disorders.⁸ Psychological distress is a risk factor for non-adherence to cancer treatment^{8, 17, 18}, increased emergency room visits¹⁹, and lower quality of life¹⁶, and it may even negatively impact survival.^{16, 20-23}

While a number of factors can cause psychological distress for cancer patients and their families, evidence

BOX 1

How does financial toxicity affect caregivers?

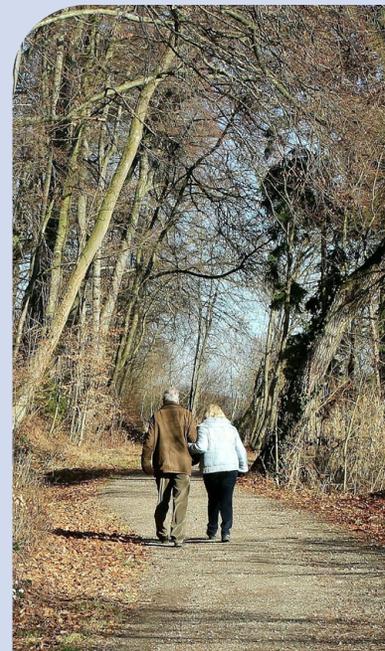
Financial toxicity commonly affects informal caregivers²⁴—such as spouses, parents, adult children, other relatives, friends, or even volunteers—who provide substantial emotional and physical support to patients and survivors.⁶

Studies that examine the costs and toll of caregiving are limited.²⁵ However, according to recent national estimates, approximately 2.8 million³ to 6.1 million adults⁶ spend significant time on cancer caregiving. Time costs per year may be as high as \$73,000 per person.²⁶

Approximately 25 percent of caregivers make extended employment changes to accommodate their caregiving responsibilities.⁵ Informal caregiving may negatively influence employment by limiting caregivers' ability to hold full-time positions, lead to high rates of absenteeism, influence opportunities for promotions, postpone retirement, or require that caregivers work longer hours to maintain insurance coverage.²⁷

In addition, caregivers can experience depression and anxiety at even higher rates than patients. In study samples, caregivers have reported rates of depression between 12 and 59 percent and rates of anxiety between 30 and 50 percent.²⁸ In comparison, patient populations have reported rates of depression between 10 and 25 percent³⁰ and rates of anxiety between 19 and 34 percent.³¹

Financial and psychological distress can negatively affect caregivers' own health and can increase their risk for chronic illnesses such as cardiovascular disease and cancer.^{24, 32, 33}



suggests financial toxicity is associated with higher levels of depression, anxiety, and stress. In a 2019 study, one-third of all cancer survivors reported psychological hardship resulting from medical bills.⁵ Psychological financial hardship was greater among people of color and among patients aged 40-49 years.⁵

Financial Toxicity in Wisconsin

Financial toxicity is increasingly recognized as a common consequence of a cancer diagnosis. Unfortunately, to date, not many studies measure financial toxicity's impact on Wisconsinites.

An ongoing annual health survey called Survey of the Health of Wisconsin (SHOW) gathers data on health and a wide range of health determinants across Wisconsin.³⁴ Some limitations in these data exist, including a small sample size in the portion of the study focused on cancer survivors (306 people); a mostly white, older, and insured sample population; and a high percentage of long-term survivors.³⁴ While data from SHOW may not accurately represent the scope and impact of financial toxicity on all Wisconsin cancer survivors and their families, it does provide insight on how financial toxicity is of concern among survivors even in the absence of racial discrimination, lack of insurance, or poor cancer prognosis.

Among cancer survivors included in SHOW, 7 percent borrowed money or went into debt as a result of cancer or its treatment, and 6 percent did not receive needed medical care, tests, or treatment because of cost-related barriers.³⁴ Rural survivors were more likely than urban residents to borrow money or go into debt for cancer treatment (8.7 percent vs. 4.9 percent).³⁴ By using Comprehensive Score for financial Toxicity (COST) measures—a standardized tool used to measure financial toxicity—the SHOW survey found greater financial hardship among Blacks/African Americans, Hispanics, younger survivors, and survivors with no insurance or public-only insurance.³⁴

In a separate study published in 2020, the Wisconsin Oncology Network examined work

limitations and employment issues among Wisconsin cancer survivors during and after treatment.³⁵ The 111 participants surveyed were mostly white, female, and averaged 48 years of age; breast cancer was the diagnosis in more than two-thirds of cases.³⁵ The study found that full-time employment decreased from 88 percent pre-diagnosis to 50 percent during treatment.³⁵ However, a majority reported they returned to work 12 months after their treatment ended, with a small percentage reporting persistent difficulties.³⁵

Future studies assessing financial toxicity among cancer survivors in Wisconsin would be beneficial to better identify common themes and potential future policy solutions to address these needs.

