CANCER CARE

EXPERIENCES AMONG PEOPLE COVERED BY MEDICARE

FINDINGS FROM THE ONCOLOGY CARE MODEL EVALUATION

DIAGNOSIS

ONCOLOGIST SELECTION

TREATMENT GOALS

TREATMENT PLANNING AND DECISIONS

COMMUNICATION

SUPPORTIVE CARE

GETTING HELP

LIVING WITH CANCER

ABOUT THIS REPORT

The information in this report derives from interviews and surveys of cancer patients who have Medicare insurance coverage. This report was produced by Abt Global, under contract to the Centers for Medicare & Medicaid Services, as part of the Evaluation of the Oncology Care Model.

Contract #HHSM-500-2014-000261 T0003.

The statements contained in this report do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. Abt Global assumes responsibility for the accuracy and completeness of the information contained in this report.

ACKNOWLEDGEMENTS

We would like to thank the people who generously shared their experiences and insights with the Oncology Care Model evaluation team during the interviews featured in this report. Their candor about personal and sensitive health topics made this report possible.

We are grateful to our colleagues whose work and guidance contributed to this report: Clarke Baer, Gabrielle Bonny, Gabriel Brooks, Lauren Davis, Andrew Evans, Diane Ferguson, Jessie Gerteis, Catherine Hersey, Nancy Keating, Morgan Michaels, Charlotte Speyer Stocks, Matthew Trombley, and Nathan West.

We would like to thank Jessica McNeely at the Centers for Medicare & Medicaid Services who conceived the idea for this report, and whose vision and close collaboration brought it to fruition.

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SPOTLIGHT ON

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INTRODUCTION

Medicare partnered with hundreds of health care practices that serve cancer patients across the nation on a new approach to oncology care.

This new approach was called the “Oncology Care Model.”

The Center for Medicare & Medicaid Innovation, also known as the CMS Innovation Center, is developing new payment and delivery models. Congress established the CMS Innovation Center in 2010 to identify ways to improve healthcare quality and reduce costs in the Medicare, Medicaid, and Children’s Health Insurance Program (CHIP) programs. The CMS Innovation Center — through its models, initiatives, and congressionally mandated demonstrations — has accelerated the **shift from a health care system that pays for volume to one that pays for value.**

Cancer diagnoses comprise some of the most common and devastating diseases in the United States: more than 1.9 million people are diagnosed with cancer each year. Cancer is the second leading cause of death in the United States, resulting in approximately 600,000 deaths per year.[2]

The costs of cancer treatment have grown rapidly in recent years. A 2011 study projected that spending for cancer care in the United States could increase by 39 percent from 2010 to 2020, from $124 billion to $173 billion.[3] Meanwhile, a 2013 report from the Institute of Medicine estimated that up to 30 percent of health care spending was potentially unnecessary.[4]

Through the Oncology Care Model, the CMS Innovation Center had the opportunity to achieve three goals: **better care, smarter spending, and healthier people.**

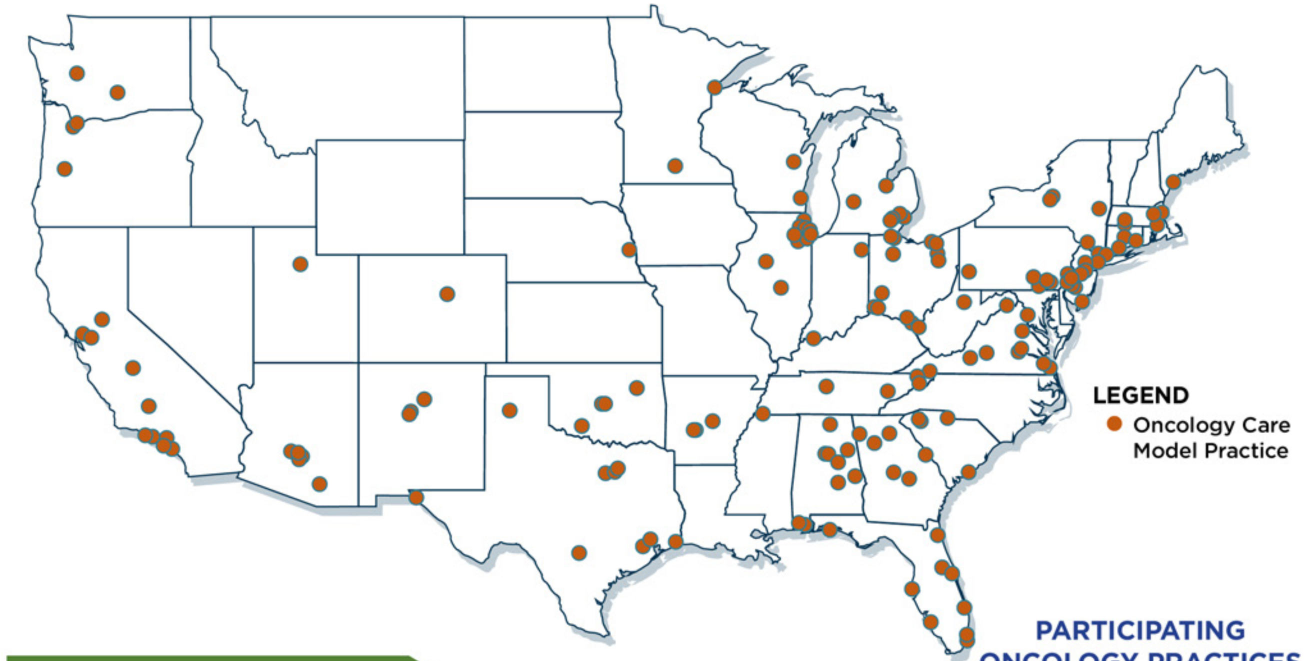
The CMS Innovation Center designed the Oncology Care Model for patients with Medicare who were undergoing chemotherapy treatment, with the goal of improving patients’ experiences with cancer care while controlling health care costs. The Oncology Care Model test ran from July 2016 through July 2022.

Over 4,500 medical oncologists across 202 physician oncology practices voluntarily participated in the Oncology Care Model. During the six years of the model test, participating oncology practices provided care to over 600,000 patients with Medicare, representing approximately 1 in 4 Medicare fee-for-service patients who received chemotherapy over that period of time.

ONCOLOGY CARE MODEL HAD BROAD PARTICIPATION AND REACH

4,500+ ONCOLOGISTS Participated in the Oncology Care Model

5% of Oncology Practices Participated in the Oncology Care Model



600,000+ PEOPLE received cancer care under the Oncology Care Model. Participating practices treated roughly 1 in 4 patients with Original Medicare receiving cancer care.

PARTICIPATING ONCOLOGY PRACTICES WERE LOCATED IN **33 STATES**

How the model worked: The Oncology Care Model tested a two-part payment system for participating practices. The two-part payment system was designed to improve care for patients by providing enhanced services while encouraging oncology practices to pay attention to the cost of care.

Enhanced service payments

The Oncology Care Model gave additional money to physician oncology practices to provide enhanced services. The goal was to improve quality, such as increased access to timely outpatient care, communication between patients and their cancer care teams, and patient navigation. Participating practices received up to $960 per chemotherapy episode.

Potential for performance-based payment

Oncology practices were held accountable for the costs of all health care services while patients were undergoing chemotherapy and they were rewarded for improving quality.

Multi-payer partnerships

The Oncology Care Model was a multi-payer model. This means that it included Traditional Medicare and other payers to transform care for oncology patients across the population. There were 13 private health plans that participated in the Model.

Assessing the Effects of the Oncology Care Model

Every CMS Innovation Center model test has a comprehensive, rigorous, third-party evaluation. Medicare contracted Abt Global to lead a team of researchers in conducting an evaluation of the impacts of the Oncology Care Model on the costs and quality of cancer care, including patients' care experiences.

The research team used many data sources to inform the evaluation of the Oncology Care Model, including: Medicare claims data, surveys about care experiences from over 200,000 patients, and in-person interviews conducted at 47 participating oncology practices to learn about participation experiences. The final evaluation report is available on the CMS Innovation Center website, the *Evaluation of the Oncology Care Model: Final Report*.

The evaluation discovered that it takes time and commitment to transform care.

The Oncology Care Model led to substantial patient-centered practice transformation. The most common improvements were in direct response to specific participation requirements, such as documenting Care Plans, consistent depression screening, estimating out-of-pocket costs to help patients plan for the financial impacts of cancer treatment, and better patient navigation.

Most of these improvements were implemented for all patients in the participating oncology practices.

In many cases, the changes benefited all patients regardless of health insurance plan. Many oncologists, nurses, and administrators told us that high-quality care should be the same for every patient, and we heard many versions of the common sentiment:

> **"If it's good for Medicare patients, we should do it for everyone."**
>
> —Oncology Care Model Practice Representatives

Oncology practices implemented strategies to enhance care coordination and symptom management, and expanded clinic access, financial counseling, and palliative care, a topic we explored more thoroughly in the **Participants' Perspective Report**. These changes were intended to improve patient care experiences, improve patients' ability to maintain oral anti-cancer drug treatment plans, and foster more appropriate care at the end of life.

Despite the considerable efforts to transform cancer care, these changes did not always lead to detectable improvements in clinical or quality outcomes.

The Model led to improvements in screening for pain and depression, but barriers remain in mental health access.

Screening for pain, depression and other psychosocial needs improved, but this did not always translate to patients' needs being met. Consistently incorporating screening results into care plans and connecting patients with resources remains an avenue for improving the patient care experience.

Patients consistently rated most aspects of care highly, but there is still room for improvement.

Most cancer patient respondents rated their cancer care team very highly. Other aspects that patients rated highly were communication, exchange of information, and access to care. Areas for improvement included shared decision-making, symptom management, and self-management.

To learn more about what patients said about these aspects of care, see the **Treatment** section on page 25.

The ability of patients to maintain prescription anticancer drug regimens (i.e., "adherence" to anticancer drugs) was high overall and improved for some groups of patients.

Participating practices redesigned care processes to identify and address financial and other barriers to oral cancer treatment drugs. They also educated patients about how to take oral drugs and manage side effects. Patient adherence exceeded 85 percent among both intervention patients (those receiving treatment from Oncology Care Model practices) and comparison patients (patients receiving care from practices not in the Oncology Care Model). While the Oncology Care Model did not improve adherence relative to the comparison group overall, the Model was associated with significantly improved adherence for cancer patients who were Black, Hispanic, or dually eligible for Medicare and Medicaid.

Improving end-of-life care proved to be challenging.

Many participating practices attempted to improve end-of-life care by hiring palliative care specialists and enhancing access to palliative care, encouraging patients and their families to engage in advance care planning, and documenting patient wishes and proxy decision-makers. However, the Model had no observable impact on the use of hospice care, the duration or timing of hospice care, or other measures of high-intensity care at the end of life.

> "The OCM focus on hospice is a good challenge. It made us push our health system to improve their hospice program."
>
> —Oncology Care Model Palliative Care Physician

Costs for cancer treatment increased by about 25 percent, primarily due to increased costs of chemotherapy and immunotherapy treatments.

The opportunity to earn additional payments for controlling the total costs of care was intended to motivate participating practices to avoid costly treatments that have little likelihood of benefiting patients, and to emphasize treatments with a higher value.

Practices targeted cost-reduction opportunities that benefited patients and seemed most within their direct control (e.g., better/faster symptom management), and that had little direct impact on their practices' reimbursement. Unfortunately, these cost-reduction areas did not necessarily reduce Medicare spending.

At the launch of the Oncology Care Model, the two aspects driving high cost of treatment were chemotherapy drug treatment and acute care hospital use, and practices had more difficulty reducing costs in these areas.

There was little evidence of value-oriented changes in chemotherapy drug treatments, except for faster adoption of three lower-cost biosimilar cancer treatments.

The chemotherapy drugs used to treat common cancers were very similar among intervention and comparison group patients, and changed similarly over time. Both intervention and comparison group practices used more efficient treatment patterns during the Model (i.e., using similarly effective but less expensive drugs). One exception was in use of three biosimilar cancer treatments. Participating practices used biosimilar drugs more frequently than non-participating practices following their availability in 2019.

Biosimilars are biological therapies that the Food and Drug Administration recognizes as being highly similar to an originator drug (the product initially approved for use). Biosimilars are generally less costly than the originator drug and offer an opportunity to reduce drug expenditures while using therapeutically equivalent treatments.[6]

One potential reason for the lack of progress in reducing payments for chemotherapy drugs is that **physicians said they focused on selecting the best possible treatment for each patient and did not consider costs in selecting chemotherapy treatments.**

> **“I don’t know the price of drugs, and I don’t want to know.”**
>
> —Participating oncologist

Participating practices did not reduce the use of hospital-based care more than similar non-participants.

CMS intended for the enhanced services and improved care coordination incentivized by the Model to reduce avoidable hospitalizations and emergency department visits. Moreover, CMS rated practices on their ability to limit emergency department visits relative to their peers. During practice interviews, many practices indicated a focus on reducing costly inpatient care.

With the emphasis on reducing unnecessary hospital-based care, the Model reduced most measures of hospital-based care. However, **non-participating practices achieved similar reductions** over this same period, without access to Model incentives.

Practices increased the use of value-oriented supportive care.

Payments for Medicare Part B non-chemotherapy drugs (those used to treat the symptoms of cancer treatment, such as anti-nausea medicine) **increased significantly less for patients in the Model than for comparison patients,** reflecting more value-oriented use of costly supportive therapies.

