ABCL-599

# Patient Perceptions of Treatment Options for Diffuse Large B-Cell Lymphoma in the United States: A Social Media Listening Study

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## BACKGROUND

- While clinical trials have provided extensive data on the benefits and risks of different treatment regimens for diffuse large B-cell lymphoma (DLBCL),[1] information on the lived experience of patients using these regimens and their caregivers is limited
- Investigating real-world impacts of DLBCL and its treatment on patients and caregivers is key for addressing unmet needs and improving outcomes
- Social media listening provides a unique approach to understanding the lived experience of patients with cancer and their caregivers by including diverse voices spanning multiple socioeconomic backgrounds[2-5]

## OBJECTIVE

- To use social media listening to explore real-world experiences of patients with DLBCL and their caregivers in the United States

## METHODS

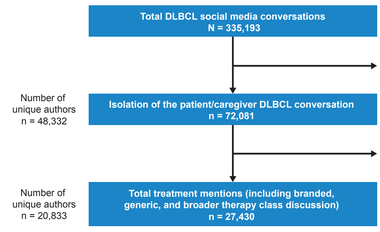
- Social media posts about DLBCL from January 9, 2024, to January 6, 2025, from public media platforms (ie, X/Twitter, online news articles, Reddit, blogs, forums, YouTube, magazines, Instagram, TikTok, newspapers, and others) were identified
- Analysts manually reviewed social media posts by patients and caregivers to identify first-hand DLBCL experiences, allowing for multiple posts by an individual. Posts mentioning first-hand experiences, such as diagnosis, treatment, or management, were included, while posts from stakeholders and those with other lymphoma types were excluded
- Eligible posts were anonymized and underwent quantitative natural language processing, supplemented with manual qualitative reading, to identify themes
- An artificial intelligence–enabled machine learning tool designated treatment mentions across rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone (R-CHOP), chimeric antigen receptor T-cell (CAR T) immunotherapy, and stem cell transplant (SCT; mentions in this group included autologous SCT, allogeneic SCT, cell transplant, and stem cell) as positive, neutral, or negative to enhance interpretability
  - Public posts from Instagram and TikTok were analyzed using manual data extraction due to data restrictions
  - Duplicate posts shared across multiple channels were automatically identified and removed using the analysis tool's built-in deduplication feature
- Burden was captured quantitatively and categorized by type (ie, treatment, psychological, logistical)
- Posts containing information on adverse events were reported to the sponsor, where applicable

## RESULTS

### Posts Analyzed

- Of a total 335,193 social media posts identified, 27,430 posts from 20,833 individuals were eligible for analysis (**Figure 1**)

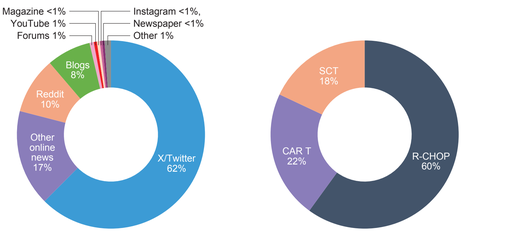
**Figure 1. Selection of Posts for Analysis**




CAR T, chimeric antigen receptor T-cell; CLL, chronic lymphocytic leukemia; DLBCL, diffuse large B-cell lymphoma; HCP, health care provider; MZL, marginal zone lymphoma; PAG, patient advocacy group; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone; SCT, stem cell transplant.

- While X/Twitter hosted the most posts, treatment mentions were spread across various channels, including news articles and Reddit (**Figure 2**)
  - Posts from X/Twitter involved both patients and caregivers sharing their experiences with DLBCL
  - Online news articles frequently covered personal experiences with lymphoma, including those of celebrities
  - Reddit posts were predominantly patients and caregivers sharing their treatment experiences and seeking advice on management
- R-CHOP had the majority share of voice within total treatment mentions (**Figure 2**)

**Figure 2. Social Media Platforms and Treatment Classes Discussed**




CAR T, chimeric antigen receptor T-cell; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone; SCT, stem cell transplant.

### Initial Diagnosis

- Patients highlighted challenges in getting a diagnosis for DLBCL and feeling physically and psychologically overwhelmed about the initiation of first-line therapy

> "Doctors initially thought it was an infection and treated me with antibiotics. I had to push hard for further tests and proper diagnosis."

> "Like you, I was an anxious mess waiting for a diagnosis and felt relieved once we knew and had a plan in place. I was diagnosed with DLBCL and started treatment within 24 hours. I can't imagine waiting 4 months; that's inhumane."

> "There was so much information to absorb; it was overwhelming. I couldn't keep track of everything the doctor was saying and felt like I was drowning in information."