Policy Protections and Implications

The financial wellbeing of cancer survivors is profoundly affected by state and federal policy decisions. Cancer survivors depend on access to comprehensive health care services paid for in part by public or private insurance, and many survivors and their families depend on employment protections or other forms of support provided by government-funded programs.

Insurance

A lack of health insurance is associated with advanced stage cancer at diagnosis, especially for cancers that can be detected early by screenings.³⁶ Without sufficient health insurance, cancer survivors are forced to forgo screenings and treatments, and face worse prognoses. Approximately 44.3 percent of private-sector employers in Wisconsin offered employer-sponsored health insurance in 2019; employers with fewer than 50 employees were less likely to provide health insurance than employers with 50 or more

1/3 of cancer survivors reported psychological hardship caused by medical bills.¹¹



employees (24.9 percent vs. 97.5 percent).³⁷ (Note, the term “private-sector employers” includes all incorporated for-profit and not-for-profit firms; it does not include government entities or people who are self-employed.³⁸)

In 2019, an estimated 2.7 percent of Wisconsinites were uninsured for the full year (153,000 people), and an additional 4.7 percent were uninsured for part of the year (265,000 people).³⁹ Job loss during the COVID-19 pandemic has further reduced access to employer-sponsored health insurance.⁴⁰ For example, according to the Kaiser Family Foundation, at least 440,000 Wisconsin residents had lost employer-provided health insurance coverage as of May 2020.⁴⁰

Affordable Care Act

The federal Patient Protection and Affordable Care Act of 2010 (commonly known as the ACA) was intended to expand health insurance options and increase coverage for preventive services through most private and public types of insurance.⁴¹ A number of the ACA’s provisions have had a substantial impact on cancer survivors and cancer care.⁴²

The ACA prohibits most insurers from using pre-existing conditions such as cancer to deny coverage or charge more for coverage.⁴³ The ACA also sets maximum out-of-pocket expenses for patients.⁴³ In 2021, these out-of-pocket maximums are \$8,550 for individuals and \$17,100 for families.⁴⁴ Prior to the ACA, an estimated one in ten cancer patients reached their lifetime or annual insurance limit and were responsible for covering the remaining costs of their treatments.⁴⁵ Under the ACA, insurers are prohibited from imposing lifetime or annual dollar limits on coverage.⁴³

The ACA requires most health plans to cover essential health benefits and preventive services recommended by the United States Preventive Services Task Force (USPSTF) at no cost or deductible cost.⁴³ The USPSTF currently recommends screening for breast, cervical, lung, and colorectal cancers; early detection is a key step in reducing cancer mortality.^{46,47} In addition, the ACA allows young adults to remain covered through

their parents’ insurance up to age 26 which may have lowered the insurance dropout rate for adolescent and young adult cancer survivors.⁴³

The ACA has been source of health insurance for those with chronic disease. During the first five years of ACA, health insurance coverage for nonelderly adults with chronic disease, such as cancer, increased by 6.9 percent.⁴⁸ However, changes made to the ACA in 2017 resulted in a decrease in coverage for people with chronic disease by nearly 1 percent.⁴⁸

Medicaid

The ACA originally required state Medicaid programs to provide coverage to low-income individuals up to 133 percent of the federal poverty level.⁴⁹ However, in 2012, the United States Supreme Court rejected this requirement, making it optional for states to expand their programs.⁵⁰

Medicaid expansion was a key provision of the ACA. It was expected that by providing coverage to low-income individuals, populations at greater risk for health disparities would have increased access to health care and improved health outcomes.⁵¹ For cancer survivors, Medicaid has been linked to lower odds of foregoing cancer care because of cost barriers.⁴² A cross-sectional study of 523,802 patients with newly diagnosed breast, colorectal, or lung cancer found decreased mortality in states with Medicaid expansion, compared to states that did not expand Medicaid.⁵²

Following the 2012 Supreme Court decision, the State of Wisconsin chose not to expand its Medicaid program, and the existing ceiling for enrollment is up to 100 percent of the federal poverty level for most adults.⁵³

Medicare

The Medicare program, which primarily covers seniors, is the largest source of payment for cancer care, covering approximately half of all



survivors.⁵⁴ Traditional fee-for-service Medicare covers 83 percent of all hospital and physician office services; however, more than 85 percent of Medicare enrollees purchase supplemental insurance coverage at an additional cost to help with cost-sharing.^{55,56} Still, 50 percent of Medicare beneficiaries with cancer pay at least 10 percent out-of-pocket towards treatment-related costs.⁵⁵

