

Pre- and Post-treatment Clinic: Providing Psychosocial Care from Diagnosis to Survivorship

In Brief

An academic comprehensive cancer program, Charleston Area Medical Center Cancer Center is the largest cancer program in southern West Virginia. In 2021, the cancer center saw 3,007 new patients (oncology and hematology) and provided chemotherapy and/or immunotherapy treatments to 1,583 new patients. Approximately 75 infusion visits are scheduled daily. The cancer center opened a new treatment clinic to offer pre- and post-treatment visits to better help patients navigate their cancer journey.

The concept of a pre- and post-treatment clinic emerged with the Commission on Cancer's (CoC) Survivorship Program Standard 4.8.¹ The CoC survivorship standard has changed throughout the years, transitioning from a focus on the number of survivorship care plans given to patients to a focus on offering a more holistic survivorship program. Since the CoC survivorship standard went into effect in 2016, many cancer programs and practices have struggled to meet its requirement of providing a survivorship care plan to at least 50 percent of cancer survivors who received treatment with a curative intent.² Successful survivorship programs adopted a model that began at the start of the patients' cancer journey—diagnosis—and then supported patients throughout their treatment trajectory.

The Charleston Area Medical Center Cancer Center Model

The cancer center's multidisciplinary treatment clinic is staffed by the Comprehensive Assistance to Resources and Education (CARE) team, which includes nurse navigators, advanced practice providers (APPs), financial navigators, a dietitian, social worker, psychologist, and chaplain. The clinic schedules newly diagnosed patients with cancer to meet all CARE team members in a single visit. The clinic also offers two visit types: a pre-treatment visit and a post-treatment visit; the CARE team provides patient education and assistance with barriers to care at both visits.

The Pre-Treatment Clinic Visit

The pre-treatment clinic visit is staffed by an oncology mid-level provider (an APP), nurse navigator, financial navigator, social worker, and dietitian. Currently, this multidisciplinary clinic

supports newly diagnosed patients with breast, colorectal, head and neck, and/or lung cancers. Patients meet many members of the CARE team in this first visit. Nurse navigators are disease-specific; patients who will be treated with an oral oncolytic meet with an oral chemotherapy nurse navigator.

Patients are scheduled for the pre-treatment visit after they meet with their medical oncologist and sign consent for their chemotherapy or immunotherapy treatment. Meeting with a medical oncologist and processing the amount of information that is provided can be overwhelming. Consenting to chemotherapy or immunotherapy is a rigorous process. Patients are provided information related to their treatment schedule, potential treatment-related side effects, treatment intent (curative or palliative), administered drugs and chemotherapy agents, education on each drug, symptom management, risks and benefits to treatment, and additional instructions like the importance of checking temperature after treatment, contact information, etc. Patients and caregivers often experience "information overload."

Typically, patients are seen for their pre-treatment clinic visit 10 to 14 days after signing their consent. The space between treatment consent and this visit is intentional, giving patients time to process the information that was provided and prepare questions about their treatment. This time is also used to conduct any additional testing that is needed prior to the start of treatment.

Ideally, bringing patients back no sooner than 1 week (5 days) and no later than 2 weeks (14 days) after the consent process means that patients are better equipped to participate in the pre-treatment visit and process treatment-related information. Patients and caregivers have had time to read through the educational material that was provided at their initial visit with their

oncologist and write down any questions or concerns they may have. Essentially, patients and caregivers receive chemotherapy or immunotherapy information and education twice before their treatment begins.

Preparing for the Pre-Treatment Clinic Visit

Prior to this visit, patients receive an email or text on their mobile device requesting that they complete a patient questionnaire from the comfort of their home. Provided by navigational software that integrates with the cancer center's electronic health record (EHR), the questionnaire includes the National Comprehensive Cancer Network Distress Thermometer and several other questions that help identify barriers to care.

