

Are We Speaking the Same Language? INSIGHTS FROM A PATIENT AND PROVIDER SURVEY ON CLL

A patient's journey through cancer is more than the sum of its parts; while diagnosis, treatment, and outcomes chart the path, the people—physicians, nurses, navigators, social workers, and caregivers—who are integrally involved in decision making, knowledge sharing, and cancer care support shape the patient experience. Although treatment options for patients with chronic lymphocytic leukemia (CLL) have improved outcomes and prolonged survival, it is important to consider other aspects of the patient journey to understand how providers can better serve their patients. The Association of Community Cancer Centers (ACCC) conducted an educational initiative focused on garnering insights into the journey of patients with CLL and to dive deep into the conversations and perceptions of providers and patients. This article explores its findings across a broad spectrum of issues, including knowledge sharing and support on diagnosis and treatment, the use of telehealth, biomarkers, the impact of the COVID-19 pandemic on disease management, and quality of life (QOL).

Provider and Patient Surveys

Patient and provider surveys were conducted in early 2022 to identify barriers and challenges to care experienced by patients with CLL, as well as pinpoint disparities in the patient and provider perceptions of the care journey, with the aim of developing targeted education, resources, and training to improve overall care. Both surveys posed similar questions to participants to determine if gaps exist between the patient and provider perspectives of the patient journey.

The patient survey garnered 114 responses from patients diagnosed with CLL. All patients were at least 21 years of age. The provider survey garnered 99 responses, comprising medical oncologists (42 percent), advanced practice providers (13 percent), oncology nurses (10 percent), and a mix of social workers, radiation oncologists, pharmacists, surgeons, nurses, financial counselors, patient navigators, and administrators (35 percent). Excluding training years, 47 percent of providers reported having 5 to 10 years of experience as a healthcare professional in a cancer program, while 22 percent had 11 to 20 years, 21 percent had 1 to 4 years, and 9 percent had more than 20 years of experience.

With regards to the number of patients with CLL treated per year, 48 percent of providers reported treating 51 to 75 patients, 21 percent treated 76 to 100, 16 percent treated 1 to 25, 11 percent treated 26 to 50, and 3 percent treated more than 100 patients per year.

Most providers were affiliated with cancer programs located in an urban area, while just 8 percent and 4 percent of providers were in suburban and rural areas, respectively. Cancer programs were community-based (52 percent), academic and/or a National Cancer Institute (NCI) cancer program (24 percent), private practice (19 percent), or part of a Veterans Affairs program (4 percent).

Patient Education and Support

Work-up and diagnosis of CLL marks the beginning of the patient journey. Cancer care teams provide patient and caregiver education on the disease and what it means to the patient, which creates an important foundation for shared decision making for treatments. While these provider-patient discussions are consistently taking place, there is a clear disconnect between what information is shared by providers and what information is received by patients (see Figure 1, page 4). Most providers (76 percent) maintained that they answered all patient questions, yet just over half of patients (54 percent) reported that all (or nearly all) of their questions had been addressed at the time of diagnosis. Because patients are often overwhelmed at their initial visit and may not fully retain information shared by their provider about their disease and treatment options, it is therefore critical that patients are informed on where and how to access evidence-based CLL-specific information from other trusted resources. While providers (58 percent) reported that they provided a direct referral to ancillary services for additional support and over half stated they supplied printed materials and shared supportive resources, such as Patient Power, the CLL Society, the Leukemia and Lymphoma Society, and CancerCare, nearly all patients (95 percent) reported that they did not receive a direct referral and an overwhelming majority of patients (75 percent–85 percent) stated they were not provided with printed material or lists of supportive resources.

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 (see Figure 2, page 4). 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 (see Figure 3, page 5). 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," (see Figure 4, page 5).

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), (see Figure 5, page 6).

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 (see Figure 6, page 6). 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 7, page 7). 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 (see Figure 8, page 7).

