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Prognostic discussions in patients with advanced lymphoma: Characteristics and challenges

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Abstract

Objectives. Prognostic discussions are critical in the care of patients with advanced lymphoma, given the disease's complexity, rapidly evolving treatments, and shifting potential for cure. However, previous research has paid limited attention to how these discussions unfold from both patient and clinician perspectives, particularly in the context of early conversations. The current study sought to identify key experiences that inform improvements in clinician communication and patient understanding of prognosis for patients with advanced lymphoma.
Methods. We conducted a qualitative study from July 2023 to June 2024 with 19 patients diagnosed with advanced lymphoma and 3 oncologists. Semi-structured interview transcripts were analyzed using thematic content analysis, and emergent themes were identified through consensus among a trained coding team.
Results. Two primary themes emerged. First, patients recalled early prognostic conversations as highly focused on curative intent. Second, oncologists cited incomplete diagnostic data and concerns about overwhelming patients as reasons for limiting early discussions, often delaying deeper prognostic conversations. Clinicians reported tension between maintaining patient hope and providing comprehensive information about disease trajectory and treatment uncertainty.
Significance of Results. Findings highlight a need for communication strategies that balance hope with realism in early prognostic discussions for patients with advanced lymphoma. Oncologists may benefit from structured, evidence-based guidance to manage information delivery over time, particularly in the face of diagnostic ambiguity. Future research should prioritize inclusive sampling and explore timing and content of ongoing prognostic discussions to better support informed decision-making and goal-concordant care.

Prognostic discussions in the context of advanced lymphoma may shape the trajectory of patient care and help define treatment expectations for patients and their loved ones. These discussions are especially paramount for patients with advanced lymphomas given the complexity of hematologic malignancies, rapidly changing treatment options, and the uncertain outcomes many patients face after diagnosis, including risk of relapse, complications from treatment, and treatment response variability (Crump et al. 2017; van Bruinessen et al. 2013). In the context of a lymphoma diagnosis and subsequent treatment, a patient's prognosis can shift abruptly from curable to incurable. This rapid change in prognosis and treatment outcomes has the potential to exacerbate patients' misunderstanding of their condition and treatment options (El-Jawahri et al. 2015).

Prognostic discussions with patients suffering from advanced lymphomas can be fraught with challenges for both patients and their oncology providers. For example, only one-third of patients with lymphoma participate in advance care planning (ACP) discussions (Trevino et al. 2020). Furthermore, initial goals of care conversations for patients with lymphoma often occur after the patient has already been hospitalized or is close to death (Hui et al. 2014; Odejide et al. 2020). Moreover, hospice enrollment is lowest among patients with lymphoma compared to all other cancer types (Odejide et al. 2016, 2020), suggesting a lack of clarity regarding the optimal timing for hospice care throughout the disease trajectory (Howell et al. 2017). Until recently, research on strategies for tailoring prognostic discussions for patients with advanced lymphomas has been limited (Trevino et al. 2020). Thus, the purpose of the current study was

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to explore patient and clinician perspectives on prognostic discussions in advanced lymphoma. Our aim was to use qualitative data to identify key experiences that can inform improvements in clinician communication and patient understanding of prognosis in this patient population.

Method

These data were collected as part of a larger study focused on understanding the extent of Black-White disparities in prognostic discussions for patients with advanced lymphoma. The goal of the parent study is to refine an existing, theory-driven communication intervention(Prigerson et al. 2023) for hematologists designed to help improve patient prognostic understanding. Cultural adaptation and refinement of the existing intervention has significant implications for increasing goal concordant EOL care for Black and White populations and for reducing EOL care racial disparities (Bazargan and Bazargan-Hejazi 2021; Aaron et al. 2021; Bajaj et al. 2023). In the current report, we focus our analysis on patient and oncologist perspectives on prognostic discussions in advanced lymphoma.