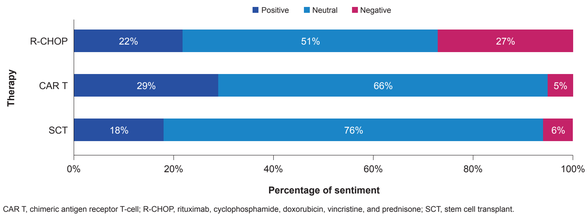
### Remission/Scanxiety

- Following R-CHOP therapy, patients often experienced "chemo brain," which impairs cognitive function and affects daily life and emotional well-being. This condition makes it difficult for patients to concentrate, remember details, and stay organized, impacting work, school, and daily activities
  - Patients often advised one another to focus on cognitive rehabilitation and mental exercises, and encouraged one another to seek support from health care providers (HCPs), to manage "chemo brain"
- The fear of cancer returning, or "scanxiety," is a major source of anxiety for patients and is heightened in the days leading up to regular scans. This anxiety is compounded by a hyperawareness of bodily changes
  - Clear communication from HCPs about scan results and relapse likelihood is necessary to help manage this fear

### Sentiment About Treatments

- Sentiment varied across treatments (**Figure 3**)
  - CAR T had the highest percentage of both positive and neutral sentiments, whereas R-CHOP had the most negative sentiment
  - Both CAR T and SCT had a high percentage of posts with neutral sentiment, potentially pointing to a high degree of information seeking and sharing practical advice

**Figure 3. Sentiment Analysis by Treatment**




CAR T, chimeric antigen receptor T-cell; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone; SCT, stem cell transplant.

### R-CHOP Therapy Sentiment and Burden on Patients

- Positive sentiments about R-CHOP noted tumor reduction and hope for a cure (**Figure 4**)
- Neutral sentiments focused on support or coping strategies
- Negative sentiments included feelings of disappointment and discouragement following disease recurrence or progression, side effects, the daily battle of treatment, and the impact on quality of life
  - When treatments like R-CHOP fail, patients often experience disappointment, discouragement, and uncertainty about their future treatment options
- Posts regarding burden highlighted treatment burden (5723 posts), psychological burden (1804 posts), and logistical burden (1057 posts) related to R-CHOP (**Figure 5**)
- Patients and caregivers frequently expressed high levels of anxiety and stress, and discussed fatigue, weakness, and emotional burden related to visible signs of treatment, particularly around hair loss

> "After a few cycles, my tumors had shrunk significantly. It was encouraging to see the treatment working."

> "The fatigue was overwhelming at times, but I learned to listen to my body and rest when needed. Support from my family made a big difference."

> "The treatment was physically draining, but I tried to stay strong. Resting and taking it 1 day at a time helped."

> "I can't imagine ever being okay with losing my hair—shaving it didn't feel empowering, it felt like a funeral. I ordered a wig, but it won't arrive for weeks. I can't bring myself to leave the house like this. It looks fine on others, but I feel like a monster."

### CAR T Therapy Sentiment and Burden on Patients

- Positive sentiments highlighted hope for a cure, minimal side effects, and a renewed sense of optimism (**Figure 4**)
  - Patients expressed disappointment upon requiring second-line treatment. CAR T therapy was often mentioned in this context, with some patients noting its reputation for favorable outcomes
- Neutral sentiments mentioned issues including treatment process and costs
- Negative sentiments related to CAR T focused on overwhelming information; anxious waiting; intensive monitoring of severe side effects; complex logistics (eg, travel, lodging); prolonged recovery; financial strain from out-of-pocket costs, extended hospital stays, and lost income; and uncertainty over long-term safety
- CAR T treatment burden (234 posts), psychological burden (59 posts), and logistical burden (87 posts) were discussed (**Figure 5**); topics also included anxiety and fear

> "The idea of CAR T therapy was both exciting and terrifying. We knew it was our best shot, but the unknowns were scary."

> "My husband's CAR T treatment begins in a week, starting with apheresis. He's doing preliminary tests this week. It's an emotional roller coaster—moving between fear, gratitude, and amazement at the technology."

> "If I could have done CAR T earlier, I would have jumped at the choice. Wished it had been first line."

### SCT Therapy Sentiment and Burden on Patients

- Positive sentiments reflected hope, resilience, gratitude, and community support (**Figure 4**)
  - Many patients or their caregivers shared success stories, expressed thankfulness for medical teams or treatment progress, and sought to uplift others going through similar challenges
- Neutral sentiments were generally informational or reflective and shared timelines, treatment plans, or updates
- Negative sentiments expressed fear, frustration, emotional distress, or grief
  - Patients and caregivers discussed difficult side effects, uncertainty, lack of support, or poor outcomes
  - Emotional language was often related to loneliness, recurrence, or trauma
- Similar to CAR T, posts regarding SCT treatment burden (545 posts), psychological burden (147 posts), and logistical burden (110 posts) were discussed, along with anxiety, fear, and posttraumatic stress disorder (**Figure 5**)

> "My first symptom was mid-July and I had an official diagnosis by October 4th. I just did round 5 of 6 for chemo and have a stem cell transplant scheduled for mid-April."