Cancer treatment sometimes causes symptoms that can be alleviated by non-chemotherapy drugs. Medications addressing the side effects of cancer treatment are called **supportive care drugs.**

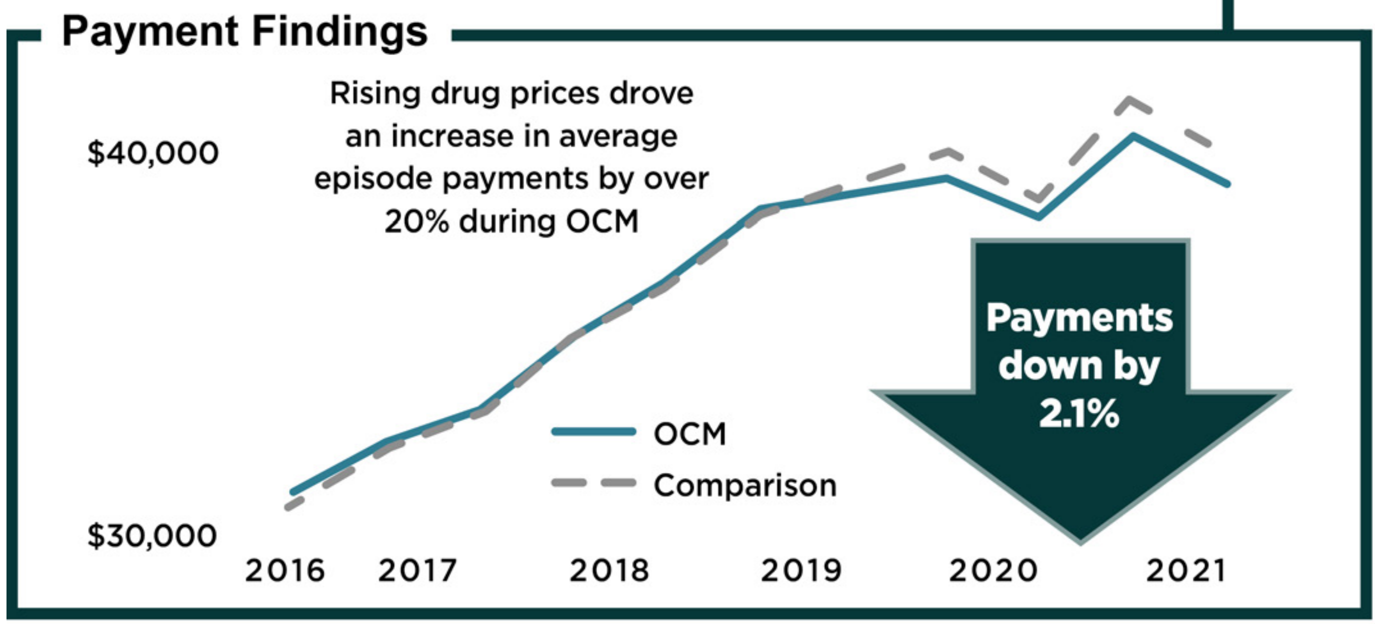
While payments went down for individual episodes of care, these savings were less than the cost of the Model.

Model payments directly incentivized practices to reduce unnecessary acute care and substitute higher-value treatment options for more expensive or less beneficial ones. CMS designed the Model with the goal of reducing the costs of care sufficiently to cover the costs of additional payments provided under the Model.

Payments for cancer care grew quickly.

Payments for cancer care grew quickly prior to the Oncology Care Model and during the first three years of the Model, for both intervention and comparison patients, but flattened in the final two years of the Model.

OCM PAYMENT REDUCTIONS WERE GREATEST IN THE FINAL TWO YEARS OF THE MODEL



The Oncology Care Model slowed the increase in total payments.

The Model reduced total payments by $616 relative to comparison payments, equal to 2.1 percent of the average payment in the time period preceding the Model.

The Oncology Care Model resulted in net costs to Medicare.

Despite reductions in Medicare spending, the Model cost Medicare more than it saved, after accounting for the additional payments made to participating oncology care practices.

Patient perspectives enhanced the evaluation.

As a part of this evaluation, we interviewed a diverse group of 30 people covered by Traditional Medicare who were being treated for cancer. About half received their cancer care from oncology practices participating in the Oncology Care Model, and the rest received care from practices that did not participate. Our purpose was to understand

what matters most to people with cancer, regardless of where they are treated.

People spoke with us about their cancer care experiences at length and with an openness that we greatly appreciated. We asked about their cancer journey and loosely guided the conversations to focus on: finding an oncologist to work with, communicating with their care team, making treatment decisions, managing symptoms, handling financial issues, getting help, and anything else that was important to them.

This report is primarily based on candid insights from these 30 people.

PATIENT CANCER JOURNEYS

Life Before Cancer

Receiving a Diagnosis and Finding an Oncologist

Treatment Goals, Planning, and Decisions

Cancer Treatment and Supportive Care

Getting Help

Living with Cancer

CANCER CARE EXPERIENCES

This section of the report describes the care and experiences people had throughout their cancer journey. The interviews, and the sections below, start with individuals' familiarity with cancer, their diagnosis, and finding an oncologist, then explore treatment planning and decisions, communication with their care teams, supportive care to address treatment side effects, and getting help during treatment.

Familiarity with Cancer

In 2020, the National Cancer Institute estimated that over 1.8 million people in the United States would be newly diagnosed with cancer that year. Several people we spoke with mentioned being familiar with cancer and cancer treatment even if this was their first experience as a cancer patient. Some had previously helped care for other people with cancer, had family or friends who had cancer, or had lost loved ones to cancer in the past.

> **"This is the first time I've ever been with cancer, but…so many loved ones had passed with cancer. I had one sister had liver cancer… My brother had lung cancer… [and] brother had brain cancer… another sister that I think she had cancer through her whole body. I had a sister who had breast cancer."**

Sometimes, cancers recur despite a successful round of treatment. **The Oncology Care Model included over 600,000 unique patients, nearly 60 percent of whom had prior cancer treatment.** During the interviews, 8 of the 30 people mentioned a prior cancer diagnosis. For some, this was the result of spread (metastasis) from the initial cancer, while others were diagnosed with an entirely new cancer.[8,9] People can live with some types of cancer for many years.

> "I was diagnosed with pancreatic cancer (stage 2B) in July of 2017. And after six months, they did a biopsy on the lymph nodes …the cancer had spread outside the pancreas. Six months after that, things looked good."

> "I was 28 years old when I had my first cancer experience. I had thyroid cancer. And then in later years they found that I had prostate cancer…and then they determined that I had lymphoma. I'm 74 years old."

Diagnosis

We asked each person about how they were first diagnosed with cancer.

People described two ways in which they received their cancer diagnosis: after experiencing pain or other symptoms, or through routine screening.

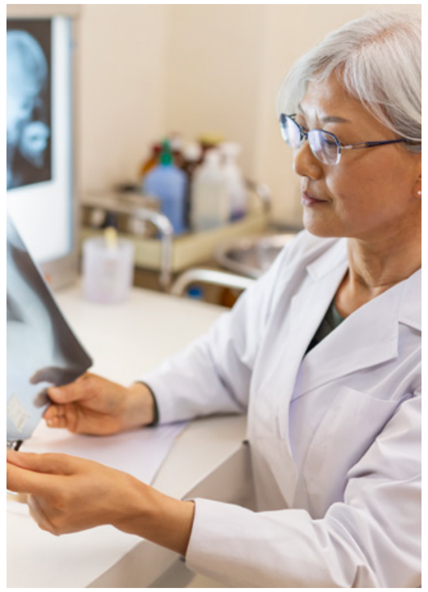
They told us that they were diagnosed by their primary care doctor, a specialist, or an emergency room doctor. Some people who experienced symptoms received their diagnosis promptly while others had to raise concerns with doctors repeatedly.

DIAGNOSED AFTER EXPERIENCING SYMPTOMS–PROMPT DIAGNOSIS

- Described symptoms to doctor
- Concerns were recognized and doctor ordered tests promptly
- Received diagnosis promptly

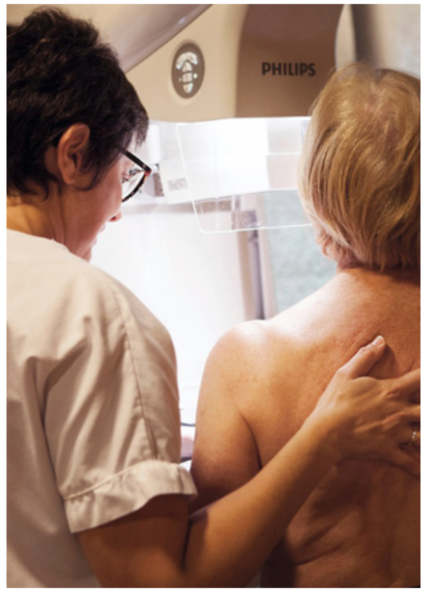
DIAGNOSED AFTER RAISING CONCERNS MULTIPLE TIMES

- Described symptoms to doctor or doctors multiple times
- Felt that doctors did not listen to their concerns
- Received diagnosis after lengthy delay



DIAGNOSED AFTER ROUTINE SCREENING

- Received routine screening test
- Screening test was positive for cancer
- Received diagnosis promptly



Diagnosed with cancer after experiencing pain or other symptoms

Some people we spoke with learned that they had cancer after telling a physician about pain or other symptoms that they had not experienced before. Two divergent experiences emerged: tests were done right away, leading to a relatively quick diagnosis, or patients complained to physicians about their symptoms multiple times before diagnostic tests were conducted that would reveal cancer. Those who had to advocate for themselves until their physicians ordered tests found the experience frustrating and sometimes physically painful.

Prompt diagnosis

> “It was an accident that I found out that I had that cancer. I found out that I had the disease because I was having nausea problems… my primary care doctor, she ordered an MRI and found out that it was some growth on the liver and the kidney. So, then we did a biopsy and found out that the one on the liver was cancerous.”

Diagnosed after raising concerns multiple times

> “I had started feeling bad and I was hurting in my back. So this went on for round about a week. So when the next Friday come, I told my daughter ‘I can’t take it no more. I got to go to the hospital.’ So, the doctor said to me that he figured that I had strained myself, they didn’t take no x-rays or anything. So, the next week came and it hadn’t gotten no better. And I got to the hospital, this time around, they did x-rays, chest x-rays and they gave me something for the pain because I was in so much pain. And when the doctor come to speak to me and my daughter and told us…they found out that I had that lung cancer.”

Diagnosed through routine screening

Many people we interviewed learned they had cancer after routine screening mammograms for breast cancer, prostate-specific antigen (PSA) tests for prostate cancer, or colonoscopies for colon cancer.

> **“I had no symptoms, no signs, no pain, nothing unusual. I just went in for my regular checkup and mammogram.** I was so shocked when they called me and said ‘You need to come back. We need to take another mammogram.’ **That’s how it began.”**

“I think about 10 years ago…I had a high PSA of 10. So, they sent me to a local urologist…and six months later my PSA was 28. And at that point they were saying it’s a slow-moving cancer, but once he gave me the second PSA test it expedited the thing – I mean, it just took off.”

“I was diagnosed through a regular mammogram, just a routine mammogram. When I was called back for further testing, the radiologist came in and asked me if I would consent to a biopsy — that there was something suspicious. I also saw a surgeon that day, just to examine me, and the surgeon also spoke very honestly with me…. She said, ‘I hope I’m wrong, but in my experience, I think I’m looking at breast cancer.’”

Oncologist Selection

After receiving a cancer diagnosis, some patients had surgery to remove a tumor and then saw an oncologist, while others went directly to a medical oncologist for cancer treatment. About half of the people we spoke with were referred to their oncologist by another physician, while others had a pre-existing relationship with their oncologist from a prior cancer episode. A few people were referred to their oncologist by a friend or family member or found their oncologist themselves.

Referred by a physician

"So, I asked her [physician] for a recommendation and she gave me two or three names. And she said they were in different practices, and that it was my call [who to pick]. When I went to the nurse navigator, we discussed it. And I think they just called to see if this person was available. She was one of the three names."

Prior relationship

"My surgeon is the one that asked me if I was going to go back to the same doctor that I had been to before [for prior cancer treatment], and I told him yes."

Referral from family or friends

"My wife's boss's mother-in-law had pancreatic cancer, and she said, 'This is the guy I recommend.' And we have a neighbor who had pancreatic cancer, and his wife said the same: the oncologist is very passionate about his patients."

Patient found oncologist on their own

"I was in the car and saw the clinic and said, 'what is this?' And somebody told me. So, I said, 'I have to go and check it out.' I always find places by myself. I'm a curious person, and I'm very independent."

Patient considered more than one oncologist before selecting one for their cancer treatment

"So, after I had surgery, he [surgeon] recommended an oncologist...We went over to this oncologist's office... And one of his first comments was, 'I haven't read your file, but this is the treatment that we give for your situation.' And after we left, my daughter and I looked at each other and went, 'It's not him."

In choosing an oncologist, distance and travel time can be important considerations for some people.

Patients living in rural areas may have few local options and often have to travel for long distances to receive cancer treatment.

> **“…One of the things we were discussing then is ‘where do you want your treatment?’ Because I'm a good 40 minutes from [teaching hospital]. And there were other facilities in the area, one of which is 20 minutes just up the road from [me]… So we chose to go to that [local] facility.”**

> “When I first went for cancer treatments [at hospital five hours away from my home], they went through the paperwork, did the blood work and everything, and I thought, ‘this would be the best place to deal with this kind of cancer.’”

> “I'm …kind of in the boondocks and [teaching hospital] is in [another part of the state]. And we had to go down there sometimes three times a week for about six weeks…Now I go once a week…Sometimes if the appointment is at eight in the morning, we're getting up at four in the morning to get there.”

Treatment

In this section, we describe aspects of cancer treatment: treatment goals, treatment planning and decisions, communication with care team, care coordination and navigation, supportive care for side effects, and symptom and pain management.

Treatment goals

An Institute of Medicine report on cancer care[10] states that it is important for doctors to convey the prognosis to each cancer patient and also convey the goal or purpose of recommended treatments—the potential for cure, or if that is not possible, the trade-offs of treatment side effects versus extending life. The pros and cons of treatment will be different for each individual, and willingness to undergo difficult treatments is a personal decision. To engage in decisions like this, a person needs to understand both their prognosis and the goal of treatment. Doctors should check to be certain that there is no misunderstanding, because being treated with chemotherapy does not necessarily mean a cure is possible. **The Oncology Care Model built on the Institute of Medicine's advice by requiring care plans for cancer patients that include prognosis, treatment goals, side effects, and other relevant information to help patients understand their treatment purpose and likely effects.**

INDIVIDUALIZING EXPLANATIONS ABOUT TREATMENT GOALS AND EXPECTED TREATMENT OUTCOMES

We visited 47 physician groups participating in the Oncology Care Model and interviewed hundreds of doctors about the Model's requirement to provide every cancer patient with their prognosis and treatment goal. Nearly all the oncologists told us they decide when and how to express what the expected treatment outcome means, in language that the patient and family will understand. Many oncologists were reluctant to put a patient's prognosis in writing or discuss prognosis prior to the start of treatment. They noted that prognosis changes, depending on how a patient responds to treatment. For this reason, most oncologists prefer to discuss prognosis with patients who have advanced disease, or after their disease has progressed. Oncologists who serve a diverse patient population were especially mindful of explaining a poor outcome in a way that is culturally sensitive and respectful of the patient's unique heritage, culture, religious beliefs, and personal/family circumstances. Oncologists also tailor their explanations about treatment goals. For example, due to potential stigma some patients associate with the term "palliative care," this is sometimes presented as "live longer with my disease."

While survival rates vary substantially by cancer type, the timing of diagnosis, and other factors, many cancer patients survive for five years or longer following their diagnosis.[12] For some people, cancer becomes a chronic disease requiring ongoing or periodic treatment long after the initial diagnosis.

Most of the 30 people we spoke with understood that they will always have cancer and the treatment goal is to extend their lives with reasonable quality of life. A few people did not initially understand their prognosis and goals of treatment and were upset when they eventually realized what the future would hold.