Patients can take their time thinking through their concerns and are often more forthcoming about their challenges on the questionnaire compared to when they are asked these questions in person. Self-report questionnaires can be an invaluable addition to comprehensive assessment. Completion of the questionnaire prior to clinic also significantly reduces the clinic appointment time because the CARE team is made aware of patients' barriers and can research available resources or solutions ahead of the clinic visit.

Nurse navigators review this information, along with the physician note, and create a detailed treatment plan with tailored, disease-specific educational information and resources.

Though most patients access and complete the questionnaire at home, some lack the technology or internet service to do so, or they may have low literacy skills. These patients are given an iPad to complete the questionnaire in the clinic prior to meeting with the CARE team. The psychosocial support coordinator assists patients who exhibit low literacy or who need assistance for various other reasons. The psychosocial coordinator also ensures that all demographic and contact information is up to date to ensure that patients do not fall through the cracks.

The Nurse Navigator Role

During the pre-treatment clinic visit, patients first meet with their assigned nurse navigator for an initial assessment and educational session.

Prior to clinic, nurse navigators review the patient's medical record to ensure all referrals have been placed and that any ordered testing is either scheduled or completed prior to the scheduled treatment start date. This one step decreased the number of rescheduled appointments in the infusion clinic, thus decreasing treatment delays. Nurse navigators then formulate a patient-centered treatment plan using EHR data and the patient questionnaire.

During the pre-treatment clinic visit, nurse navigators meet with patients to:

- Review National Comprehensive Cancer Network Distress Thermometer results and provide education on the distress screening program
- Identify any barriers to care
- Provide a written individualized treatment plan
- Ensure that chemotherapy infusion orders are up to date
- Ensure that patients have all necessary adjunct medication

- Provide education on caring for a port site
- Provide education on percutaneous endoscopic gastrostomy tube and care
- Provide education on regimen-specific symptom management
- Provide lab orders that are needed for infusion (labs are taken on the same day if possible)
- Provide treatment calendars when regimens are complicated
- Ensure that ordered diagnostic tests, such as scans, labs, port placements, and genetic testing, are pre-authorized and scheduled
- Offer referrals to the psychologist, chaplain, or dietitian as needed
- Provide a brief overview of what to expect during patients' cancer treatment journey
- Schedule the post-treatment clinic visit for patients who qualify. (Appointments are scheduled at six weeks after treatment ends.)

"The pre-treatment clinic visit builds rapport with the patient that is hard to obtain without meeting face to face," said Lori Russell, a nurse navigator who focuses on patients diagnosed with lung, head and neck, and esophageal cancers at Charleston Area Medical Center Cancer Center. "It is an opportunity for the patient and caregiver to ask questions and receive much-needed education. Many patients have expressed their gratitude for the clinic for easing anxiety that surrounds starting [anti]-cancer treatment. Knowledge is power, which can bring much comfort in a time of chaos."

Emma Gilham, a nurse navigator who focuses on patients diagnosed with colorectal cancers at Charleston Area Medical Center Cancer Center, shared a similar sentiment: "Patients love that they can share their story and discuss their concerns with us. We have been able to review processes to ensure that patients are scheduled and seen in a timely manner."

The Financial Navigator Role

Prior to clinic, financial navigators research patients' insurance to ensure adequate coverage. If there are out-of-pocket costs, financial navigators run the treatment plan on a computer program, NEXT Bar, to obtain a breakdown of patients' insurance plan details, including benefits and total out-of-pocket costs. Armed with this information, financial navigators can assist patients with their healthcare costs. Options may include internal and/or external patient assistance, pharmaceutical manufacturer-based assistance, and Medicaid as secondary coverage. Financial navigators also help file claims for cancer and critical illness policies, and they counsel patients on applying for Social Security Disability.

Meeting with the financial navigator at the onset of patients' treatment journey helps ease anxiety about treatment-related costs. The literature shows that patients often receive less information related to treatment costs than other aspects of treatment.³ By meeting with financial navigators prior to treatment, patients have a chance to address any cost-related concerns.

