

UNDERSTANDING OF PATIENT EXPERIENCE WITH DIFFUSE LARGE B-CELL LYMPHOMA (DLBCL) THROUGH SOCIAL MEDIA LISTENING

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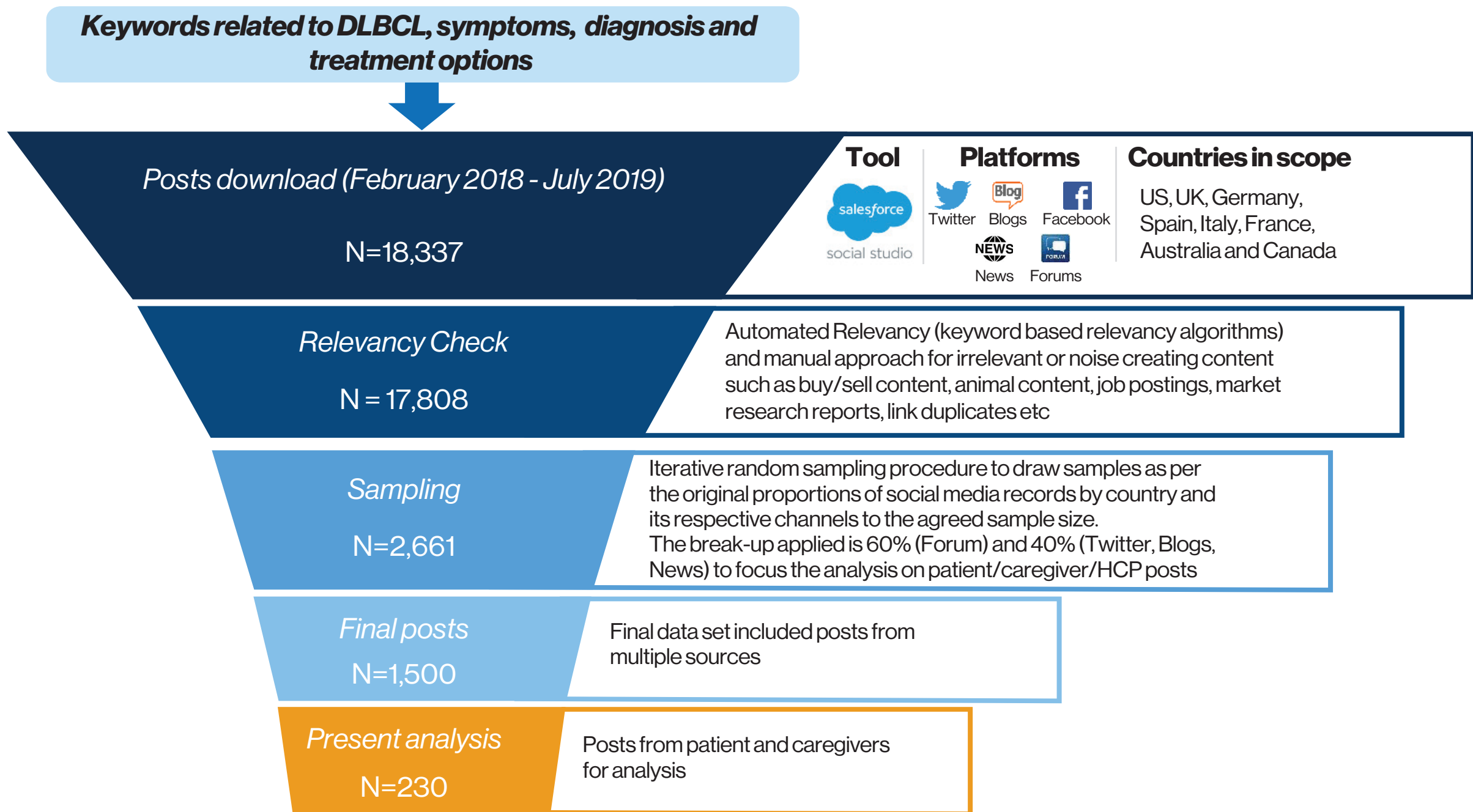
Background and Objectives

- In today's digital era, patients discuss treatment, symptoms, and disease experiences on online forums and social media platforms¹
- Patient experiences shared on such platforms serve as genuine and unprompted insights to discover patient relevant outcomes that can be incorporated in drug development¹
- Diffuse large B-cell lymphoma (DLBCL) is the most common and aggressive type of non-Hodgkin's lymphoma. The main early clinical symptom is an indolent swelling of lymph nodes and spleen which are often not recognized. Other symptoms include fever, night sweats, unexplained weight loss, and fatigue^{2,3}
- DLBCL is also associated with high clinical burden and poor quality of life (QoL) attributed to different aspects^{2,3}
- In order to identify unmet needs and patient relevant outcomes in DLBCL, a social media listening (SML) was conducted

