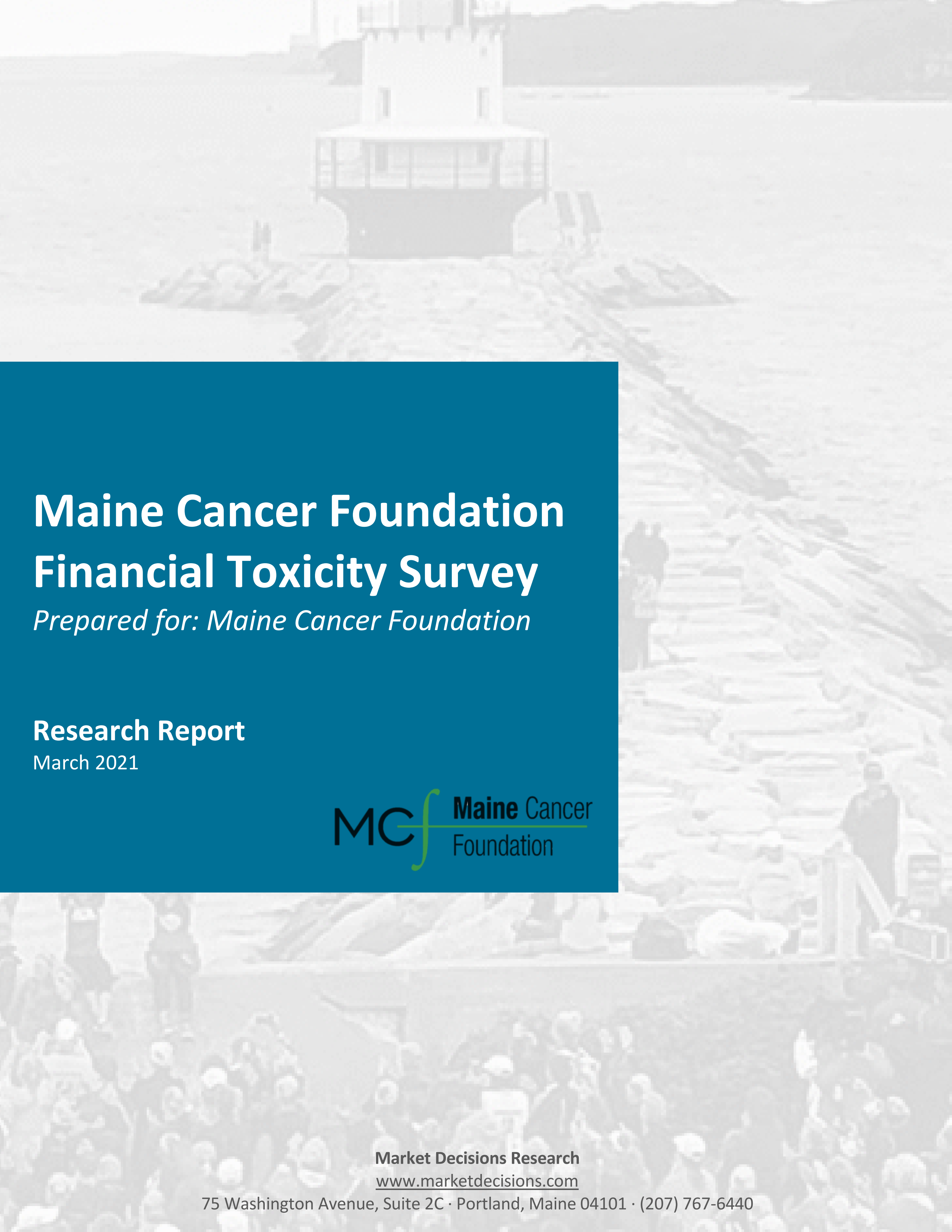

Maine Cancer Foundation Financial Toxicity Survey

Prepared for: Maine Cancer Foundation

Research Report

March 2021

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Acknowledgments

This study is an effort of Maine Cancer Foundation (MCF) to better understand the financial burden of a cancer diagnosis on cancer patients and their families.

The report was prepared by the research team at Market Decisions Research of Portland, Maine.

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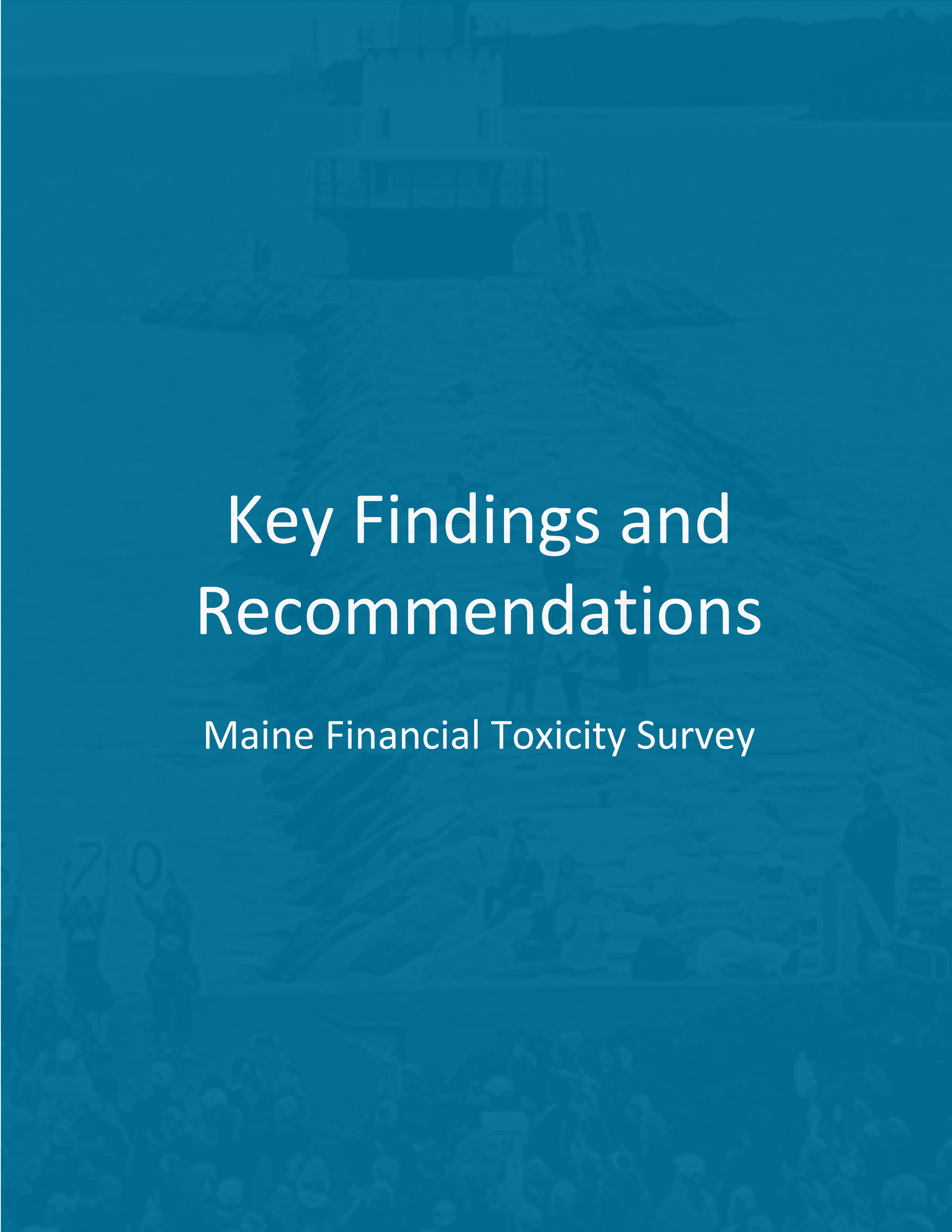

Key Findings and Recommendations

Maine Financial Toxicity Survey

Key Findings

About the Survey Respondents

The survey collected the opinions and experiences of a wide range of individuals across Maine who had been diagnosed with cancer personally or been a close caregiver to a loved one who had been diagnosed with cancer.

- Survey respondents were a mix of patients diagnosed with cancer within the past five years (60%) and caregivers of patients with cancer (40%).
- 63% of caregivers were either a spouse, parent, or grandparent and 61% were living with the patient.
- 71% of respondents were 55 or older.
- The survey was completed by residents from every county in the state, the most common counties being Cumberland and York.
- Breast and lung cancer were the most common diagnosis among respondents. However, respondents reported many different types of cancer diagnoses.

Treatment

Patients mostly receive their care (mainly surgery, chemotherapy, or radiation) in Maine and are likely to experience at least one hospital admission during their care.

- Many respondents are either currently receiving cancer treatment or have already completed treatment and are in remission.
- 68% of respondents receive their treatment in Maine while 31% have gone to another state for treatment.
- If patients have gone to another state for treatment, it is most likely Massachusetts (83%).
- The most common types of treatment among patients are surgery (64%), chemotherapy (63%), and radiation (62%).
- Only 27% of patients with cancer receive treatment for other comorbidities and chronic illnesses.
- Most patients have experienced at least one hospital admission due to cancer (74%).
- Just about half of the patients (47%) did not have an emergency room visit due to their cancer diagnosis while a quarter (25%) had one to two visits.

Key Findings

Challenges

Mainers diagnosed with cancer face many significant challenges. Emotional and mental health struggles are the most common challenge, with many reporting depression, strains on personal relationships, and fear and anxiety. Financial issues such as a loss of employment and wages, medical bills, difficultly paying for regular bills, and debt are also a common experience.

- 79% of respondents reported depression as a major challenge related to their cancer. 75% said the strains of personal relationships became difficult.
- Many respondents experienced some sort of financial challenge. 58% said dealing with lost wages was a struggle while 47% had trouble paying for treatment. 46% of respondents had issues keeping up with their regular bills while 42% struggled to pay for medication.
- Additional challenges chosen by participants included emotional struggles (such as the fear of death), physical pain, and employment challenges.
- When the respondents had to choose their single biggest challenge while receiving cancer care, 27% reported emotional struggles.

Resources

Patients with cancer benefit from working with social workers and patient navigators. However, not everyone takes advantage of these opportunities. There is an opportunity to increase access and use of this type of resource as well as links to additional community-based organizations and open discussions about financial costs of treatment with healthcare teams.

- 64% of patients did not discuss their financial situation with their healthcare team at the beginning of treatment.
- Out of those respondents who did discuss the cost of treatment, 67% said they were advised or given resources to help manage the cost of cancer care.
- Many respondents (56%) worked with an oncology social worker, patient navigator, or some other case worker. Patients were most likely to work with social workers.
- 93% reported this type of resource was helpful, and 50% of respondents said the social worker, navigator, or case worker asked the patient about treatment costs.
- Most respondents (84%) said they did not work with any community-based organizations in Maine for financial resources and assistance. Those that did receive help found this resource valuable.

Key Findings

Health Insurance

Health insurance changes were common among patients especially transitioning from private insurance to Medicare or Medicaid.

- At the time of diagnosis, many respondents had private health insurance through a job (39%) or Medicare (29%).
- Medicare or Medicaid coverage increased while private health insurance coverage decreased.

Home Life

Patients are likely to live with a family member during their care but are much less likely to participate in physical or social activities due to their diagnosis.

- Patients usually live with at least one other person during the time of their cancer diagnosis. 14% lived alone.
- Patients were more likely to not have any dependent children living with them at time of cancer diagnosis (69%).
- After receiving a diagnosis, patients are much less likely to participate in physical, social, and normal daily activities. Spending time with family either increased or stayed the same.

COVID-19

COVID-19 has significantly affected patients with cancer in Maine, limiting access to services and support and increasing mental health issues.

- 51% of patients reported that COVID-19 greatly affected their cancer treatment and care.
- The biggest struggles for patients related to COVID-19 were feeling isolated, the inability to see family, and limited access to support and services.
- It was also common for patients to feel fearful of catching the virus.

Recommendations

Results from this study and others demonstrate that financial toxicity is not an abstract concept, but an issue that directly impacts those who have been diagnosed with cancer in myriad of ways.

Financial toxicity can lead to forgoing or delays in cancer care, mental health problems, loss of employment and income, debt and bankruptcy, poor quality of life, and lower survival rates. It can also be one of the biggest impediments to acceptance of a diagnosis as well as recovery from cancer. In short, financial toxicity is a vast and complex problem that crosses many domains in addition to health care.

Addressing the issue of financial toxicity among cancer patients must be met at all levels, across disciplines, and consistently over time. The recommendations provided here combine results from this survey with findings and discussion from other published studies and articles on the issue.

1. Improve cancer **patients' ability and willingness to discuss costs** of treatment and care.
2. Improve **cancer care providers ability to engage with patients** about costs of treatment and care.
3. Consider **"value" when discussing treatment options** and administering treatment with patients.
4. **Reduce the cost of care** or shift burden of payment away from patients.
5. Provide patients with **affordable prescription medication** options.
6. **Addressing mental health** is as important as providing financial assistance.
7. **Personal and social needs** are often neglected due to financial toxicity and should be a focus.
8. **Employers** have a role beyond a paycheck.
9. Develop a **Maine task force** to address the issue of financial toxicity.

1. Improve Maine cancer patients' ability and willingness to discuss costs of treatment and care.

Only about one-third of Maine cancer patients said they discussed cost with their care team prior to treatment. There are various barriers that prevent patients from discussing costs of health care – including a lack of knowledge or expertise, self-consciousness, fear that it might lead to sub-optimal care, and an unwillingness to provide financial details. However, it is critical that patients are willing and able to have open conversations with their care team about the financial implications of cancer care and the cost of treatments.

There are many ways that this could be accomplished. Patients – especially those with lower educational attainment, racial/ethnic minorities, or those with lower socioeconomic status - need improved cost-related health literacy so they are aware of potential costs and resources. Patients need to have the skills to be able to have conversations with their physician and care team about cost and financial impact of care. Involve patient navigators, social workers, and community organizations to help provide this education. Respondents to the survey found clinical and community resources overwhelmingly helpful when used, however, many patients do not use them.

Online resources also exist to help provide patients with information on the cost of treatment and other medical care. These include tools on CompareMaine.org and CancerCare.org. Maine Health Cost from Maine Health Data Organization provides information on health plan costs and provides other cost transparency information. Others have looked closely at what types of questions patients should ask about costs of care.[1] This helpful information for patients could be developed into educational materials specifically for Maine, if it does not already exist.

2. Improve cancer care providers' ability to engage with patients about costs of treatment and care.

Physicians and other care providers also need to consider costs and the impact of finances in their work. They should be proactive in engaging patients and have clear and comprehensive discussions about the expected costs and benefits of treatment. This provider/patient engagement can reduce financial toxicity for patients by ensuring that treatments truly match the needs, values, and preferences of patients. However, such discussions should ensure that patients do not feel that care is being decided based on their ability to pay.

Much like patients, physicians and other care providers should be educating themselves in the cost and value of cancer care and the resources available to address issues of financial toxicity. Many studies address issues of financial toxicity for oncologists, including having the difficult and urgent conversation about the cost and value of cancer treatment, availability of and access to resources, and assessment of financial toxicity as part of supportive care in the provision of comprehensive cancer care. Several health care professional organizations have developed frameworks/protocols for helping their members confront the costs of care and navigate health care cost conversations with patients.[2] Opportunities exist for interventions

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[1] The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. Available from: https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21443

[2] Minimizing the "Financial Toxicity" Associated With Cancer Care: Advancing the Research Agenda. Available from: https://academic.oup.com/jnci/article/108/5/djv410/2412632

that assist multidisciplinary cancer care team members to define their role in the discussion of cancer care costs and helping patients manage the financial toxicity of cancer care.

3. Consider “value” when discussing and administering treatment with patients.

Oncologists play an important role in reducing the costs of cancer treatment given their knowledge of the options available and specifics of the patient. However, they may put less or no emphasis on cost when discussing options. Studies have provided examples of low value practices that can be replaced to help lessen the financial toxicities to patients.[3] There are also frameworks that can be used by providers that consider the concept of value and clinical benefit, side effects, and improvement in patient symptoms or quality of life and provide relative rankings for decision making. These include the ASCO value framework, Choosing Wisely initiative and the ESMO Magnitude of Clinical Benefit Scale (MCBS).[4]

4. Reduce the cost of care or shift burden of payment away from patients.

All Mainers should have the right to adequate health insurance. State and local agencies, hospitals, community organizations and others in Maine can help the uninsured obtain health insurance coverage. Providers also need to work with cancer patients who lack the ability to pay to reduce their burden.

Health insurers have been shifting the cost of care onto patients for many years though higher premiums and co-pays and high deductible plans. As a result, patients are spending more out-of-pocket than in the past. Unfortunately, this shifting of the cost burden onto patients is not sustainable. Providers and payers need to identify ways to reduce this burden, such as the implementation of value-based payment models, which place a focus on patient centered care and outcomes, to make health care more affordable for everyone.