The ACA required Medicare to cover the screenings recommended by the USPSTF, such as mammograms and colonoscopies.⁴³ Within the first two years of this requirement, an estimated 8,400 additional diagnoses of early-stage colorectal cancer were detected nationwide.⁵⁷ Similarly, the rates of detection of breast, colorectal, and lung cancers for those newly eligible for Medicare increased by 11 percent.⁵⁸

Other state laws

The State of Wisconsin has taken some steps to expand access to cancer screenings and treatments. The state requires that insurers provide coverage of routine medical services for cancer treatment during clinical trials to insured patients if the services would be covered under the policy if the patient were not enrolled in the clinical trial.⁵⁹ Insurers that cover any diagnostic or surgical procedures are required to cover colorectal cancer examinations for people over age 50, or under age 50 if they are at a high risk for colorectal cancer.⁵⁹

Additionally, insurers must provide women between ages 45 and 49 with two mammograms, and annual mammograms for women between ages 50 and 65.⁵⁹ Finally, insurers that cover injected or intravenous chemotherapy are prohibited from requiring a higher copayment, deductible, or coinsurance for oral chemotherapy.⁵⁹

Employment

Cancer survivors who are of working age face unique challenges and are more likely to be limited in their ability to perform their jobs full time or at all.^{35,60,61} Cancer survivors undergoing treatment missed 22.3 more workdays per year than persons without a cancer history.⁶⁰ For survivors with employment-based health

insurance, the inability to work could result in the loss of critically needed coverage for treatments and care.⁶² In a study of 9.5 million newly diagnosed cancer patients, at least 40 percent of cancer patients had to stop working during initial treatment and had absences ranging up to 6 months.⁸ Cancer patients who work for employers with 50 or more employees may be eligible for unpaid leave under the federal and state Family and Medical Leave Act (FMLA).⁶³ The federal FMLA allows eligible employees to use up to 12 weeks of unpaid leave per year for family- and medical-related reasons without losing their job or health insurance.⁶³ The Wisconsin Family and Medical Leave Act allows eligible employees to use up to two weeks of job-protected unpaid leave per year for family- and medical-related reasons.⁶³

However, employers in Wisconsin with fewer than 50 employees are not required to provide family and medical leave under state or federal FMLA laws.⁶³ This limitation affects a large portion of Wisconsin's workforce. For example, a total of 134,028 private-sector employers were operating in Wisconsin in 2019; among these employers, 98,167—about 73 percent—employed fewer than 50 people.⁶⁴ Furthermore, the lack of income during FMLA leave can create additional financial burdens for patients and families.

Disability

Cancer survivors who are able to continue working during or after treatment may turn to the Americans with Disability Act (ADA) in working with their employer to accommodate their health condition.⁶⁵ The ADA allows people to continue working, or return to work, if they are able to perform the essential parts of their job.⁶⁵

Survivors who are unable to work may seek assistance from the Social Security Administration under the Social Security Disability Insurance or Supplemental Security Income programs.⁶⁶ The Social Security Administration established Compassionate Allowances for individuals with severe medical conditions, including some forms of cancer, which allows the Social Security Administration to expedite cases quickly.⁶⁶

Opportunities for Change

The growth and aging of the population, coupled with advances in early detection, treatment, and follow-up care, are leading to increases in cancer diagnoses and survival. As a result, more patients and families are at risk of experiencing financial toxicity.

Fortunately, opportunities exist to minimize cancer's economic burden. Policy makers, health care systems, and communities all have roles to play in solving the financial toxicity crisis.

Policy Opportunities

To reduce financial toxicity for cancer patients, survivors, and caregivers, policy makers should consider opportunities that reduce patient costs, strengthen workplace protections, and ensure access to affordable health insurance and quality care.

Drug pricing

The high cost of prescription drugs is a major driver of financial toxicity for cancer patients and survivors.⁵⁵ Policies that reduce patient costs for prescription drugs would help cancer patients who are struggling to pay for treatments and would increase patients' financial ability to follow treatment protocols set by their health care professionals.⁵⁵ Any policy that reduces prescription drug prices should not interfere with the quality and innovation of treatments that improve patient outcomes.

Insurance access

For many patients and families, unexpected health care bills can contribute to financial instability and psychological stress.¹⁶ Unexpected bills may result from various practices such as co-billing, inadequate insurance coverage, and/or high deductibles.⁶⁷ To address this concern, policy makers may work to expand access to quality health insurance, which would help health care systems reduce the practices that contribute to unexpected costs.