The Social Worker Role

The oncology social worker assesses patients' social and economic situations, identifying barriers to their healthcare to help identify needed services, including:

- Home health services
- Outpatient palliative care
- Medicaid waiver for caregivers
- SNAP (Supplemental Nutrition Assistance Program) benefits
- Medicaid application assistance
- Durable medical equipment
- Transportation arrangements
- Lodging assistance (based on need and guidelines)
- Advanced medical directives
- Available community resources.

The Dietitian Role

The dietitian provides nutrition education before, during, and after patients' anti-cancer treatment. All patients who have head and neck cancers meet with the cancer center's dietitian; all other oncology patients are offered appointments as needed. During the pre-treatment clinic visit, the dietitian:

- Provides education on healthy eating and how to shop for and prepare healthy meals
- Provides education on the potential nutritional side effects of specific anti-cancer treatments and offers tips on managing those nutritional side effects
- Dispels common nutrition myths that contribute to nutritional anxiety during treatment
- Educates patients with prophylactic feeding tubes on nutrition via the feeding tube
- Schedules follow-up appointments as needed.

"The pre-treatment clinic visit is extremely beneficial for the patient and support person," said Margaret Loftis, a registered dietitian at Charleston Area Medical Center Cancer Center. "It allows the patient and support person to meet members of the CARE team, have questions and concerns addressed, and receive crucial information that will assist them throughout treatment. Several patients have expressed to me the benefits of the pre-treatment clinic visit. They feel less stressed and more prepared for treatment. Some patients have mentioned that because of the amount of information received, it can feel a little overwhelming at times. These patients are encouraged to follow-up to review information as needed."

The Mid-Level Provider Role

The APP (nurse practitioner or certified physician assistant) provides medical care during the pre-treatment clinic visit. This care may include:

- Conducting physical assessments
- Entering orders for any referrals (port placement, physical therapy, etc.)
- Reviewing lab work
- Prescribing needed medications
- Addressing health concerns

- Counseling and/or educating patients on their expected treatment course.

Referrals to Psychological and Spiritual Support

These referrals are made on an as-needed basis. The pre- and post-treatment clinic visits incorporate a large amount of information, and patients often need time to digest this information before participating in additional appointments.

Patients are referred to behavioral health services when habits, behaviors, stress, worry, and/or emotional concerns about physical or other life problems interfere with their daily life or anti-cancer treatment. Patients can meet with the clinical psychologist to participate in individual or group-based, cancer-specific behavioral health treatments either in person or via telehealth. Presenting concerns include anxiety about treatment, anxiety about recurrence, depression, loss of meaning, and other mental health concerns. The psychologist works closely with the medical oncologist to evaluate the mind-body-behavior connection and provide brief, solution-focused interventions.

Often, patients exhibit spiritual concerns throughout their cancer journey. They question, "Why me? Why now? What have I done wrong? What happens next? Why does God hate me?" Ken Toler—the chaplain at Charleston Area Medical Center Cancer Center—helps people through this dark time in their lives. By providing spiritual intervention, he brings a sense of hope and light into their situation. Toler said, "I help them [patients and caregivers] work through the questions they have. As we walk these paths, we find out that bad things happen to good people. No matter how hard we try, we live in a world that sometimes is hard and hard to understand. We do our best to shed a little light on the dark place to see our future a little clearer." Patients can schedule in-person or telehealth visits with the chaplain and seek chaplaincy support during infusion services.

The Post-Treatment Clinic Visit

Prior to implementation of the pre-treatment clinic visit, identifying and scheduling appropriate patients for a post-treatment clinic visit presented a huge challenge. Now all patients who receive treatment with a curative intent are scheduled for a post-treatment clinic visit at their estimated completion of treatment, ensuring that survivorship care is introduced early on and patients are not missed.