One innovative and resource-wise strategy to address this issue is expanding the use of telehealth. This has the potential to decrease healthcare and patient out-of-pocket costs and improve patient adherence to recommended treatment and/or surveillance.[5]

5. Provide patients with affordable prescription medication options.

The costs of medications can be prohibitive for many. Locally, it is important that patients are connected with resources to help them better understand their options, as well as help offset the cost of medications. Physicians can consider the cost and value of medications in their discussions with patients. Nationally, interventions can focus on lowering cost of drugs by price negotiations, value-aligned pricing strategies, policies separating physician reimbursements from the cost of interventions, and supporting trials testing cheaper alternatives to expensive treatments.

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[3] Low-value practices in oncology contributing to financial toxicity. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5365336/

[4] Financial toxicity of cancer treatment: Moving the discussion from acknowledgement of the problem to identifying solutions. Available from https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30013-4/fulltext

[5] Socioeconomic disparities, financial toxicity, and opportunities for enhanced system efficiencies for patients with cancer. Available from: https://pubmed.ncbi.nlm.nih.gov/28105638/

6. Addressing mental health is as important as providing financial assistance.

Mental health is an extremely important aspect of financial toxicity that is often given less attention than medical expenses. However, results from the survey show that more patients are impacted by mental health issues than financial ones. Four in five patients reported experiencing depression as a result of their diagnosis, while three quarters noted strains on personal relationships. Patients were also much less likely to participate in physical, social, and even normal daily activities as a result of their diagnosis.

Studies suggest that activities such as problem-solving, cognitive-behavioral therapy, family and group support, and meaning-centered therapy can help to decrease cancer-related distress, even when financial toxicity cannot be fully alleviated.[6] It is important that Maine cancer patients understand what mental health resources are available (especially free or low-cost ones) and are provided adequate access to counselors, therapists and support groups that fit a patient's specific needs. It may be impossible to completely address the effect of cancer on finances, but it is possible to improve a patient's ability to cope with hardships.

7. Personal and social needs are often neglected due to financial toxicity and should be a focus.

Experts note that due to the high financial burden placed on most cancer patients, combined with loss of employment/income, even modest household and personal expenses can become undue hardships. Many studies overlook the burden of everyday bills and additional personal expenses for those receiving cancer treatment. This survey identified many instances where ability to pay for mortgages, utilities, transportation and even food was impacted by financial toxicity. This survey also confirmed that cancer patients often need to pay for additional services such as housekeepers, personal care aides, or CNAs to assist with their day-to-day lives.

The state, local governments, community organizations and others at the community level provide a critical role in Maine by connecting cancer patients with many of these overlooked social service needs including housing, transportation, food, heating, and personal care and items.

The MCF Transportation Needs Assessment[7] found that local communities play a critical role in making sure that patients have access to transportation services where no other options exist. This is especially true in rural areas where there are few other options available. The same applies to other financial, social, and personal services. Grants or funding should be made available to Maine organizations to help address this issue and fill the gaps that often occur when treating cancer.

8. Employers have a role beyond a paycheck.

Most employers probably do not think about the critical function they serve in the long-term health of their employees. Not only are they a

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[6] The Hidden Cost of Cancer: Helping Clients Cope with Financial Toxicity. Available from: https://media.cancercare.org/publications/original/366-hidden_cost.pdf

[7] Maine Cancer Foundation: Maine Transportation Needs Assessment Report. Available from: https://mainecancer.org/sites/default/files/pdf/Maine%20Cancer%20Foundation%20Transportation%20Needs%20Assessment%20-%2010.05.2017.pdf

common source of health insurance, but they can also be a link to other support and wellness services for employees who need help. It is important that employers provide access to adequate health insurance and offer paid sick leave to employees wherever possible. Only 42% of cancer patients who were employed at the time of their diagnosis said their employer had a paid sick leave policy at their job. In addition, employers should provide employees with flexibility, understanding, and support in these difficult situations to help address both the financial and mental health hardships that patients often face.

9. Develop a Maine task force to address the issue of financial toxicity.

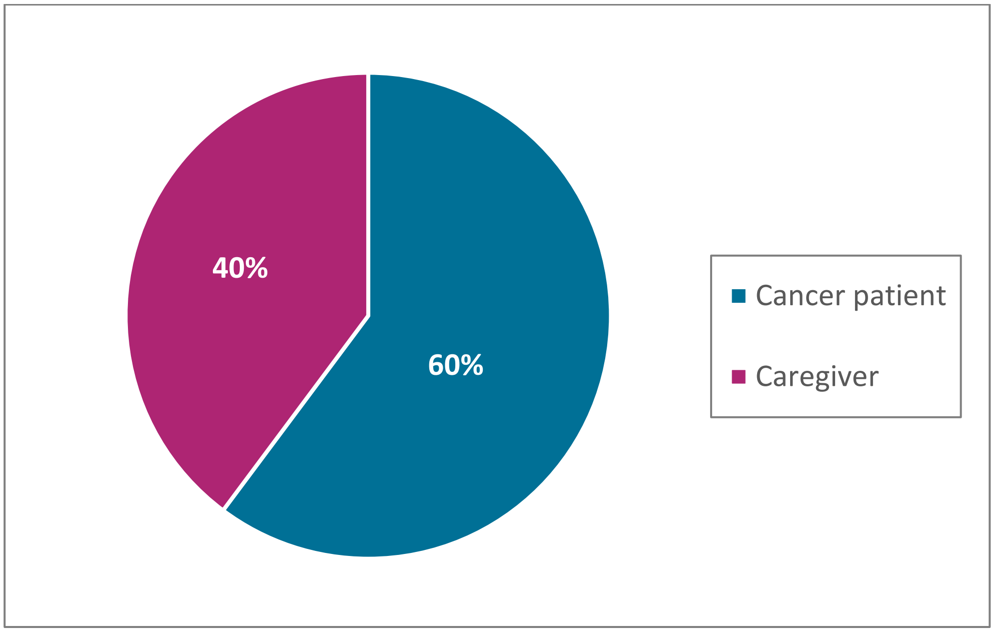
As noted in this report, financial toxicity is a huge, complex problem that will require extensive time and effort to address. It will also require a diverse group of passionate people who can work will all facets of Maine's infrastructure – including health care and public health, state and local governments, payers, community organizations, businesses, and patients themselves. Ultimately, financial toxicity and its impact must be communicated to key stakeholders, including policymakers and patients, to build awareness of the problem and support appropriate policy, programs, and interventions to address the issue.

Detailed Findings

Maine Financial Toxicity Survey

Cancer Status

Have you been diagnosed with any type of cancer in the past 5 years, or are you a caregiver to someone who was diagnosed with cancer in the past 5 years? (n=191)



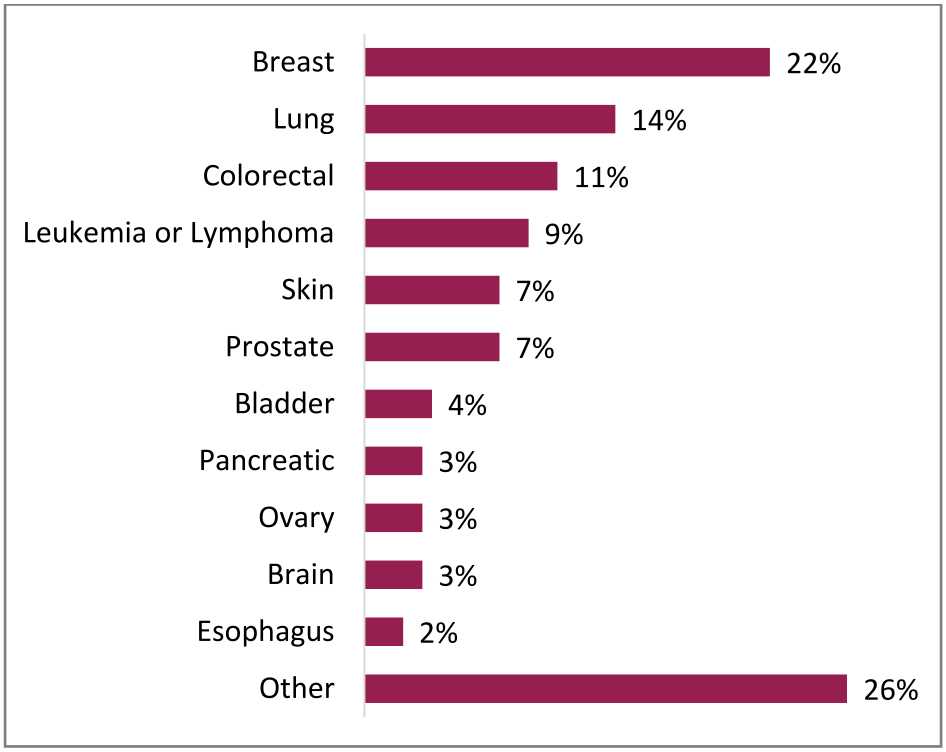
Summary

60% of survey respondents are patients who have been diagnosed with cancer over the past five years.

40% of respondents are a caregiver to someone diagnosed with cancer within the past 5 years.

Cancer Type

What type(s) of cancer have you been diagnosed with (in the past 5 years)? (n=189)



**Multiple responses accepted*

Examples of other types of cancer:

"Cancer of the appendix" "Kidney cancer" "Endometrial Stage III" "Liver"

"Optical and liver" "Blood" "Peritoneal" "Thyroid" "Bowel" "Oral"

"Large cell desmoid sarcoma" "Stomach--digestive system" "Throat" "Sarcoma"

Summary

The most common types of cancer reported in the survey were: Breast (22%), Lung (14%) and Colorectal (11%).

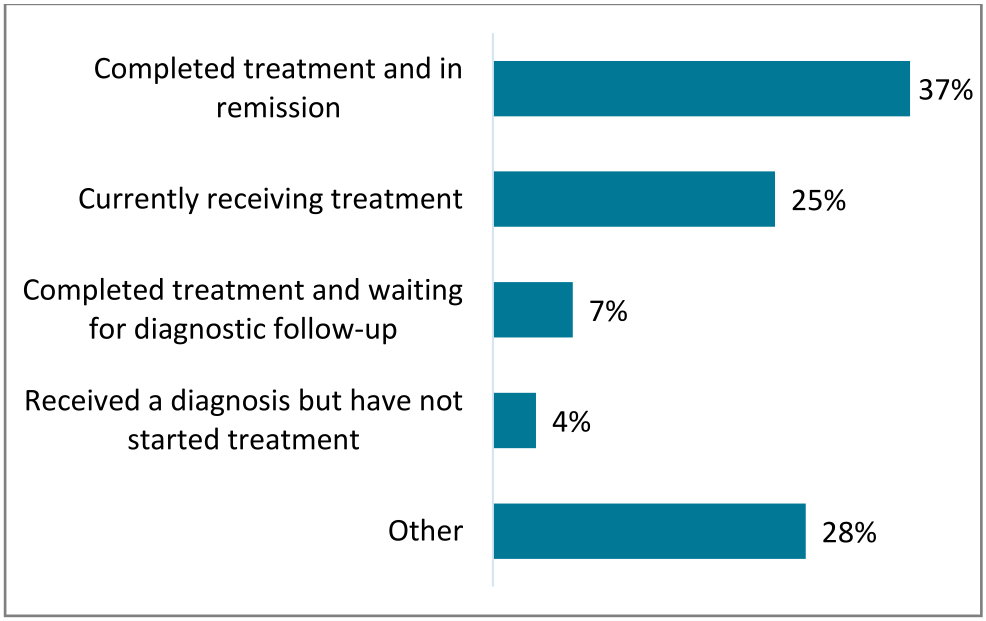
The most common types of cancer reported in the survey were: Breast (22%), Lung (14%) and Colorectal (11%).

Bottom Line

Respondents reported a wide variety of cancer diagnoses, reflecting the overall population of the state.

Treatment

What is the current status of your treatment? (n=185)



Examples of other types of treatment status:

"Cancer cells removed but monitoring required (scans) indefinitely."
"Passed away"

"Completed treatment but continuing follow-up MRIs every 3-4 months."

"Receiving comfort care at this time, until he passes." "PET scan every 3 months."

"Has annual bloodwork to determine remission status."

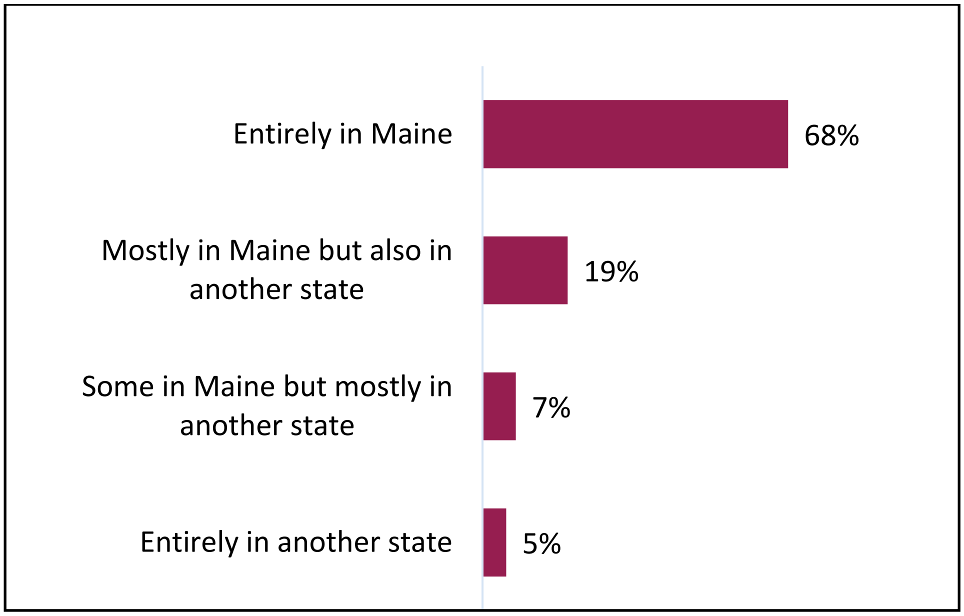
Summary

37% of patients completed treatment, and a quarter (25%) are currently receiving treatment.
28% reported other current status of treatment.

Bottom Line

Respondents were in various stages along the cancer care continuum – from initial diagnosis through remission.

In which state did you receive the majority of your cancer care? (n=189)



Other States where Cancer Care was Received

Massachusetts	83%
New Hampshire	9%
Other state	16%

Summary

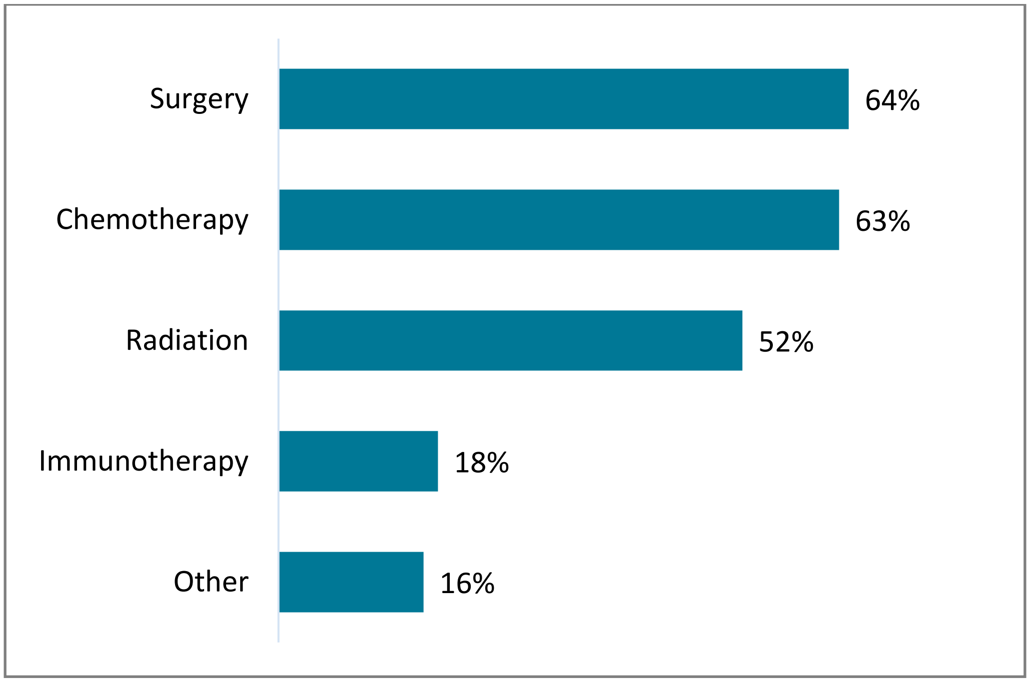
Over two-thirds (68%) of patients received all their treatment in Maine.
If treated in another state, 83% reported Massachusetts.