Value-based reimbursement

Many health insurers in the state and nation use a fee-for-service model, in which health care

providers are reimbursed according to the number of services they provide, such as appointments, tests, and medical procedures.⁶⁸ The fee-for-service model is a recognized driver of rising health care costs and poorly coordinated patient care.⁶⁹ Opponents of this model argue that it prioritizes quantity of health care services over quality, inflates medical costs, promotes unnecessary medical interventions, and fails to include patient outcomes when measuring success.⁶⁹

Policy makers looking to address rising costs and poor outcome in health care may consider policies that incentivize value-based reimbursement models in state and federal health insurance plans. Under value-based models, such as accountable care organizations (ACOs), costs are based on the quality of care provided, rather than the number of services given or the number of patients treated.⁷⁰ Value-based models may give patients access to better treatments at lower costs and may help reduce financial stress and hardship for patients receiving medical care.⁷⁰

Strengthening FMLA

State and federal FMLA laws provide employment protections for workers who are unable to work for a period of time because of family- or medical-related reasons.⁶³ In a national study of newly diagnosed cancer patients, at least 40 percent of cancer patients were unable to work during treatment and were absent



from work for as long as 12 months,⁸ far exceeding the 12 weeks of leave provided by the federal FMLA and the two weeks provided by state FMLA.⁶³

While taking FMLA leave, employers are not required to pay employees on leave, and employees must continue to pay their premiums to continue enrollment in their employer-provided health insurance.⁷¹ Work absences without pay is a significant driver of financial toxicity for cancer patients and caregivers.⁸

Policies that address the limitations of FMLA would help to reduce the severity of financial toxicity experienced by cancer patients, caregivers, and their families.

Maintaining ACA protections

Under the ACA, insurers are prohibited from imposing lifetime or annual dollar limits on health care coverage.⁴² The ACA also prohibits most insurers from using pre-existing conditions such as cancer to deny coverage or charge more for coverage.⁴² Maintaining these protections is critically important to cancer patients and survivors, for minimizing the financial burden that can result from significant medical expenses during and after treatment, and for ensuring access to future health coverage.

Community and Institutional Opportunities

Financial toxicity has been correlated with quality of life and is a clinically relevant patient-centered outcome.⁷² Health care systems, employers, and researchers can engage in community-based and institutional opportunities to lessen the financial burden for patients.

Assessing patient and family needs

Health care systems should rigorously and routinely assess cancer patients' financial needs. For example, health care institutions should routinely assess patients for financial toxicity using the Comprehensive Score for financial Toxicity (COST) questionnaire. In a study

among older adults with advanced cancer, fewer than 50 percent of patients experiencing financial toxicity had a conversation about the costs with a medical provider.⁷³

Policy makers, health care systems, and communities all have roles to play in addressing the financial toxicity crisis.

Interventions that address financial needs

Merely assessing patients and families for financial toxicity is not sufficient. Health care systems and communities must work to create interventions that help to address the financial burdens faced by patients, survivors, and caregivers. This includes ensuring access to supportive services, as well as making patients and caregivers aware of these services early on.

Institutions and health care systems can work to better connect patients with patient navigators, social workers, financial navigators, and other existing community resources. For example, making financial counselors available in the hospital can help patients learn about health insurance plans and cost-saving methods related to their specific treatment plan. In addition, studies find that community health workers can effectively assist patient navigation and utilize culturally appropriate interventions.⁷⁴

Insurance coverage and reimbursement

Health care systems and health insurance companies can work together to increase access to affordable, quality care for cancer patients and survivors. For example, just as it is essential for health care providers to understand and address the unique medical, financial, and psychosocial needs of survivors, it is equally important for these services to be considered medically necessary and adequately covered by health insurance.

Barriers to timely treatment, such as late authorizations and denials of coverage, can result in increased out-

of-pocket expenses and may cause patients to cancel essential and/or supportive services. Health care systems and insurance companies should take steps to reduce these barriers, such as streamlining their authorization processes.⁷⁵

In addition, health care systems and health insurance companies can adopt value-based reimbursement models as described above, wherein costs are based on quality of care, instead of number of services given or patients treated. Value-based pricing can allow patients to access high-quality care at lower costs and may help reduce financial stress and hardship.

Employer-offered paid leave

Employers should consider offering and maximizing paid family leave benefits to cancer patients and caregivers to help minimize the negative financial impact of cancer. Access to paid medical and family leave makes a positive difference for cancer patients, survivors, and caregivers.