> "These next few weeks will be hard, but you will succeed. And then you'll get to spend some time outside, in the sun, listening to the birds, knowing you've done something amazing. To this day, sitting in the sun overwhelms me with joy because it reminds me of those first few days out of the hospital."

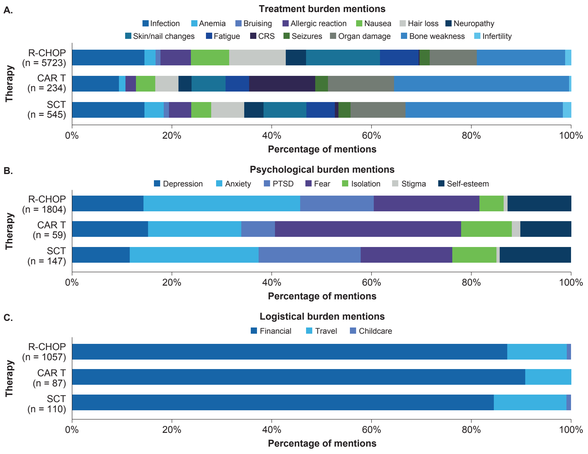
> "I totally understand the spiraling, I did it too… Then I ended up in the unlucky 5-10% that aren't cured."

**Figure 4. Examples of Sentiments for R-CHOP, CAR T, and SCT Therapy**

| | Positive | Neutral | Negative |
|---|---|---|---|
| **R-CHOP** | • Significant tumor reduction<br>• Sense of hope and motivation<br>• Aggressive solution that may quickly cure DLBCL<br>• Sense of relief in finding the "right one" | • Little time to prepare for R-CHOP following diagnosis<br>• Sharing tips and strategies for coping<br>• Diet, managing side effects, and impact on work/family life | • Physical burdens (eg, pain or chronic fatigue)<br>• Loss of appetite and rapid weight loss<br>• Impact on quality of life, relationships, and sense of self<br>• Risk of infertility<br>• Disappointment if treatment is unsuccessful |
| **CAR T** | • Viewed as a "new lease on life"<br>• Hope to those feeling hopeless and deflated from disease progression<br>• Renewed sense of optimism<br>• Return to "normal life"<br>• When making comparisons, patients often framed CAR T as more tolerable than R-CHOP<br>• Viewed as a "potential cure" | • Cost and insurance approval<br>• Queries on process and recovery time<br>• Long-term safety concerns<br>• How to monitor scans and understand results | • Overwhelmed by complexity of process<br>• Fear of unknown neurological symptoms<br>• Fear that treatment may not work<br>• Anxiety and uncertainty surrounding therapy area as a whole |
| **SCT** | • Stories of remission or reduced disease after treatment<br>• Appreciation for support groups or online communities<br>• Encouragement to others who are newly diagnosed | • Factual recounts of treatment (eg, cycle numbers, transplant steps)<br>• Sharing routines or progress<br>• Discussing medical procedures | • Struggles during chemotherapy or SCT recovery<br>• Dealing with relapse, terminal diagnoses, or difficult decisions<br>• Frustration with health care systems or communication barriers |

CAR T, chimeric antigen receptor T-cell; DLBCL, diffuse large B-cell lymphoma; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone; SCT, stem cell transplant.

**Figure 5. Treatment, Psychological, and Logistical Burdens of Therapy**




CAR T, chimeric antigen receptor T-cell; CRS, cytokine release syndrome; PTSD, posttraumatic stress disorder; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone; SCT, stem cell transplant.

### LIMITATIONS

- This study may not be representative of all patients with DLBCL since not all sentiments are posted online and only posts from the United States were included
- Patient characteristics, including lines of therapy, were unknown
- Longitudinal capture was limited
- Other DLBCL treatments were not represented (ie, monoclonal antibodies, bispecific antibodies, etc)
- A greater number of responses were received for R-CHOP (60% of mentions), which may have skewed sentiments
- As many patients are cured by their initial treatment, a limited number of patients would have provided comments on other therapies

## CONCLUSIONS

- Social media listening forms a valuable, novel, and quantifiable method of identifying challenges and unmet needs and capturing the digital voices of patients with DLBCL and their caregivers
- Social media posts from patients with DLBCL and their caregivers were primarily related to R-CHOP treatment, and more than one-quarter of posts about R-CHOP were associated with negative sentiments
- Nearly all social media posts about CAR T or SCT expressed positive or neutral sentiments
- Given the routine use of R-CHOP as a first-line treatment for DLBCL prior to CAR T or SCT, these results may highlight the need for additional support services to help patients cope with their diagnosis and prepare for treatment

### PLAIN LANGUAGE SUMMARY

- Analyzing social media posts from patients with DLBCL and their caregivers is a new way to understand their experiences, including their challenges and needs
- When treatments like R-CHOP fail, patients may experience disappointment, discouragement, and uncertainty about their future treatment options, highlighting the need for additional support and clear communication from HCPs

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### DISCLOSURES

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