Bottom Line

The majority of Maine residents receive cancer treatment in Maine. If they go elsewhere, it is usually Massachusetts.

Treatment (cont'd)

What kind of treatment have you received? (n=185)



**Multiple responses accepted*

Examples of other types of treatment:

"Clinical trial for PARP inhibitor" "Blood transfusions" "Blood thinners"

"No treatment. Watch and wait." "Targeted Therapy" "Kept Comfortable"

"Bone Marrow Transplant" "Aromatase Inhibitor - Letrozole" "RNA altering"

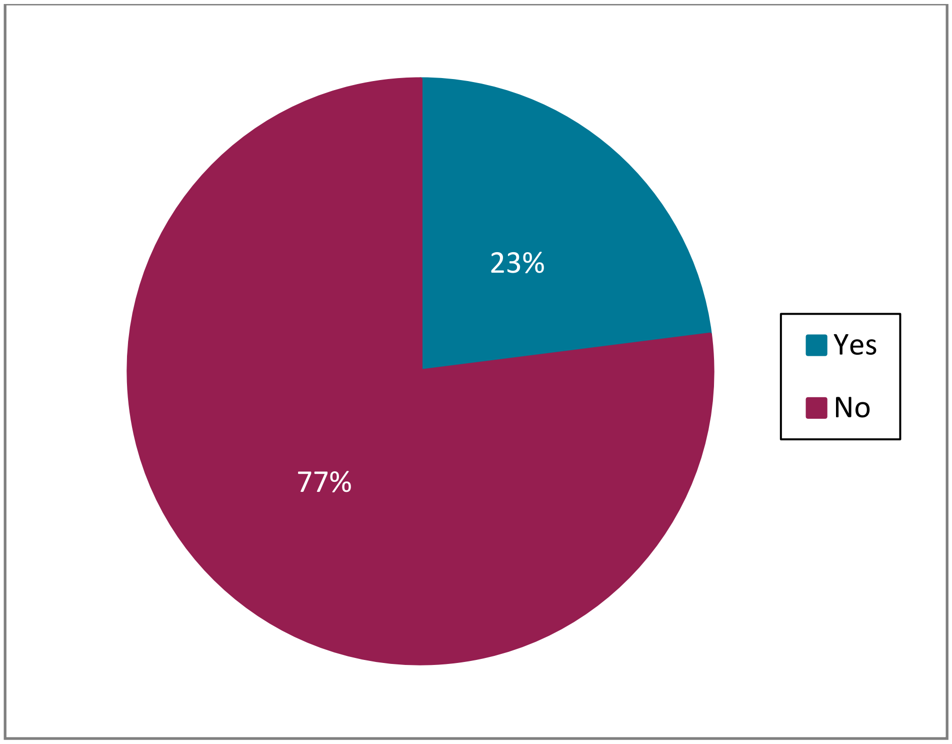
"Hormone suppressors" "Physical Therapy" "Palliative exclusively" "Tamoxifen"

Summary

The most common types of treatment received by patients is surgery (64%), chemotherapy (63%) and/or radiation (52%) for their cancer.

Treatment (cont'd)

At the time of your cancer diagnosis, were you receiving treatment for any other type of chronic conditions (such as diabetes, heart disease or stroke)? (n=187)



Summary

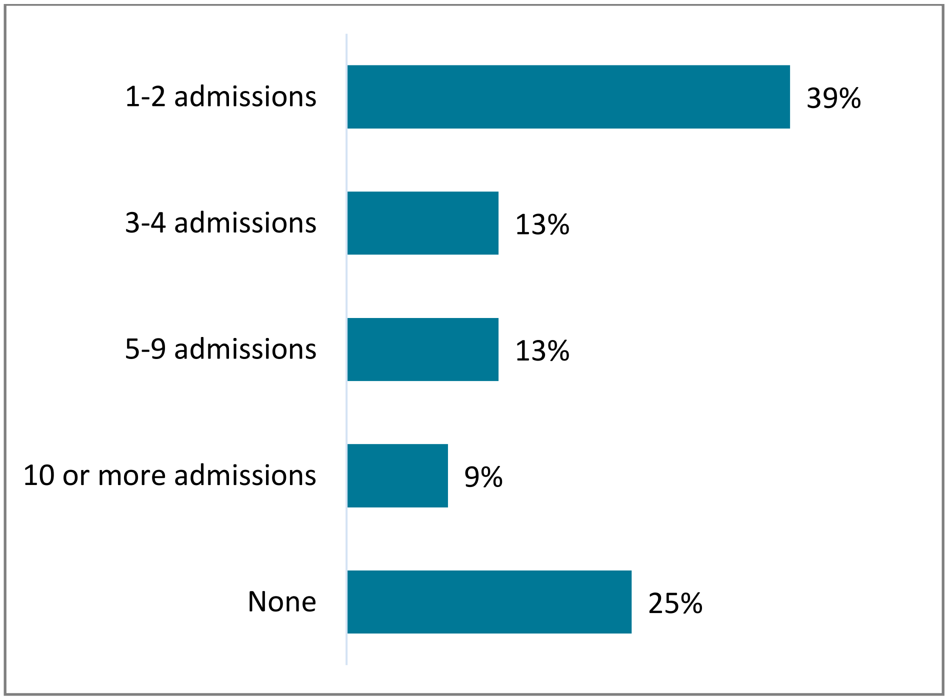
23% of patients at cancer diagnosis received treatment for co-morbidities whereas 77% of patients were not receiving treatment for comorbidities during cancer diagnosis.

Bottom Line

Many Maine cancer patients do not receive treatment for other chronic conditions at the time of diagnosis.

Inpatient Admissions

How many inpatient admissions have you had because of your cancer diagnosis? (n=179)



Summary

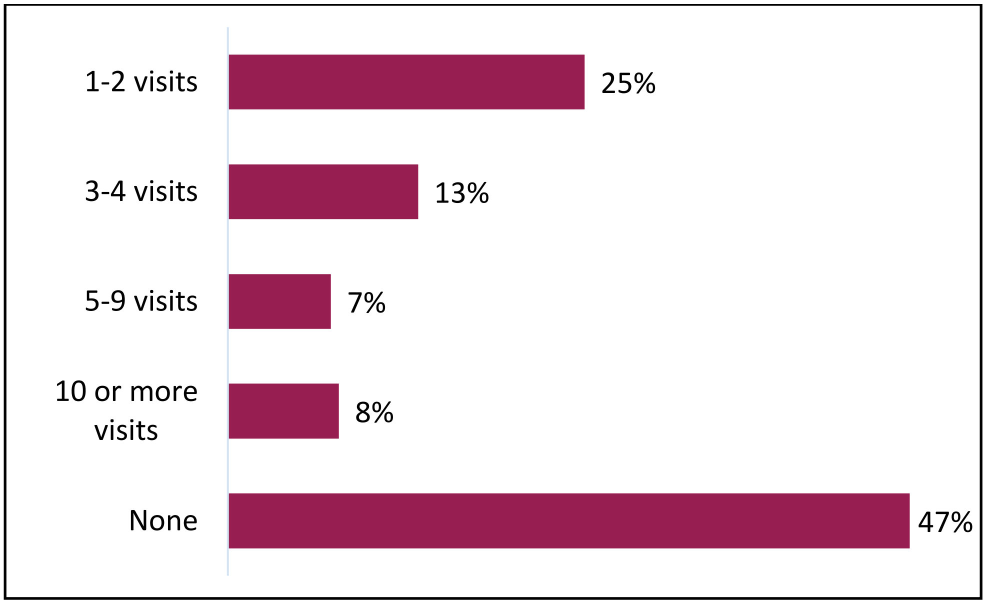
More than half of patients (64%) had 2 or less inpatient admissions due to their cancer diagnosis.

Bottom Line

It is common for patients with cancer to experience at least one hospital admission.

Emergency Visits

How many emergency room visits have you had because of your cancer diagnosis? (n=182)



Summary

Just about half (47%) of patients did not have an emergency room visit, whereas a quarter (25%) reported 1-2 ER visits due to their cancer diagnosis.

Bottom Line

On average, a cancer diagnosis did not result in emergency room visits for patients.

Challenges

While receiving care, what major challenges have you faced as a result of your cancer diagnosis? (n=190)

Major Challenges	% Yes Overall	% Yes Lost job, retired or unable to work*
Depression	79%	83%
Strains on personal relationships	75%	70%
Lost wages	58%	76%
Trouble paying for treatment (including co-pays and deductibles)	47%	61%
Trouble paying regular bills (utilities, grocery)	46%	63%
Emotional struggles (e.g., Fear of death)	45%	78%
Trouble paying for medication (including co-pays and deductibles)	42%	61%
Trouble paying rent or mortgage	35%	56%
Limited access to promising new treatments or clinical trials	33%	41%
Trouble paying for health insurance	27%	50%
Limited access to cancer specialists	25%	24%
Lack of Transportation during treatment	23%	37%
Finding lodging during treatment	20%	28%
Challenges related to childcare	16%	30%
Denial of health insurance	12%	18%
Some other challenge	44%	50%

**Respondents who said they lost their job, retired, or were disabled as a result of their cancer or cancer treatment; Multiple responses accepted*

Summary

Depression (79%) and strains on personal relationships (75%) are among the top challenges faced because of cancer diagnosis.

58% of respondents reported lost wages and 47% had trouble paying for medical bills.

Bottom Line

Mental health and financial strains are common challenges as a result of cancer diagnosis. They are significantly more common among those who lost their job, are retired, or unable to work.

Challenges (cont'd) – Examples of Other Challenges

While receiving care, what major challenges have you faced as a result of your cancer diagnosis? (n=107)

What they are saying:

"Challenges related to pet care."

"Dementia progression quickening"

"COVID had made it impossible to work due to low immunity."

"Difficulty managing treatment and having someone to care for me!"

"Doctors not wanting to treat cancer aggressively because of patient age (elderly)."

"Durable medical equipment not paid for by insurance i.e., ramp to house, wheelchair, walker, leg braces for neuropathy."

"Entire lifestyle change. Expected to go back to work two weeks after surgery; never able to return."

"Finding Health care professionals who are knowledgeable about my condition and who do not dismiss my concerns. Also finding support to care for my ill spouse while I was having treatment."

"Emotional: dealing with scared loved ones and needing to be strong (outwardly)"

"Handling hair loss issues"

"Not getting direct answers when asking questions about why certain things are happening to me. I have to find out on my own."

"Sex life problems"

Summary

There are many additional types of challenges that patients and caregivers face during cancer care.

There are many additional types of challenges that patients and caregivers face during cancer care.

Challenges (cont'd)

What is the ONE biggest challenge you have faced while receiving care? (n=166)

Single Biggest Challenges	**%**
Emotional struggles (e.g., Fear of death)	27%
Depression	14%
Strains on personal relationships	13%
Trouble paying for treatment (including co-pays and deductibles)	9%
Trouble paying regular bills (utilities, grocery)	7%
Trouble paying rent or mortgage	6%
Lost wages	5%
Lack of transportation during treatment	4%
Trouble paying for medication (including co-pays and deductibles)	4%
Trouble paying for health insurance	4%
Limited access to cancer specialists	4%
Limited access promising new treatments	2%
Finding lodging during treatment	1%
Denial of health insurance	1%

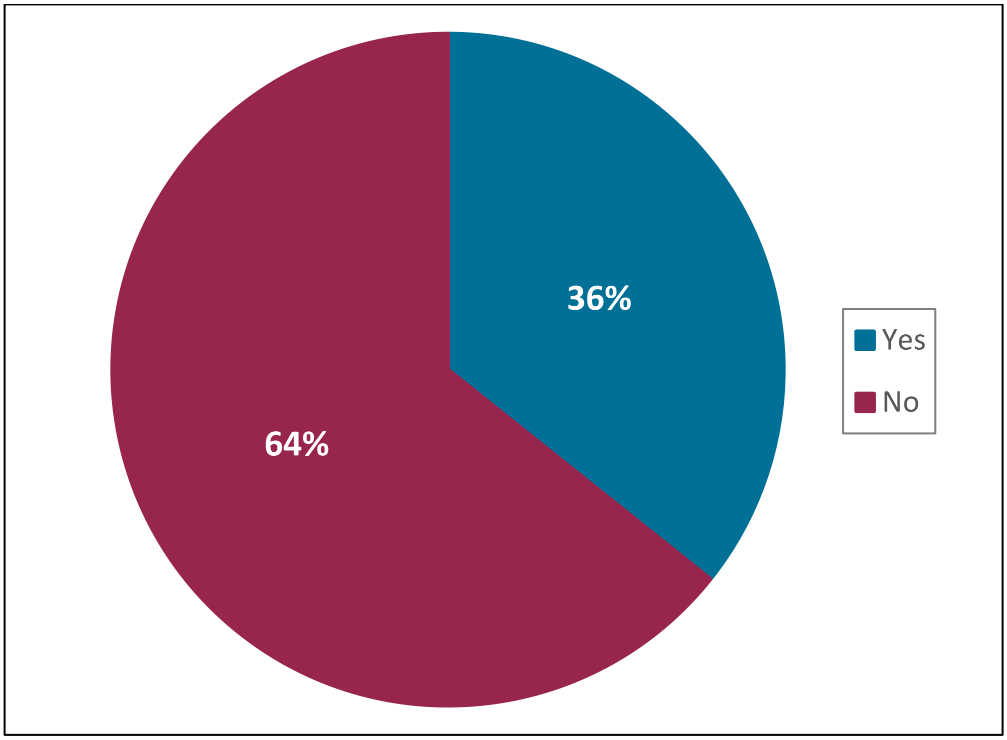
Summary

When asked to report the single biggest challenge while receiving care, 54% reported mental health challenges such as emotional struggles or depression and about a quarter (27%) reported financial strain.

Bottom Line

Mental health and difficulties paying for care and other bills were the biggest single challenges faced during treatment.

Did you discuss the cost of treatment with your health care team prior to treatment? (n=168)



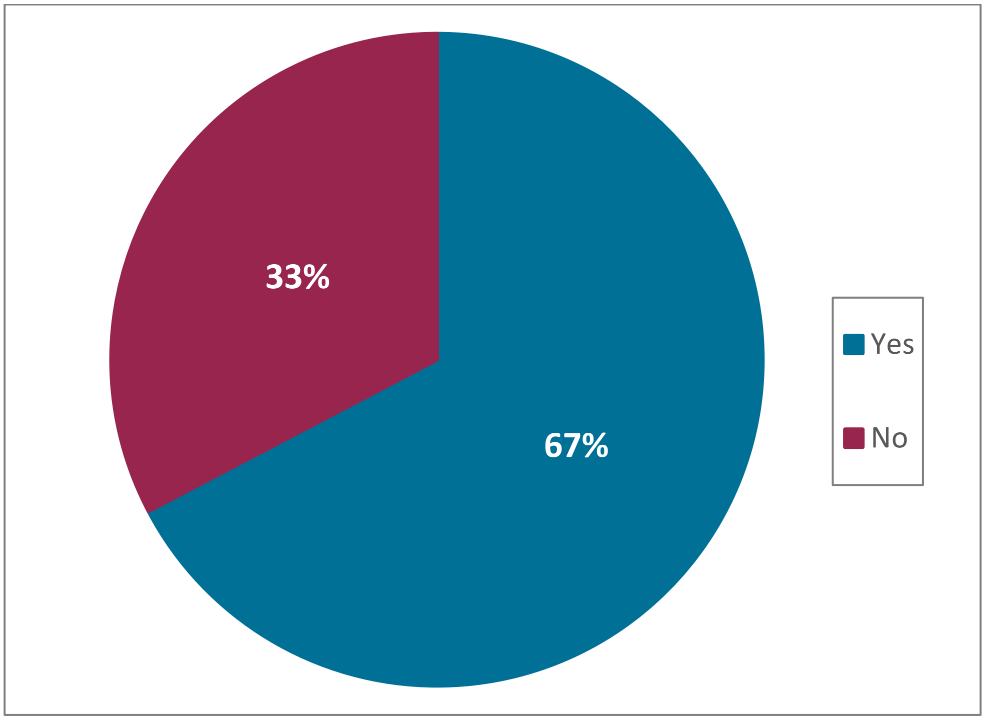
Summary

Over a third of patients (36%) report discussing the cost of treatment with their health care team prior to treatment. Whereas 64% reported NOT discussing the cost of treatment.

Bottom Line

Many patients do not discuss the cost of treatment with their health care team prior to treatment.