The post-treatment visit focuses on:

- Identifying and managing long-term and late treatment effects
- Educating patients about the importance of monitoring for cancer recurrence
- Screening for new cancers.

Patients receive a survivorship care plan, and the visit includes education on how to optimize their health and quality of life. A copy of the survivorship care plan is provided to patients' primary care providers for coordinated, patient-centered care. Patients are scheduled six weeks to eight weeks out at their anticipated post-treatment completion, which allows enough time for them to complete scans and follow-up appointments with their medical oncologist. Survivorship care plans are prepared by the nurse

navigator and reviewed by the mid-level provider for accuracy. The nurse navigator and mid-level provider participate in the post-treatment clinic visit together to identify patients' needs and address concerns experienced after treatment completion. The survivorship care plan is compiled using medical documentation from the EHR and a secondary software, which includes patients' questionnaire responses. The result is a plan that provides:

- Educational content addressing the specific needs of the patient
- Follow-up and screening schedule recommendations
- Access to resources for optimizing any ongoing survivorship needs
- Referrals to supportive services, including physical therapy, survivorship support groups, nutrition, and any other concerns that may affect coping with cancer survivorship.

Benefits of the Pre- and Post-treatment Clinic Visit


- **A 15 percent reduction in treatment delays.** Since implementing the pre- and post-treatment clinic, delays in scheduling chemotherapy and immunotherapy infusions decreased by 15 percent. The pre-treatment clinic visit helps to identify and resolve potential delays, such as incomplete labs, missing scans, port placement, and cardiology and dental clearance.
- **Positive feedback from patients and staff.** Many patients state that at the end of their pre-treatment visit they feel more prepared and have less anxiety and uncertainty about their first infusion and/or radiation therapy appointment. Patients who participate in telehealth clinic visits appreciate being able to access resources from their home without having to travel multiple times to the cancer center, which can become costly or prohibitive. Staff in the infusion suite and clinic have verbalized that they are seeing reductions in first-dose scheduling issues that were resulting in delayed patient care. The CARE team now provides needed services to patients in a more efficient manner.
- **Improved psychosocial distress screening.** CoC Psychosocial Distress Screening Standard 5.2 requires that all patients be screened for psychosocial distress at least once during the first course of treatment.⁴ By screening at the pre- and post-treatment clinic visits, we ensure that all patients are being screened at pivotal moments in their cancer journey in a meaningful way. Moreover, all patients receive education on the rationale of distress screening and have contact information for whom to reach out to in the future. Essentially, the CARE team is connecting the survivorship and psychosocial distress screening standards.
- **Patients meet with multiple providers and CARE team members on the same day, which reduces the number of visits and ensures that patients' needs are met.**

Limitations of the Pre- and Post-Treatment Clinic Visits

- **Cancer types.** The pre- and post-treatment clinic is limited to certain cancer types: breast, lung, colorectal, and head and neck cancers. We are currently piloting the treatment clinic to meet the top cancer types seen in our cancer center, but there are many cancer types that are not included. We want to ensure

that we can address the top cancer types and staff these appointments before incorporating other cancer types.

- **Time.** Another limitation includes time spent by the CARE team when preparing for clinic. Preparation by the navigators for the clinic can be intensive, and it can be frustrating when patients do not attend the visit. Though there is a preferred vendor add-on software to the clinic's EHR that pulls data for plan preparation, many data fields still require manual transfer of patient information, which is vital for building an individualized patient care plan.
- **Telehealth.** The option of telehealth services has helped ensure that more and more patients attend these pre- and post-treatment clinic visits. However, there are limitations to telehealth use. Many patients do not have access to computers or mobile devices. Some who do have access to these devices may not have the needed data or internet service for proper use. Telemedicine hubs are available at four locations in the state to connect patients with telehealth clinic visits.
- **Staffing.** Serving all cancer diagnoses requires additional staffing and clinic space. Additional nurse navigators, as well as a dedicated APP and medical assistant, are needed for clinic expansion. Availability of additional clinic rooms within the cancer center to expand scheduling days has stunted the growth of pre- and post-treatment clinic because we are often scheduled to capacity for oncology clinic appointments.
- **Billing.** When staffed by the mid-level provider, these visits are billable; however, due to staffing issues, there are times when the APP is pulled to cover other areas of the cancer center. When this occurs, patients are still seen in the clinic by the CARE team, which ensures that all education and referrals are made, but the appointment cannot be billed.