> **"He [the oncologist] indicated that…there is no cure for lymphoma. It's just a fact of treating it, and sort of trying to keep it in remission… for as long as we can."**

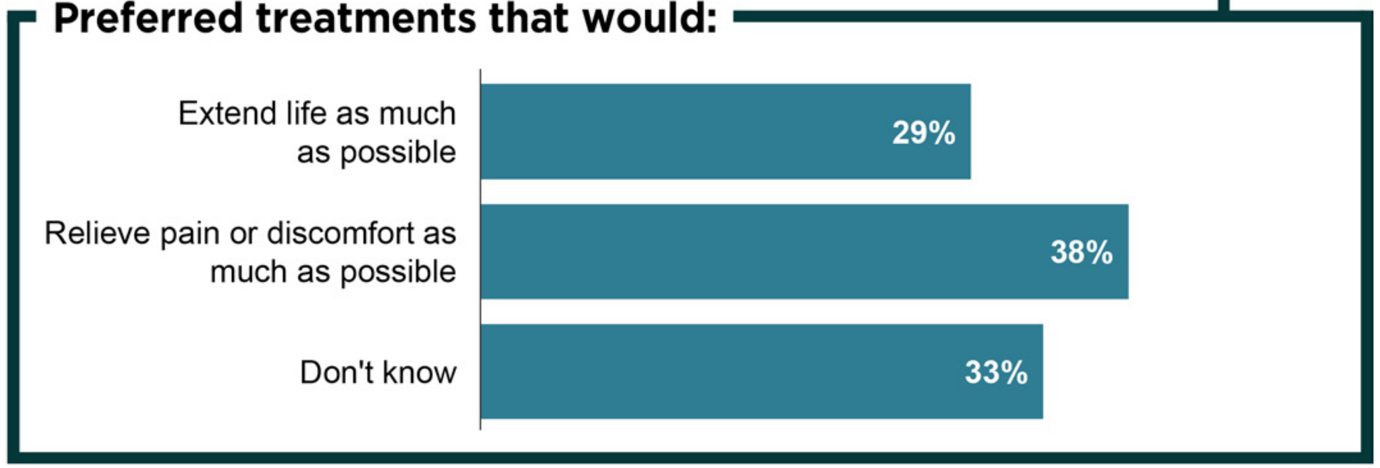
> "I was thinking 'I can handle anything for six months'… I then had six months of the nastiest treatment I would never wish on anybody…and then it was clarified to me that it [chemotherapy] would be for the rest of my life."

Tradeoffs

Patients may have options in how aggressively to treat their cancer, making tradeoffs between extending their life and managing symptoms. Oncology care teams play an important role in helping patients understand these decisions.

The Oncology Care Model Patient Survey included a question asking patients whether they preferred to receive care that would extend life as much as possible, even if it means having more pain and discomfort, or to receive care that focuses on relieving pain and discomfort as much as possible, even if it means not living as long. **While more respondents to the patient survey indicated a preference to relieve pain and discomfort as much as possible (38 percent), nearly as many preferred treatments that would extend their life as much as possible even in the face of greater pain and discomfort (29 percent), and roughly a third of respondents were undecided between the two options.**

SURVEY RESPONDENTS WERE SPLIT IN PREFERRING TREATMENT THAT EXTENDS LIFE OR TREATMENT THAT RELIEVES PAIN AND DISCOMFORT.



Preferred treatments that would:

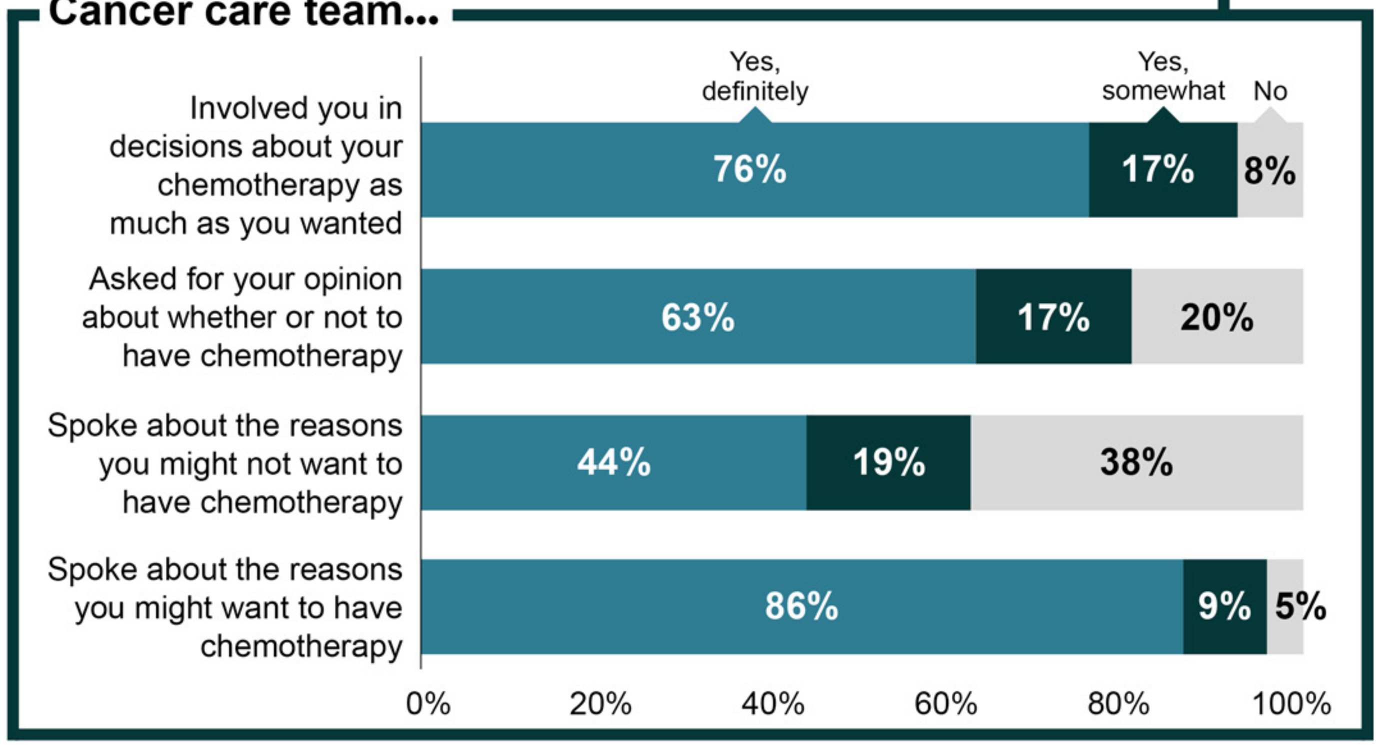
Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 182,657 survey responses. Estimates were weighted for sampling and non-response. The full survey question asked: “If you had to make a choice today, would you prefer treatment that extends your life as much as possible, even if it means having more pain and discomfort, or would you want treatment that focuses on relieving pain and discomfort as much as possible, even if it means not living as long?”

Treatment planning and decisions

For many people with cancer there is more than one reasonable treatment option, and decisions about the best approach will depend on each person's values and preferences.

The Oncology Care Model Patient Survey asked a few questions about whether patients were involved by their care teams in decisions about undergoing chemotherapy. Roughly three out of every four respondents checked "yes, definitely," indicating that they were involved as much as they wanted to be, but one-quarter checked either "yes, somewhat" or "no," indicating that they would have liked more involvement. *While nearly all patients reported that their cancer care team spoke with them about reasons they might want to get chemotherapy, less than half reported speaking with their care team about reasons they might not want chemotherapy.*

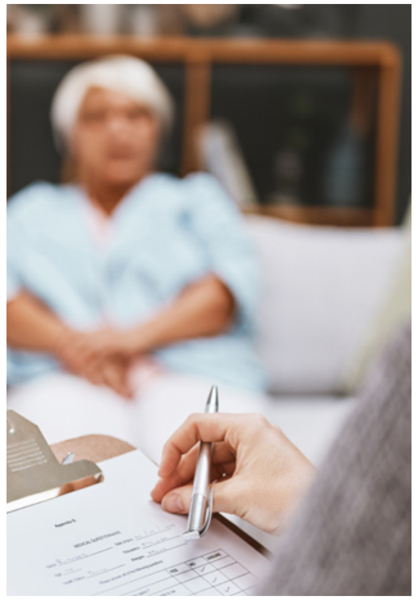
MOST BUT NOT ALL SURVEY RESPONDENTS WERE INVOLVED IN DECISIONS ABOUT THEIR CHEMOTHERAPY AS MUCH AS THEY WANTED TO BE.

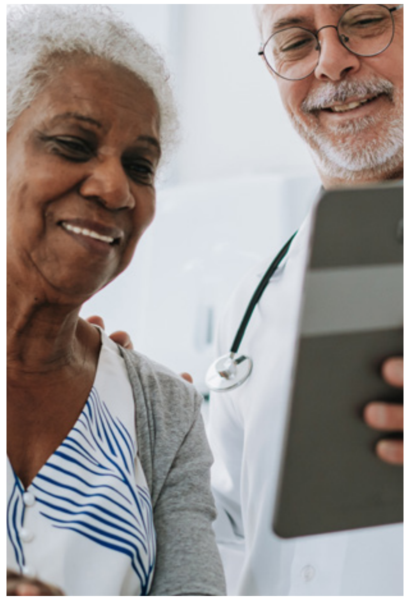


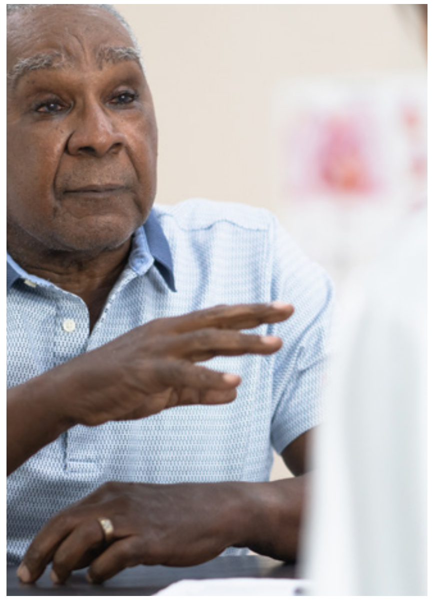
Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 184,735 survey responses. Estimates were weighted for sampling and non-response.

We noticed three patterns when people spoke with us about treatment planning and decisions: those who wanted to understand all their treatment options and discuss possible approaches with their doctors, family, and friends; those who preferred to leave treatment decisions entirely to their doctors; and those who had strong opinions about which treatments were unacceptable and expressed those opinions to their doctor.

TRUSTED ONCOLOGIST TO MAKE TREATMENT DECISIONS	ACTIVELY INVOLVED IN TREATMENT PLANNING	DECLINED INITIAL TREATMENT PLAN
● Completely trusted doctors to make treatment decisions ● Felt unable to assess treatment plan (lacked expertise), but content with decisions ● Saw no other option, left decision to doctors	● Searched for and read relevant information ● Involved family/friends ● Discussed options with doctors ● Negotiated with doctors about certain treatments	● Declined specific treatments ● Could not reach agreement with doctor about other options ● Sought second opinion ● Changed doctors







Trusted oncologist to make treatment decisions

> **“I surrendered myself to them with full confidence.”**

Nine of the thirty people we interviewed told us that they trusted their doctors and did not feel the need—or lacked the expertise—to participate in making these important decisions.

They generally felt well cared for and left treatment planning to their doctors.

Four of these nine people said they received all the information they needed and had opportunities to ask questions.

These people expressed total confidence and trust in their doctors to make the right decisions.

Five of these nine people preferred to follow their doctor’s advice, because they lacked the knowledge necessary to make these important decisions.

Even so, they were mainly comfortable with the process and felt confident that their doctors made the right treatment decisions.

> “I told him I was satisfied with the treatment he was doing, and I really trusted him.”

> “Well, he talked it over with me, and told me what he was going to do. But I wasn’t educated as far as cancer.”

Actively involved in treatment planning

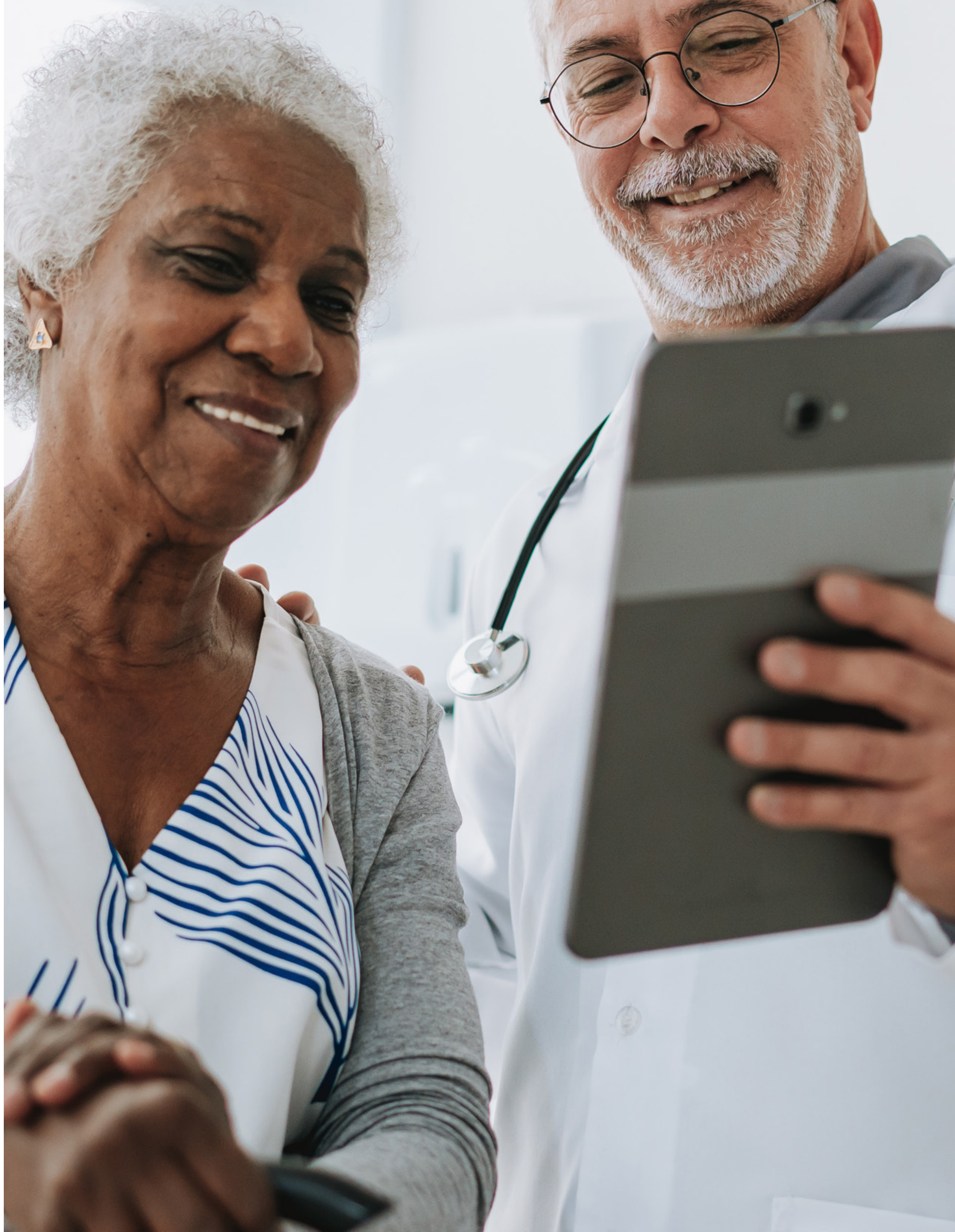
> “The surgeon answered all my questions. She gave me paperwork so I could take it home. She did explain that sometimes you just need to read it and understand it for yourself. She said, ‘Share it with family members.’