Methods

- A cross-sectional study using SML was conducted to collect social media posts from patient forums (open), Twitter, Facebook, News and Blogs for a period of 18 months between February 2018 and July 2019 using the Social Studio[®] tool
- A search strategy was prepared based on existing therapy knowledge, desk research and patient representative keywords related to DLBCL, symptoms, diagnosis, and treatment options. The search was limited to English language posts only and to countries such as the US, UK, Canada and Australia where English is the predominant language. In order to gather diverse inputs, English posts from France, Germany, Italy and Spain were also included in scope
- Posts obtained were screened in multiple steps such as automated relevancy check based on keyword relevancy algorithms and manual screening (**Figure 1**)
- Iterative random sampling was used to draw social media posts relevant to the research objective

Figure 1. Data collection and screening



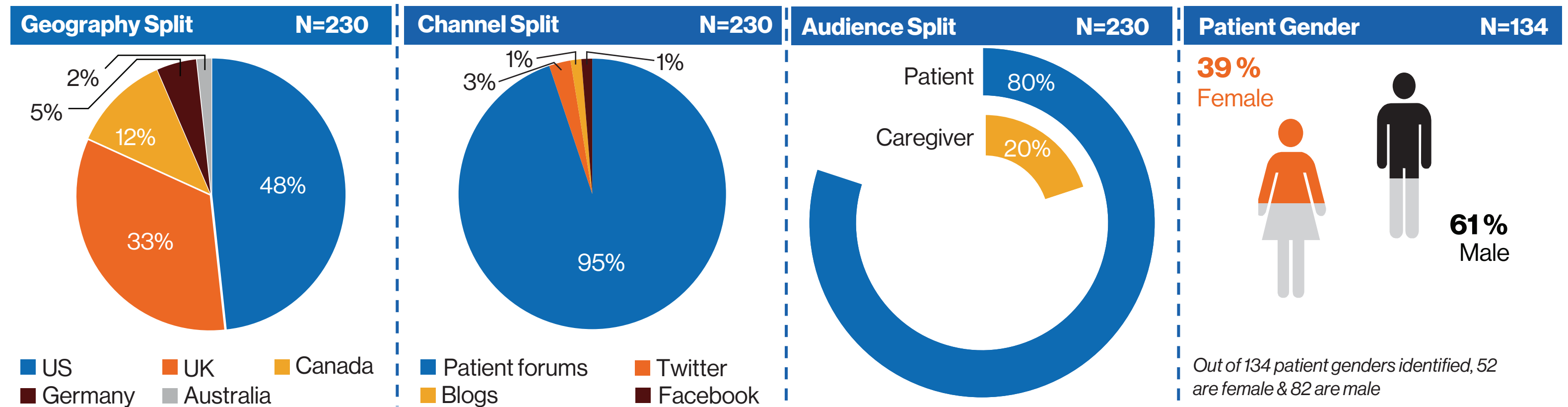
DLBCL, diffuse large B-cell lymphoma; HCP, healthcare practitioner; US, the United States; UK, the United Kingdom

Results

Patient demographics

- The full set of posts was comprised of patients, caregivers, physicians, healthcare professionals, researchers, patient advocacy groups, support groups and reporters (n=1,500) from which we extracted the patient and caregivers posts (n=230) to conduct this analysis
- Majority of the posts were from the US (48%) and the UK (33%). Male patients were found to be more active online; caregivers' posts were associated with older or late stage patients and sought advice on possible treatment options post relapse (**Figure 2**)