The CoC survivorship program standard encourages continual goals related to supporting survivors of cancer. By starting at diagnosis with the pre-treatment clinic, we can identify and provide care throughout the cancer care continuum, including at the post-treatment clinic visit. We are excited to see where the future takes this clinic. 

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Telehealth

Telehealth services rapidly expanded during the COVID-19 pandemic, owing to the need to reduce in-person visits to minimize the risk of viral exposure and transmission, as well as a shift in government and payer policies.² The U.S. Centers for Disease Control and Prevention identified a 154 percent increase in telehealth visits among four of the largest telehealth providers during the last week of March 2020 compared with the same week in 2019. Similarly, centers funded by the Health Resources and Services Administration demonstrated a 95.4 percent increase in telehealth visits in mid-July 2020 compared with the same week in 2019. However, despite these reports, nearly 50 percent of patients who participated in the ACCC survey indicated that they had not interacted with any of their cancer care providers through telehealth visits. Of the 52 percent of patients who had used telehealth, 34 percent stated a continued preference for in-person visits. Among providers, 65 percent reported using telehealth with their patients, but that most patients prefer in-person visits. Just 13 percent of providers stated that they had not used telehealth with their patients. Post-pandemic, patients were divided on whether they preferred future healthcare visits to be held only in-person or a hybrid model of in-person and telehealth visits, while 75 percent of providers preferred a hybrid model.

Among all survey respondents (patients and providers) who had not participated in telehealth visits, the primary reason provided was a preference for in-person interaction and that the healthcare practice/institution did not offer a telehealth option.

Biomarkers and Treatment

The National Comprehensive Cancer Network (NCCN) clinical practice guidelines for CLL/small lymphocytic lymphoma recommend biomarker testing for chromosome 17p deletion (del[17p]) by fluorescent in situ hybridization (FISH), TP53 and IGVH mutation status through DNA sequencing, and CpG-stimulated karyotype to provide important prognostic information.⁵

In the ACCC survey, most patients (71 percent) and providers (65 percent) confirmed that biomarker testing had taken place before treatment options were discussed. However, while 65 percent of patients reported that they understood the critical importance of biomarker testing before any treatment decisions are made, many providers underestimated their patients' understanding of this critical importance. One-third of providers (34 percent) believed that their patients understood biomarker testing to be "somewhat important," while 20 percent of providers believed that their patients were "not sure if it [testing] is important."

With regards to treatment, the initial strategy is based primarily on Rai Stage.⁵ For patients with a low to intermediate risk Rai Stage (0-II) who are asymptomatic, have good organ function, and do not have hematologic signs for therapy, the recommended treatment approach is "watch and wait" or active surveillance. While eligible patients indicated that their providers explained the meaning of this approach, many providers had misperceptions about the feelings that this treatment elicits among patients. Providers believed that confusion was the most typical response of their patients, when in fact most patients (48 percent) reported feeling relieved more than any other emotion, followed by anxiety (37 percent) and then confusion (25 percent).

