



REFRAMING THE CONVERSATION

Navigating the New Landscape
of Diffuse Large B-Cell
Lymphoma

By Nicole Colwell, MD

Despite being known as the most common and aggressive type of lymphoma, diffuse large B-cell lymphoma is widely considered curable. A remarkable 60% to 70% of patients diagnosed with this disease are cured with first-line therapy.¹ Given that treatment for this diagnosis is so likely to be effective, it is crucial to empower patients and their caregivers with information regarding prognosis and to set expectations for treatment. To maximize patient outcomes and enact the most impactful treatment plans, effective communication between patients and providers is essential. Toward that end, leaders from the Association of Cancer Care Centers (ACCC) and the Leukemia and Lymphoma Society (LLS) coordinated a joint effort to explore best practices for patient-provider communication to establish rapport, gain trust, and empower patients with a thorough understanding of expectations during diagnosis and treatment.

In September 2023, ACCC held focus groups in partnership with LLS to explore how cancer programs and practices could reframe the conversation between patients and providers. One focus group was held with members of the multidisciplinary cancer care team, and 2 focus groups were held with patients and patient advocates. Focus group discussions examined 4 key categories:

- Involving involvement of multidisciplinary care teams
- Communication about the diagnosis
- Discussions about treatment options
- Monitoring of treatment and provision of psychosocial support.

Multidisciplinary Care Teams

Focus group participants identified the need for a comprehensive lymphoma care team to ensure adequate biopsy sampling, ancillary testing, and treatment planning. Regardless of where care is received (eg, large tertiary care centers vs smaller cancer programs), effective communication across the care team is necessary to prevent misinformation or conflicting medical advice.

Nurse navigators were recognized as a crucial component of care coordination, especially during the initial diagnostic process when ancillary tests may be required to tailor treatment plans. In addition to providing support during diagnosis, nurse navigators also can help patients retrieve outside medical records, facilitate access to assistance programs, and help coordinate appointments when patients require multimodal treatment. In some cancer programs or practices, navigation tasks may be distributed across a team of nurses, social workers, and other members of the care team.

In addition to nurse navigators, social workers can address psychosocial concerns and help patients with finding and applying for financial assistance programs or coordinating with transportation services. More, as the treatment journey for patients with diffuse large B-cell lymphoma is often lengthy and possibly associated with treatments that affect the heart, clinicians from the sections of cardio-oncology and integrative oncology should be included in the care team.

Communicating the Diagnosis

The ideal provider-patient conversation should begin with the provider asking how much detail patients would like to receive about their diagnosis.² This question allows the provider to tailor the conversation and adjust the level of information so that patients are not overwhelmed. Some patients who have a greater level of health literacy and knowledge about lymphoma may want to learn more about the specifics of the diagnosis, whereas others may prefer to receive a general overview. Experts recommended the following measures to effectively communicate with patients during diagnosis:

- Recognize that patients have different levels of health literacy and awareness about lymphoma.
- Ask patients about their concerns during the initial visit and acknowledge that these subjects are likely to experience strong emotions (eg, shock and fear). By building trust and rapport with the patient, providers can better explain the diagnosis, prognosis, and treatment options.
- Incorporate brochures, education materials, and resources like LLS support groups so that patients can learn more about their diagnosis and receive additional support.
- Let patients know that test results may become available on the patient portal before they have a chance to speak with their providers. Some patients may prefer to see their results, and others may prefer to wait and discuss results with their providers.

Discussing Treatment Options

When discussing treatment options with patients, providers should incorporate principles of shared decision-making to align their treatment plans with patients' goals and preferences.³ Providers should prepare patients for their treatment journey by explaining that it may be lengthy and include multiple modalities (eg, chemotherapy, radiotherapy).

Several patients shared stories about hearing conflicting recommendations from cancer providers. For example, 1 patient was told

by a radiation oncologist that radiotherapy would be beneficial, but their medical oncologist did not think that the potential benefits outweighed the potential risks. This difference in opinion made the patient feel confused and frustrated. Patients found it comforting when their providers explained plans to adjust therapies if the initial treatment was not effective. After learning about additional treatment options (eg, transplant, bispecific antibodies, or chimeric antigen receptor [CAR] T-cell therapy), patients felt more hopeful about their long-term prognosis.