Were you advised or given any resources to help you cope with the cost of cancer care? (n=52)



Summary

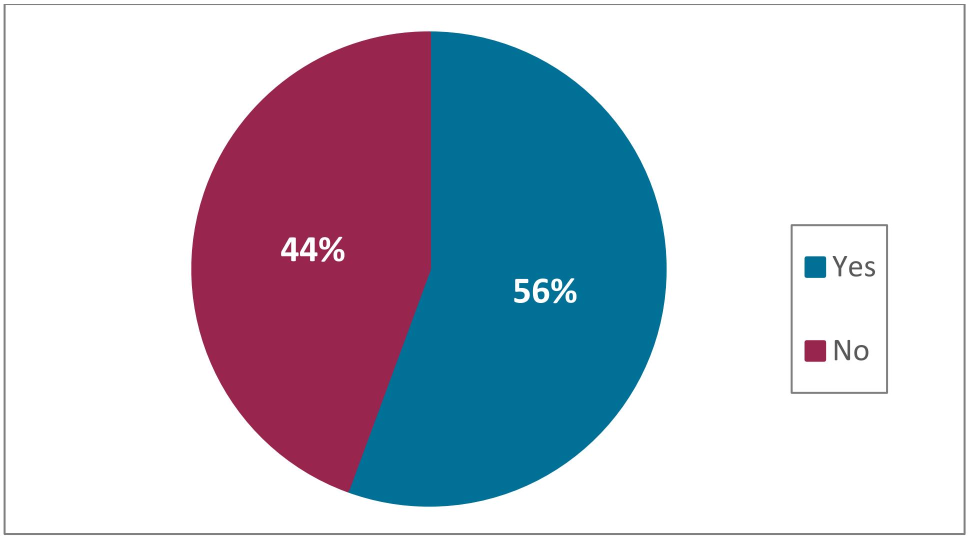
67% of respondents said they were advised or given resources to help cope with the cost of their cancer care, whereas a third (33%) were not.

Bottom Line

Patients are likely to be advised or given resources to help cope with the cost of cancer care but there is still room for improvement.

Resources (cont'd)

Did you work with an oncology social worker, patient navigator or some other case worker who helped you through this time? (n=160)



Type of Resource (n=81)	
Social Worker	48%
Navigator	35%
Case worker/ manager	10%
Financial Coordinator	5%
Hospice or homecare	4%
Named person, type unspecified	2%
Other	7%

Summary

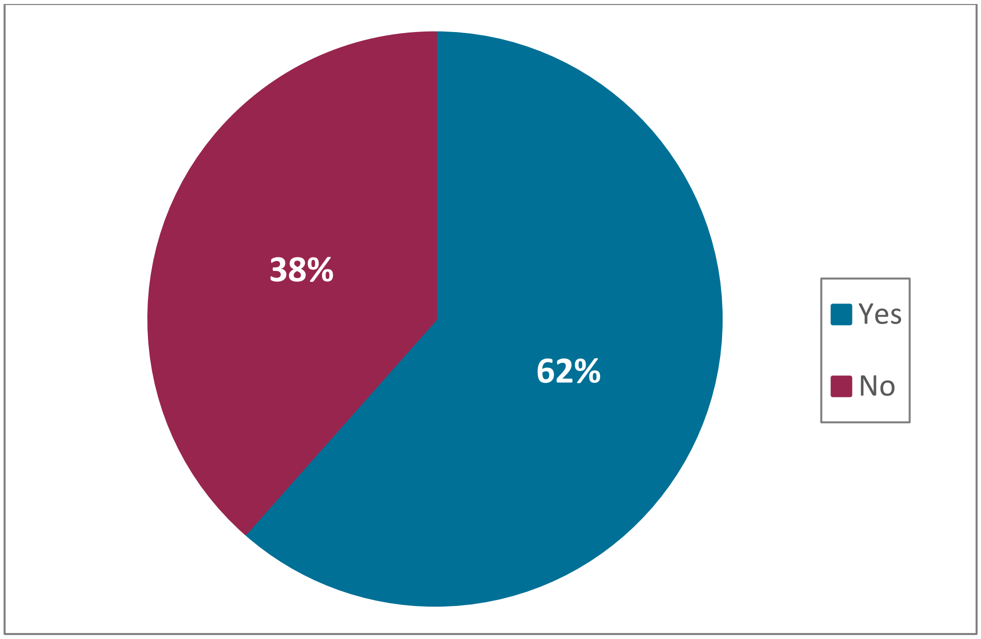
Over half (56%) reported working with an oncology social worker, patient navigator, or some other case worker whereas 44% did not work with these roles.

Bottom Line

Oncology social workers, patient navigators, and case workers are common resources for help during cancer care.

Resources (cont'd)

Did this social worker, patient navigator, or case worker ask about your financial situation or ability to pay for ongoing care? (n=78)



Summary

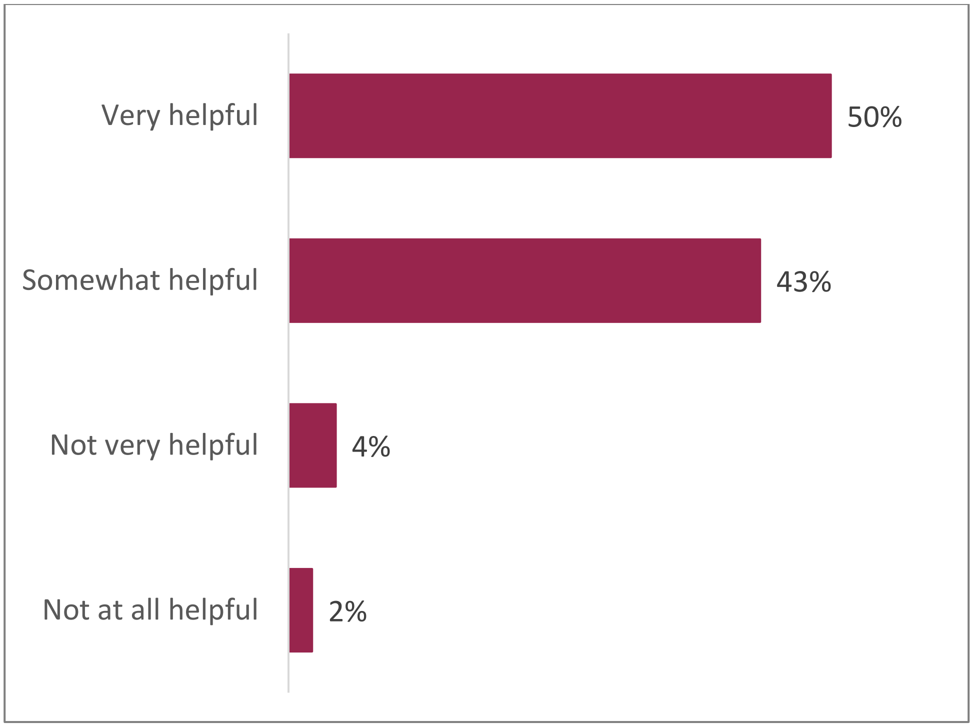
62% of those using social workers, patient navigators, or case workers said they asked the patient about their financial situation or ability to pay for ongoing care.

Bottom Line

Many resource roles ask their patients about their financial ability to afford cancer care, though there are still some patients who did not get this consultation.

Resources (cont'd)

How helpful was this social worker, patient navigator, or case worker in their ability to assess your financial burden and advise you on the cost and payment of care? (n=46)



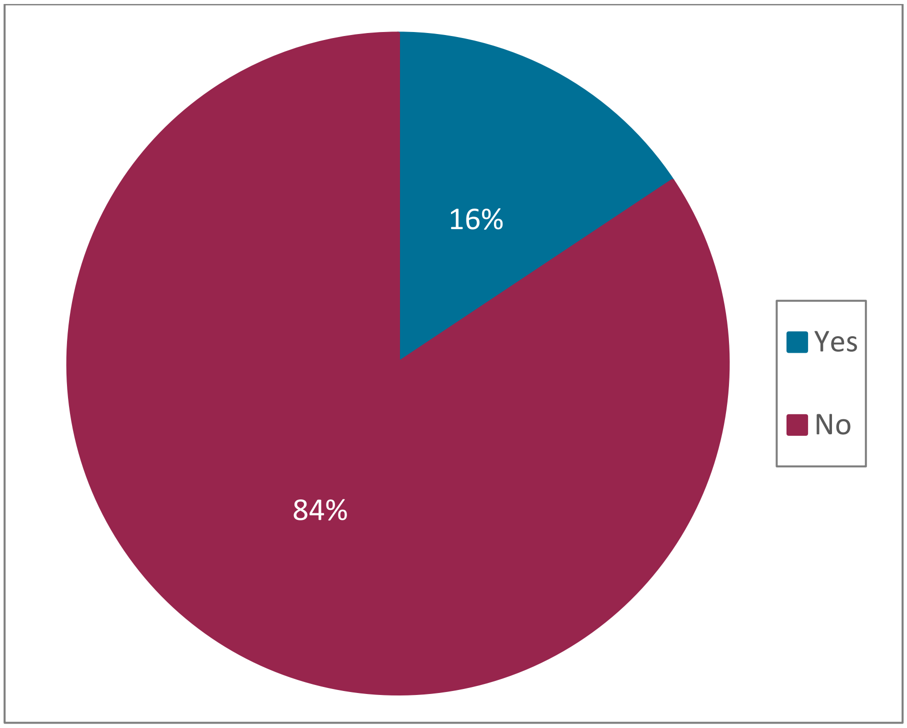
Summary

For those that used a social worker, patient navigator or case worker, they reported the resource being helpful (93%) in their ability to assess financial burden and advise.

Bottom Line

Social workers, patient navigators, or other case workers provide valuable financial assistance and advice to patients.

Did you work with any community-based organizations in Maine to help connect you with financial resources and assistance? (n=166)



Summary

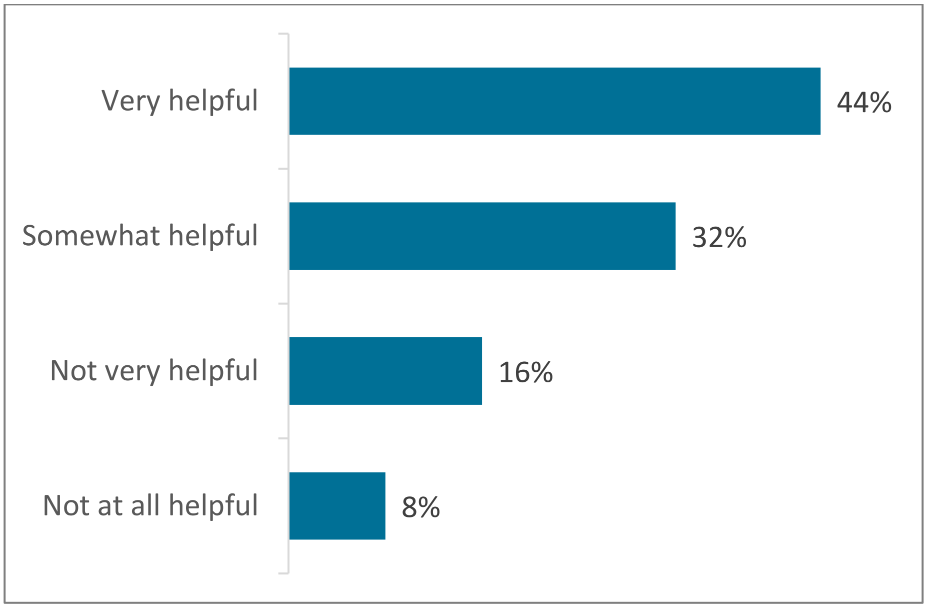
Most respondents (84%) said they did not work with any community-based organizations in Maine for financial resources and assistance.

Bottom Line

There is an opportunity and need for more community-based organizations in Maine to connect cancer patients with financial resources.

Resources (cont'd)

How helpful was this community-based organization in their ability to connect you with financial resources and assistance? (n=25)



Summary

Patients or caregivers that used community-based organizations found them helpful (76%) in their ability to connect them to financial resources and assistance.

Bottom Line

Patients found that using community-based organizations for financial resources or assistance is helpful.

Resources (cont'd)

Are there any additional financial resources or information that you accessed that were helpful? (n=113)

Additional Financial Resources	%
Family member paid or helped	5%
Medicare/ Medicaid	5%
Disability	5%
Community assistance	5%
Website, online fundraising	4%
Insurance company	4%
American Cancer Society	4%
Fundraising	3%
Dempsey Center	3%
Leukemia and Lymphoma Society	3%
Angel Flight	1%
Other	13%
No/ None	51%

Summary

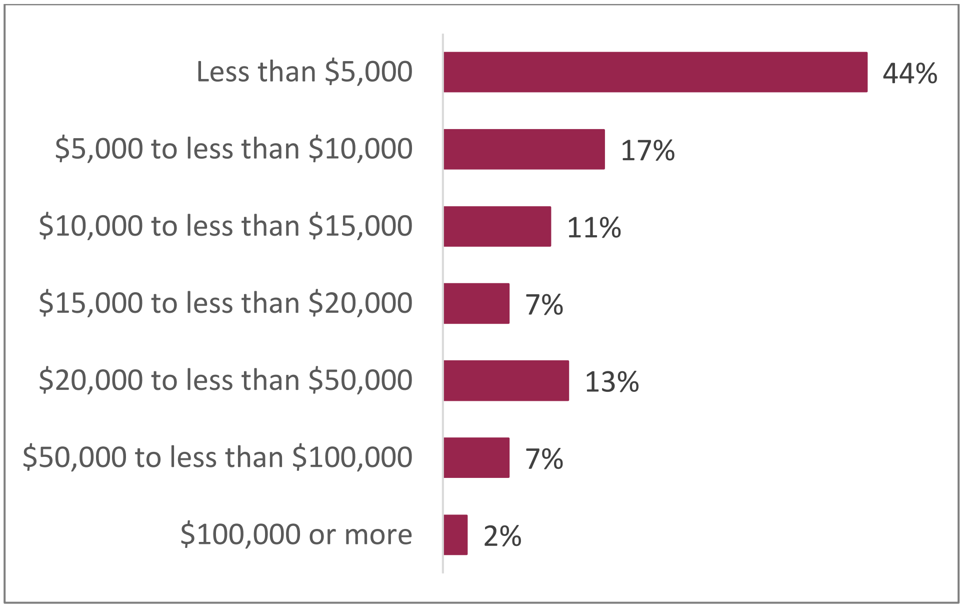
About half (51%) of respondents did not use or find any additional financial resources that were helpful.

Bottom Line

Patients or caregivers had trouble finding additional financial resources.

Out-of-Pocket Cost

How much have you spent out-of-pocket for medical treatment for cancer? (n=163)



Summary

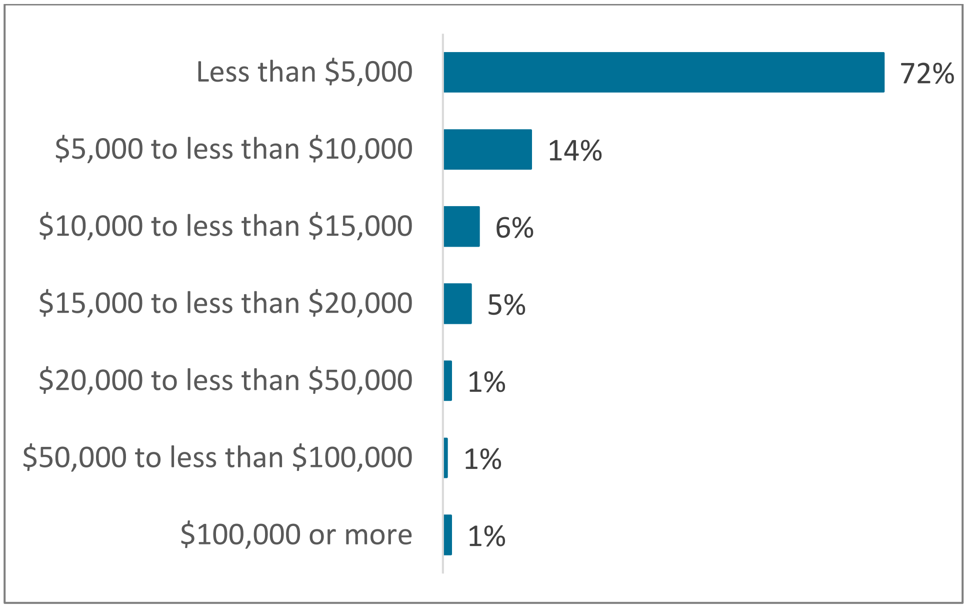
44% reported that they spent less than $5,000 for out-of-pocket medical treatment for cancer. 17% of respondents spent between $5,000 and $10,000, and 11% spent closer from $15,000 to $20,000.

Bottom Line

Approximately one-quarter of patients spent more than $20,000 out of pocket on cancer treatment.