Figure 2. Demographics

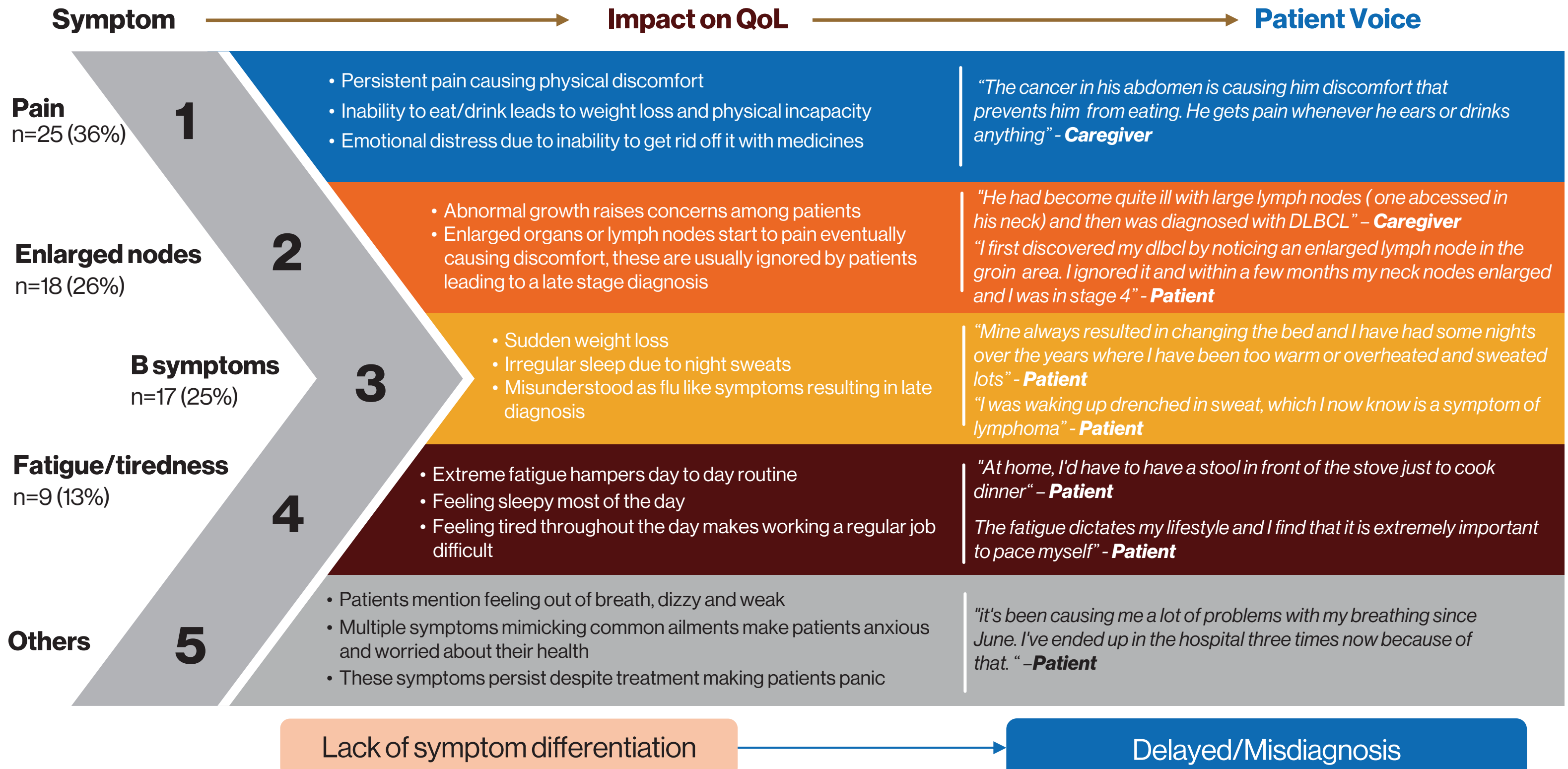


N= Number of posts, n= number of mentions

Symptoms and diagnosis

- Social media conversations were primarily driven by patients and caregivers seeking advice/information on disease symptoms and its management
 - "I started to get pain in my arms. Severe muscle ache, then bone ache, then shoulder joint ache" – Patient
 - "I have had this lump on my throat. I've had it for about over a month. Finally I saw a Dr" – Patient
 - "I was waking up drenched in sweat, which I now know is a symptom of lymphoma" – Patient
- DLBCL symptoms mimicking common ailments led to delayed diagnosis
- Delay in diagnosis was a concern that may be attributed to lack of disease awareness among patients, symptomatic treatment, and lag in referral to specialists (**Figure 3**)
- Physical pain was the most commonly experienced symptom shared on social media by DLBCL patients

Figure 3. Symptom burden and QoL impact



B-symptoms, fever, night sweats, weight loss; DLBCL, diffuse large B-cell lymphoma; n, number of patient / caregiver posts mentioning a symptom; QoL, quality of life