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 (see Figure 9, page 8). 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 (see Figure 10, page 8). 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. What was provided at the time of CLL diagnosis?

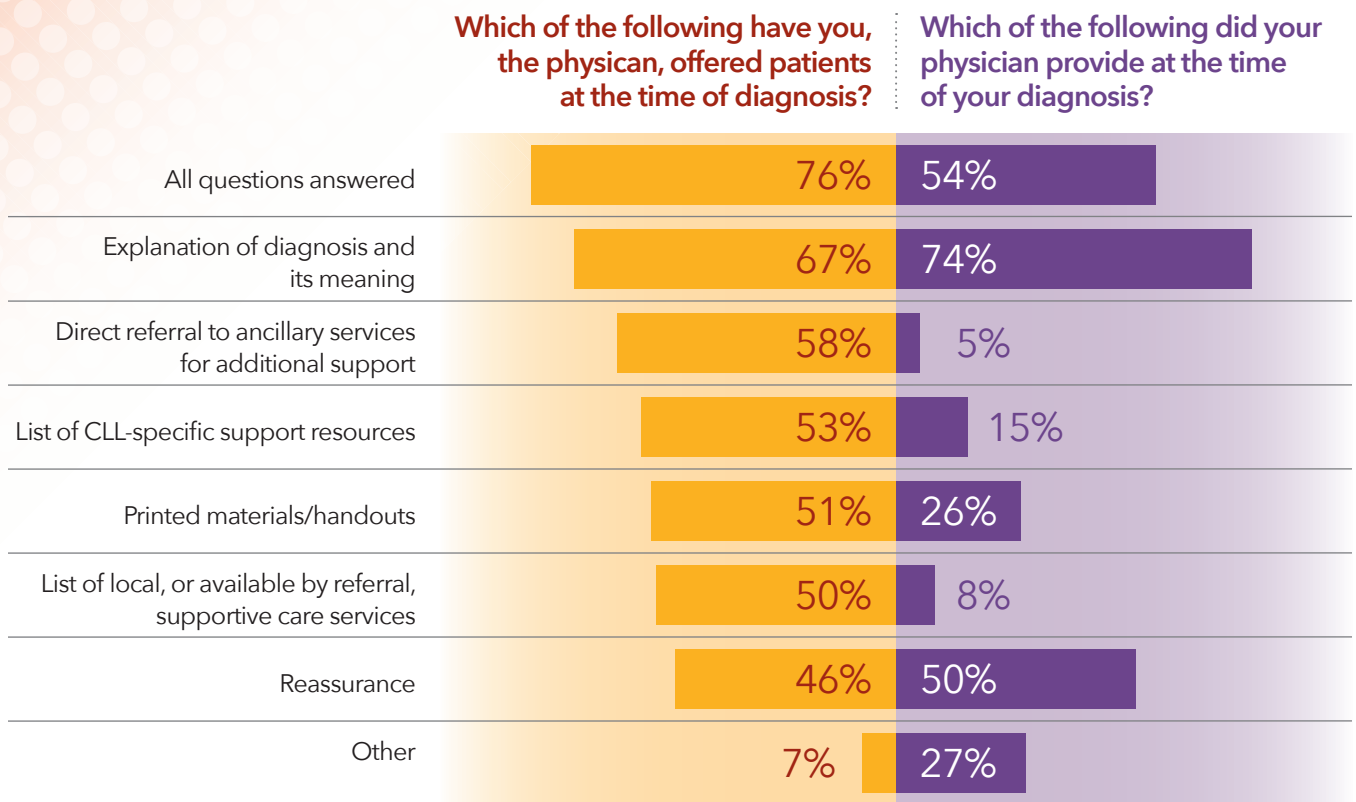


FIGURE 2. Telehealth Visits

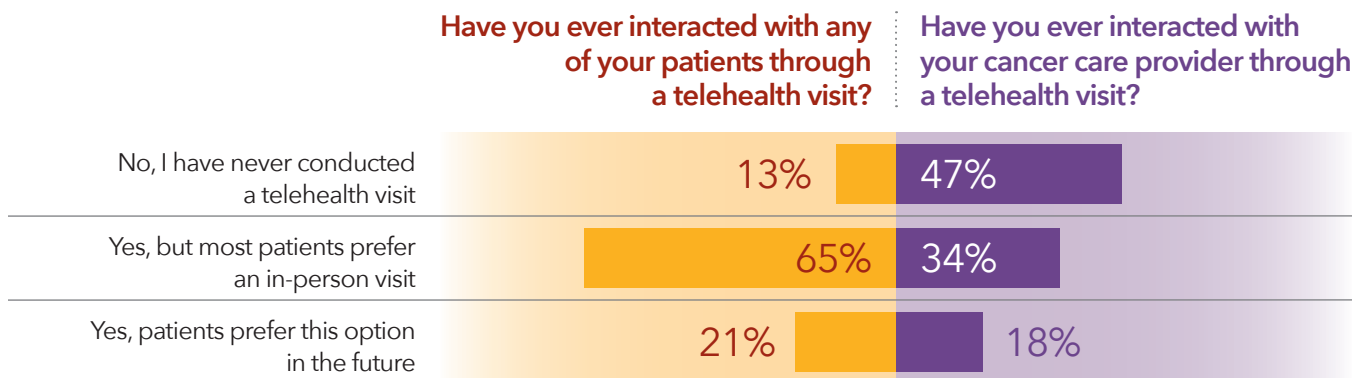


FIGURE 3. Biomarkers