Sampling and recruitment

From July 2023 to June 2024, we conducted individual and group interviews (2–4 participants) with patients ($n = 19$) and oncologists who treat patients with lymphoma ($n = 3$). Eligibility criteria for patients included a diagnosis of diffuse large B-cell lymphoma (DLBCL) including DLBCL-transformed follicular lymphoma (TFL) and primary mediastinal B-cell lymphoma (PMBCL), relapse/refractory disease within 12 months of 4 cycles of first-line therapy or relapse after 2 cycles of later line therapy or autologous stem cell transplant (ASCT), self-identifying as Black and/or White, 18 years of age or older, and ability to converse in English. Eligibility criteria for oncologists included currently providing care to patients with DLBCL at a U.S.-based cancer center, which they do not plan to leave in the next 12 months.

Data collection

Interviews followed semi-structured interview guides developed by study team members with content (K.M.) and methodological (J.G.) expertise. The patient interview guide focused on experiences of cancer and prognostic discussions, whereas the clinician interview guide was concerned with experience engaging patients in prognostic discussions. Interviewers also introduced probing questions throughout the interview (Robinson et al. 2023). Interviews were audio recorded, transcribed verbatim, and de-identified for analysis. Both patients and oncologists responded to a series of questions posed by the moderator during their respective focus groups. For the current analysis, we focused on participant responses to questions about initial prognostic discussions between patients and their oncologist (Table 1).

Interviews and focus groups were conducted by either a qualitative methods specialist (Q.M.S. and J.G.) or a clinical research coordinator (CRC) trained by the QMS in qualitative data collection methodology. Interview and focus group length ranged from 37–87 min, depending on the number of participants.

Table 1. Study participants and focus group/interview questions of interest in the current analysis

Participants	Focus Group/Interview questions of interest
Oncologists treating patients with advanced lymphoma	When a patient presents early in their diagnosis with DLBCL, how do you communicate prognostic information?
	(Probes for: most important things to cover such as treatment options, goals, adverse events/side effects, and additional treatments)
Patients with advanced lymphoma	Thinking back to early in your diagnosis, do you remember discussing prognosis with your oncologist? How did the conversations go?
	(Probes for: types of information discussed such as treatment options, goals, side effects, and additional treatments; reactions to conversation)

Data analysis

All transcripts were analyzed using thematic content analysis (Vaismoradi et al. 2013). The QMS and a CRC trained in qualitative data analysis methodology independently coded each transcript using NVivo version 14 (Lumivero, Denver, CO, USA), highlighting significant statements within each domain. The coding team met regularly to reach consensus regarding code definitions and application and discrepancies in coding, and to discuss primary themes as they emerged. In the final phase, the team analyzed code reports to identify key themes observed across transcripts. Due to the small sample size, themes highlighted here are only those which were salient across all interviews (Hennink and Kaiser 2022).

Results

Sample characteristics appear in Table 2. The mean age of patients was 64.8 ($SD = 10.90$), while the mean age of oncologists was 38.7 (3.79). Most patient and oncologist participants were White, and most patients had a graduate-level degree or higher (61%). Two unique themes related to early prognostic conversations were identified through analysis of the qualitative study data: (1) focus on curative intent and (2) incomplete diagnostic information and concerns about patient retention of information (Table 3).

Theme 1: Focus on curative intent

Patients consistently noted that the emphasis on curative intent in early prognostic conversations left a strong impression. Many patients recalled that their initial conversations with oncologists included basic information about their diagnosis, as well as an overview of the planned treatment approach. These early discussions centered on the curative potential of first-line treatment, with oncologists expressing optimism about the ability of initial therapy to eliminate the disease. In some cases, patients reported that oncologists mentioned the possibility of additional lines of treatment, particularly if the first-line regimen did not turn out to be effective or could not be well tolerated.