Treatment dynamics

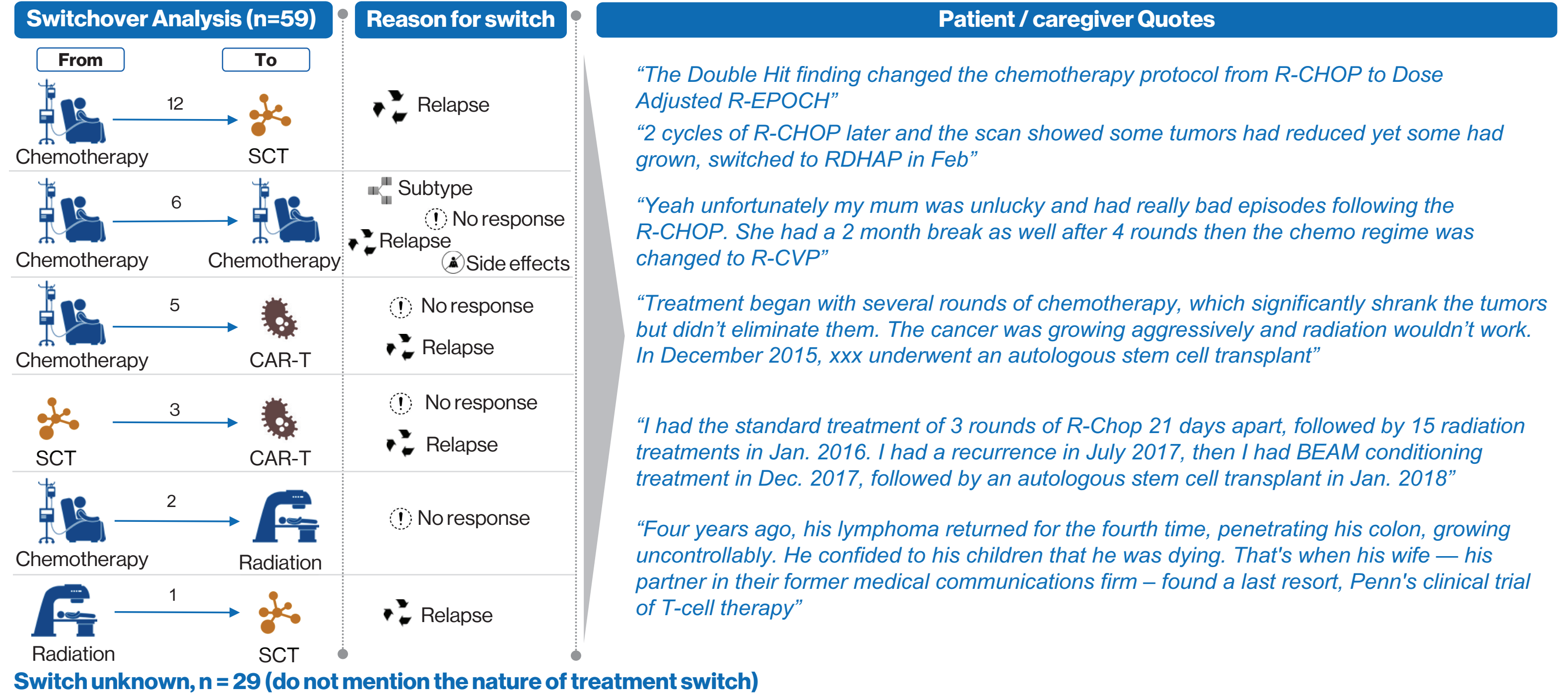
- Most of the patients and caregivers posts were about treatment, with discussions primarily focused around chemotherapy and need for effective treatment post relapse. Challenges experienced by patients with treatment are presented in **Table 1**
- Patients tended to switch between treatments due to disease relapse or until effective control was achieved
- A total of 59 posts were related to treatment switch patterns. Approximately 20.3% (n=12) mention treatment switches to SCT after experiencing multiple relapses and failures from chemotherapy. Switching between chemotherapy regimens (10%; n=6) was found to be due to intolerability, refractory disease, or relapse (**Figure 4**). Nearly half of the posts (n=29) did not describe the type of therapy to which they were switching

Table 1. Summary of patient experience by treatment

Treatment	Summary of patient experience
Chemotherapy	Some patients described mentally preparing themselves to undergo the pain and suffering associated with chemo and recovery <ul style="list-style-type: none">R-CHOP was the most discussed treatment followed by SCT
SCT	<ul style="list-style-type: none">Conflicting opinions about the effectiveness of SCT in addition to the pain and discomfort associated with the procedure sometimes pushed patients to consider CAR T-cell therapy as a replacement for SCTSome patients shared their experience of initially receiving an SCT, which led to a significant remission period but was followed by a relapse
Radiation	Patients/caregivers are reluctant to go for radiotherapy due to: <ul style="list-style-type: none">Fear of side effectsLack of information on QoL and life expectancy without treatment
CAR-T cell therapy	Some patients were confused about the availability of CAR-T cell therapy, and mentions on social media channels around patient experiences with CAR-T were low