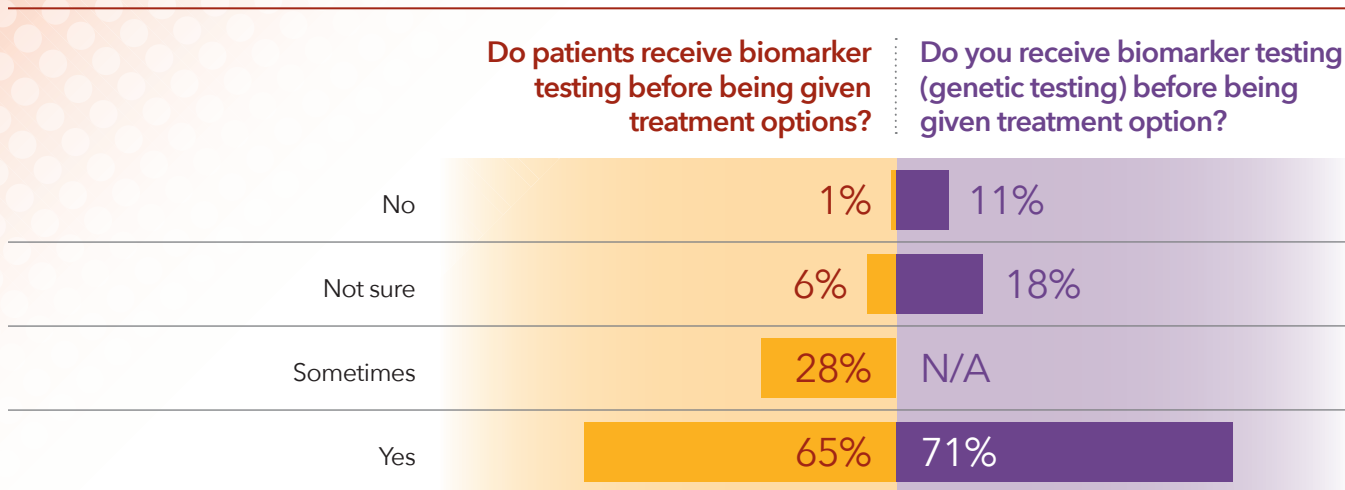


FIGURE 4. Understanding Biomarkers

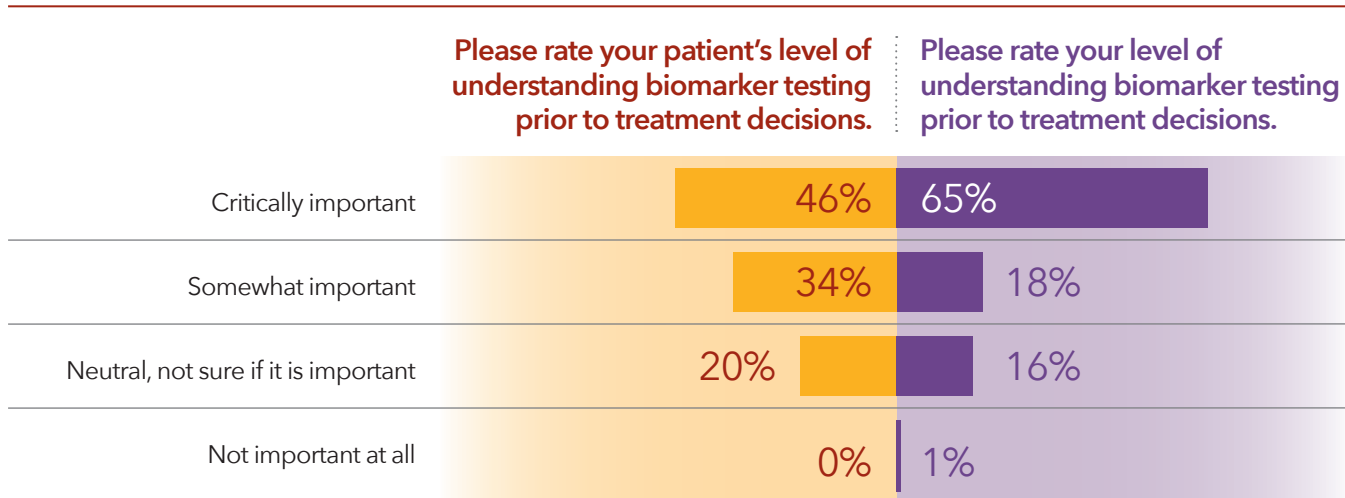


FIGURE 5. Response to being told that immediate treatment was not needed