Out-of-Pocket Cost (cont'd)

How much have you spent on care and services that are not for treating your cancer but necessary because of your cancer? Examples include products such as wigs; wellness therapies such as massage therapy, acupuncture or reiki. (n=153)



Summary

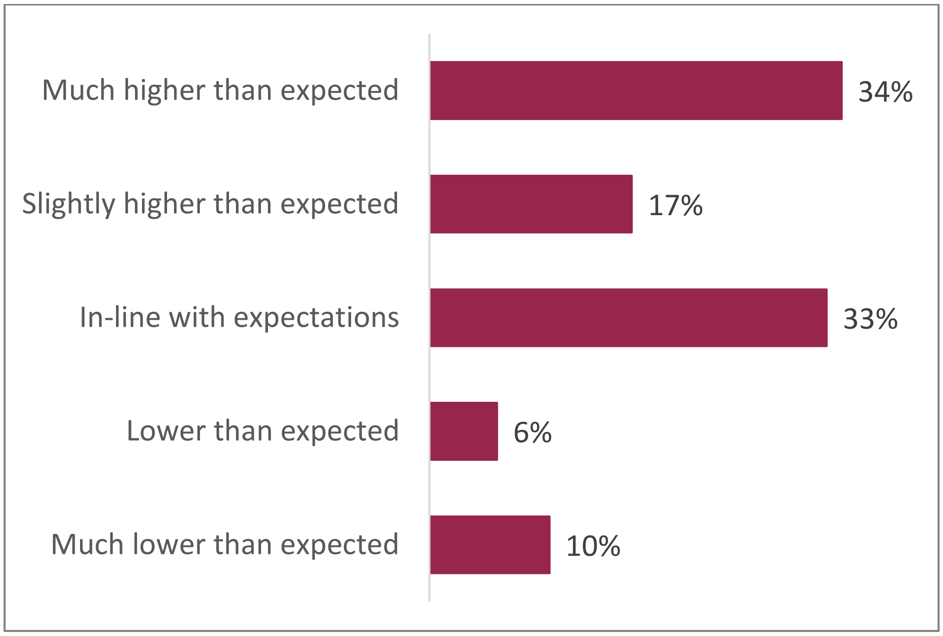
The majority of respondents (72%) spent less than $5,000 on care and services that were not for cancer treatment but was necessary for their care.

Bottom Line

One quarter of Mainers diagnosed with cancer spent $5,000 or more on care unrelated to treatment.

Out-of-Pocket Cost (cont'd)

Are/were your out-of-pocket health care costs higher than expected? (n=160)



Summary

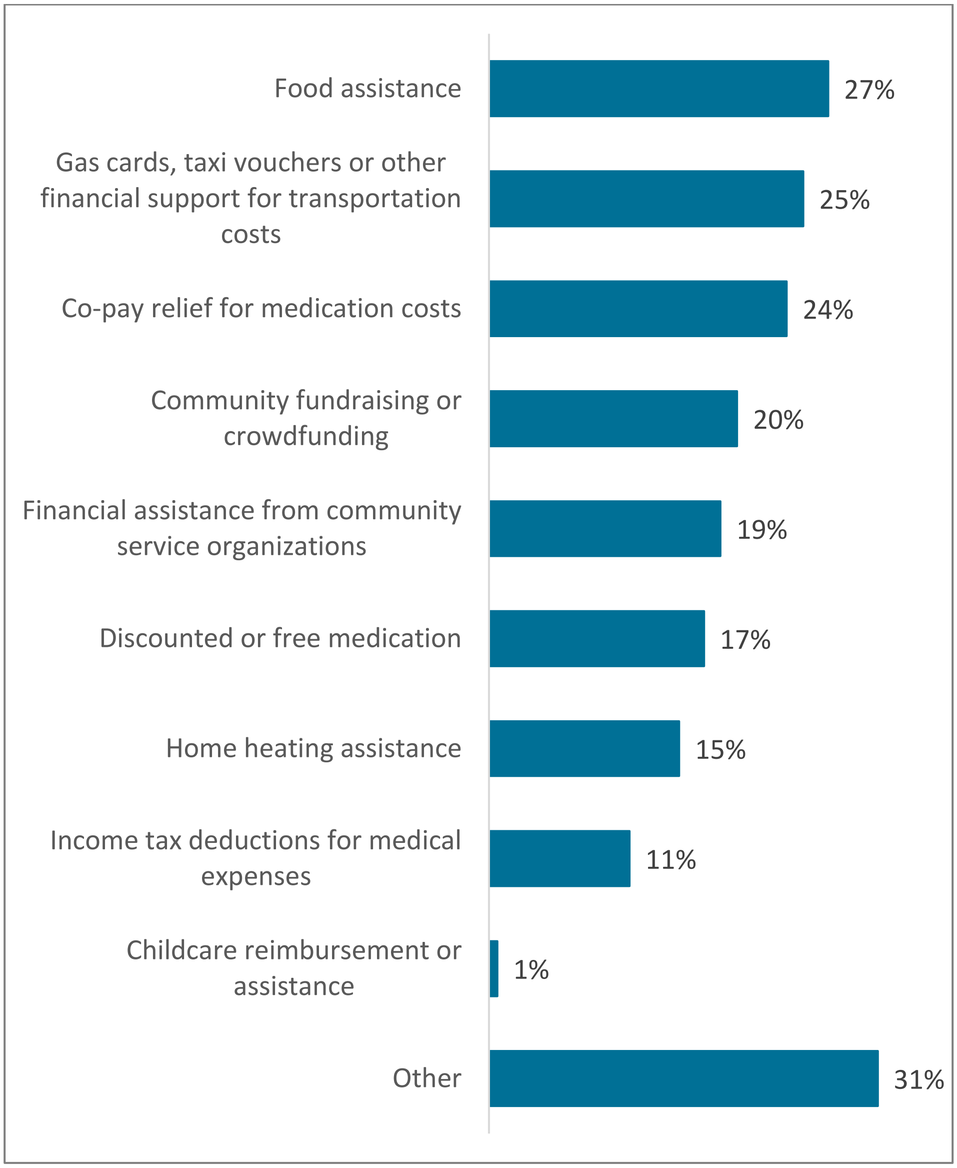
34% of respondents thought their out-of-pocket health care was much higher than expected, 17% reported slightly higher than expected, and 33% reported out-of-pocket health care expenses were in-line with expectations.

Bottom Line

Out-of-pocket health care costs related to cancer care are often higher than expected.

Financial Assistance

Did you receive any of the following types of financial assistance during your treatment? (n=150)



**Multiple responses accepted*

More than half (56%) of those under the age of 45 turned to crowdfunding to help finance their care.

Summary

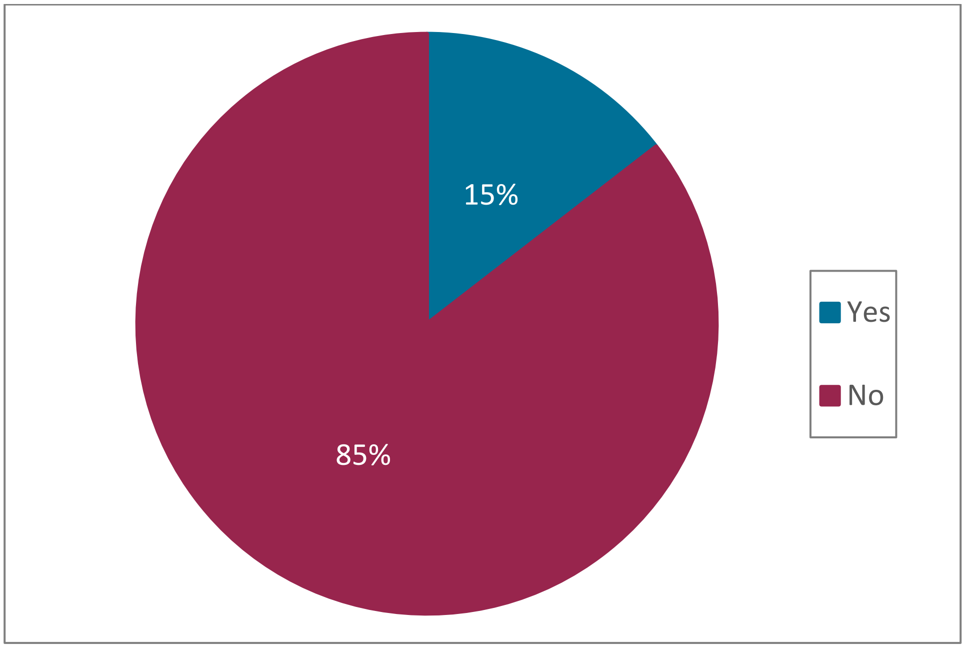
More than a quarter (27%) of respondents received food assistance, another quarter (25%) reported gas cards, taxi vouchers or other financial support for financial costs, and 24% received co-pay relief for medication costs.

Bottom Line

Food, transportation, and co-pay relief are common financial resources during patients' treatment, however few received childcare reimbursement or assistance.

Financial Hardship

Have you experienced any delays in getting cancer care due to cost or because you could not afford it? (n=179)



54% of uninsured patients experienced delays in care.

Summary

85% of patients did not experience a delay of cancer care due to financial reasons, whereas 15% reported delays.

Bottom Line

One out of seven Maine cancer patients experienced a delay in their care due to financial issues.

Financial Hardship (cont'd)

Have you ever done any of the following to cope with the cost of cancer care expenses…? (n=184)

	% Yes	
Major Coping Mechanisms	**Overall**	**Lost job, retired or unable to work***
Postponed or canceled other (non-cancer) health care services or treatments	40%	63%
Delayed or spread-out follow-up appointments	27%	44%
Delayed or spread-out treatment	23%	40%
Took less than prescribed amount of medication	19%	38%
Did not have recommended test	18%	28%
Replaced prescriptions with over-the-counter medications	18%	26%
Did not fill a prescription	17%	39%
Did not have recommended procedure	13%	23%
Used someone else's prescription	4%	14%

**Respondents who said they lost their job, retired or were disabled as a result of their cancer or cancer treatment; Multiple responses accepted*

Summary

40% of respondents had to postpone or cancel non-cancer health care services and treatments.
27% had to delay or spread-out appointments, and 23% reported having to delay or spread-out treatment.

Bottom Line

To offset the cost of cancer care expenses, many postponed or canceled non-cancer services or treatments. Another common way that Maine cancer patients offset costs was to delay or spread-out follow-up appointments or treatment.

Financial Hardship (cont'd)

Please share any additional financial hardships that you experienced as a result of your cancer diagnosis. (n=114)

Additional Financial Hardships	
Loss of employment, wages or insurance	16%
Cost of medical expenses/supplies out of pocket	15%
Debt/Increased debt	11%
Insurance costs, deductibles, co-pays, premiums	9%
Loss of business or home	6%
Inability to pay for car or transportation issue	6%
Cost of food	4%
Disability/Inability to work	3%
Other	7%
None/I didn't experience any additional financial hardships	35%

Summary

35% of patients and caregivers said they did not experience additional financial hardships related to their diagnosis. Slightly common additional hardships were loss of employment, wages, or insurance (16%), costs of medical expenses or increased debt (11%).

Bottom Line

A cancer diagnosis can cause many additional financial hardships beyond the cost of treatment.

Please share any additional financial hardships that you experienced as a result of your cancer diagnosis. (n=114)

What they are saying:

“Abandoned a business plan and switched to a lower paying more flexible career.”

“College Loan”

“Delays to car & home repairs due to finances. Having to reshuffle tuition payments.”

“Foreclosed on the house”

“I had a terrible time getting my work disability to pay me on time and made the rest of trying to pay bills horrific.”

“I just did not buy things. Cancelled subscriptions.”

“I'm living in poverty because of cancer. It took my savings and a big portion of my income”

“I've been very blessed throughout my journey as I have been pointed in the right direction for insurance, fuel assistance, etc. I am getting disability and have an EBT card -- if not for these, it would be a very different situation for me.”

“Lack of upward mobility in my workplace”

“Main issue is transportation related. I drive myself even when I really shouldn't, and rural area means driving 700+ miles for 5 days chemo monthly.”

“My family missed out on things/experiences, no vacations, no eating out, no going out, no new clothes, decreased groceries, less meat, cheaper food items, limited back to school supplies/clothes. Kept household heat lower.”

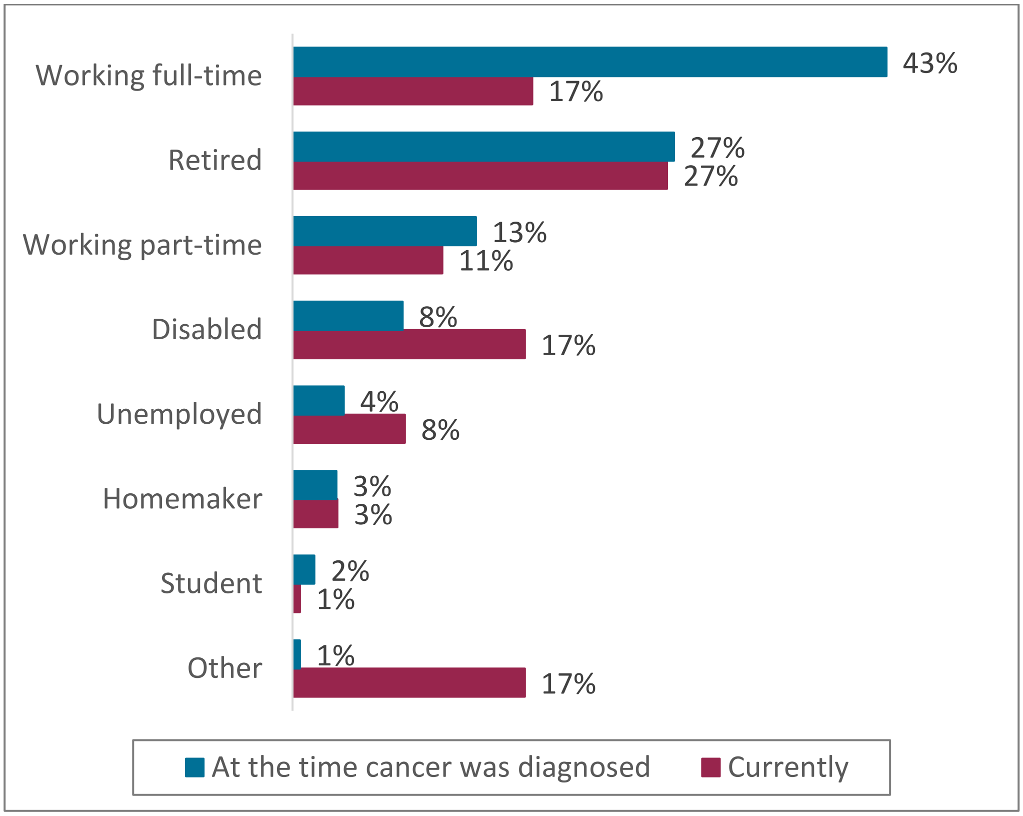
“Sued by credit card companies”

Summary

There are many additional hardships that patients and caregivers face during cancer care.

Employment

What was/is your employment status? (n=190)



Summary

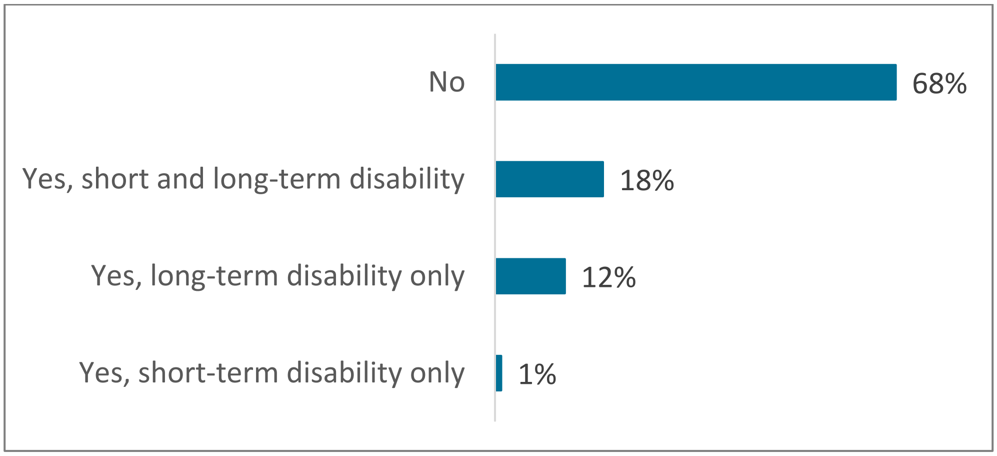
43% reported working full time at the time of their cancer diagnosis, compared to 17% who reported working full time at the time of the survey. Those on disability increased from 8% at diagnosis to 17% and unemployment increased from 4% to 8%.

Bottom Line

In addition to health care costs, a cancer diagnosis impacts employment and, as a result, long-term financial wellbeing.