In a 2017 national survey from the American Cancer Society Cancer Action Network (ACS CAN), cancer patients who used paid medical leave reported that paid leave helped them: complete their treatment (80 percent), manage side effects or symptoms (70 percent), and afford treatments (64 percent).⁷⁶ Caregivers had reduced access to paid leave in the ACS CAN survey but cited that paid leave helped them to improve their overall ability to care for their loved one and go to doctor appointments.⁷⁶

Other studies have demonstrated that paid sick leave is associated with a greater likelihood of job retention and reduced personal financial burden among patients with serious illnesses such as cancer.⁷⁷

Research opportunities

More studies are needed to determine interventions and assess patient needs. Costs of new interventions, and particularly measures of financial toxicity, should be reported and published.

Other community-based opportunities

Additional community-based opportunities to reduce financial toxicity and improve health outcomes may include: programs that address indirect costs such as travel expenses and child care; job retraining supports for survivors; additional supports for caregivers; and the referral and use of non-clinical support services, such as community health workers and patient navigators, within health systems and from broader community partners to better connect survivors and caregivers to the resources they may need.⁶¹

Conclusion

Financial toxicity is a significant issue with major implications for families, communities, and health care systems, now and in the future. Policy solutions that financially protect cancer patients, prevent or reduce health care costs, and help patients manage their costs should be considered to ensure that quality cancer care is accessible and affordable for everyone in Wisconsin.



References

1. State Cancer Profile- Wisconsin. National Cancer Institute (NCI). <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=wisconsin#t=3>. Accessed 3/25/2020.
2. Financial Toxicity (Financial Distress) and Cancer Treatment (PDQ®)–Patient Version. National Cancer Institute (NCI). <https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>.
3. Mariotto AB, Robin Yabroff K, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010–2020. *Journal of the National Cancer Institute*. 2011;103(2):117-128.
4. Data from: Annualized Mean Net Costs of Care per Patient. National Cancer Institute (NCI). <https://costprojections.cancer.gov/annual.costs.html>
5. Ekwueme DU, Zhao J, Rim SH, et al. Annual Out-of-Pocket Expenditures and Financial Hardship Among Cancer Survivors Aged 18-64 Years - United States, 2011-2016. *MMWR Morb Mortal Wkly Rep*. Jun 2019;68(22):494-499. doi:10.15585/mmwr.mm6822a2
6. Miller KD, Nogueira L, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin*. Sep 2019;69(5):363-385. doi:10.3322/caac.21565
7. Bestvina CM, Zullig LL, Yousuf Zafar S. The implications of out-of-pocket cost of cancer treatment in the USA: a critical appraisal of the literature. *Future Oncol*. Nov 2014;10(14):2189-99. doi:10.2217/fon.14.130
8. Gilligan AM, Alberts DS, Roe DJ, Skrepnek GH. Death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer. *The American journal of medicine*. 2018;131(10):1187-1199. e5.
9. Ramsey S, Blough D, Kirchoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)*. Jun 2013;32(6):1143-52. doi:10.1377/hlthaff.2012.1263
10. Zajacova A, Dowd JB, Schoeni RF, Wallace RB. Employment and income losses among cancer survivors: estimates from a national longitudinal survey of American families. *Cancer*. 2015;121(24):4425-4432.