Seventeen of the thirty people told us they felt well-informed and actively involved in making treatment decisions with their doctors.

Many people read information provided by the cancer care team and involved friends and family in discussing the treatment plan. Some searched online for more information before making a treatment decision, or talked with other patients who had the same type of cancer and treatment.

> “They laid everything out: why I couldn’t have surgery…here’s what we’re going to do, here’s how you’re going to feel.”

> “When I was first diagnosed with cancer I was flooded with material and special meetings that explained what was happening. My family came in and we all talked about it.”



Several people negotiated with their doctors for more aggressive or different treatments

Their doctors were flexible and willing to consider options that were more in sync with the individual's values and priorities.

> “The doctors were satisfied with it [the cancer] being stable. I wanted something a little more tangible, a little more aggressive. So, we talked about it, and he gave me this option of treatment [immunotherapy].”

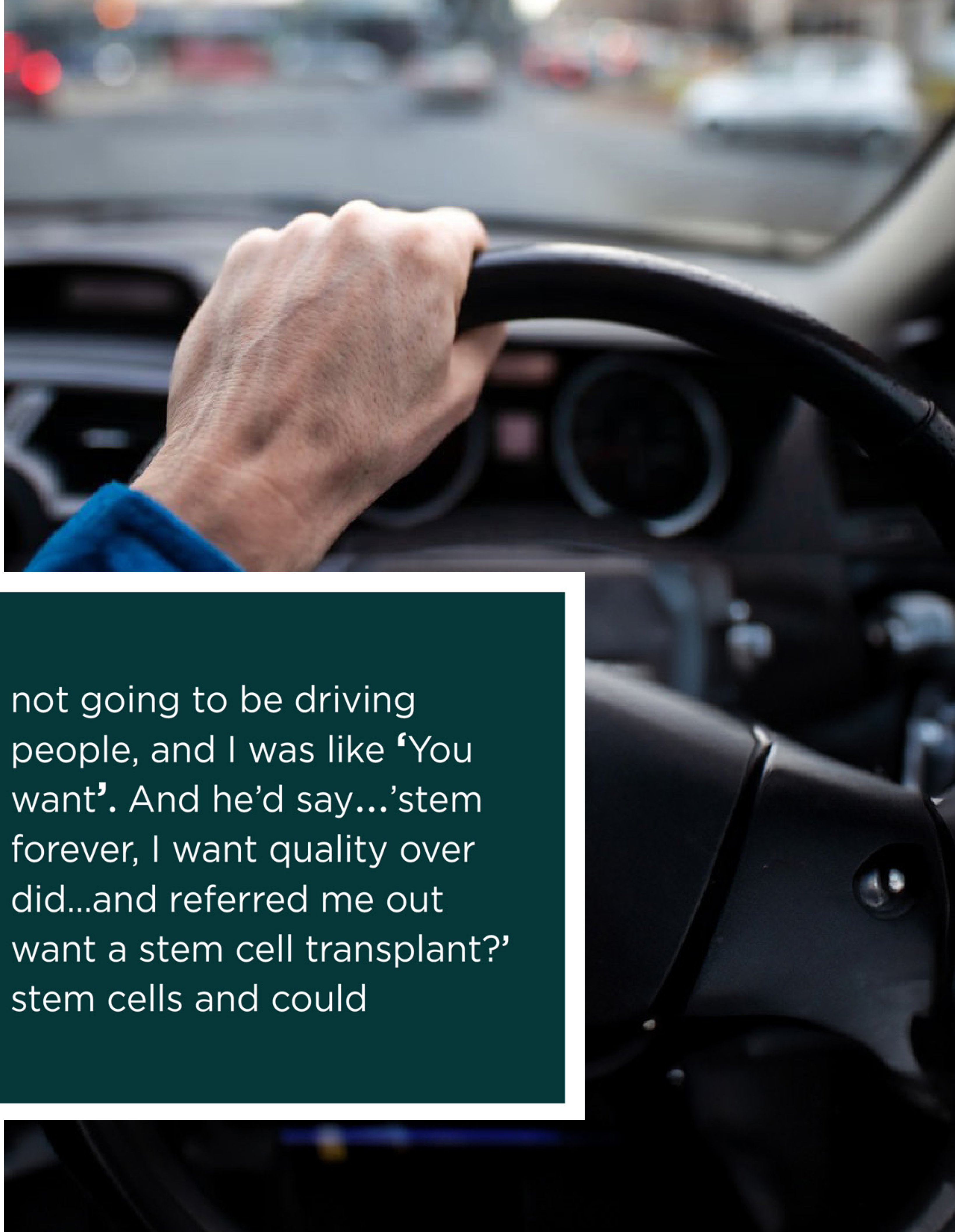
Declined initial treatment plan

Four people told us about conflicts with their doctors that could not be overcome. Two people declined certain treatments their doctor recommended. The remaining two could not reach agreement with their doctor about a different approach and decided to find a new doctor.

> “She [medical oncologist] wanted to send me back to the previous doctor, and yet the previous doctor [radiation oncologist] had told me there was nothing more that his treatments could do for me. So, I'm bouncing back and forth, and I lost confidence. I reached out to another cancer center… because everything I was getting from my original clinic was going south.”

SPOTLIGHT ON EMPOWERED DECISION MAKING

A former nurse, living in a rural area, had been living with multiple myeloma for over 10 years. After her initial treatments, her doctor said a stem cell transplant would be the next step and offered the best chance at a lasting remission. The patient spoke with other patients and did some searching online. She learned that a stem cell transplant would be harsh, and she would be on the same long-term maintenance drugs whether or not she had the transplant. She also learned that survival might be the same, with or without the transplant. She decided against the transplant, but her doctor did not agree. There is no other oncologist available within hours of her home so she felt forced to stay with this doctor, while maintaining her adamant decision.



> “This is me: I’m going to be driving this bus; you’re not going to be driving this bus. I read some articles, I talked to some people, and I was like ‘You need to ask me what I want for me; not what you want’. And he’d say…’stem cell transplant’ and I’d say ‘No, I don’t want to live forever, I want quality over quantity.’ He got frustrated with me, I know he did...and referred me out [for a second opinion], and they asked me ‘Do you want a stem cell transplant?’ and I said ‘No.’ They said ‘Okay, fine’…I didn’t need stem cells and could continue on medication.”

Communication with care team

Effective and clear communication between doctors and patients can help people with cancer feel heard, respected, and in control. Since most people lack detailed knowledge about cancer and its effective treatments, they rely on their doctors and care teams to communicate essential information.[13]

Many people we interviewed spoke about excellent communication, even when the news was not good, and how much they appreciated the clear communication, knowledge, and compassion of their doctors and nurses.

> **“...and then all of a sudden it [test results] started to climb back up again. He [oncologist] said, ‘Sometimes that happens, don’t get discouraged; this is a marathon, it’s not a sprint.’ I remember him saying that and I just loved him, he was so compassionate.”**

> “He asks me what’s going on, and if there’s been blood work done or there’s been a CT scan...and anything it shows or didn’t show. It’s back and forth between us.”

> “And the nurses, when you went in for infusions, were unbelievably knowledgeable, and made it as enjoyable as something like that can be.”

For some people, poor communication seemed to be the underlying cause of negative experiences.

One person pleaded unsuccessfully for better communication and collaboration with her care team.

> “You go into it with a plan, and that’s the way I tried to explain it to them: ‘We are on a team together here... come and tell me what’s going on, so I can work with you to help me.’ ...I don’t feel that happened.”

The importance of communication in influencing care experiences more broadly was also apparent in responses to the patient survey, as shown below.

IMPORTANCE OF COMMUNICATION

We used data from the Oncology Care Model Evaluation Patient Survey to identify which aspects of care experience mattered most to patients undergoing chemotherapy.

We combined responses to survey questions into aggregated measures across five domains of patient experience with care:

(1) *access to care*

(2) *communication*

(3) *exchanging information*

(4) *enabling patient self-management*

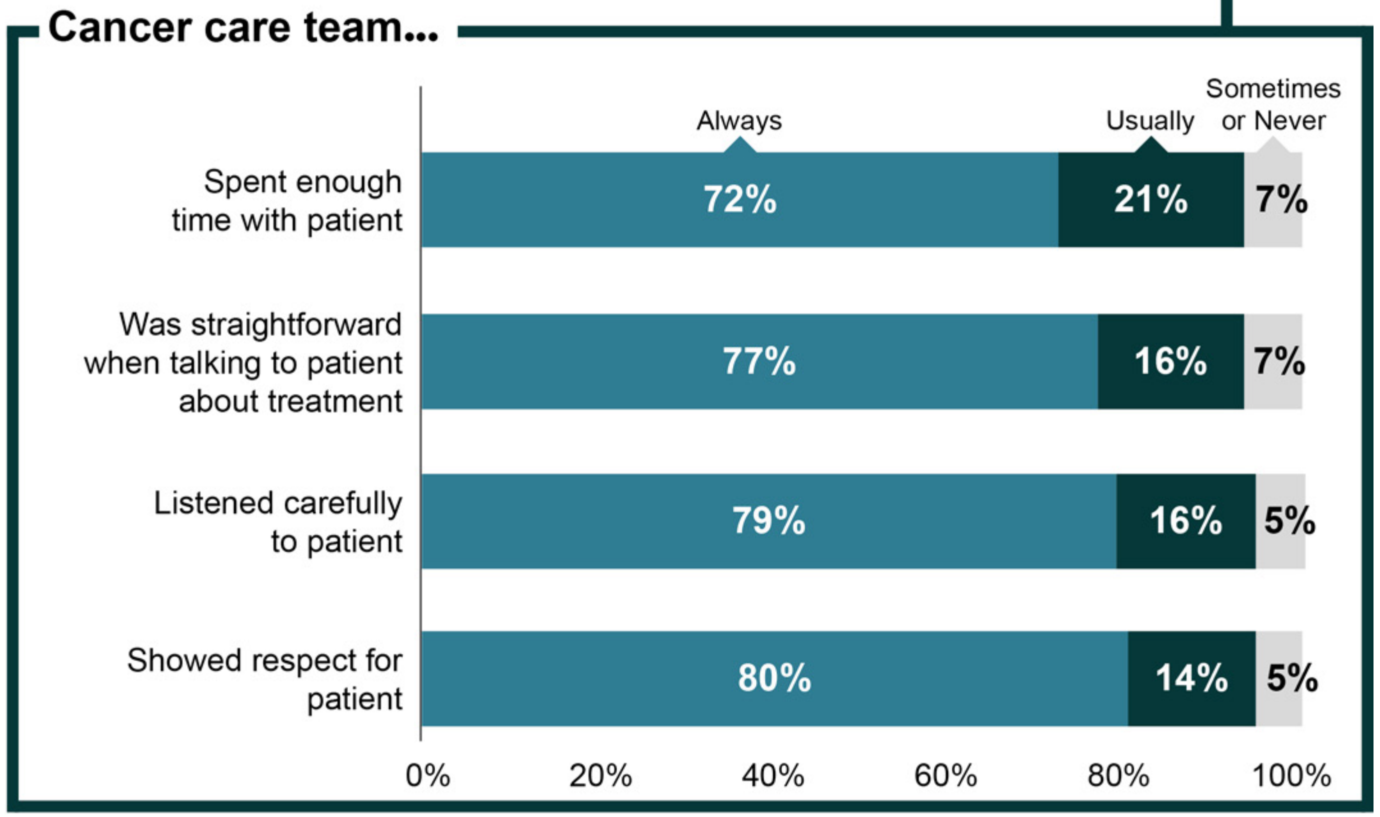
(5) *shared decision making*

We also asked respondents to give an *overall rating of their cancer care team.* Together, these measures were used to understand the impact of the Oncology Care Model on patient experience with care in several annual Oncology Care Model Evaluation reports.

While all of the domains were positively associated with the overall rating, **respondents' ratings about their communication with their care team mattered most.**

The Oncology Care Model Patient Survey asked several questions about communication. **More than 9 out of 10 survey respondents indicated that their cancer care teams always or usually spent enough time with them, listened to them carefully, communicated in a straightforward manner, and showed them respect.**

SURVEY RESPONDENTS GAVE THEIR CANCER CARE TEAMS HIGH RATINGS FOR COMMUNICATION.



Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 187,090 survey responses. Estimates were weighted for sampling and non-response.

Survey respondents also had generally positive experiences with how their cancer care teams explained aspects of treatment.

MOST SURVEY RESPONDENTS REPORTED THAT THEIR CANCER CARE TEAMS EXPLAINED ASPECTS OF THEIR TREATMENT CLEARLY.

Cancer care team definitely...

68%	73%	89%
Explained what the next steps in treatment would be	Clearly explained how cancer and drug therapy would affect normal activites	Explained medications in a way that was easy to understand

Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 183,097 survey responses. Estimates were weighted for sampling and non-response.

Care coordination and patient navigation

Cancer care can be extremely complicated, with many different specialists, tests, and treatments (such as surgery, chemotherapy, or radiation therapy). Side effects are often unpleasant, and people need medications and other support to minimize pain, nausea, and other problems. Ideally, all of the tests, treatments, and support happen in the same medical center near the person's home; however, often this is not possible and different elements of care happen in different places. This can be especially challenging for people who live in smaller towns where all the necessary specialists and resources are not available. Some people are fortunate to have a care coordinator or "navigator" assigned to help with logistics and act as a single point of contact to handle referrals, coordinate schedules, and answer questions. Sometimes, however, cancer patients and their families must navigate the complexities themselves, trying to ensure that test results get from one place to another, referrals happen on time, schedules are coordinated, and nothing falls through the cracks due to poor coordination and communication.