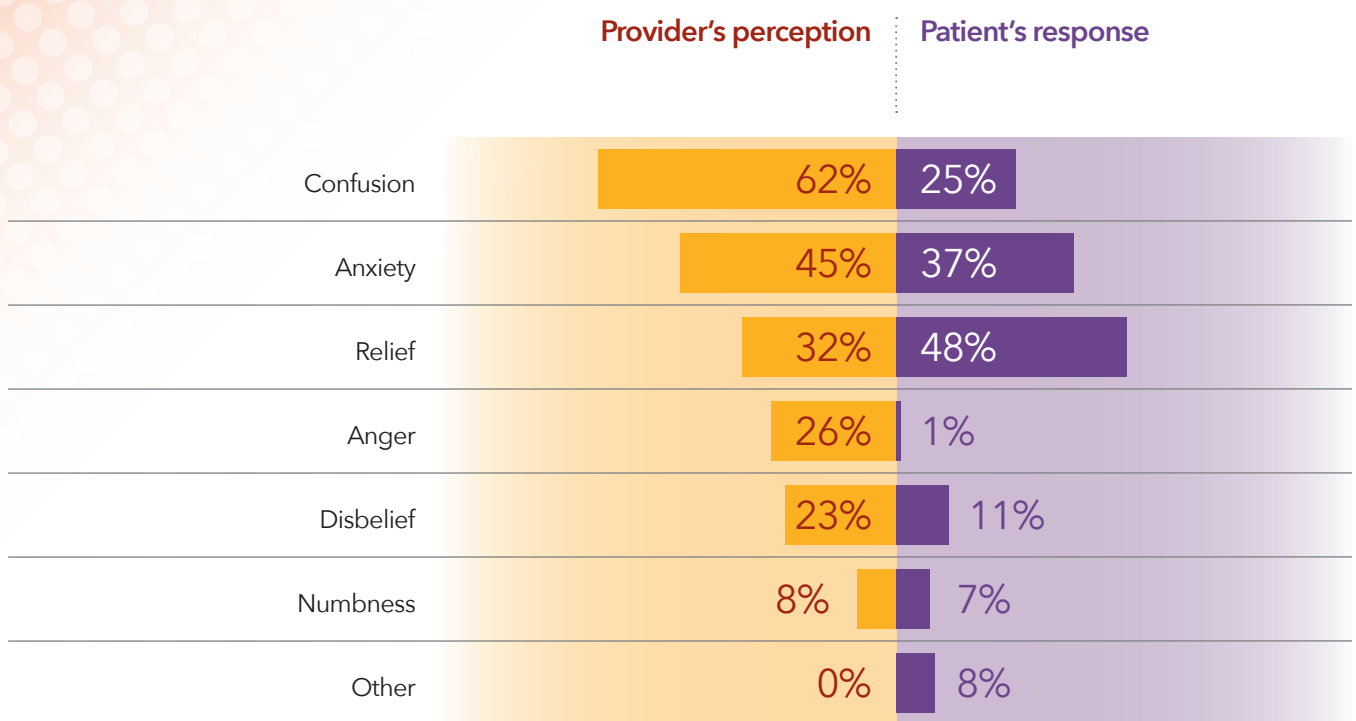


FIGURE 6. Personal challenges to "Wait & Watch" period

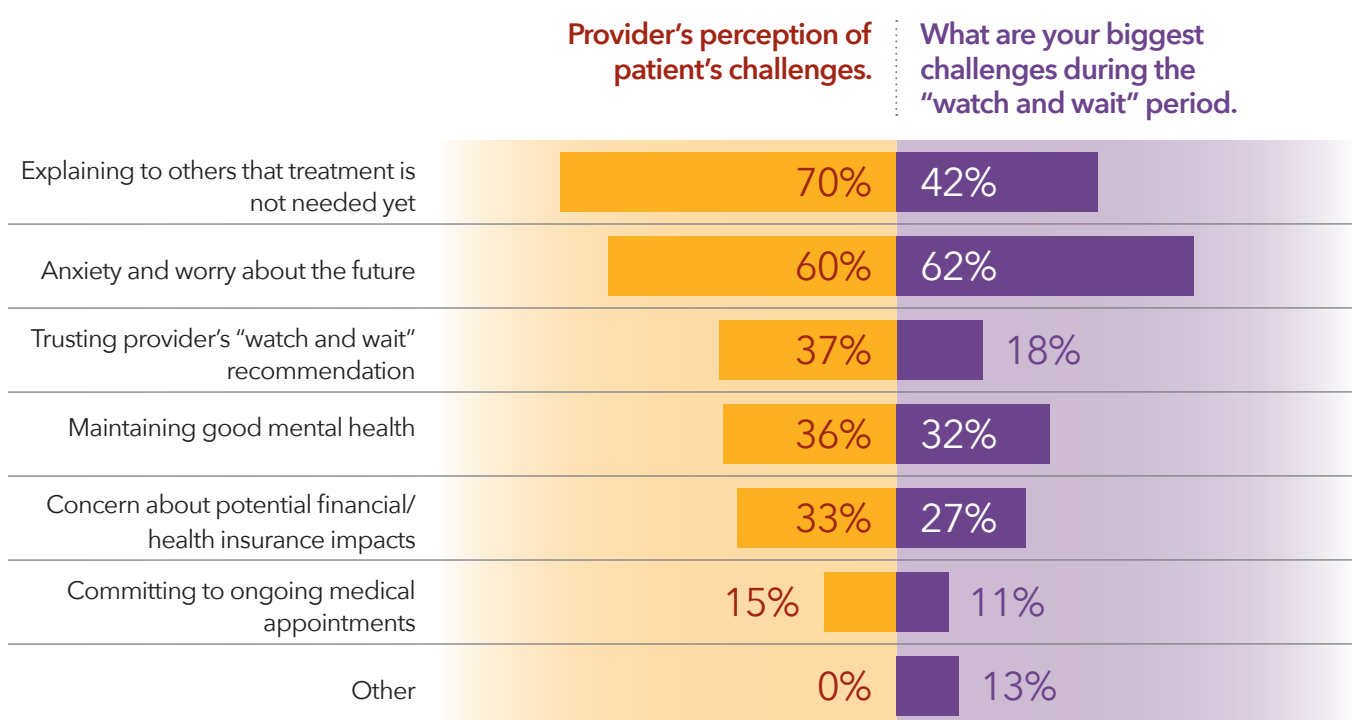


FIGURE 7. Which is the most important factor when considering treatment options?