Per reports from patients, alternative treatment pathways were not always discussed in depth during the initial conversation. Patients' reactions to these brief descriptions of treatment options

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Table 2. Sample characteristics

Age	Patients ($n = 19$)	Oncologists ($n = 3$)
Age		
N (missing)	18 (1)	3 (0)
Mean ± SD	64.8 ± 10.90	38.7 ± 3.79
Median	65.5	37
Range	44, 80	36, 43
Race, *N* (%)		
White or Caucasian	13 (72.2)	2 (66.7)
Asian	0 (0)	1 (33.3)
Black or African American	4 (22.2)	
Multi-racial	1 (5.6)	
Ethnicity, *N* (%)		
Hispanic or Latino/Latina	0 (0.0)	0 (0.0)
Gender, N (%)		
Female	8 (44)	2 (66.7)
Male	10 (56)	1 (33.3)
Education, *N* (%)		
Graduated high school or equivalent	3 (16.7)	
Some college	2 (11.0)	
Graduated college	1 (5.6)	
Some post-graduate/ professional courses	1 (5.6)	
Completed post-graduate/professional courses	11 (61.0)	

Table 3. Qualitative themes and illustrative quotations

Theme 1. Focus on curative intent
"I was advised don't be worried. It's Stage IV. It can't go higher than that. So, they would work on it with good feet. I mean, I'll be all right because they fix over 80%. That is good." – Patient, interview 1
"When I first got the diagnosis, I remember the first visit with the oncologist. She said, you know, you're going to hear a lot of information today and you're not going to remember any of it probably, but the only thing that you should remember is you're going to be cured and you're going to be fine." – Patient, interview 2
"She said that the kind of lymphoma that I had was 90% or 95% curable. Her success rate was about the same, and not to worry about what was going on. She said everything was – and she also followed if the treatments didn't work, there are other alternatives and that also was successful, so everything was on a positive note." – Patient, interview 3
"Well, they said the type of lymphoma I had is very curable. I don't really remember the rates they had. I should've asked if they didn't say it, because the cancer did come back after six rounds and now, I'm doing a new treatment." – Patient, interview 3
"I was told that if it didn't work that there could be other options. I wasn't told what the other options were, and I should've asked. It was incumbent of me to ask, but I didn't." – Patient, interview 1
"She said she was very hopeful that those six rounds of R-EPOCH would help, and this would be it. I do remember her saying that ultimately, if this doesn't work, there are other options. I didn't ask what the options were. I didn't want to know what the options were." – Patient, interview 3
Theme 2. Incomplete diagnostic information and concerns about patient retention of information
"When I first meet them, I speak in general terms. Like, this is an aggressive lymphoma, what [aggressive] means in terms of without treatment what survival would be, but that we are treating with curative intent in most cases, but how successful we will be is based on additional testing that we need, staging information, and other things." – Oncologist, interview 1
"I focus more on what the intention of treatment is. So, if someone is fit to get curative treatment, then my discussion is that we're giving you this treatment. Our objective is to cure you or to get you into long-lasting remission, and that with this treatment, X percentage of patients, in general, tend to achieve that result. If not, these are the other options." – Oncologist, interview 2
"I think maybe my biggest thing is when you start to introduce the idea that we're treating this with curative intent, then they start kind of backing off and they kind of miss that kind of concept that it can come back or not everyone responds." – Oncologist, interview 1
"I think also sometimes patients get so overwhelmed at the first visit, they don't retain it." – Oncologist, interview 1
"But if at the end of treatment there's not a complete response and we're talking about next steps in therapy, there are still curative options available. The percentage of patients who will be cured in that setting is lower, but it's sort of something that I don't, in the initial treatment phase, we don't spend a lot of time on it because for 70% of people it's not…they'll never have to think about it, and there's already so much that they have to consider, and worry, and think about." – Oncologist, interview 2

and pathways varied. Some patients expressed a desire to receive more comprehensive explanations about treatment and possible next steps up front, including what might happen if first-line treatment failed. These patients felt that having a fuller understanding of possible treatment trajectories would have helped them feel more prepared and informed. Others, however, preferred a more focused conversation that concentrated only on immediate treatment plans. Several also noted that even when second-line treatments were mentioned, these options were sometimes presented with the same language of cure as first-line therapies. This consistent framing of multiple treatment stages as potentially curative was comforting to some patients. Furthermore, patients described feeling reassured by the hopeful tone used by their oncologists, particularly when physicians supported their messages with encouraging statistics or used confident, empathetic language to reinforce the curative potential of treatment. Many patients viewed this emphasis on cure as a critical emotional anchor, helping them cope with the shock of diagnosis and maintain a sense of optimism during an uncertain time.