> "They have a special person you can call if you had a concern about how you were feeling, or if you wanted to change an appointment, or had a financial problem. It was the same person who gave me the binder and the phone numbers. She was our go-to girl...If I needed to talk with the social worker, she would make arrangements for that."

Several people we interviewed told us about good experiences with well-coordinated care, and care team members who excelled as navigators or coordinators.

One person spoke about the importance of team-based care, when there are many specialists involved who need to communicate and coordinate.

> "The radiation oncologist was a member of the same health system, so there was continuity where they were sharing information...I think the team approach is critical because each has their own niche to deal with. The surgeon takes care of this, the chemo doctor takes care of this, and the radiation oncologist takes care of this."

People who live in smaller towns, far from a major medical center, want their local doctors to collaborate with experts in the city.

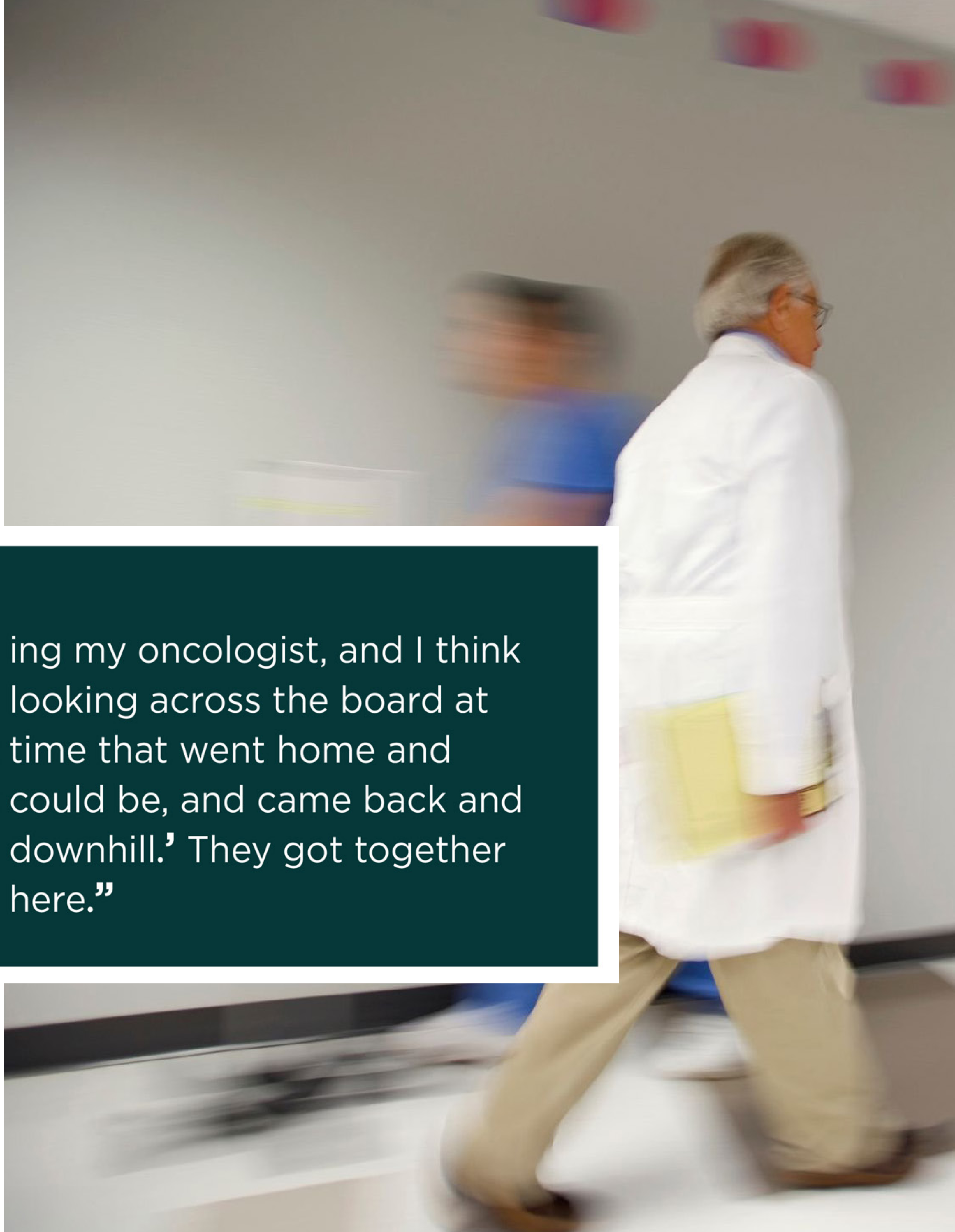
Some people we interviewed got services in multiple locations and told us about the coordination required on their part to share records, ensure that specialists' recommendations reach the care team in a timely manner, and overcome logistical barriers.

> "I believe there should be some doctor... who would organize all my treatments, so that I wouldn't have to go to so many different places just to figure out what's going on with my body...Why would I have to call [urban medical center] and then [local hospital] and then finally end up at [clinic]?"

SPOTLIGHT ON POOR COORDINATION BETWEEN CARE TEAMS

Many times, cancer patients have multiple conditions and issues that arise, which may or may not be the result of the cancer or its treatment. Systems that are not patient-centered may fail to effectively communicate and coordinate across all providers on behalf of a cancer patient.

> “I had a nephrologist and different doctors, including my oncologist, and I think each one was working in their own silo, and never looking across the board at each other. I luckily had an oncology nurse at that time that went home and studied at night and, sort of, figured out what it could be, and came back and told the doctors, ‘I think this is why he’s going downhill.’ They got together and agreed and changed my treatment. And I am here.”



Supportive care: side effects, symptom management, and pain management

More than half the people we spoke with experienced distressing side effects from their cancer treatments.

These side effects from chemotherapy and radiation treatments varied in type, frequency, and severity. The impact ranged from a one-time episode or mild inconvenience to more severe problems that required a pause or change in treatment.

Side effects from treatment

Common side effects included fatigue, nausea, diarrhea, hair loss, mouth sores, dehydration, fluid retention, and weight gain. Other less common, but no less distressing, side effects included lymphedema, radiation burns, cold hypersensitivity, blood clots, skin eruptions, cardiac symptoms, electrolyte imbalances, and shingles.

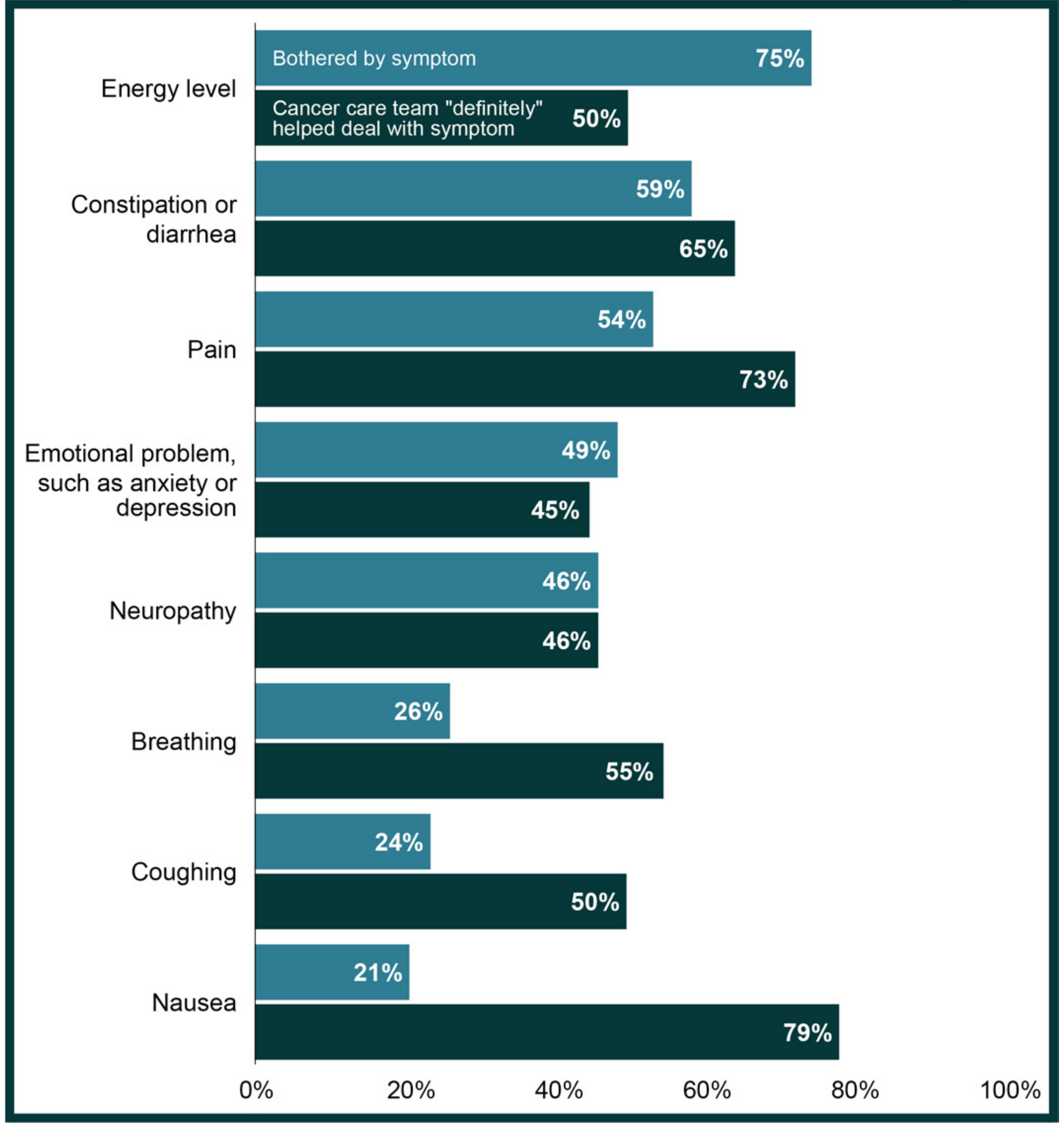
> **"Chemo is hard. Anybody that says it's easy is crazy because it's not."**

The Oncology Care Model Patient Survey asked about the occurrence of symptoms and whether cancer care teams helped with symptom management. In the chart on the next page, the blue bars show the percentage of respondents who reported having each of several symptoms, and the dark green bars show the percentage of respondents who reported that their cancer care team “definitely” helped them deal with that symptom, among those who reported having each symptom.

Among respondents who experienced symptoms, many but not all indicated that their cancer care team “definitely” helped them deal with the symptoms.

For example, nearly four out of every five respondents who experienced nausea indicated that their care team definitely helped them deal with the nausea. Fewer than half who experienced neuropathy or emotional problems such as anxiety or depression indicated that their care team definitely helped them deal with those issues.

MOST SURVEY RESPONDENTS WITH SYMPTOMS GOT HELP FROM THEIR CANCER CARE TEAMS.



Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 183,968 survey responses. Estimates were weighted for sampling and non-response.

More than half the people we spoke with experienced distressing side effects from their cancer treatments.

Neuropathy is commonly described as prickling, burning, or numbness related to the nervous system, with varying levels of severity. Some chemotherapy drugs can cause neuropathy, although not everyone who receives chemotherapy will experience neuropathy. Five people told us they experienced neuropathy, which for some was debilitating. For one person, walking became very difficult. Another had trouble holding onto a hot cup of tea.

> **“One day I was picking up something and I dropped it. I didn’t realize I had dropped it until I heard it hit the floor… That’s why everything that I have in my kitchen right now is in plastic…”**

Some people mentioned cold hypersensitivity, a type of neuropathy from a specific chemotherapy drug used to treat colon cancer, rectal cancer, and other gastrointestinal cancers. People who experience this symptom can be bothered by even brief exposure to cold temperatures, such as when removing items from the freezer, eating cold foods, or drinking cold liquids. Symptoms can occur within hours of receiving chemotherapy and often resolve within a week of treatment, though they may recur following additional cancer treatment.[16]

> “I couldn’t even pick up a spoon or fork because a part of that treatment is that things feel very cold. Even things at room temperature are cold, too cold for me to touch or drink.”

SPOTLIGHT ON SIDE EFFECTS AND TREATMENT PLAN ADJUSTMENTS

A retired female educator in her early 70s was diagnosed with breast cancer after a routine mammogram. She met with the nurse navigator, then had an immediate surgical consult and referral to medical oncology. Surgery was performed one month later, followed by chemotherapy. Based on her disease status, the advice from the medical oncologist was to undergo three to four courses of chemotherapy. At the start of treatment, the patient's biggest concern was the potential for neuropathy as a side effect. She agreed to the treatment plan once the oncologist explained that every person reacts differently. Unfortunately, her neuropathy was so severe that she decided to forego the fourth (final) cycle of chemotherapy.

> “I completed three rounds of chemo, and each time I did it, the neuropathy got worse. It was not so much my feet; it was my hands. ... I started with the neuropathy right from [the] get go. And by the third round, it did not go away. It was staying with me. ... And I made the decision not to get the fourth round of chemo. It was a personal decision. ... And then, also the neuropathy was a big thing. Did they try to talk me into completing the fourth round? Yes. Looking back, should I have gotten it? Maybe I should have, only time will tell.”

Pain

A few people mentioned pain as a major symptom or treatment side effect, but most spoke about other kinds of side effects that had greater impact on their everyday life.

> **"I'm just lucky... I've had a couple of instances with lesions showing up on my bones but nothing that's you know, nothing's ever really been painful."**

> "So, I don't have any pain or any of the other potential consequences of cancer... all of the pain and suffering that I've been through has been a result of the treatments."

Responsive patient-centered systems

Most people we interviewed described receiving education, guidance, and support to manage their treatments and resulting side effects.

Many said they were able to easily reach a consistent member of the care team for support and guidance. Most people told us that their care teams were responsive, answered questions, and quickly helped address side effects.

> **"I think one of the biggest parts of their job ... is to help you with the side effects. I was always in there saying, 'well, this is going on and I've never experienced this in my life,' and they're going, 'well, you know, you can do this, you can do that."**

Inadequate symptom management.

A few people described poor communication or inadequate systems that were not set up to address patients' symptoms in a timely manner.

One person experienced a three-day delay in response over a weekend. Another felt that staff did not prepare them for side effects, and they had to find answers on their own.

> **"They said, 'If there's ever an issue, call us.' I called them, left the message, but I did not hear back from them, and I was waiting...and then finally...they got back to me on Monday morning."**

> "I didn't get a lot of instruction. No one gave me anything to read. No one gave me literature about the drugs that I was on; I had no information whatsoever... I was sort of [finding] my own way through it and reading as much as I could on my side..."

SPOTLIGHT ON RESPONSIVE, PATIENT-CENTERED SYSTEMS

Responsive organizations not only educated patients to call with issues but also had clear protocols and a consistent staff member assigned to listen carefully and respond in a timely and appropriate manner to address symptoms. The most patient-centered systems also followed up promptly with patients afterwards to be sure all needs were addressed.