CAR-T, chimeric antigen receptor therapy; QoL, quality of life; R-CHOP, rituximab, cyclophosphamide, doxorubicin, vincristine, prednisone; SCT, stem-cell therapy

Figure 4. Treatment switch-over analysis



BEAM, carmustine, etoposide, cytarabine, melphalan; CAR-T, chimeric antigen receptor therapy; CHOP, cyclophosphamide, doxorubicin, vincristine, prednisone; DHAP, dexamethasone, cisplatin, cytarabine; EPOCH, etoposide, prednisone, vincristine, cyclophosphamide, doxorubicin; n, number of posts discussing treatment switch patterns; R, rituximab; SCT, stem-cell therapy

Quality of life (QoL)

- Impact of DLBCL on different aspects of patient QoL was discussed in 104 posts. **Table 2** details out various aspects of QoL discussed as experienced by DLBCL patients / caregivers

Table 2. Impact of DLBCL on patient QoL

Domain (n=104)	Summary of patient experience
Physical (n=35)	Post-treatment side effects cause significant physical burden due to exhaustion, weakness and fatigue Negative emotions are attached to the pain associated with disease and treatment which leads to lack of sleep, inability to eat & walk Post-recovery, patients share the positive experience of feeling fit and active again while slowly regaining normalcy
Emotional (n=34)	Diagnosis of cancer leads to shock and worry Inefficacy of treatment causes depression, despair among patients & caregivers Patients constantly have a fear of relapse even after undertaking treatment
Social (n=8)	Hair loss due to chemotherapy results in social awkwardness Inability to travel to social gatherings due to increased risk of infection
Functional (n=8)	Continuous treatment due to relapse results in patients skipping work frequently or leaving their jobs
Financial (n=9)	High cost and ineffective treatment for remission results in financial burden on patients & caregivers Undergoing treatment like SCT means no income during the period for some working patients Patients undergo financial debts in search for effective treatment Delayed insurance approval, causes disease to advance
Caregiver burden (n=10)	Caregivers express helplessness when they are unable to help patients with treatment & symptom management They feel scared & worried for patients and seek online help for better treatment decision making

Unmet needs

- Table 3** summarizes the unmet needs in DLBCL, inferred from patient / caregiver perspective

Table 3. Key unmet needs in DLBCL

Delayed / misdiagnosis	Delay due to lack of early referral due to both patient and GP/PCP (first point of contact) perceiving the unspecific cancer symptoms as a cause of other illnesses Underlying need to educate GP/PCP/patients/caregivers about the importance of early diagnosis
Treatment	Lack of treatment options with a better chance of survival for transplant ineligible patients was identified as a key unmet need in DLBCL Side effects from current treatment and prolonged recovery period are a cause of concern
Communication	Patients often express concern and frustration that they do not receive counseling post diagnosis from physicians about disease subtypes, laboratory findings and treatment outcomes, especially during treatment, which results in them seeking answers from online peers

Limitations of the study

- Insights may be more relevant in context of the social-economic and health care environment of US and UK due to majority number of posts from these countries
- Social Media data analysis is from unprompted conversations in open data sources. No SML is performed on closed groups/forums/ channels due to data privacy guidelines. Facebook data is limited due to APIs restriction
- SML does not allow for confirmation that posts are from actual patients and caregivers; however, references to disease symptoms, diagnosis and treatments can help to qualify content of posts
- The results do not reflect all current clinical treatment practices; treatments discussed in this poster reflect only those in posts from patients and caregivers in our sample
- There were no posts on issues related to treatment access from patient / caregivers
- Literature review, patient interviews and formal concept elicitation studies would help to validate the findings and understand the entire spectrum of patient experiences

Conclusions

- SML may add to understanding patient, caregivers and others experience with various diseases and the insights may uncover relevant unmet needs
- Physical and emotional impact of pain seem to underline the patient experience in DLBCL from diagnosis through treatment and recovery
- Delayed diagnosis, side effects, poor survival and fear of relapse are key expressed areas of concern for patients and caregivers
- Inadequate treatment options for relapsed DLBCL patients, especially those ineligible for SCT, indicate the need for new treatments

References

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