Theme 2: Incomplete diagnostic information and concerns about patient retention of information

Oncologists identified incomplete diagnostic information and concerns about patient retention of information as unique challenges in early prognostic conversations. At the time of initial consultations, clinicians may still be awaiting key diagnostic results – such as LDH levels, FISH testing, or PET scans – which are critical to forming a comprehensive treatment plan. Lack of complete diagnostic information significantly limits the ability of oncologists to provide specific or individualized prognostic details. As a

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result, oncologists reported that they tend to offer general information about aggressive lymphomas, emphasizing typical treatment approaches and the common goal of curative intent, while cautioning that individual treatment plans will be refined as more data become available.

In parallel, oncologists expressed concern about overwhelming patients with too much prognostic and treatment information too early. They reported deliberately limiting the scope of information provided during initial visits not only because comprehensive information was sometimes lacking, but also to help patients process key messages without becoming confused or distressed. To reduce information overload, oncologists reported avoiding detailed discussion of second- or third-line treatments. Oncologists noted that even when they attempted to balance hope with realism, patients tended to "latch on" to statements made about the curative intent of treatment and overlook important caveats about the uncertainty of outcomes or the potential need for additional therapies. Of note was that oncologists disagreed about the approach to discussing additional lines of treatment during the initial visit. Some preferred to make a general statement that additional treatment needs would be determined based on disease response, while others noted that they never mention additional treatment needs to patients until more information about prognosis and test results become available. Oncologists reported worrying about patients' ability to retain high volumes of information at an initial visit, noting the inherent overwhelm and how that can impact the amount of information patients absorb and understand. Ultimately, clinicians reported an ongoing tension between wanting to support patient understanding and hope, while wanting to avoid overloading or worrying them unnecessarily.

Discussion

The aim of this study was to examine patient and clinician perspectives about prognostic discussions in advanced lymphoma, using qualitative data to identify experiences that can guide improvements in communication and support patient understanding of prognosis. Two key themes emerged from our analysis. The first theme captured patients' recall of prognostic discussions as cure-focused, and their perceptions that their cancer would likely be curable. The second theme highlighted providers' tendency to limit information provided to patients during early prognostic discussions, largely because they are often lacking key data and insights to guide comprehensive prognostic discussions, and because they fear overwhelming patients with information so early on. The insights that stem from our findings reveal important opportunities to enhance patient–clinician communication in the context of prognostic discussions with patients with advanced lymphoma.

One prominent message emerging from our conversations with patients was that their oncologists' focus on curative treatment provided reassurance and conveyed "optimism" about their situation. Previous work has demonstrated that balanced communication about prognosis, that includes optimism and also includes accurate, realistic information about treatment options and likely outcomes, is likely the best approach for ensuring that patients develop a realistic perception of their disease course that matches their provider's understanding (Robinson et al. 2008). Importantly, patient perceptions of the framing of second-line treatments and beyond as having primarily curative intent may contribute to misunderstandings about the disease trajectory, particularly for patients who ultimately require additional lines of treatment with reduced likelihood of cure (Danese et al. 2017).

In parallel, oncologists expressed concerns that patients might over-identify with messages of curative treatment intent, depending on how treatment options were framed. At the same time, they worried that presenting too much information early on could overwhelm patients, limiting their recall of key details about the possibility of future or ongoing treatment. Prior research in lymphoma has shown that balancing the volume of information is crucial – not only to help patients understand their treatment options, but also to prevent unrealistic optimism (Campbell et al. 2010). Our findings underscore the need to systematically integrate this awareness into structured communication guidance, supporting oncologists in delivering nuanced prognostic discussions that incorporate both hopeful possibilities and realistic limitations of possible future treatment options.

