

Issue Brief

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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?

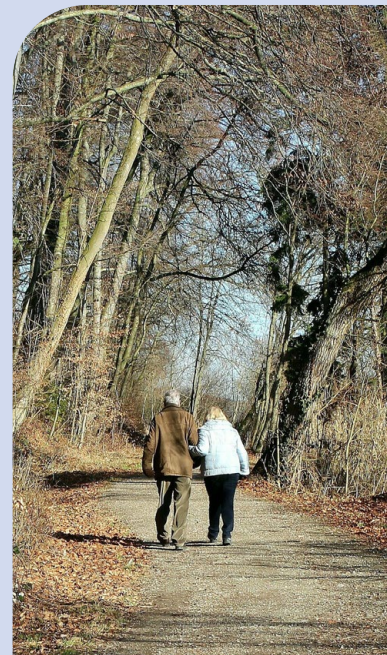
Financial toxicity commonly affects informal caregivers²⁴—such as spouses, parents, adult children, other relatives, friends, or even volunteers—who provide substantial emotional and physical support to patients and survivors.⁶

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.



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