11. Islami F, Miller KD, Siegel RL, et al. National and state estimates of lost earnings from cancer deaths in the United States. *JAMA oncology*. 2019;5(9):e191460-e191460.
12. Gegechkori N, Haines L, Lin JJ. Long Term and Latent Side Effects of Specific Cancer Types. *The Medical clinics of North America*. 2017;101(6):1053.
13. Trego ML, Baba ZM, DiSantis KI, Longacre ML. Food insecurity among adult cancer survivors in the United States. *J Cancer Surviv*. Aug 2019;13(4):641-652. doi:10.1007/s11764-019-00783-9
14. Amir Z, Wilson K, Hennings J, Young A. The meaning of cancer: implications for family finances and consequent impact on lifestyle, activities, roles and relationships. *Psycho-Oncology*. 2012;21(11):1167-1174.
15. Knight TG, Deal AM, Dusetzina SB, et al. Financial Toxicity in Adults With Cancer: Adverse Outcomes and Noncompliance. *J Oncol Pract*. Oct 2018;JOP1800120. doi:10.1200/JOP.18.00120
16. Riba MB, Donovan KA, Andersen B, et al. Distress management, version 3.2019, NCCN clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network*. 2019;17(10):1229-1249.
17. Mausbach BT, Schwab RB, Irwin SA. Depression as a predictor of adherence to adjuvant endocrine therapy (AET) in women with breast cancer: a systematic review and meta-analysis. *Breast cancer research and treatment*. 2015;152(2):239-246.
18. Lin C, Clark R, Tu P, Bosworth HB, Zullig LL. Breast cancer oral anti-cancer medication adherence: a systematic review of psychosocial motivators and barriers. *Breast cancer research and treatment*. 2017;165(2):247-260.
19. Xiang X, Larrison CR, Tabb KM. Trends in health care utilization among adults with serious psychological distress: 2003–2014. *Psychiatric Services*. 2016;67(7):743-748.
20. Batty GD, Russ TC, Stamatakis E, Kivimäki M. Psychological distress in relation to site specific cancer mortality: pooling of unpublished data from 16 prospective cohort studies. *bmj*. 2017;356:j108.
21. Kissane D. Beyond the psychotherapy and survival debate: the challenge of social disparity, depression and treatment adherence in psychosocial cancer care. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*. 2009;18(1):1-5.
22. Pirl WF, Greer JA, Traeger L, et al. Depression and survival in metastatic non-small-cell lung cancer: Effects of early palliative care. *Journal of clinical oncology*. 2012;30(12):1310.
23. Massie MJ. Prevalence of depression in patients with cancer. *JNCI Monographs*. 2004;2004(32):57-71.
24. Houts PS, Nezu AM, Nezu CM, Bucher JA. The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Education and Counseling*. 1996;27(1):63-73.
25. Ferrell BR, Kravitz K. Cancer care: Supporting underserved and financially burdened family caregivers. *Journal of the advanced practitioner in oncology*. 2017;8(5):494.
26. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer*. Sep 2009;115(18 Suppl):4362-73. doi:10.1002/cncr.24588
27. Yabroff KR, Lund J, Kepka D, Mariotto A. Economic burden of cancer in the United States: estimates, projections, and future research. *Cancer Epidemiology and Prevention Biomarkers*. 2011;20(10):2006-2014.
28. Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Cmaj*. 2004;170(12):1795-1801.
29. Hauser JM, Kramer BJ. Family caregivers in palliative care. *Clinics in geriatric medicine*. 2004;20(4):671-688.
30. Pirl WF. Evidence report on the occurrence, assessment, and treatment of depression in cancer patients. *JNCI Monographs*. 2004;2004(32):32-39.
31. Traeger L, Greer JA, Fernandez-Robles C, Temel JS, Pirl WF.

