Preferences and Perceptions Regarding Treatment Decision-Making for Relapsed or Refractory Diffuse Large B-Cell Lymphoma (R/R DLBCL)

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Background

- Patients with relapsed or refractory diffuse large B-cell lymphoma (R/R DLBCL) face complex treatment-related decisions. Shared decision-making (SDM) has the potential to improve patient experience, engagement, and treatment satisfaction; however, there are few tools and resources for patients whose cancer has relapsed.[1]
- The National Comprehensive Cancer Network (NCCN) DLBCL guidelines recommend a number of systemic therapies for 2nd- and 3rd-line treatment regimens. Depending on eligibility, patients can undergo either an autologous or allogeneic stem cell transplant or chimeric antigen receptor (CAR) T-cell therapy after failure of 1st-line treatment. Recommended therapy options for non-transplant eligible patients include Tafasitamab in combination with lenalidomide, polatuzumab vedotin with or without rituximab and with or without bendamustine, or gemcitabine and oxaliplatin with or without rituximab.[2]
- Limited real-world evidence (RWE) exists on patient preferences or use of SDM in R/R DLBCL treatment decision-making, particularly with respect to 2nd- and 3rd-line treatment decisions. Existing studies largely focus on lymphoma or non-Hodgkin's lymphoma patients more broadly, rather than the R/R DLBCL patient population specifically.[3,4,5,6,7]

Aim

- To better understand treatment decision-making of patients, their caregivers, and physicians for R/R DLBCL.

Patients and methods

- Performed a targeted literature review to better understand the current state of evidence regarding preferences and SDM among R/R DLBCL patients, caregivers, and physicians. The literature review informed development of in-depth interview guides.
- Enrolled 14 adult patients diagnosed with R/R DLBCL, 8 caregivers of R/R DLBCL patients, and 8 oncologists who treat R/R DLBCL patients who met our recruitment criteria (see Figure 1). Patients and caregivers were linked; no oncologist was the treating physician of any patient.
- Conducted 1-on-1 semi-structured interviews with enrolled patients, caregivers, and physicians. Avalere staff took detailed notes and recorded each interview.
- Researchers transcribed all 30 interviews.
- Researchers used template analysis to code transcripts using 6 codes that were decided a priori.
- Two interviewers double coded 4 patient interview transcripts, 2 caregiver interview transcripts, and 2 physician interview transcripts to ensure interrater reliability >75%. Researchers independently coded the remaining 22 interviews.

Figure 1: Recruitment Inclusion and Exclusion Criteria

Patient	Caregiver	Physician
Inclusion Criteria		
• Patients with R/R DLBCL who are in or have recently completed (within past 5 years) 2nd-line or 3rd -line treatment	• Caregivers of patients with R/R DLBCL who are in or have recently completed (within past 5 years) 2nd-line or 3rd-line treatment	• Community-based oncologist that treats R/R DLBCL patients • Oncologist who works in an academic and/or large health system setting*
Exclusion Criteria		
• Non-English speaking	• Non-English speaking	• Non-English speaking • Oncologist who does not treat R/R DLBCL patients

Figure 2: Research Questions and Coding Schema

Key Research Questions	Themes (Number of Subthemes)
Patients	
RQ1: What are patient attitudes and beliefs about their involvement and their caregiver's involvement in treatment-related decisions?	• Background on Treatment Experience (4) • Decision-Making Involvement (2)
RQ2: What preferences and goals do patients have for their 2nd and 3rd line treatment?	• SDM: 2nd/3rd Line Preferences and Goals (4) • SDM: Data / Resources (2) • SDM: Communication (0)
RQ3: What are the impacts of SDM on patient treatment satisfaction, motivation following treatment schedules, and quality of life?	Treatment Satisfaction (3)
Caregivers	
RQ1: What are caregiver attitudes and beliefs about their involvement in treatment-related decisions?	• Background on Treatment Experience (2) • Decision-Making Involvement (2)
RQ2: What are current caregiver practices around SDM?	• SDM: 2nd/3rd Line Preferences and Goals (3) • SDM: Data / Resources (2) • SDM: Communication (0) • Decision-Making Process Satisfaction (2)
Physicians	
RQ1: What are physician attitudes and beliefs about involving patients and caregivers in treatment-related decisions?	• Attitudes and Beliefs: Patients (2) • Attitudes and Beliefs: Caregivers (1)
RQ2: What are physician attitudes & beliefs regarding SDM?	• Communication Process (3) • Communication Results (3)
RQ3: What are current physician practices around SDM?	• General Workflow (3) • Treatment Selection (3)

Results

Attitudes and Beliefs Regarding Patient and Caregiver Involvement in Treatment Decisions

- 71% of patients and 38% of caregivers perceived they had limited ability to be actively involved in treatment decision-making given that their treating physician had communicated that they were following a well-established standard of care. It was reported that the shock from their diagnosis or from failing treatment further constrained their and their caregivers' ability to be actively involved in treatment decision-making.
  - All physicians reported that the limited 2nd- and 3rd-line treatment options available offered limited opportunities to integrate patient and caregiver preferences into treatment selection.
- All physicians believed that patients should have a high degree of autonomy in their treatment decisions; however, 5 physicians (62%) identified lack of patient understanding or education on treatment options as a major barrier to involving patients in decision-making.
- 50% of patients shared that caregiver involvement was important for supplementing their understanding of 2nd- and 3rd-line treatment options; however, only 1 caregiver explicitly said that they had enough time to make an informed decision. Generally, physicians also said that they encourage caregivers to be included in treatment planning.