Our interviews with oncologists also underscored the cascading effects of incomplete diagnostic information on their ability to communicate clearly with patients, support patient prognostic understanding, and conduct effective treatment planning. These findings point to the importance of conducting repeated prognostic discussions with patients, particularly as the disease changes over time, and as clearer disease information and understanding is made available to oncologists. Oncologists had varied opinions and cited lack of consensus about how to broach successive prognostic discussions with patients related to the goals of each line of treatment, including in the context of an inherently shifting prognosis. These perspectives juxtaposed with patients' perceptions of an emphasis on curative intent during early discussions with their oncologists and descriptions of second-line treatments as also having curative intent, even though cure is less likely and may not be the primary treatment intent. Therefore, further empirical and clinical investigation is necessary to define best practices and standards for treatment planning during prognostic discussions for patients with lymphoma.

It is important to note that prognosis for patients with advanced lymphoma is historically difficult to predict, particularly in light of recent treatment advances. As paradigms for prognostication of lymphoma shift with improvements in testing and technology (Gallamini et al. 2024), oncologists must not only consider new options for treatment planning, but also consider how new treatments and data on these treatments may shape communication with patients. Ongoing clinical ambiguity regarding best practices for prognostication and treatment in advanced lymphoma, combined with the findings from the current work, emphasize the need to ensure that oncologists clearly communicate both the potential for cure and the reality of disease progression, ensuring that patients maintain a realistic, accurate, and comprehensive understanding of their prognosis throughout their treatment journey.

Limitations and future directions

Our final sample size for this pilot work was small. Furthermore, the sample was primarily White, which constrained our ability to examine racial differences in the patient experience and to more carefully examine the communication needs of Black patients with cancer during prognostic discussions. Future research should also prioritize purposive sampling and targeted data collection for sociodemographic groups of interest, as understanding racial, ethnic, and cultural differences in patient perceptions of prognostic discussions is key to achieving equity in cancer care and treatment. Additional investigation with more patients and oncologists would also provide the opportunity to replicate our findings and subsequently inform next steps. Interviews in the current study were

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also limited primarily to understanding the content and details of early prognostic discussions. As a result, future research is needed to establish the optimal timing for discussions about additional lines of treatment and the range of treatment options available to patients at different stages of the disease course, including whether these discussions are more likely to focus on cure or palliation. Lastly, because all the data collected in the current study were self-reported, it is impossible to establish an in-depth understanding of what prognostic information was communicated to patient participants by their oncology teams, or how it was communicated. In other words, our study was not designed to examine patient recall bias or precise language used by oncologists to share prognostic information. Future research should leverage data triangulation from multiple sources (e.g., audio recordings of prognostic discussions, surveys administered directly after patient appointments) to develop more robust conclusions.

Conclusion

These data provide a unique and informative snapshot of the current landscape of prognostic discussions in the context of advanced lymphoma, from the perspective of patients and their oncologists. The findings highlight a clear need for the development of tailored communication strategies that are responsive to the specific prognostic challenges associated with this disease and attuned to patients' individual disease trajectories. Importantly, this need includes ensuring that such discussions are inclusive and effectively engage diverse patient populations, who may have differing informational needs and preferences regarding understanding their prognosis and establishing goals for future treatment. The insights gained from this preliminary work lay a critical foundation for the design of scalable, evidence-based communication interventions that optimize prognostic discussions in a way that improves patient understanding and supports oncologists in designing conversations that are both informative and supportive. Our work also points to the ongoing need for additional research to elucidate best practices in early and ongoing prognostic discussions for patients with advanced lymphoma.

Competing interests. The authors have no conflicts or relationships to disclose.

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