Employment (cont'd)

Did you apply for disability benefits because you were unable to work as a result of cancer? (n=92)



Applied for Disability Benefits	**Overall**	**Lost job, retired or unable to work***
No	68%	30%
Yes, short and long-term disability	18%	41%
Yes, long-term disability only	12%	27%
Yes, short term disability only	1%	3%

**Respondents who said they lost their job, retired or were disabled as a result of their cancer or cancer treatment*

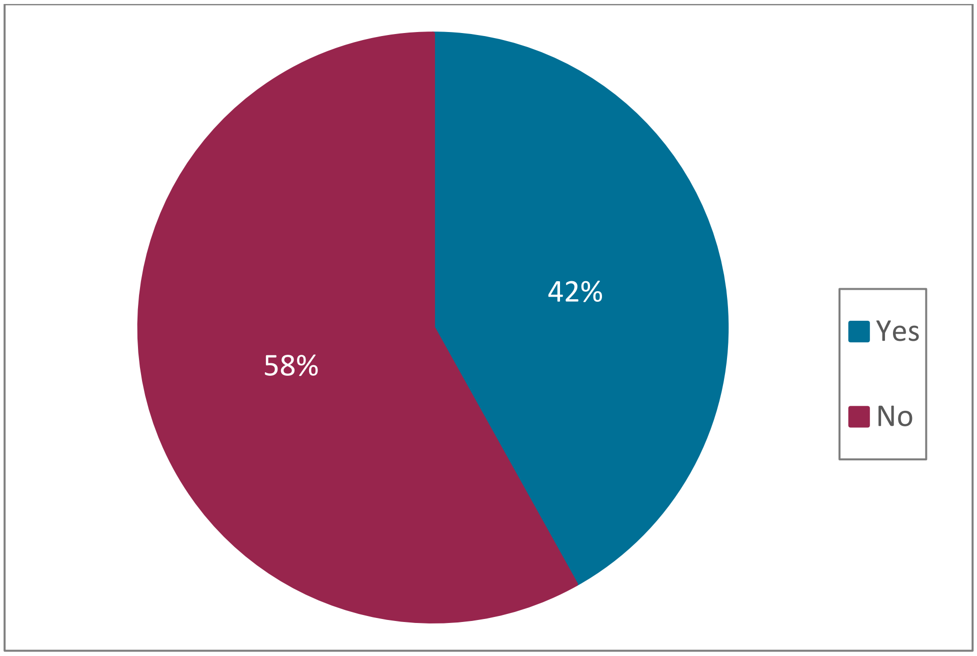
Summary

68% of patients did not apply for disability benefits due to inability to work while less than a quarter (18%) applied for both short and long-term disability.

Bottom Line

Patients may not know enough about disability benefits available to them.

Did you have a paid sick leave policy at your job at the time of your cancer diagnosis? (n=105)

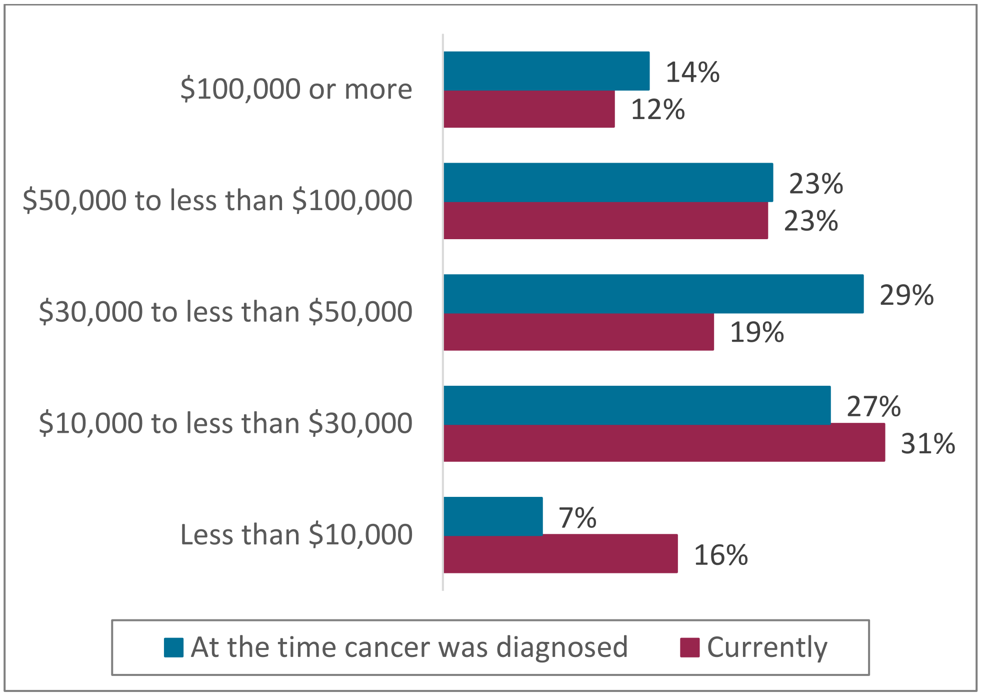


Summary

42% report having a paid sick leave policy at their job at the time of their cancer diagnosis where 58% did not have a paid sick leave policy.

Income

Which category best describes your annual household income, before taxes? (n=175)



Summary

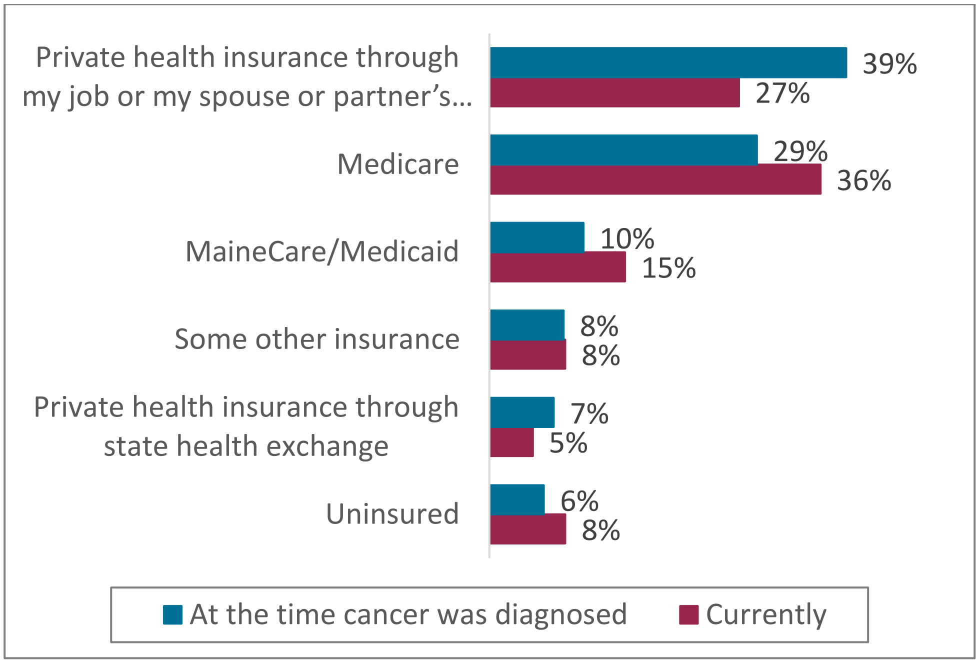
Close to one third (29%) of respondents said their annual household income was $30,000-$50,000 at the time of cancer diagnosis. This declined to 19% at the time of the survey.

Bottom Line

Annual household income was higher at time of cancer diagnosis than at the time of the survey. Significantly more Mainers diagnosed with cancer had incomes of less than $10,000 after being diagnosed.

Health Insurance

What type of health insurance did/do you have? (n=184)



Summary

At the time of cancer diagnosis, many had health insurance through a job (39%) or through Medicare (29%).

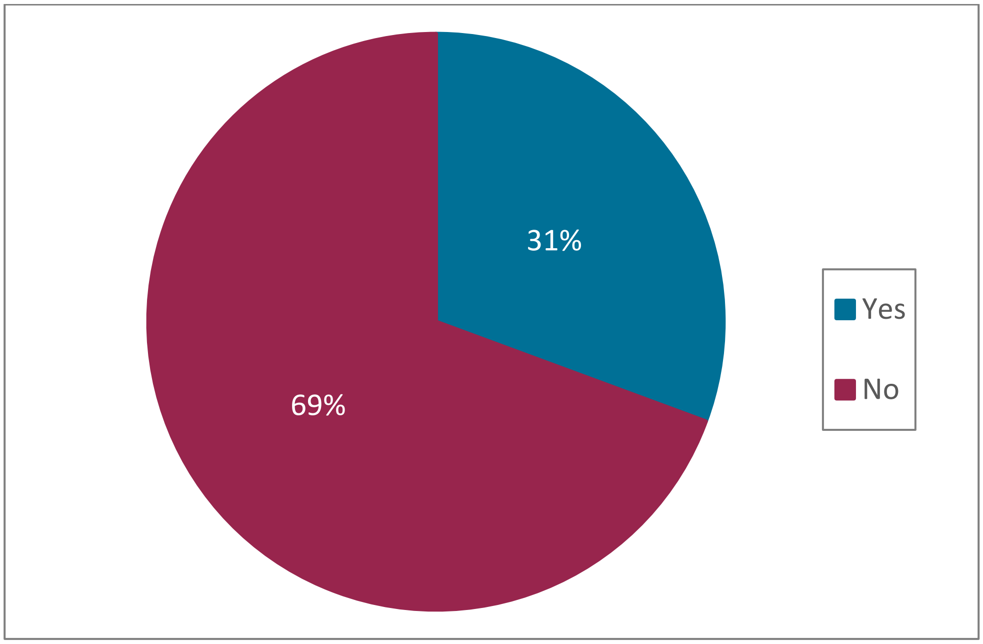
At the time of the survey, 27% of patients had private health insurance through a job, 38% had Medicare, and 15% had MaineCare or Medicaid.

Bottom Line

Among with employment concerns, a cancer diagnosis also leads to a decline in private health insurance coverage and an increase in state or federally sponsored health insurance.

Household Composition

Did you have any dependent children living with you at the time of your diagnosis? (n=160)

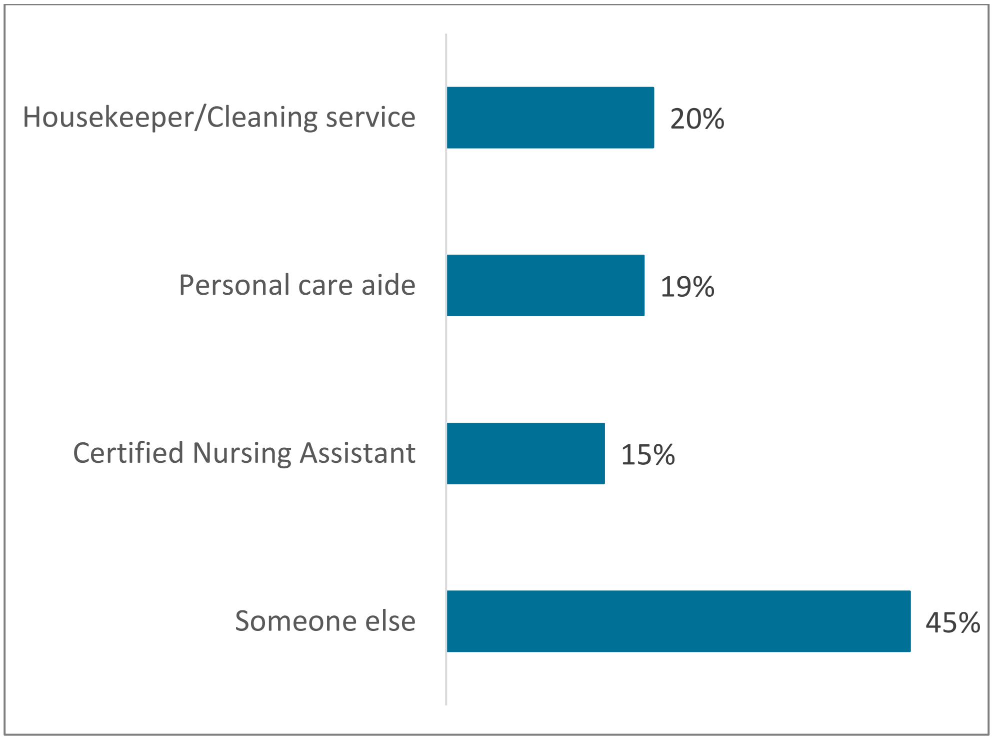


Summary

Three quarters (69%) of patients had no dependent children living with them at time of diagnosis whereas a third (31%) of patients reported having dependent children living with them at time of diagnosis.

Home Services

Were you required to hire any of the following in home services to assist you while receiving cancer care? (n=104)



Summary

While receiving cancer care, patients reported having to hire housekeepers or a cleaning service (20%), personal care aide (19%), Certified Nursing Assistant (15%), or someone else (45%).

Bottom Line

Home services are a common need among patients with cancer.

Activities

After receiving your cancer diagnosis, did you participate more often or less often in the following…? (n=186)

	Much more often	Somewhat more often	About the same	Somewhat less often	Much less often
Spending time with family	14%	20%	34%	17%	15%
Support groups	7%	19%	41%	3%	30%
Self-care activities that make you feel good	4%	10%	34%	17%	34%
Physical activity or exercise	1%	10%	23%	14%	52%
Spending time with friends	2%	7%	31%	24%	36%
Normal daily activities	1%	2%	33%	27%	37%
Social events	1%	1%	22%	23%	54%

Summary

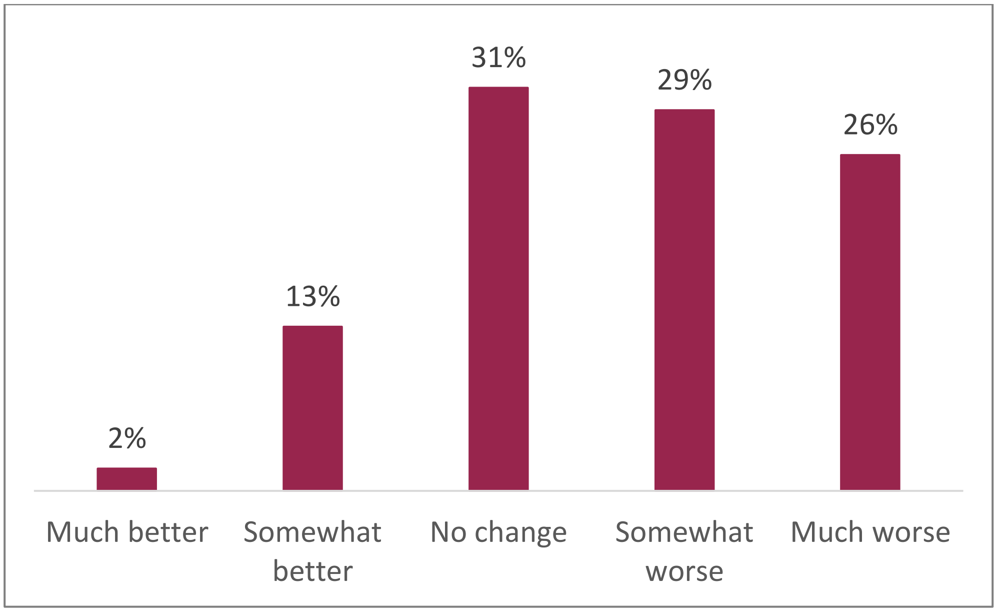
Patients participated much less often in social events (54%), physical activities or exercise (52%), normal daily activities (37%) and spending time with friends (36%) after cancer diagnosis.

Bottom Line

Maine cancer patients are much less likely to participate in physical, social, and even normal daily activities.