Focus group participants offered the following recommendations for effectively communicating with patients when discussing treatment options:

- Appreciate that, in an ideal setting, the entire multidisciplinary treatment team would meet with the patient and recommend a coordinated multimodal treatment plan (eg, an integrated multidisciplinary clinic practice model for cancer care). If they cannot offer a group meeting, providers could hold a video conference that includes medical and radiation oncology professionals to discuss treatment recommendations with patients and caregivers.
- Encourage patients to be very clear about their treatment goals. Some patients are able to voice this, yet others may need to consider the potential risks vs benefits of treatment to make certain decisions about their personal goals. Advocacy groups such as LLS offer resources that can help patients learn more about treatment options and find support.
- Prepare patients by being honest about the physical and emotional difficulties of the treatment journey.

Treatment Monitoring and Psychosocial Support

Some patients who start therapy may have difficulty coordinating multiple appointments and traveling to receive care. Navigators, financial advocates, and social workers can address these issues by meeting with patients and proactively screening for psychosocial distress and barriers to access. Protocols and clinical pathways to monitor treatment should outline how symptoms should be evaluated and managed. Additionally, patients should be educated about treatment-related adverse events and reminded about when and how to communicate information about signs or symptoms or other concerns to their care teams.

Patients noted that they preferred access to 1 primary staff member when they had a question, experienced distress, or needed any form of assistance. A nurse navigator served this function for most patients throughout their entire cancer treatment journey. When a nurse navigator was not involved, patients often established a close rapport with an oncology nurse who became their trusted primary point of contact.

Additionally, it is critically important for providers to check in with

caregivers. The caregiver burden is often overlooked and not documented in the patient's electronic health record. Caregivers may be at risk of emotional and mental exhaustion; it is important to make caregivers aware of any resources that can address these issues and encourage these valuable members of the patient care team.

Focus group participants offered the following recommendations for effective communication during treatment monitoring:

- For patients with technology proficiency, digital tools that include patient portals and secure messaging platforms can be effective ways to track adherence to oral therapies and monitor for treatment-related adverse events. Telehealth visits can also be effective in evaluating how patients are doing and in monitoring patients for adverse events.
- Remember to ask patients whether they would like to discuss any other concerns beyond their medical care. This may help patients feel more comfortable in bringing up any emotional distress they are experiencing.
- Ask caregivers if they would like to learn about resources that can offer support.

Closing Thoughts

Several available resources outline the current therapeutic landscape of diffuse large B-cell lymphoma treatment including rapidly emerging and recently approved treatment modalities. For example, ACCC created this [infographic](#) of the anticipated **communication roadmap** between patient and providers; this roadmap outlines key topics that are often discussed during management of this cancer type.

The therapeutic promise of treatment for diffuse large B-cell lymphoma depends upon effective shared decision-making between patients and providers. A high cure rate with first-line treatment is certainly reason for cautious optimism; still a cancer diagnosis for any patient is devastating news. A foundation of trust created by effective patient-provider communication is the cornerstone of a successful therapeutic relationship.

Nicole Colwell, MD, is a senior writer and editor for the Association of Cancer Care Centers, Rockville, Maryland.

References

1. Josfeld L, Keinki C, Pammer C, Zomorodbakhsch B, Hübner J. Cancer patients' perspective on shared decision-making and decision aids in oncology. *J Cancer Res Clin Oncol*. 2021;147(6):1725-1732. doi:10.1007/s00432-021-03579-6
2. Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and evaluating shared decision making in oncology practice. *CA Cancer J Clin*. 2014;64(6):377-388. doi:10.3322/caac.21245
3. Crump M, Neelapu SS, Farooq U, et al. Outcomes in refractory diffuse large B-cell lymphoma: results from the international SCHOLAR-1 study. *Blood*. 2017;130(16):1800-1808. doi:10.1182/blood-2017-03-769620