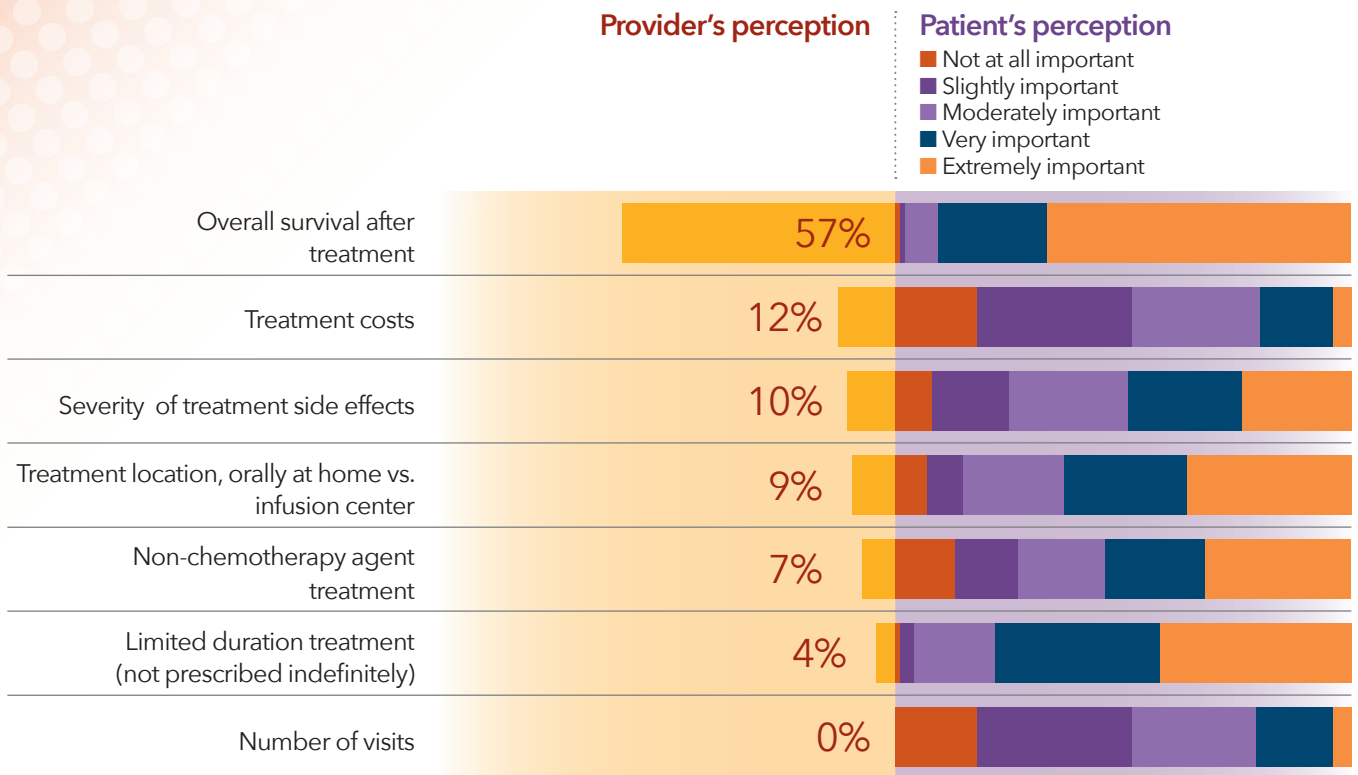


FIGURE 8. Second Opinions

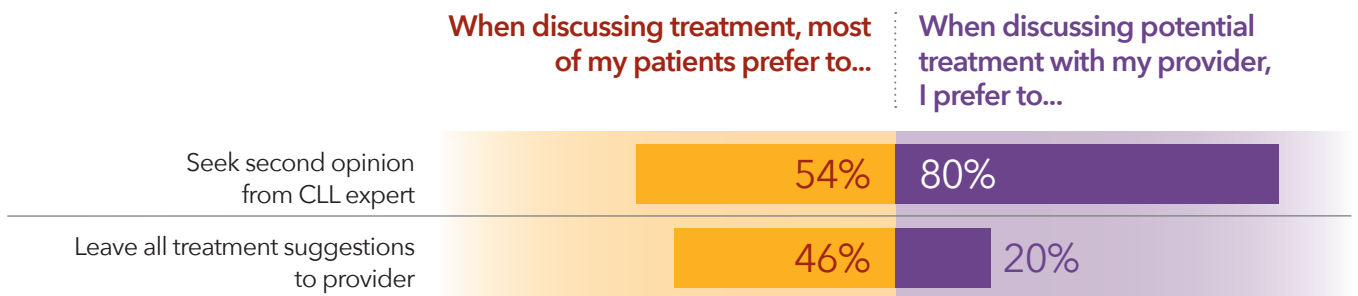