- Evidence-based treatment of anxiety in patients with cancer. *Journal of Clinical Oncology*. 2012;30(11):1197-1205.
32. Boele FW, Given CW, Given BA, et al. Family caregivers' level of mastery predicts survival of patients with glioblastoma: a preliminary report. *Cancer*. 2017;123(5):832-840.
 33. Litzelman K, Yabroff KR. How are spousal depressed mood, distress, and quality of life associated with risk of depressed mood in cancer survivors? Longitudinal findings from a national sample. *Cancer Epidemiology and Prevention Biomarkers*. 2015;24(6):969-977.
 34. Fredrick C, Trentham-Dietz A, Chu K, Zhang X, Malecki K, Rolland B, Kerch S, LeCaire T, Tevaarwerk, A and LoConte N. Financial Hardship Reported by Rural and Urban Cancer Survivors in Wisconsin. American Society of Preventive Oncology Conference2020.
 35. Tevaarwerk AJ, Kwেকেboom K, Buhr KA, et al. Results from a prospective longitudinal survey of employment and work outcomes in newly diagnosed cancer patients during and after curative-intent chemotherapy: A Wisconsin Oncology Network study. *Cancer*. Nov 2020;doi:10.1002/cncr.33311
 36. Han, X., Zang Xiong, K., Kramer, M. and Jemal, A., 2016. The Affordable Care Act and Cancer Stage at Diagnosis Among Young Adults. *Journal of the National Cancer Institute*, 108(9), p.djw058.
 37. Meps.ahrq.gov. 2021. Table II.A.2: Percent of private-sector establishments that offer health insurance by firm size and State: United States, 2019. https://meps.ahrq.gov/data_stats/summ_tables/insr/state/series_2/2019/tiia2.htm. Accessed March 19, 2021.
 38. KFF. 2021. Percent of Private Sector Establishments That Offer Health Insurance to Employees, by Firm Size. [online] <https://www.kff.org/other/state-indicator/firms-offering-coverage-by-size/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed March 19 2021.
 39. Dhs.wisconsin.gov. 2021. <https://www.dhs.wisconsin.gov/publications/p45369a-19.pdf>. Accessed March 19, 2021.
 40. Wispolitics.com. 2021. Bill Kaplan: 446,000 Wisconsin-ites lost health insurance | WisPolitics.com. <https://www.wispolitics.com/2020/bill-kaplan-446000-wisconsin-ites-lost-health-insurance/>. Accessed March 19, 2021.
 41. Sabik, L. and Adunlin, G., 2017. The ACA and Cancer Screening and Diagnosis. *The Cancer Journal*, 23(3), pp.151-162.
 42. Graves, J. and Swartz, K., 2017. Effects of Affordable Care Act Marketplaces and Medicaid Eligibility Expansion on Access to Cancer Care. *The Cancer Journal*, 23(3), pp.168-174.
 43. CancerCare. 2021. Affordable Care Act (ACA). https://www.cancercare.org/publications/179-understanding_the_affordable_care_act. Accessed March 19, 2021.
 44. Out-of-pocket maximum/limit - HealthCare.Gov glossary. <https://www.healthcare.gov/glossary/out-of-pocket-maximum-limit/>. Accessed March 19, 2021.
 45. National Survey of Household Affected by Cancer. Accessed March 19, 2021. <https://www.kff.org/wp-content/uploads/2013/01/7591.pdf>.
 46. U.S. Preventive Services Task Force. Accessed March 19, 2021. <https://uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-and-b-recommendations>.
 47. Soni A, Simon K, Cawley J, Sabik L. Effect of Medicaid Expansions of 2014 on Overall and Early-Stage Cancer Diagnoses. *American Journal of Public Health*. 2018;108(2):216-218. doi:10.2105/ajph.2017.304166.
 48. Myerson R, Crawford S. Coverage for Adults With Chronic Disease Under the First 5 Years of the Affordable Care Act. *Medical Care*. 2020;58(10):861-866. doi:10.1097/mlr.0000000000001370.
 49. Medicaid Expansion & What it Means for You. [Healthcare.gov](https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/). <https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/>. Accessed March 19, 2021.
 50. Status of State Action on the Medicaid Expansion Decision. Accessed March 19, 2021. <https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.
 51. Lyon SM, Douglas IS, Cooke CR. Medicaid Expansion under the Affordable Care Act. Implications for Insurance-related Disparities in Pulmonary, Critical Care, and Sleep. *Annals of the American Thoracic Society*. 2014;11(4):661-667. doi:10.1513/annalsats.201402-072ps.
 52. Lam MB, Phelan J, Orav EJ, Jha AK, Keating NL. Medicaid Expansion and Mortality Among Patients With Breast, Lung, and Colorectal Cancer. *JAMA Netw Open*. Nov 2020;3(11):e2024366. doi:10.1001/jamanetworkopen.2020.24366
 53. DeLeire APST. Medicaid Expansion In Wisconsin Would Lower Premiums For those With Private Insurance: Health Affairs Blog. *Health Affairs*. <https://www.healthaffairs.org/doi/10.1377/hblog20190605.87178/full/>. Published June 6, 2019. Accessed March 19, 2021.
 54. Park J, Look KA. Health Care Expenditure Burden of Cancer Care in the United States. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 2019;56:004695801988069. doi:10.1177/0046958019880696.
 55. Yousuf Zafar S. Financial Toxicity of Cancer Care: It's Time to Intervene. *Journal of the National Cancer Institute*. 2015;108(5). doi:10.1093/jnci/djv370.
 56. The Costs of Cancer. American Cancer Society Cancer Action Network. <https://www.fightcancer.org/policy-resources/costs-cancer>. Published November 23, 2020. Accessed March 19, 2021.
 57. Lissenden B, Yao N“A. Affordable Care Act Changes To Medicare Led To Increased Diagnoses Of Early-Stage Colorectal Cancer Among Seniors. *Health Affairs*. 2017;36(1):101-107. doi:10.1377/hlthaff.2016.0607.
 58. R Myerson, R Tucker-Seeley, D Goldman, D Lakdawalla. Does Medicare improve cancer detection and mortality outcomes? *Journal of Policy Analysis and Management*, 2020; 39 (3) 577-604.
 59. Fact Sheet on Mandated Benefits in Health Insurance