While both patients and providers agreed that one of the biggest personal challenges for patients during the "watch and wait" approach was anxiety and worry about what may happen in the future, there was a disconnect between providers and about what other personal challenges patients faced. Many providers (70 percent) believed that patients found the task of explaining the "watch and wait" approach to others a major challenge, however, only 42 percent of patients identified that as a personal challenge. Instead, 62 percent of patients identified anxiety and worry about the future as their biggest personal challenge, with others being maintaining good mental health (32 percent) and concern about potential financial and health insurance impacts (27 percent). As a result, these differences may impact the type of education, support, and other resources that providers offer or recommend to their patients.

For patients who show indications for a need for treatment, NCCN first-line treatment recommendations include acalabrutinib with or without obinutuzumab, venetoclax plus obinutuzumab, ibrutinib, or zanubrutinib.⁵ Treatment selection among these options include considerations about efficacy, safety, administration, and costs. Patients reported overall survival after treatment, limited treatment duration, and treatment location (orally at home vs. infused center) as the most important factors when considering treatment options (see Figure 1, last page of this article). Patients also rated a chemotherapy-free regimen, and the severity of side effects as important. Treatment costs were considered less important. By contrast, providers considered the efficacy of treatment as the most important consideration, followed by treatment cost, and severity of treatment side effects.

Furthermore, while more than half of providers (54 percent) recognized that patients preferred to seek a second opinion from a CLL expert before making a treatment decision, an overwhelming majority of patients (80 percent) indicated this preference.

Finally, both patients and providers indicated that at least half of patients were somewhat knowledgeable about clinical trial participation at their initial consultation. This highlights an opportunity for providers to educate patients about clinical trials and whether they may be eligible.

Impact of the COVID-19 Pandemic

In the initial period of the COVID-19 pandemic, there was great concern that patients with CLL might be at higher risk for contracting the virus and for developing severe COVID-19 or death because patients with CLL are typically older, with a median age of 70 at diagnosis, and are likely to have comorbidities. In addition, clinicians hypothesized that the immunosuppressed state due to hematologic malignancy and its treatment could put patients at greater risk.³ It is now known that patients with CLL do not appear to be at any greater risk of contracting COVID-19 compared with the general population, but if patients contract the virus, they are at greater risk of poor outcomes.^{1,4} Hematologic malignancy results in a reduced immune response to the virus and its vaccine.

In the ACCC survey, both patients (82 percent) and providers (66 percent) rated increased mortality risk associated with COVID-19 as the greatest challenge that impacted patients personally. Patients were also concerned about contracting COVID-19, including more than half of patients reporting concerns about what might happen if or when they needed to go out in public or needing to go to healthcare visits during the pandemic. Patients also expressed frustration around the lack of information about the effect of COVID-19 on patients with CLL (43 percent).

While providers reported similar concerns for their patients, they also felt that their patients were challenged by social isolation and had concerns about vaccines.

At the time of the survey, 86 percent of patients reported that they had already been vaccinated against COVID-19, while another 11 percent indicated that they planned to get vaccinated. Only 2 percent of providers stated that they did not believe there was adequate clinical data to recommend COVID-19 vaccination for their patients with CLL who were undergoing active treatment.

Quality of Life

Overall, most patients (78 percent) rated their QOL as very good or good while living with CLL. Just 8 percent of patients reported that their QOL was poor or very poor. Interestingly, providers generally underestimated patient QOL, as 51 percent of providers believed their QOL was good and 23 percent

believed QOL was poor. Only 8 percent of providers reported that their patients had a very good quality of life while living with CLL.