Financial Situation

How much has your overall financial situation changed since your cancer diagnosis? (n=169)



Summary

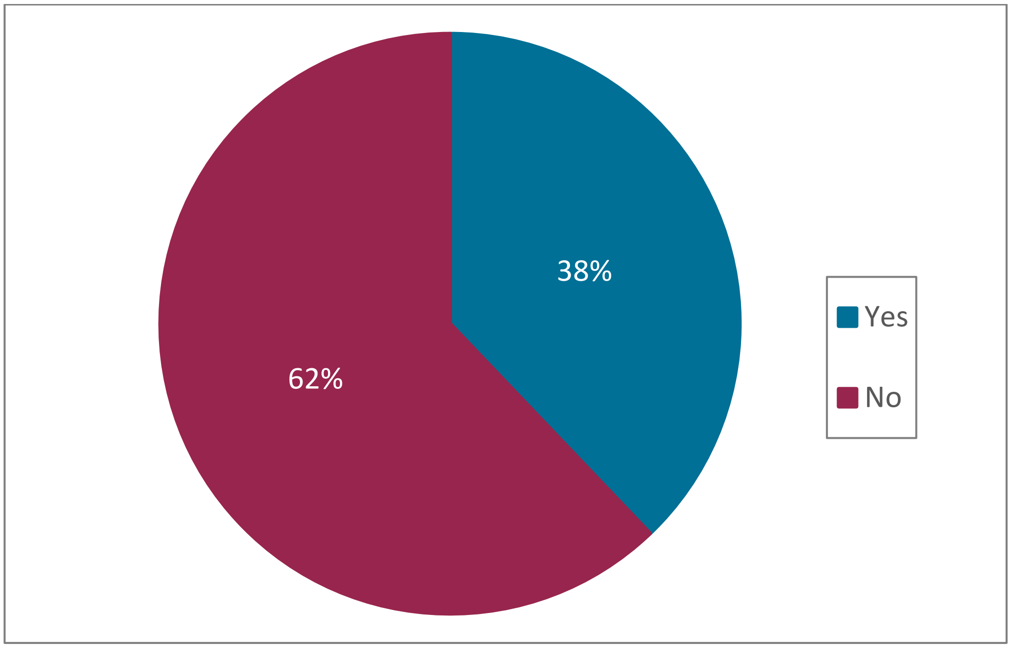
Almost a third of patients since their diagnosis report their overall financial situation had no change, 29% say it was somewhat worse, and 26% was much worse.

Bottom Line

A cancer diagnosis is likely to significantly and negatively impact patients' financial wellbeing.

Debt

Do you currently have medical debt due to your cancer treatment? (n=169)



Patients that are retired are less likely to have incurred medical debt

Summary

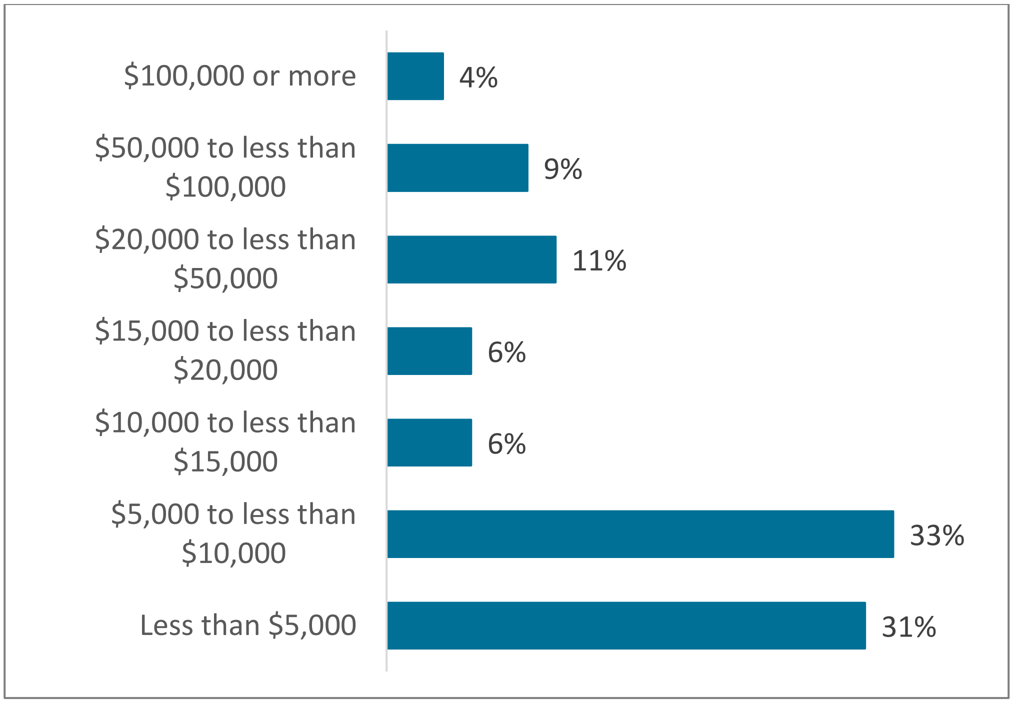
38% report that they currently have medical debt due to cancer treatment whereas 62% do not.

Bottom Line

Close to two in five Maine cancer patients incur medical debt as a result of their care.

Debt (cont'd)

Which category best describes the amount of medical debt you have due to your cancer treatment? (n=54)



Summary

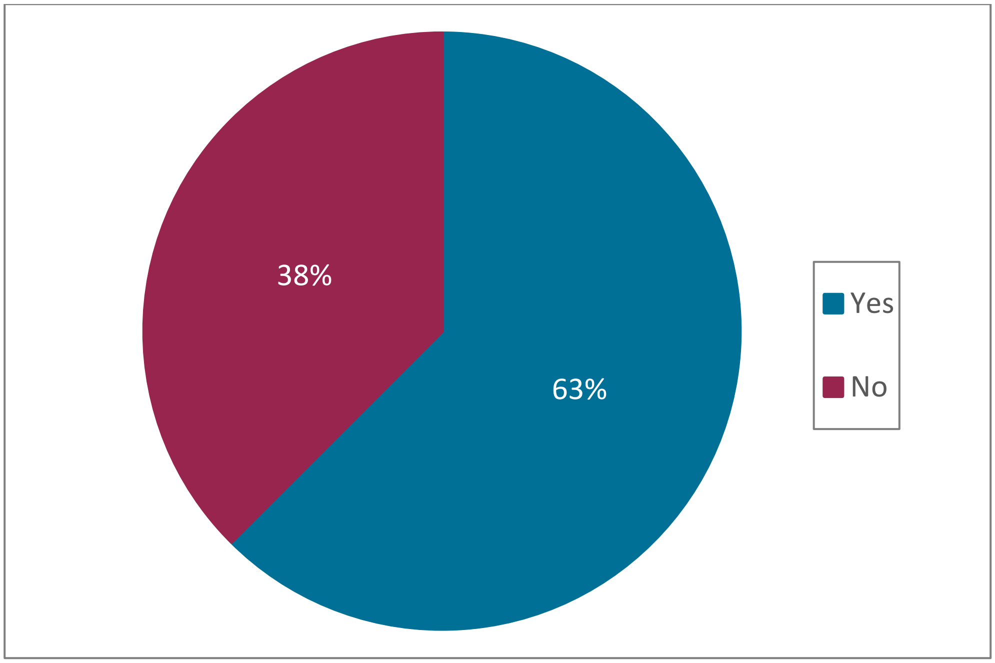
Of those patients reporting medical debt: 33% have $5,000 to less than $10,000 of medical debt due to cancer treatment and 31% have less than $5,000 of medical debt due to cancer treatment.

Bottom Line

One quarter of Mainers diagnosed with cancer have medical debt due to their cancer treatment that exceeds $20,000.

Debt (cont'd)

Are you currently repaying this debt? (n=56)



Summary

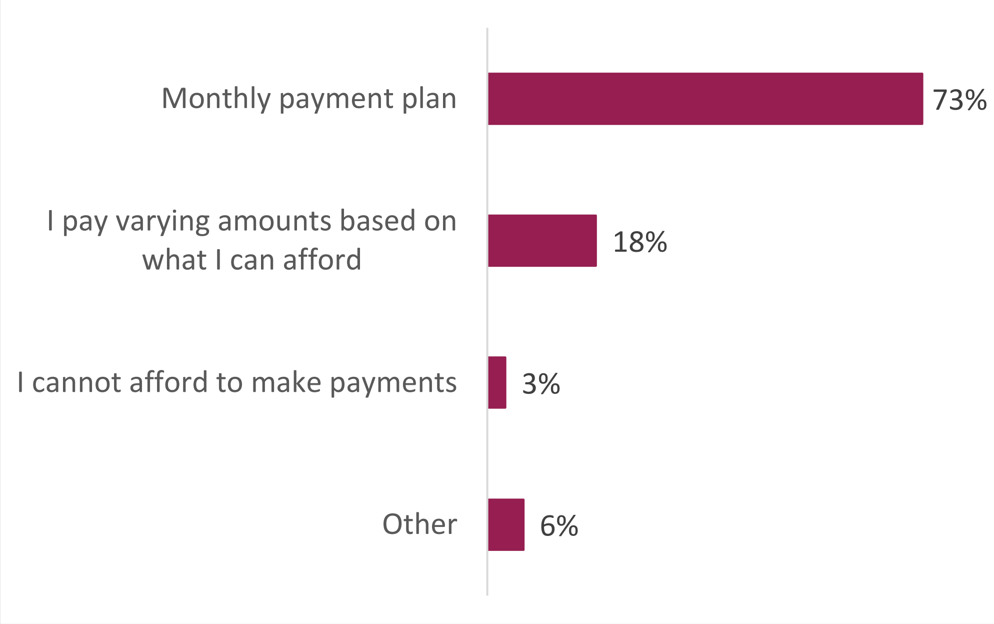
63% of patients are currently repaying this medical debt whereas 38% are not.

Bottom Line

Many patients diagnosed with cancer within the past five years are still paying off their medical debt.

Debt (cont'd)

Which of the following best describes your strategy for paying down the debt? (n=33)



Summary

Three quarters (73%) of patients are signed up for a monthly payment plan for their medical debt.

Bottom Line

Monthly payment plans are common for those who have medical debt related to cancer.

Coping with Cancer Care Expenses

Have you ever done any of the following to cope with the cost of cancer care expenses…? (n=183)

Ways to Cope with Costs of Cancer Care	Overall	Among Uninsured
Reduced spending on leisure activities like vacations, eating out, or movies	72%	85%
Used all or portion of savings	63%	77%
Reduced spending or put off home repairs	60%	77%
Reduced spending on basics like food or clothing	52%	67%
Used credit such as a loan or credit card	40%	54%
Borrowed money from friends or family	35%	62%
Used money from a retirement account	33%	46%
Sold other personal items	31%	58%
Sold or lost your vehicle	13%	39%
Defaulted on a loan	11%	23%
Worked longer hours	9%	23%
Sold your home	7%	23%
Ended paid childcare outside of the home	3%	15%
Declared bankruptcy	3%	7%
Something else	8%	29%

88% of those between 45-54 years old used all or some of their savings and more than half (62%) of this same group has borrowed money from a friend or family member.

Summary

Patients reduced spending on leisure activities (72%), used all or a portion of savings (63%), reduced spending or put off home repairs (60%), reduced spending on basics like food or clothing (52%) and used credit such as a loan or credit card (40%).

Bottom Line

Cancer care expenses impact the daily lives of individuals in many ways – including reduced everyday spending, spending down savings, delaying repairs, and incurring credit card debt.

Underinsured patients are significantly more impacted.

COVID-19

In what ways has COVID-19 affected your experience? (n=84)

Effects of COVID-19 on Experience	%
Isolation/Inability to see family	36%
Limited access to support/ services	33%
Fear of catching COVID	20%
Delayed/canceled appointments	18%
Travel restrictions, or travel challenges	7%
Loss of work, inability to pay bills	4%
Other	5%
None	2%

Summary

Isolation and the inability to see family (36%) and limited access to support/ services (33%) had the biggest affects to the patients' experience due to COVID-19.

Bottom Line

COVID-19 has increased isolation, limited access to needed services and support and has increased fear and anxiety.

In what ways has COVID-19 affected your experience? (n=84)

What they are saying:

"Access to services."

"Anxiety and fear."

"Because of the tightened restrictions in the hospital the patient hasn't been able to have visitors while inpatient"

"Being sent home with pill form chemotherapy and no real follow up."

"Cancelled appointments and treatments due to risk, has made travel difficult/impossible, no physical therapy and counseling due to my suppressed immune system from treatment, cancelled tests/procedures due to risk and hospital cancellations."

"Delayed appointments and procedures."

"Delayed follow up appointments, tele-health appointments instead of face-to-face appointments."

"Further isolation. Unable to visit father who died in hospital of COVID-19."

"Going to treatments alone."

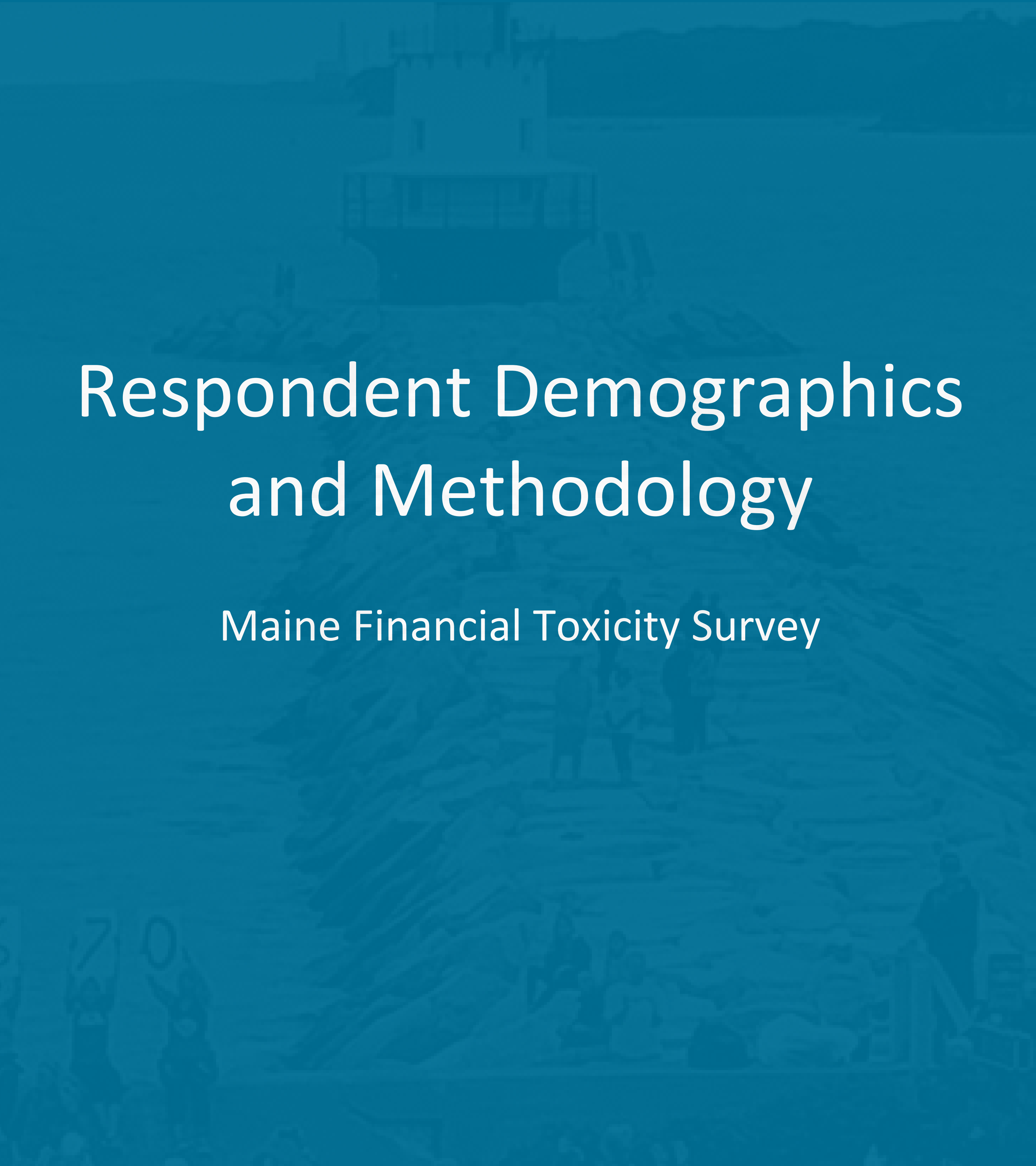
"I was not able to travel to see my dear friends who helped me during treatment after my treatment was completed and I was feeling stronger. I am stuck at home alone away from the activities that bring me happiness and my friends that support me emotionally."

"Less emotional support, less follow up oncology/medical/dental care."

"She can only see so many people while hospitalized and she is scared for her life."

Summary

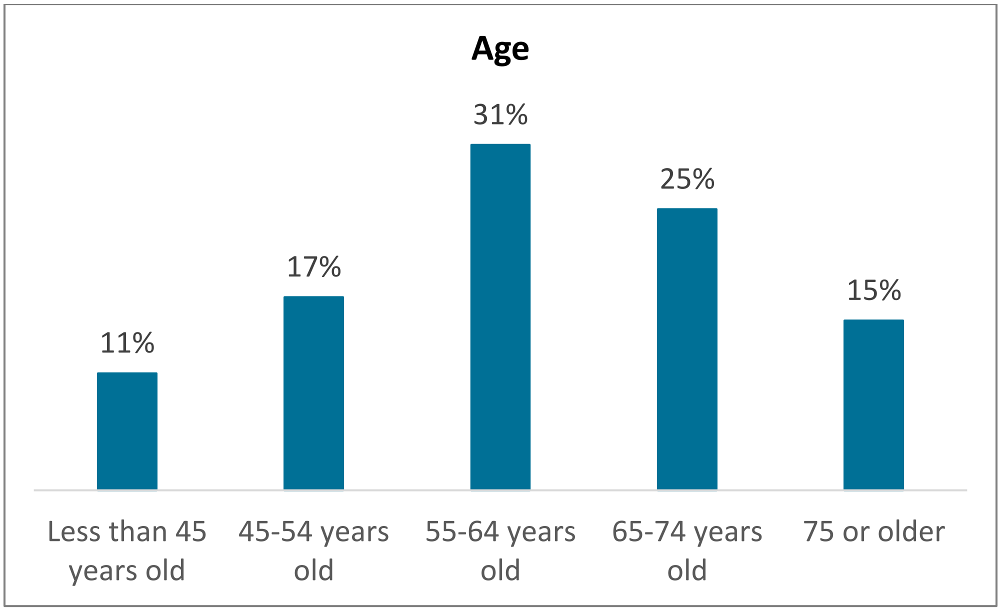
Covid-19 is significantly affecting patients and caregivers in many ways.