FIGURE 9. Challenges Faced During the COVID-19 pandemic

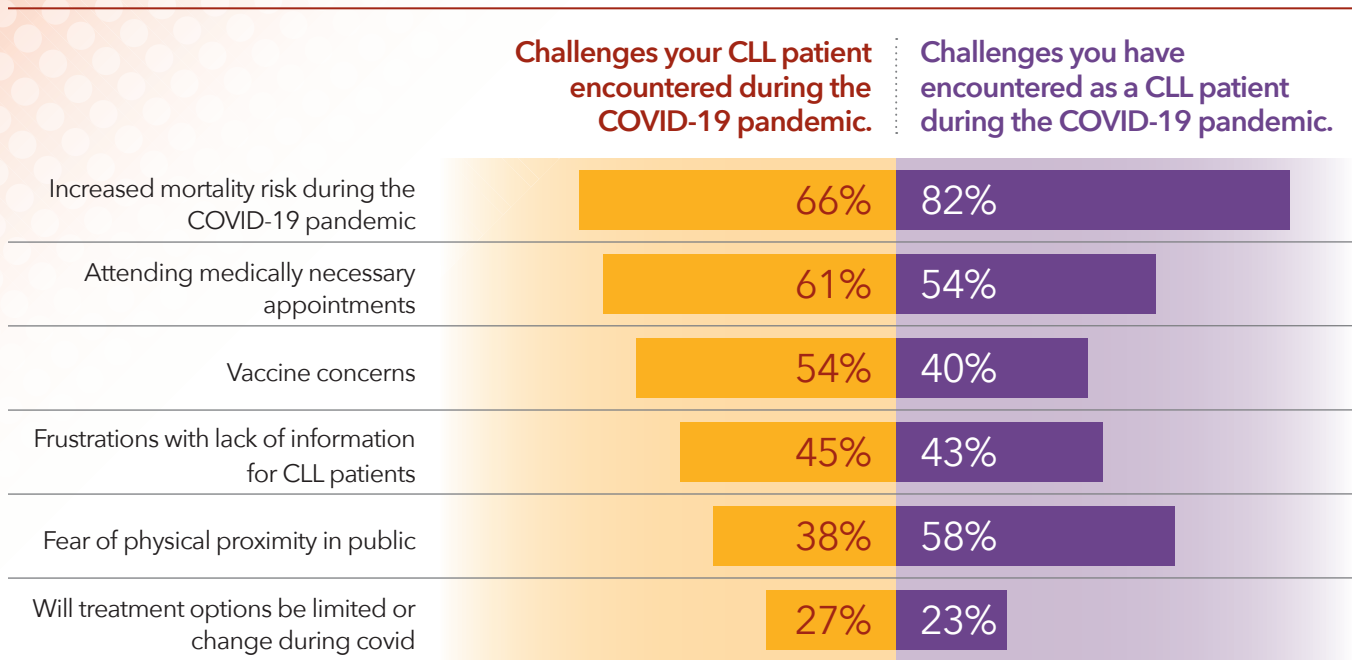
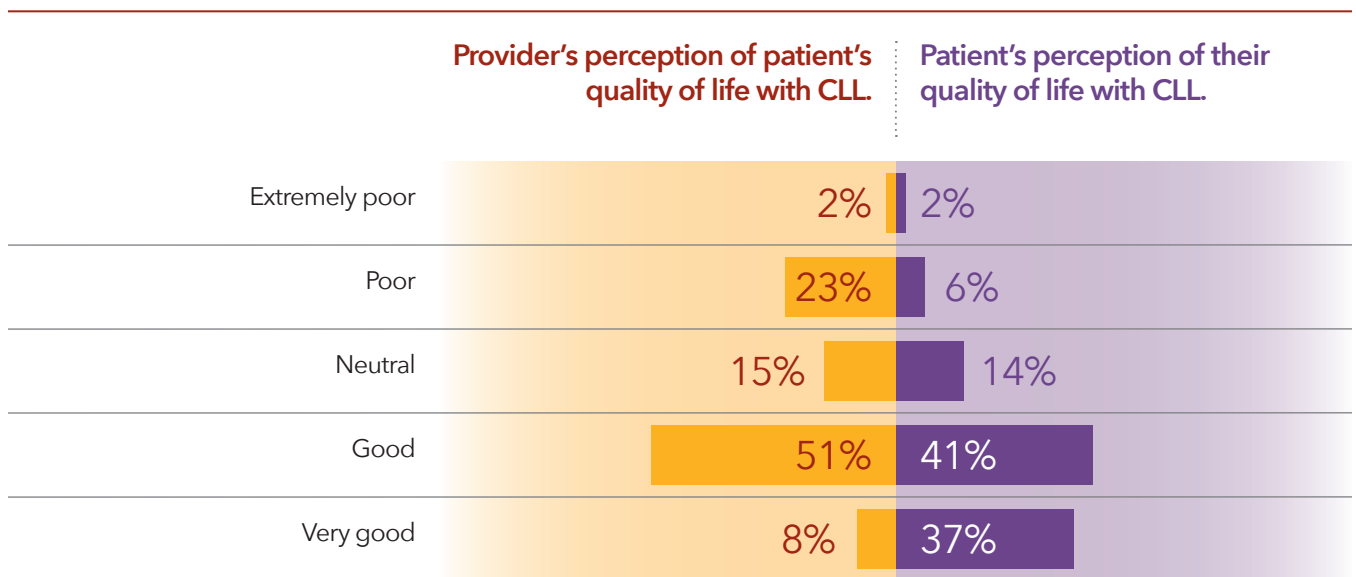


FIGURE 10. Overall Quality of Life with CLL



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