Current Caregiver and Physician Practices Around SDM

- There is a lack of external resources that provide context to the R/R DLBCL treatment pathway and potential treatment outcomes for individuals in a caregiver role. Unexpected outcomes or situations reportedly exacerbated the degree of shock that patients and caregivers experience after "failing" a line of therapy or experiencing unanticipated treatment side effects.
- 75% of physicians typically ask patients about their support system and social needs (e.g., living situation, access to transportation) during the initial treatment planning visit. Only 1 physician referenced asking about specific life events that impacted their treatment selection (e.g., weddings, religious ceremonies, or travel plans).
- Generally, oncologists practicing in community-based settings reported that, due to resource constraints, they did not operate their practice under a care team model. As a result, while they are the patients' main point of contact, they have limited time to interface with patients and comprehensively address their concerns.

Patient 2nd/3rd-Line Treatment Preferences and Goals

- Among 6 patients (43%), cumulative treatment experiences shaped treatment preferences and perceptions of autonomy during later lines of treatment, consistent with some physician observations.
- 5 patients (36%) stated that their physician had overemphasized the effectiveness of their 1st-line treatment, leading them to feel unprepared for the possibility of treatment failure or additional lines of treatment.
- Younger patients perceived that the treatment planning process failed to consider the impact of treatments on issues pertinent for young adults (e.g., fertility, major life events).

Treatment Satisfaction

- While 71% of patients felt satisfied with their treatment experience, some shared that they would have appreciated a more individualized approach.
  - 3 patients (21%) reported feeling overwhelmed when details of their care journey (e.g., route of administration) did not adhere to what was previously communicated or when their treatment plan was changed with limited notice.
  - 4 patients (29%) shared that their physicians were not equipped to address ancillary health concerns (e.g., mental health support).
  - 2 patients stated that their physicians or care teams were limited to making recommendations based on the standard of care and could not offer support beyond that (e.g., novel methods to relieve treatment symptoms).

Table 1: Summary of Patient and Caregiver Demographics

Demographic Variables	Patients N = 14	Caregivers N = 8
Age		
18-29	3 (21%)	0 (0%)
30-39	2 (14%)	0 (0%)
40-49	2 (14%)	1 (13%)
50+	7 (50%)	7 (87%)
Race/Ethnicity		
American Indian or Alaskan Native	0 (0%)	0 (0%)
Asian	3 (21%)	0 (0%)
Black or African American	0 (0%)	0 (0%)
Hispanic, Latino, or of Spanish origin	0 (0%)	0 (0%)
Native Hawaiian or other Pacific Islander	0 (0%)	0 (0%)
White	11 (79%)	8 (100%)
Education Level		
High school graduate	1 (7%)	1 (13%)
Some college, no degree	5 (36%)	2 (25%)
College graduate	2 (14%)	0 (0%)
Some post-graduate studies, no degree	1 (7%)	0 (0%)
Advanced degree	5 (36%)	5 (62%)
Total Household Income*		
Less than $50,000	3 (21%)	1 (13%)
$50,000 - $99,000	6 (43%)	3 (37%)
$100,000 or more	4 (29%)	3 (37%)
Health Insurance**		
Insurance through employer	3 (21%)	0 (0%)
Self-purchased insurance	7 (50%)	7 (87%)
Medicare/Medicaid	2 (14%)	1 (13%)

*1 patient participant and 1 caregiver participant did not provide household income
**2 patient participants did not provide health insurance information

Figure 3: Gaps to Promoting Effective SDM in R/R DLBCL



Discussion

- Study results highlighted the following major gaps related to promoting patient and caregiver engagement in R/R DLBCL treatment decision-making:
  - Caregivers were consistently identified as a critical component of a patient's treatment decision-making process by both patients and physicians, but few tailored materials exist to guide caregivers in their roles.
  - Though treatment options may be limited for R/R DLBCL patients, preferences related to key patient-centered outcomes can be discussed and incorporated into the long-term treatment planning process.
  - Physicians do not have existing go-to resources that can support them in integrating aspects of patients' lived experiences into their typical workflows, leading to duplicative efforts in individual patient interactions.
  - All parties noted that the shock of diagnosis and subsequent treatment failure for R/R DLBCL patients, combined with the limited time given to process their diagnosis before starting treatment, negatively impact the quality of patient-provider discussions in the treatment decision-making process.
- RWE generated from this study fills a major gap in evidence on the preferences and goals for this patient population specifically.

Conclusions

- The findings from this qualitative research study suggest that there may be opportunities to:
  - Further integrate aspects of patient and caregivers' lived experiences into treatment decision-making for R/R DLBCL
  - Increase use of individualized multidisciplinary support services that can support the holistic health needs of R/R DLBCL patients (e.g., mental health services)
  - Develop tailored educational materials for caregivers that can equip them as trusted and engaged members of the patient's treatment decision-making process
- Given the difficulty of recruiting minority patients that met the strict inclusion criteria for this study, further RWE generation studies focusing on racial and ethnic minority R/R DLBCL patients' and caregivers' preferences and beliefs regarding 2nd- and 3rd-line treatment decision-making are needed.

Acknowledgments

Assistance with participant recruitment for this research was provided by the Leukemia and Lymphoma Society (LLS), the Cancer Support Community, and the Community Oncology Alliance (COA). Joshua Seidman, Courtney Ramus, Rina Bardin, Jasmaine McClain, Mali Khan, and Oladeji Faborode contributed to this research. Nuwan Kurukulasuriya is a former employee of MorphoSys and also supported this research. All authors contributed to the development of the poster and maintained control over the final content. John Collins is an employee of MorphoSys and is the presenter of this research poster.

Disclosures

M Vukcevic is an employee of MorphoSys. Support for this research was provided by MorphoSys.
M Yung, M Khan, B Houpt, and **F Schnell** have no relevant conflicts to disclose.

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