> “And that was important to me because when you meet with the medical oncologist, they have a nurse practitioner that comes in and they go over all the side effects; they give you paperwork and every thing. Well, I’ll admit that I’m an odd duck. Some of the symptoms or some of the side effects I did not get; and some that were not listed, I did get. So, I think in talking to her and then talking to the medical oncologist’s office, I was able to better navigate that whole thing.
>
> And let me tell you, they got me in very quickly and addressed it. I got the cream [I needed] and all that good stuff. Then the nurse navigator called me and asked me, how [are] you feeling? And if I called, she got right back to me.”

Emergency department visits to manage symptoms and side effects

Five people we spoke with reported visiting a hospital emergency department because of symptoms from their cancer or treatment side effects.

Reasons for these visits included high fever, pain when breathing, nosebleeds, dehydration, and a blood clot. For some, symptoms were serious and clearly required hospital resources. For others, their needs could possibly have been met in the outpatient setting rather than in a hospital.

> **“I had to go [to the emergency department] once for a temperature of over 103. I stayed there [in the hospital] for maybe four or five days because they thought I had some kind of serious infection.”**

> “And then suddenly in the afternoon, I feel like I couldn’t understand what I wrote. And it’s like, it was not my writing. Then my husband immediately called my doctor... she said, ‘Okay, take her to emergency.’ Then they took me to emergency, and they say I have like a blood clot, but a very, very, very tiny [one].”

Self sufficiency, positive attitude

Several of the people we spoke with were committed to being self-sufficient and tended not to call or reach out to the cancer care team, even when issues with side effects arose.

They preferred to manage on their own or wait until their next scheduled visit to report the issue. One person spoke about having a positive mental attitude.

> **“One time I can remember going back to the car and not being able to go home because I was just really sick... I just sat in the [car], until I felt good enough to go home.”**

> “I didn’t call them, but they told me to call them if I had any problems, but since I was going back the next week anyway, I just waited until I got back.”

> “I tend to be self-sufficient and will approach things logically. I’m trying to remember if I ever had to call. No, I don’t think so... I’m not a caller.”

Getting Help

We asked people about the types of help they may have needed during their cancer treatment. They described needing help in a number of different areas—activities at home, transportation, emotional support and mental health care services, nutrition, and financial support.

Activities at home

Many people mentioned needing help at home with activities of daily living—such as showering, cooking, climbing stairs, and getting in and out of bed—due to pain or weakness resulting from their cancer treatment.

Although some people described a single type of home-based assistance, most recalled receiving several kinds of help. This home-based assistance was typically provided by informal support networks, such as a spouse or children. Only one individual mentioned receiving help from a paid caregiver—in this case, the patient's sister—who was paid by Medicaid for five out of the seven days each week that she spent time in the home.

Mobility

"My daughter came up from Florida, and my son came down from Connecticut, and another son came later to help me, when I got out of the hospital from Oklahoma. I mean, when I got out of the hospital, I could not walk up one step. I couldn't get out of a chair myself. Had to use the walker and barely got around."

Cooking

"I would do most things for myself when I was at home. Though there were days I didn't feel like it and I will let my sons [help]. Like I normally cook every day, so days when I didn't feel like it, when my sons got off of work, they would do the cooking."

Shopping

"Today I have to go to the supermarket. There are things that I need and I have a car, but I'm having problems in my legs, especially walking. I have to walk maybe like a block and a half to get to the parking lot...So, I'm waiting for my son to take me to the supermarket..."

Showering

"I did have a skin cancer that was so, so bad they had to send me to the wound center for several treatments. And I remember for some reason I had to have my leg wrapped the whole time and they had me wash with a certain solution. And I don't think I could wash it in the shower. It was just something I think my husband used to have to wrap plastic around when I would get in the shower. And I said, 'oh my gosh, I wonder when I'm going to get this leg clean?"

Home Maintenance

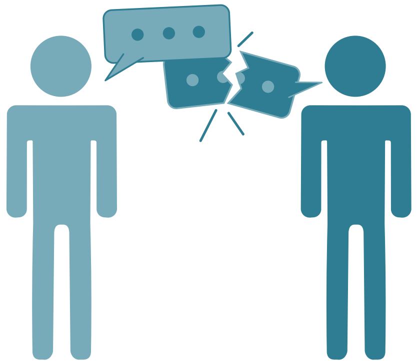
"In our shower, there was one thing on the showerhead, it got down to the point where it would not put out much water because we have a lot of condensate in the water supply here. And my wife and I collaborated on getting that working again, but I'm just not as strong and I'm more shaky and I get tired more easily than I used to, which is frustrating when you want to get through a project like that and get it done."

Unmet needs and living independently

While most people described receiving help on the home front, several recalled unmet needs. Two people expressed frustration at the lack of available agency- or community-based support.

Unmet Home Needs

“There wasn’t anybody. There’s nobody around here that you can get to come in to help… [Normally] county services could send somebody in to help with some of the housework and stuff, but they had nobody to do it. They had no help.”



A handful of people described living independently during their cancer treatment, with workarounds to accommodate any limitations.

Maintaining Independence

“I don’t need help per se…On the days that I’m really feeling weak, which is the days following the treatment, I normally eat something… that really don’t need a whole lot of cooking, or I lean on the counter while I prepare whatever it is.”

Transportation

Sixteen people, **more than half of those we spoke with, described asking for transportation help and receiving it,** and no one reported unmet needs related to transportation. Most people received transportation assistance from their family or friends.

> **“The majority of time it's me driving. Unless I'm really bad off, and then my daughter will go along and my wife, and they’ll help me. I went where I've gotten sick on the way and everything kind of went bad. But other than that, I usually kind of go by myself.”**

> “I have a girlfriend who I call my caregiver. Basically, it's either her or my girls. My girls live in a different town, but most of the time it's my friend. She drives me…They won't let me drive to [city] by myself.”

Several people living in more rural areas specifically mentioned distance as a reason for needing transportation to medical appointments, while others recalled fatigue or discomfort.

> **“My daughter, she took me when I went so that I didn't have to drive home. Because it's 70 miles to go there and 70 miles back.”**

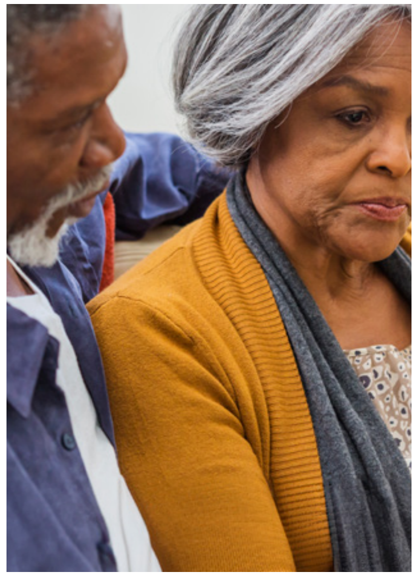
> “I was grateful…that she told me to have someone take me, not to drive myself to the chemo treatment, because when you do chemo, sometimes you get really tired.”

> “I have been able to drive myself with no problem. The city does have a small bus system that I know some people have used. But I did not get to the point where I had to do that. I was able to drive myself.”

Emotional support and use of mental health care services

Many people told us they received emotional support from their family or friends, as well as from their oncology care team. A few got assistance from mental health providers, and seven people described unmet mental health needs. Eight people said they did not need mental health or emotional support.

NEEDED ADDITIONAL EMOTIONAL SUPPORT AND RECEIVED IT	NEEDED ADDITIONAL EMOTIONAL SUPPORT AND DID NOT RECEIVE IT	DID NOT NEED FORMAL MENTAL HEALTH SUPPORT
● Received non-medical support from communicative and encouraging cancer care teams ● Supported by informal networks of family and friends ● Received prescription medication for anxiety and depression	● Expressed reluctance to seek assistance for emotional needs ● Cancer team did not inquire about emotional needs or did not respond to request for help	● Needs were met by informal networks ● Did not feel a need for emotional support due to positive outlook



Needed additional emotional support and received it

Many people cited their oncology team as a source of emotional support during cancer treatment.

> My spouse and I were both were going through [cancer] at the same time, and [my oncologist and nurses] saw that. I'm sure they did it with everybody else, but I just feel like that they felt like, 'Hey, we need to go the extra mile here,' which they did... It gives you confidence in trying to fight it the best you can. It also ... just helps you emotionally...."

For example, one individual recalled frequent encouragement from doctors and nurses when he was experiencing bouts of severe side effects from medication. Others described a highly trusting and communicative relationship with their cancer care team, who checked in on their personal (in addition to medical) well-being.

> “I was supported because of the anxiety that I was having because of where my sister was [in relation to her own cancer]. The primary oncologist and surgeon were all very aware of what was going on with me personally, and they fully supported that. I got the support from all angles from the team.”

Many people also credited informal support networks, such as family and friends, for providing emotional support.

One individual, whose sister was undergoing cancer treatment at the same time, relied on her best friend for support instead of “burdening” her family. Other people recalled family or friends accompanying them to medical appointments as a form of emotional and logistical support. Several people described the therapeutic value of support groups, both for medical informational exchange and feelings of camaraderie.

> **“Nobody in my family knows except my sister. I do have a best friend; he took me everywhere…And any time I needed anything; he’s just been there.”**

> “My daughter drove me to appointments and she stayed there. She dialed my other daughters and they listened in to while the doctor talked to me. They were all concerned.”

> “I had group therapy to speak to people to express myself, how I feel about the cancer and how the cancer was being treated.”

Several people described taking medication for anxiety and depression during their cancer treatment.

Another person expressed immense gratitude for her antidepressant and suggest that medication to help with depression and anxiety be offered automatically as part of all chemotherapy regimens.

> "I mean, it's sort of expected. How could you not be depressed about a cancer diagnosis? The anti-depressant I ended up on was something really mild, but I'm telling you that it made all the difference in the world…"

Needed additional emotional support and did not receive it

Many people expressed unmet emotional needs but were reluctant to ask for assistance or follow through on recommendations.

> “My cancer team reached out about my mental as well as my financial situations, like ‘Did I need social service? Did I need assistance getting there?’…They gave me a list of phone numbers for if I needed additional help. But I did not call for any of that type of help [mental health services].”

A couple of people avoided seeking professional mental health support because they considered it to be an added challenge. For example, one individual experienced depression and fatigue as side effects of a hormonal therapy shot but feared that asking for mental health support would start another treatment process with potentially more complications.

> “No, I didn’t mention any of that because I didn’t want somebody to go off on another thing. I’d always heard that if you mention something like that [depression], you’re going to really end up in a predicament.”

CHALLENGES IN MEETING CANCER PATIENTS' MENTAL HEALTH NEEDS

Anxiety, depression, and other emotional problems are common among cancer patients and are often treatable through medication and therapy. However, clinicians in several of the Oncology Care Model practices we visited described mental health care access barriers that they could not resolve:

- Insufficient financial resources to employ mental health practitioners in the practice
- Inadequate community mental health resources and long waits for appointments

A few people were frustrated by the lack of emotional support from clinicians—specifically social workers—during their cancer treatment.

For example, one individual, who was raising her granddaughter following the deaths of her sister and daughter, said that her social worker did not inquire about the patient's backstory or potential sources of grief during their initial meeting, and then became difficult to track down. Another individual emphasized the need for mental health support to be integrated into a holistic treatment approach.

> **"… So much been going on since I have been diagnosed with cancer… I don't think she [social worker] knows all this, but she ne'er asked either. She ain't never asked."**

> "My biggest complaint is that to me, cancer treatment should be a full-body approach. And the only thing they did was do blood tests and pump me full of pills. On my own, I was doing yoga, meditation, exercise program, you know, relaxation…But I am disappointed that the cancer treatment center didn't have [additional supports]."

Did not need formal mental health support

Several people declined formal mental health support because their needs were being met by informal networks, such as family and friends.

A few people cited their own positive outlook and psychological stability as reasons for not needing support.

> **"They also have counselors on staff that I could meet with. I haven't done that. I haven't felt the need to do that. I have a very supportive family, but those resources are there if needed."**

> "I think I had a pretty good outlook. Look, I don't think I got all stressed out about it."

> "I also had the mental attitude that I was going to beat this…I kept telling myself and my family and my friends: that cancer does not have me, I've got it."

Nutrition

Cancer and cancer treatment sometimes affect nutrition. Because good nutrition is important to healing, fighting infections, and having enough energy, cancer patients sometimes receive care from a dietician or nutritionist.[17] **People we spoke with who were referred to dietitians or nutritionists had mixed experiences.** Two people received actionable and practical recommendations, while one person stopped seeing a nutritionist due to their insufficient assistance with meal plans. Another person was offered a meal plan that was inappropriate for her health conditions.

> **“I don't know what happens, but my body just won't accept food...I've had a nutritionist and a dietician, and I've talked to my pain manager about it and that's why she recommended a little pill that I take... it helps me with the nausea and the not being able to eat.”**

> “We tried to go to a nutritionist that they provided. But we were looking for meal plans and the nutritionist just couldn't provide that. So, we dropped her...”

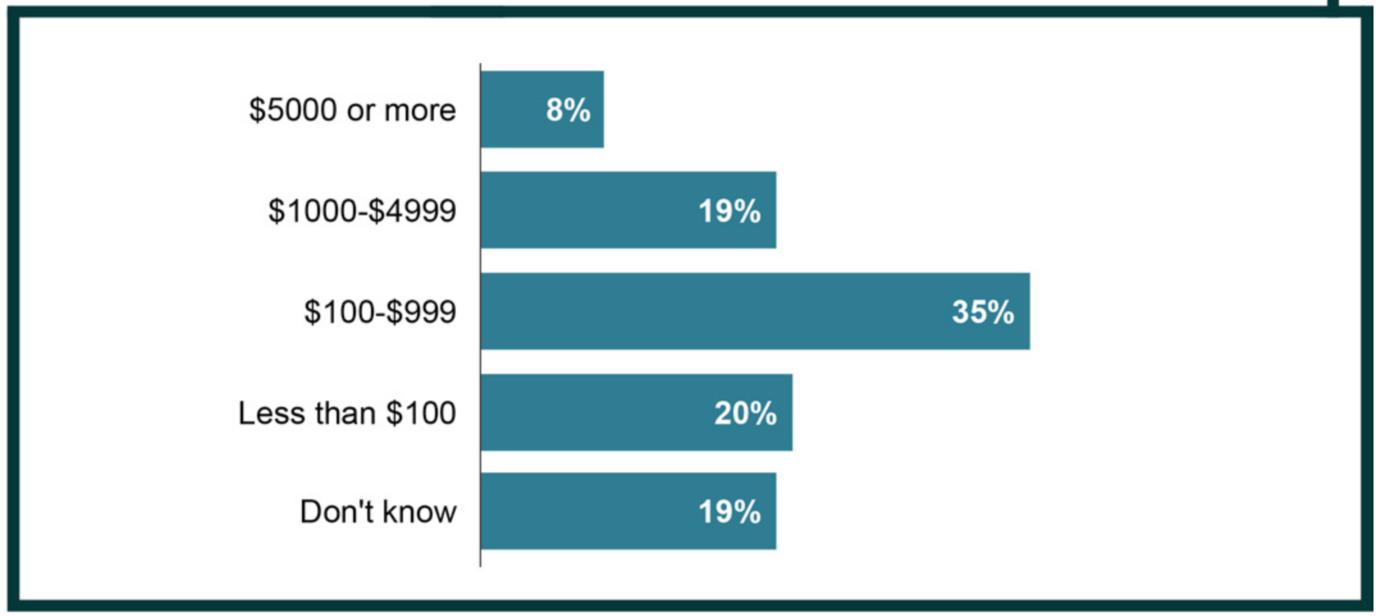
Financial needs, financial support, and out-of-pocket costs

Eighteen people we spoke with did not need help paying for their cancer treatment or related costs. These individuals told us that most, if not all, of the costs that were not covered by Medicare were covered by an employer, retiree supplemental insurance, or Medicaid.