- Policies. State of Wisconsin Office of the Commissioner of Insurance. <https://oci.wi.gov/Documents/Consumers/PI-019.pdf>. Accessed on March 19, 2021.
60. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. *Journal of the National Cancer Institute*. 2016;109(2). doi:10.1093/jnci/djw205.
 61. Tevaarwerk AJ, Lee J-W, Terhaar A, et al. Working after a metastatic cancer diagnosis: Factors affecting employment in the metastatic setting from ECOG-ACRIN's Symptom Outcomes and Practice Patterns study. *Cancer*. 2015;122(3):438-446. doi:10.1002/cncr.29656.
 62. Financial Toxicity and Cancer Treatment (PDQ®)—Health Professional Version. National Cancer Institute. <https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq>. Accessed March 22, 2021.
 63. Wisconsin Family And Medical Leave Act (FMLA). Wisconsin Family And Medical Leave Act (FMLA) - the law, posting a notice, and Employee Rights posters - Department of Workforce Development Equal Rights Division. <https://dwd.wisconsin.gov/er/civilrights/fmla/>. Accessed March 22, 2021.
 64. Number of Private Sector Firms, by Size. KFF. <https://www.kff.org/other/state-indicator/number-of-firms-by-size/?currentTimeframe=0&sort-Model=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D>. Published September 11, 2020. Accessed March 22, 2021.
 65. Americans With Disabilities Act: Information for People Facing Cancer. American Cancer Society. <https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/americans-with-disabilities-act.html>. Accessed March 22, 2021.
 66. Borland J, 30 OM, 24 LDJ, et al. Social Security Supports People Battling Cancer. *Social Security Matters*. <https://blog.ssa.gov/social-security-supports-people-battling-cancer/#:~:text=Social%20Security%20supports%20people%20who,eligible%20for%20a%20Compassionate%20Allowance.&text=There's%20no%20special%20application%20or,to%20submit%20for%20Compassionate%20Allowances>. Published November 6, 2020. Accessed March 22, 2021.
 67. Ganguli I, Souza J, McWilliams JM, Mehrotra A. Practices Caring For The Underserved Are Less Likely To Adopt Medicare's Annual Wellness Visit. *Health Aff (Millwood)*. 02 2018;37(2):283-291. doi:10.1377/hlthaff.2017.1130
 68. Glossary of Terms. *Healthcare.gov*. <https://www.healthcare.gov/glossary/fee-for-service/>. Accessed March 23, 2021.
 69. The Origin of Fee-For-Service. American College of Cardiology. <https://www.acc.org/membership/sections-and-councils/cardiovascular-management-section/section-updates/2018/07/10/14/42/the-origin-of-fee-for-service>. Accessed March 23, 2021.
 70. Accountable Care Organizations (ACOs): General Information. Innovation Center. <https://innovation.cms.gov/innovation-models/aco>. Accessed March 22, 2021.
 71. Fact Sheet #28A: Employee Protections under the Family and Medical Leave Act. U.S. Department of Labor Seal. <http://www.dol.gov/agencies/whd/fact-sheets/28a-fmla-employee-protections#:~:text=If%20family%20member%20coverage%20is,maintained%20during%20the%20FMLA%20leave.&text=An%20employee%20on%20unpaid%20FMLA,order%20to%20maintain%20insurance%20coverage>. Accessed March 22, 2021.
 72. De Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: the validation of the Comprehensive Score for financial Toxicity (COST). *Cancer*. 2017;123(3):476-484.
 73. Arastu A, Patel A, Mohile SG, et al. Assessment of financial toxicity among older adults with advanced cancer. *JAMA Netw Open*. 12 2020;3(12):e2025810. doi:10.1001/jamanetworkopen.2020.25810
 74. Wenzel J, Jones R, Klimmek R, Szanton S, Krumm S. Exploring the role of community health workers in providing cancer navigation: perceptions of African American older adults. *Oncol Nurs Forum*. May 2012;39(3):E288-98. doi:10.1188/12.ONF.E288-E298
 75. Corder JC. Streamlining the insurance prior authorization debacle. *Mo Med*. 2018 Jul-Aug;115(4):312-314.
 76. Public Opinion Strategies. Key Findings- National Surveys of Cancer Patients, Survivors, and Caregivers. 2017. <https://www.fightcancer.org/sites/default/files/ACS%20CAN%20Paid%20Leave%20Surveys%20Key%20Findings%20Press%20Memo%20FINAL.pdf> Accessed March 24, 2021.
 77. Veenstra CM, Regenbogen SE, Hawley ST, Abrahamse P, Banerjee M, Morris AM. Association of paid sick leave with job retention and financial burden among working patients with colorectal cancer. *JAMA*. 2015 Dec 22-29 2015;314(24):2688-90. doi:10.1001/jama.2015.12383

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Funding for the Wisconsin Cancer Collaborative is provided by the Centers for Disease Control and Prevention and the Wisconsin Department of Health Services.