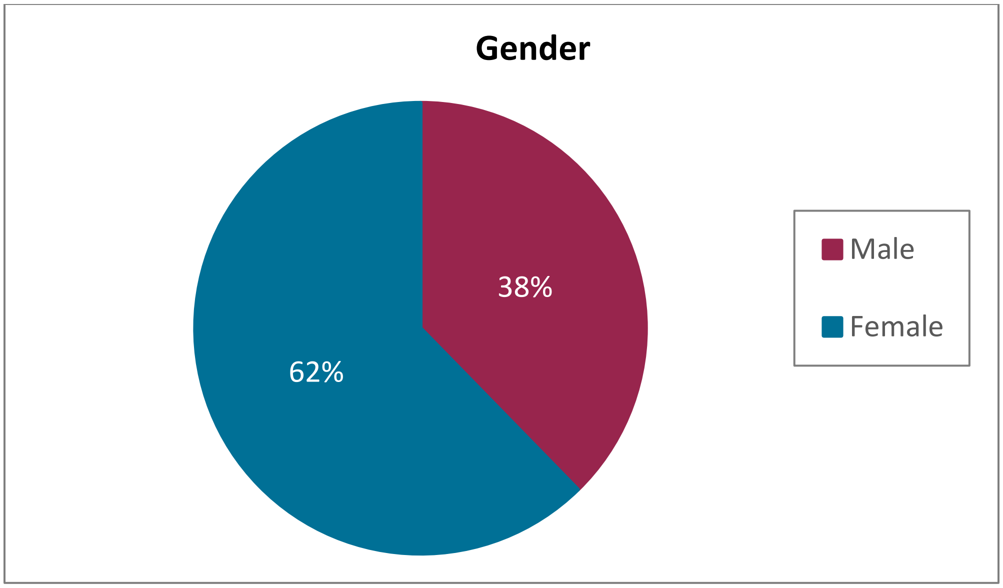


Respondent Demographics and Methodology

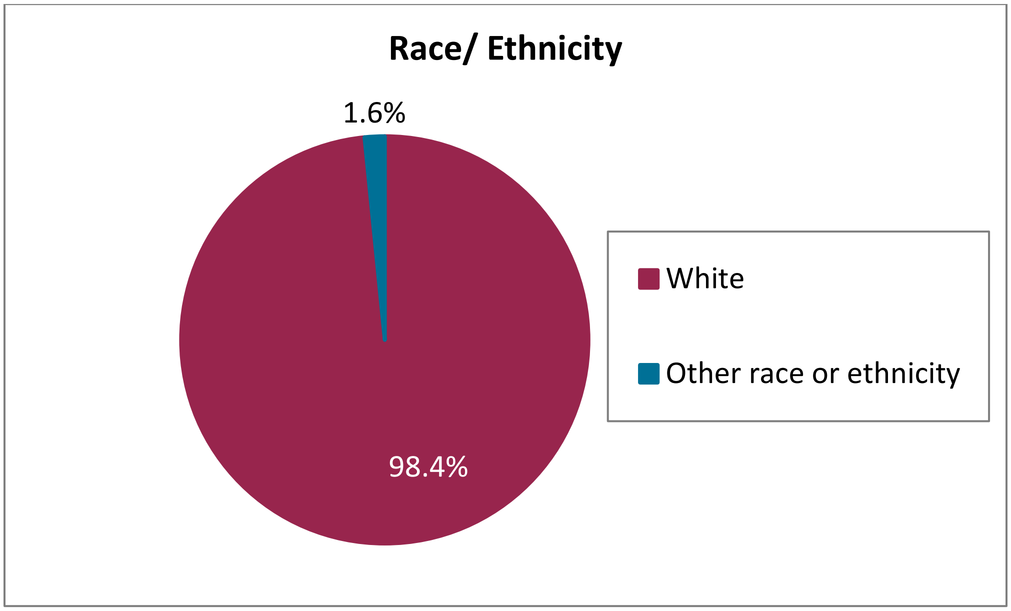
Maine Financial Toxicity Survey

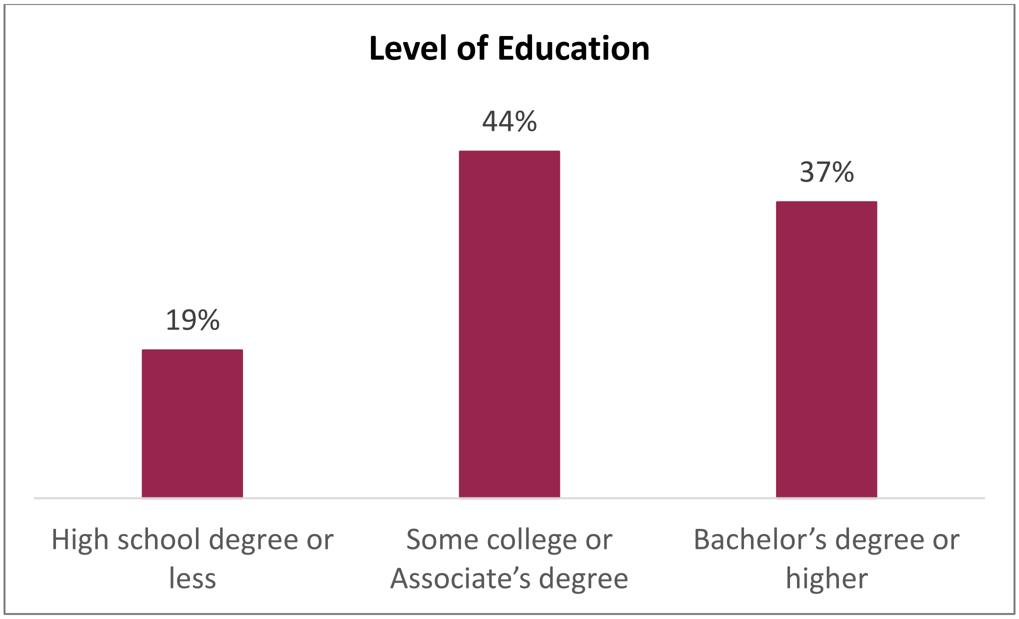
Demographics of Patients



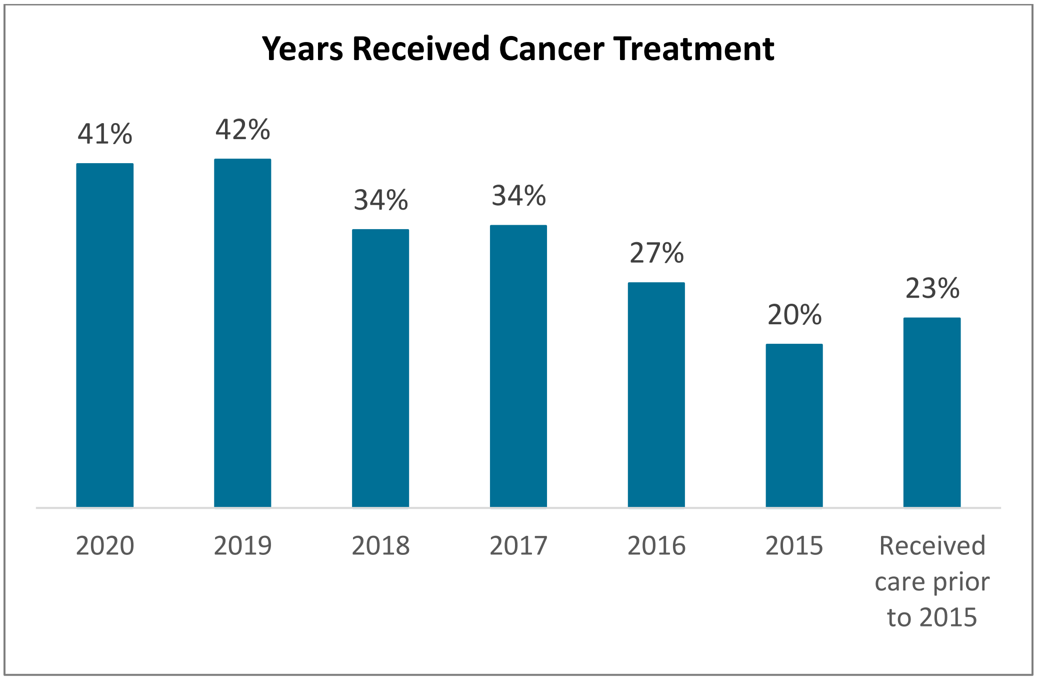


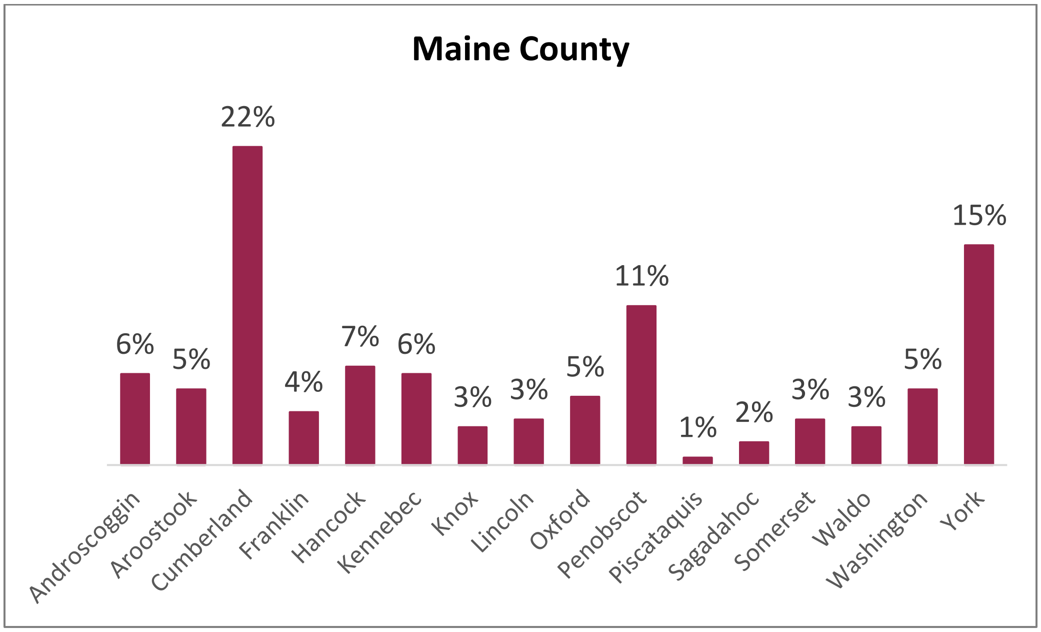
Demographics of Patients



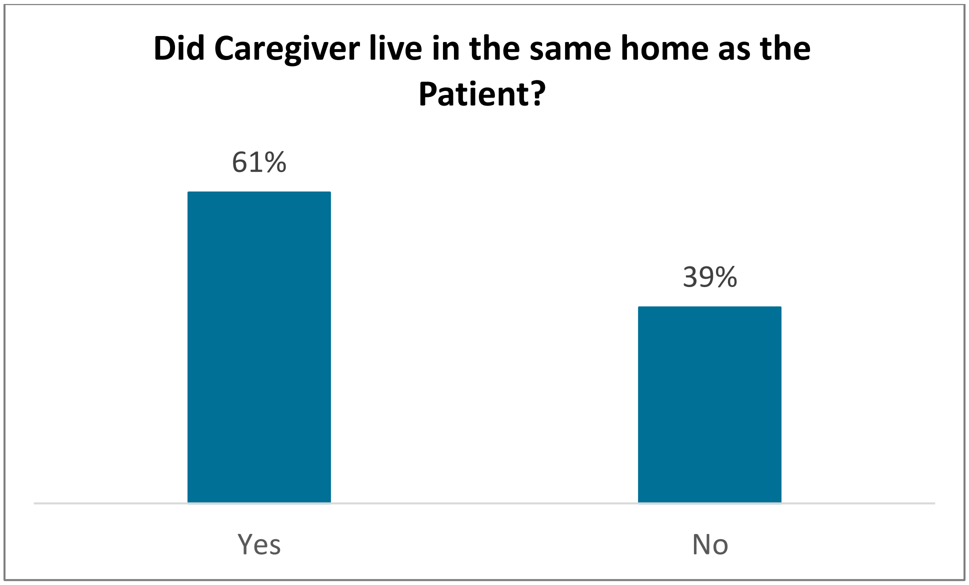


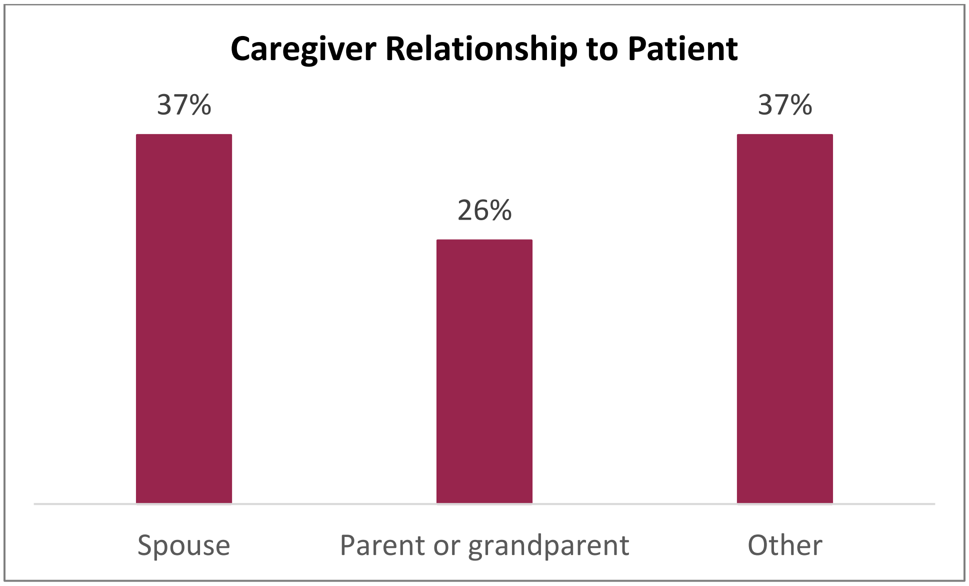
Demographics of Patients





Demographics of Caregivers





Survey Methdology

Background

Maine Cancer Foundation (MCF) was interested in understanding more about the concept of financial toxicity in Maine as it relates to a cancer diagnosis, treatment, and recovery.
Research has shown that the cost of treatment impacts the care decisions of cancer patients. The purpose of this research was to help MCF understand the nature of financial toxicity in Maine, the impact of cancer on the finances and decisions of patients and caregivers, and the options to help address this issue in the state.

Sample

The primary target population for this study were individuals aged 18 or older living in Maine who had a cancer diagnosis within the past 5 years. Caregivers were also allowed to participate on behalf of recent cancer patients. Given the narrow eligibility criteria and low incidence of this group in the overall population, respondents were recruited on social media and through an online panel called Samplify®.

Survey Instrument

The questionnaire for this research was designed by Market Decisions Research in collaboration with MCF and took 15 minutes to be completed on average.

Data Collection

Data collection took place between November 8, 2020 to January 4, 2021. All surveys were conducted by MDR using our VoxCo Online Survey software. To encourage participation in the survey and to thank participants for their time, a $10 cash incentive or gift card was provided to those who completed the survey. **191 Mainers participated in the online survey**. It is not possible to calculate a response rate for the survey given the sampling and data collection protocols that were used.

Limitations

While Market Decisions Research took extensive precautions to ensure that the findings presented in this report are statistically sound and accurate, it is important to keep in mind that the survey is based on nonprobability convenience samples and respondents may not be representative of the overall population.

In addition, due to the nature of the group of interest, sample size for some sub-groups may be low for some questions. Hence, it is important to use caution when interpreting results as they may be solely the opinions of those who participated in the surveys.