This was consistent with results from our patient survey, indicating that over half of respondents spent less than $1,000 out-of-pocket in the past year for expenses not fully covered by their insurance. One reason out-of-pocket costs were so low, even when total costs for cancer care are quite high, is that over 90 percent of survey respondents had Medicaid, retiree, or supplemental insurance, in addition to Medicare Parts A and B.

Even with rising costs, most patients have out-of-pocket costs below $1,000.

THINKING ABOUT EVERYTHING YOU PAID FOR WITH YOUR OWN MONEY IN THE PAST YEAR FOR CARE RELATED TO YOUR CANCER OR MEDICATIONS TO TREAT IT, THAT WAS NOT COVERED BY INSURANCE, HOW MUCH DID YOU SPEND?



Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 186,454 survey responses. Estimates were weighted for sampling and non-response.

Many people who had supplemental insurance in addition to Medicare expressed gratitude for good insurance coverage and minimal out-of-pocket expenses and considered themselves "lucky" and "fortunate" to have few cancer-related expenses. Several also acknowledged that not all cancer patients are as fortunate**.**

> **"I'm in an income bracket that qualifies me for Medicaid. But gosh, the cost of the prescription drugs that they're covering is incredible... I can't believe what some of this stuff costs and why I should be getting it...I didn't ask for any of it, it just appeared. All I can say is 'Thank you.'"**

> "I was very lucky to have very good insurance… and honestly, I didn't really think about [finances] at all… I was able to get very good supplemental insurance. Actually, today I pay $5 for an office visit, which is amazing."

> "I have Medicare and I have supplemental insurance through my work. But I must say it is a shocker when you see the actual bills coming through….I worry about people who may not have the wherewithal and see this and panic and then maybe want to stop the treatment because of the cost, you know?"

FINANCIAL AND INSURANCE ASSISTANCE FROM CARE TEAM STAFF

All 47 physician groups participating in the Oncology Care Model that we visited had strategies to assist patients who faced high copays or fees that insurance did not cover, such as:

- Helping eligible patients enroll in Medicaid.
- Helping patients arrange secondary/supplemental insurance to cover Part B copays (which can be very high for infused drugs).
- Helping patients identify Medicare Part D plans that will cover their drugs.
- Helping patients apply for support from drug company foundations from charitable foundations.
- Sending patients to an affiliated/nearby hospital outpatient department for chemotherapy infusions, or to buy drugs at the hospital pharmacy, to take advantage of the hospital's "charity" program.
- Finding public or charitable support for other costs of living (e.g., rent, utilities) so patients have cash for out-of-pocket medical costs.

Four people, whose insurance did not fully cover their expensive treatment, received support from philanthropic foundations. A financial representative, clinician, or friend helped them apply for these grants.

> **“[Teaching hospital] has this department that is sort of philanthropic; if you have expenses that aren't covered by Medicare and your supplement, they will cover it, or up to so many thousand dollars... I think $20 in the last five years is all I have ever had out of pocket on anything.”**

> “I found out it would be thousands of dollars every month for me as a copay, I told the doctor ‘I can't do that.’ So, he got me a grant that is renewed every year and the grant will pay my copay.”

> “My friend also applied for me to get a grant to help me pay for medication, because that is very expensive. The first time, they gave me $8,000 to help me out. And I had to pay $25 or $50 to cover the rest. But now I don't pay anything.”

Several people mentioned receiving financial assistance from other sources, including care coordinators, pharmacists, and financial representatives at their oncology clinics, community organizations, and family members. Some of this was for assistance with costs related to getting care, such as transportation**.**

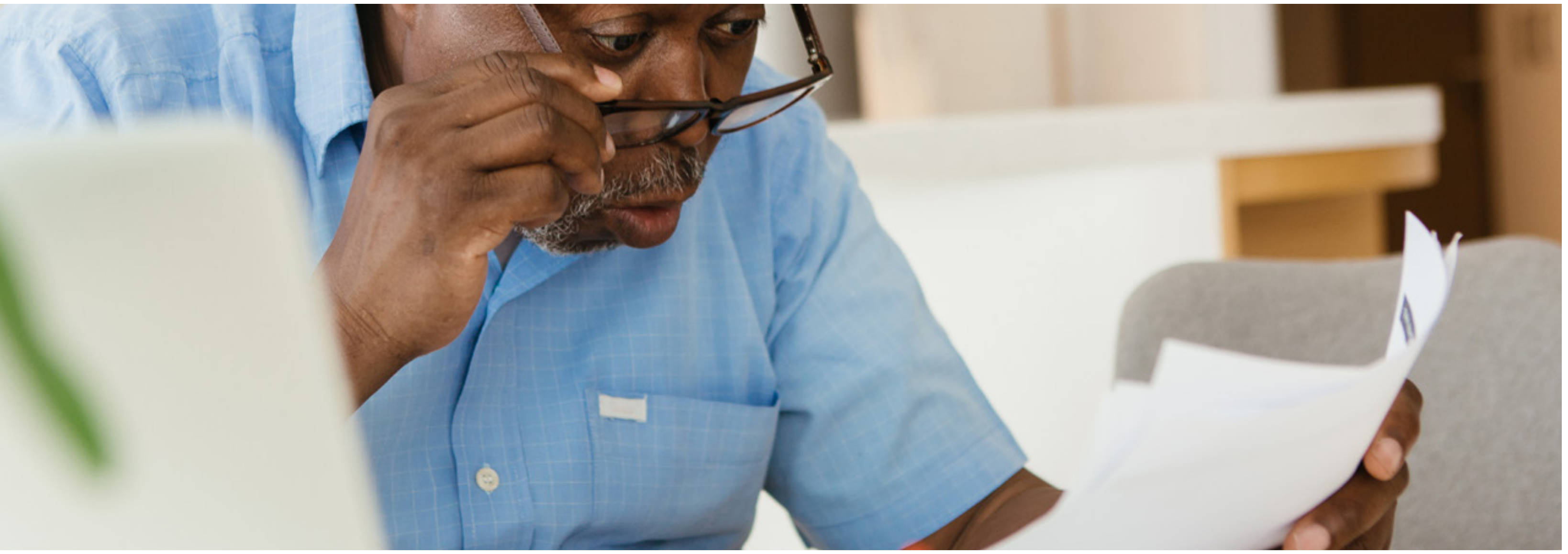
> **“My prescription insurance said they would cover the medicine for four years only. So, then the oncologist or the cancer treatment center used a specialist pharmacy, and they are absolutely awesome. They found me a program that paid the difference that my insurance didn't pay for two years and that worked. So, I ended up not having to pay for that medicine.”**

> “The out-of-pocket expenses were getting a little high, it started getting into the $600 per month range, but the pharmacy that belongs to the [oncology] practice managed to come up with some sort of alternate funding. Although, I have to admit it, I didn't want to take something that somebody else needed, because I knew I had enough money to pay for it... but they said no, that they would let me take advantage of that, and that worked out fine.”

> “There’s a senior place about 25 minutes from my house. So, I just walked in there and asked for some assistance, and the lady said, ‘I'm going to try to help you, because for you to go all the way over there [treatment center] is $100 round trip.’ She said she would send somebody to pick me up and the person will wait for me also. So, I just have to give a tip.”

Three people expressed some concern about being able to afford treatment but did not mention requesting financial assistance. One individual, who took pride in his self-sufficiency, specified that he chose not to ask for help**.**

> **“I haven't asked for anything. I mean, all I do is I just deal with it myself. I just take the money out of the bank, I drive to [large urban academic medical center]. And I don't know who to ask or anything like that and so that's what I do. I just don't reach out.”**



> “I have Medicare and Medicaid. They were good. I mean, we only have our Social Security checks, which amount to [a total of] $1,500 a month. Yeah, I was kind of concerned.”

A few people told us they needed but did not receive financial assistance or guidance during their cancer treatment.

> “I went in to have a scan, and they said that Medicare might not pay for this. I was concerned about that—I didn't order a scan for myself, so why would I have to be responsible for the payment? I went to talk to the financial advisor, and the only thing she could tell me was you know it's the beginning of the year and everything changes, but I got no satisfaction from what she was saying. I pay very close attention to the bills that come in... It could pop up at the end of the year. I think it was like $8,000 or something.”

LIVING WITH CANCER

A person's living situation may affect the type, source, and level of support they receive during cancer treatment. Some people may live alone and continue to live independently throughout their treatment with very little help. People who live with others (for example, spouse or adult children) or have family or close friends nearby, may rely on loved ones for assistance. Sometimes people with cancer move in with family members or have others stay with them to provide care and support during treatment.

Living alone:

> **"No, I live alone... So, I had to do all of this alone. I don't really have a support person in town."**

Living with or near caregivers:

> **"I have a daughter that lives right here in town, and she helps me a lot. She comes in if I need something that I can't do very good, and my grandson mows our grass, so that's under control."**

EMPLOYMENT IMPACTS FROM CANCER AND TREATMENT

- Two-thirds of people we spoke with had retired either prior to their most recent cancer episode or entered into retirement once it began

IMPACTS OF CANCER ON CARING FOR OTHERS

- People receiving cancer treatment may be caregivers themselves

IMPACTS OF CANCER ON INDEPENDENCE

- Some people talked about being self-reliant and managing independently
- Others were frustrated by new physical limitations

IMPACT OF CANCER ON LEISURE ACTIVITIES

- A few spoke of interests that keep them active and busy
- Some continued to enjoy activities, while others started new hobbies

Cancer treatment led to significant lifestyle changes for some people who spoke with us. They described retiring from full- or part-time jobs jobs and losing the ability to do some activities independently. For others, the effects of cancer care were less pronounced. Some people were able to continue activities they had pursued prior to having cancer, often in limited or different ways.

Employment impacts from cancer and treatment

Two-thirds of people we spoke with had retired either prior to their most recent cancer episode or entered into retirement once it began.

Their work encompassed a variety of professions, including carpentry, teaching, health care, research, engineering, and law. Of those who were working at the time, some stopped due to the rigor of their treatments and related side-effects. Others were able to continue working part time or from home.

> **“I had actually stopped working and was transitioning into retirement when this happened. I was a nurse executive, so I wasn't sure where I was going but obviously, this changed the path considerably and this has really become my full-time job.”**

> “I was a flooring contractor. So, once I started doing the [hormone therapy] it was kind of like, I couldn't keep up. It just takes everything out of you. So, I didn't have the energy to work anymore, and I had to finally stop.”

Impacts of cancer on caring for others

People receiving cancer treatment may be caregivers themselves. These people must manage their own treatments and symptoms while carrying responsibility for the care of a family member. People we spoke with described how cancer affected their caregiving.

> **"The day that I was given my diagnosis my sister was also diagnosed... [with] stage 4 breast cancer...I kind of forgot about me. Instead, I went into taking care of her."**

> "Me and my wife ... during this time she's had brain tumors that she's had to have taken out. She's had breast cancer along with radiation. I've been able to support her during her trials. And she's been there supporting me during mine. So, we've done fine."

> "Prior to my diagnosis I was babysitting for my great-nephew and -niece two days a week. I had to stop all that."

Impacts of cancer on independence

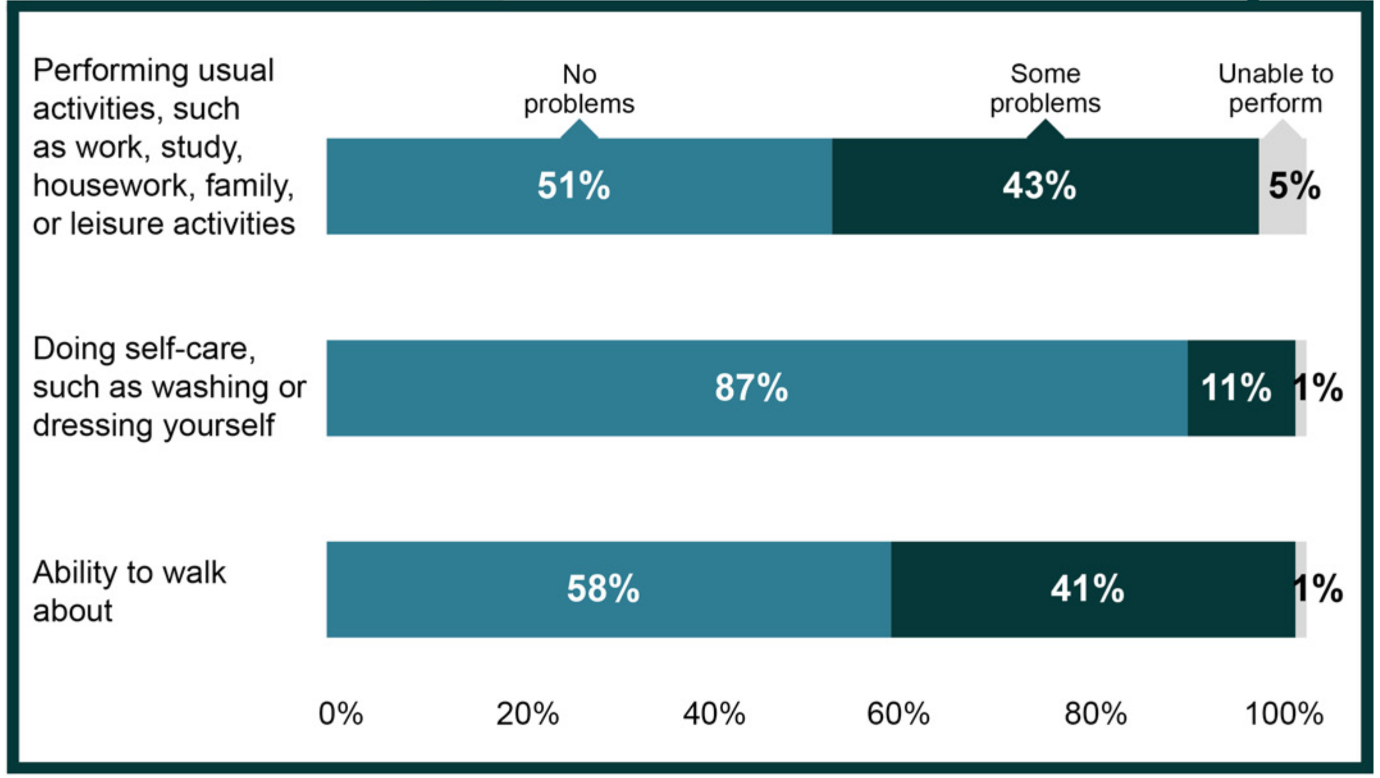
Some people talked about being self-reliant and able to manage independently, despite their cancer and treatments. These people were determined to do as much as they could themselves.