Conclusion

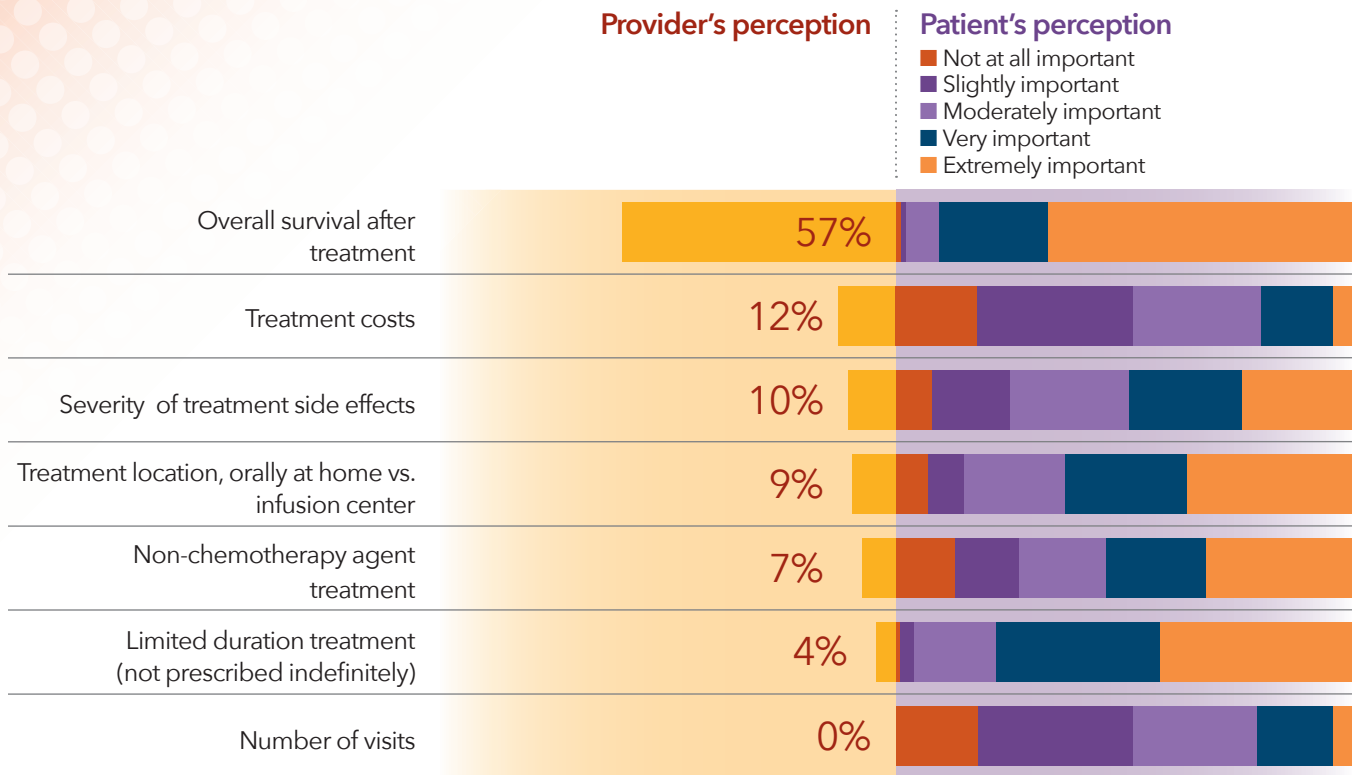
Supporting patients with education materials, training, lay navigation, and community resources promote patient autonomy and respect the patient's role as co-equal partner in shared decision making on the best course of care. Gaps in perception between patients and providers with respect to beliefs and attitudes about quality of life, the need for patient education and provision of materials and resources, the use of telehealth, the impact of the COVID-19 pandemic on disease management, and understanding challenges related to biomarkers and treatment options were identified through the ACCC surveys.

While both providers and patients value shared decision making, differences persist. These differences may be attributed to a gap in communication, underestimating patients' knowledge and experience, and understanding and addressing expectations, and may result in misinterpretation of needs. These findings suggest that while progress has been made in aligning patient preferences and providers' delivery of quality cancer care that respects patients as an equal partner in shared decision-making, there remains significant room for further improvements. Understanding and analyzing where these gaps persist can aid providers in bridging the divide and developing targeted education, resources, and training to improve the overall patient care journey.

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FIGURE 1. Which is the most important factor when considering treatment options?



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