> **“I have a close friend who was [dropping] me off and picking me up after surgeries and bringing me home, but after that I basically was just taking care of myself.”**

> “It's frustrating… the hardest thing for me is losing my ability to do just about anything because I had prided myself on that, and that was kind of part of my identity…. You need something built, I can build it; you need something fixed, I can fix it. You know, just tell me what you want to do. And I've lost that. So, it's been a real adjustment.”

The interview findings align with the results of the Oncology Care Model Patient Survey. In the survey, we asked respondents whether they had problems performing their usual activities, such as work, study, housework, family, or leisure activities. Roughly half of respondents reported not having any problems with usual activities, but 43 percent had some problems performing usual activities, and 5 percent were unable to perform usual activities. Most survey respondents reported being able to independently perform self-care, although many had some problems performing activities such as housework and walking about.

ROUGHLY HALF OF OCM SURVEY RESPONDENTS REPORTED PROBLEMS PERFORMING USUAL ACTIVITIES AND WALKING ABOUT.



Source: Oncology Care Model Patient Survey (2017-2022).
Notes: N = 172,547 survey responses. Estimates were weighted for sampling and non-response.

Impact of cancer on leisure activities

While many people mentioned slowing down since beginning cancer treatment, a few spoke of interests that keep them active and busy. Some continued to enjoy activities they had pursued before having cancer, while others started new hobbies.

> **“I'm always fatigued. But I go to a pottery studio every day, and I try to keep myself moving, but by two o'clock I have to take a break. And then I kind of pick up again around five and move about again, but I'm not exactly how I used to be.”**

> “They send me to a free program that they have for cancer patients, and it is exercise. I started taking tai chi twice a week and yoga…the teachers are excellent…they're very, very, very good, very positive.”

CONCLUSION AND IMPLICATIONS

A few important themes arose in these 30 interviews, some of which overlapped with the survey responses from roughly 200,000 patients.

Most people who we interviewed were happy with the cancer care they received.

While some interview participants told us about poor experiences related to their cancer treatment, most felt that their cancer teams communicated clearly, responded to their needs, and generally provided high-quality care. This corroborated survey findings from patients treated by practices participating in the Oncology Care Model.

While most people we interviewed wanted to be active participants in making treatment decisions, people's preferences varied.

A sizeable share (9 of the 30) felt most comfortable putting their trust in their physicians and engaged minimally in the treatment planning process. A few people objected to their physician's treatment approach and advocated strongly for alternatives. Oncologists may have opportunities to enhance patient-centered care by recognizing that the processes of making care decisions, and the decisions themselves, are different for each patient.

People who live in rural areas and smaller towns often face unique challenges regarding cancer care.

Overall, patient survey results showed high scores for access to cancer care, but our interviews found that people with cancer who live in rural areas and smaller towns may have to travel long distances to receive care. Although these patients may receive their initial diagnosis after surgery at a hospital in the city, it is not always possible for them to travel there for every chemotherapy or radiation treatment. Some must rely on local providers and may therefore have fewer choices, while others rely on family and friends for transportation to treatment in distant cities.

Living situation is important.

Whether a person with cancer lives alone or has support at home or nearby, and whether they are caregivers themselves (for example, caring for an ill family member) directly affects access, care experiences, and even completion of treatment. Understanding each person's unique living situation and how it may affect transportation, resilience, and treatment decisions may help cancer care teams improve patient outcomes.

Financial issues were relatively minor.

Most people who responded to the patient survey had out-of-pocket costs below $1,000. Having Medicare, along with Medicaid or supplemental insurance, meant that the people we interviewed did not have to choose between cancer treatment and financial jeopardy.

Mental health support was the biggest gap in symptom management.

Oncology Care Model patient surveys found that care teams were less likely to address emotional problems (anxiety or depression) than other symptoms. This was the case despite the Model requirement that cancer patients be screened for depression. Several people we interviewed (some who received care from Oncology Care Model participants, and some who received care from non-participating oncology practices) also described mental health needs that their oncology care teams did not adequately address. Ultimately, improving timely access to high-quality mental health care for people undergoing cancer treatment may require broader efforts to improve mental health access throughout the health care system.

The Oncology Care Model was a six-year voluntary initiative to improve cancer care delivery and patients' experiences, while controlling costs. Additional findings from the evaluation are contained in the final evaluation report — the *Evaluation of the Oncology Care Model: Final Report*. Building on the lessons learned from this evaluation, the CMS Innovation Center launched a second initiative to improve cancer care – the **Enhancing Oncology Model**, which will run from July 2023 through June 2028.

CANCER RESOURCES

Some people we interviewed wished that they had known more about what to expect from cancer treatment, available support, and improvements in cancer care. This section provides links to a selection of resources about cancer from the federal government and other organizations.

Resources about cancer and cancer treatment

Resources for Patients (National Cancer Institute)

Landing page for resources provided by the National Cancer Institute. Provides patient focused guidance on cancer types, cancer basics, advanced cancer, diagnosis, treatment, coping, and managing cancer care. https://www.cancer.gov/resources-for/patients

National Cancer Information Service (National Cancer Institute)

The National Cancer Institute's Cancer Information Service (CIS) provides answers to cancer-related questions for patients, families, or friends. Questions can be submitted by phone, email, or live chat. https://www.cancer.gov/contact

After Diagnosis: A Guide for Patients and Families (American Cancer Society)

A guide for cancer patients and family members in the early stages of diagnosis. The guide includes information on cancer, coping, communication, treatments, and questions to ask. https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/after-diagnosis-a-guide-for-patients-and-families.pdf

Cancer Survivor Network (American Cancer Society)

The Cancer Survivor Network provides a safe place for cancer patients, survivors, caregivers, families, and friends to connect and discuss through online public forums. https://csn.cancer.org/

Older Adults Coping with Cancer (CancerCare)

Fact sheet sharing important information for older adults with cancer. Topics include managing care, support, and asking questions. https://media.cancercare.org/publications/original/291-2022_Older_Adults_Coping_With_Cancer.pdf.

Talking to Your Health Care Team about Treatment and Side Effects (CancerCare)

Fact sheet providing guidance on how to communicate with health providers about cancer treatments and side effects. https://media.cancercare.org/publications/original/335-2020_Talking_to_Your_Health_Care_Team_About_Side_Effects.pdf

Resources about government efforts to improve cancer care

Cancer Moonshot (The White House)

Landing page for the Biden Administration's Cancer Moonshot, aimed at transforming and improving cancer care. Provides progress updates and press releases for the initiative. Allows you to share your story and explore the stories of other patients. https://www.whitehouse.gov/cancermoonshot/

New Actions and Commitments to End Cancer as We Know It (The White House Cancer Moonshot)

Fact sheet outlining current progress and new priorities of the Cancer Moonshot initiative. https://www.whitehouse.gov/briefing-room/statements-releases/2023/09/13/fact-sheet-as-part-of-president-bidens-unity-agenda-white-house-cancer-moonshot-announces-new-actions-and-commitments-to-end-cancer-as-we-know-it/.

Oncology Care Model (Center for Medicare & Medicaid Innovation)

Landing page for the Oncology Care Model, a voluntary model to improve the quality of cancer care while controlling Medicare costs that operated from 2016 to 2022. The page contains fact sheets and results from an independent evaluation of the program. https://www.cms.gov/priorities/innovation/innovation-models/oncology-care

Enhancing Oncology Care Model (Center for Medicare & Medicaid Innovation)

Landing page for the Enhancing Oncology Care Model, a voluntary model to improve quality of care while controlling costs to Medicare that began in 2023. The page contains fact sheets and will include results of an independent evaluation as they are available. https://www.cms.gov/priorities/innovation/innovation-models/enhancing-oncology-model

APPENDIX

In this section we provide additional information about the research methods used in producing this report.

Interview approach

In Spring 2022, we selected over 600 people with Traditional Medicare insurance who underwent cancer chemotherapy between January and March 2021 to be interviewed. We sent them letters explaining the purpose of the interviews (i.e., that CMS wanted to learn about experiences people have while being treated for cancer) and let them know that our research team would be calling to request their participation in an hour-long telephone interview. The letter was written in English on one side and Spanish on the other. Roughly a week later, Abt Global staff began outreach calls to schedule interviews. We made recruitment calls to 504 people to schedule and complete 30 interviews. Each interview lasted approximately one hour. We offered interviewees $50 in appreciation of their time.

We conducted interviews with a diverse group of 30 people who had recently been treated for cancer. About two-thirds were female, and roughly half were between 70 and 74 years of age. The most common cancer types among them were breast cancer, multiple myeloma, and lymphoma. Six of the 30 people were enrolled in both Medicaid and Medicare, and 24 had Traditional Medicare but not Medicaid. The 30 people represented a range of races and ethnicities: 9 Black, 9 Hispanic, 5 White, and 7 identified as other races or ethnicities. Roughly one-quarter lived in a rural area. One-fifth lived in lowest-resourced neighborhoods and one-fifth lived in the most resourced neighborhoods. Half were in the midst of their first cancer treatment experience. Many had prior experience receiving cancer treatment. Additional information about the people we interviewed can be found here.

Interviews were audio-recorded with individuals' permission, as approved by Abt Global's Institutional Review Board. After completing the interviews, we coded key themes using NVivo® software.

A subset of the 2022 interviewees provided feedback on sections of a draft report in 2023. We incorporated their recommendations into the final report. Interviewees were offered $50 as a gesture of our gratitude.

Survey analysis of what matters most

Methods. The patient survey contained five composite measures calculated from responses to several survey questions related to patient experience and one single-item measure of overall satisfaction with the cancer care team (**Exhibit 1**). See **Appendix C** of the *Evaluation of the Oncology Care Model: Final Report* for additional detail on the survey questions that make up each composite. All six measures were scored on a scale of 0 to 10, where 0 was the worst possible score and 10 was the best possible score.

Exhibit 1: Validated Measures of Patient-Reported Care Experience Covered Multiple Domains

Care Experience Measures	Description
Rating of cancer care team	Single-item measure rating the cancer care team on a scale of 0 to 10.
Access	Composite measure reflecting patient experiences with the accessibility and convenience of cancer care, including between visits, after hours, and if side effects occurred.
Communication	Composite measure reflecting whether patients felt that their cancer care team respected, listened to, spent enough time with, and explained care aspects clearly to them.
Enabling patient self-management	Composite measure reflecting whether the cancer care team spoke with patients about three symptoms (pain, changes in energy levels, and depression/anxiety) and helped address symptoms when needed; also reflects whether patients spoke to their cancer care team about services to manage cancer at home and about things to do to maintain health during treatment.
Exchanging information	Composite measure reflecting whether patients felt the cancer care team explained side effects of treatment, next steps in treatment, test results, and medications.
Shared decision making	Composite measure reflecting whether patients spoke with their cancer care team about reasons to have (or not have) chemotherapy treatment, asked for their opinion about having chemotherapy treatment, and involved them in decisions as desired.

We used multivariate regression to assess how the five Oncology Care Model Patient Survey composite measures were associated with the overall rating of the cancer care team, before and after controlling for other factors.

See **Appendix C.5** of the ***Evaluation of the Oncology Care Model: Final Report*** for additional details about the methodology and findings of this analysis.

END NOTES

[1] https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2022.html.

[2] Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer Statistics, 2021. CA Cancer J Clin. 2021;71(1):7-33. doi:10.3322/caac.21654.

[3] Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. J Natl Cancer Inst. 2011;103(2):117-128.

[4] Institute of Medicine. Best care at lower cost: The path to continuously learning health care in America. Washington, DC: National Academies Press; 2013.

[5] To ensure that the sample was diverse, we stratified the sample by race, ethnicity, rural versus urban location, and Area Deprivation Index (ADI) values. ADI is a validated measure of community resources that enable better health and access to care. Unfortunately, we had no prior information about English proficiency and therefore could not deliberately select people facing this challenge to participate in interviews, but we did recruit people of Hispanic ethnicity and offered to conduct interviews in Spanish rather than English. We also had no prior information about social determinants of health, but we did try to select people living in disadvantaged areas.

[7] Nahleh Z, Lyman GH, Schilsky RL, et al. Use of biosimilar medications in oncology. JCO Oncol Pract. 2022 Mar;18(3):177-186.

[8] As explained by Demoor-Goldschmidt and de Vathaire (2019), "Improvements in cancer survival have made the long-term risks from treatments more important… Subsequent malignancies in cancer survivors now constitute 15 to 20% of all cancer diagnoses in the cancer registries."

[9] Demoor-Goldschmidt C, de Vathaire F. Review of risk factors of secondary cancers among cancer survivors. Br J Radiol. 2019 Jan;92(1093):20180390. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6435077/.

[10] Institute of Medicine. Delivering High Quality Cancer Care. Available at: https://nap.nationalacademies.org/catalog/18359/delivering-high-quality-cancer-care-charting-a-new-course-for.

[12] Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, Jemal A, Kramer JL, Siegel RL. Cancer treatment and survivorship statistics, 2019. CA: a cancer journal for clinicians. 2019 Sep;69(5):363-85.

[13] *"A lack of understandable and easily available information on prognosis, treatment options, likelihood of treatment responses, palliative care, psychosocial support, and the costs of cancer care contribute to communication problems, which are exacerbated in patients with advanced cancer."* Institute of Medicine. 2013. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Washington, DC: The National Academies Press. https://doi.org/10.17226/18359.

[14] As Harold Freeman explains in his 2012 article on the history of patient navigation, patient navigators initially helped address barriers to timely diagnosis and treatment of cancer, especially for breast cancer, and later became involved in providing support more broadly, throughout the care continuum.

Freeman HP. The origin, evolution, and principles of patient navigation. Cancer Epidemiology, Biomarkers & Prevention. 2012 Oct 1;21(10):1614-7.

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