Mining Social Media to Understand Unmet Need and Treatment Experience in Patients with Atypical Hemolytic Uremic Syndrome (aHUS)

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Background

- Atypical haemolytic uremic syndrome (aHUS) is a progressive and potentially life—threatening disease characterized by complement—mediated thrombotic microangiopathy (TMA).[1]
- The estimated incidence of aHUS is approximately 0.23 to 1.9 per million population, affecting all age groups, from neonatal period to the adult age.[2]
- The condition is associated with poor clinical outcomes with high morbidity and mortality. It predominantly affects the kidneys but has the potential to cause multi—organ system dysfunction.[3]
- Though the introduction of anti—C5 agents has significantly improved the morbidity and mortality and largely improved the quality of life (QoL) of aHUS patients, studies have suggested that anti—C5 treatment has not completely eased the burden associated with aHUS.[4-6]
- In this new 'digital age', where there is abundant use of social media, innovative ways can be employed to capture patient insights and understand the burden associated with the condition from a patient's perspective.

Objective

- The objective of this study was to understand the patient journey, quality of life (QoL), unmet needs, and experiences with available treatments from the aHUS patient's perspective, through social media listening (SML).

Methods

- This retrospective SML study gathered publicly available data from Twitter, forums, Facebook, blogs, and news outlets from 2017—2020.
- A search strategy was developed using Medical Subject Heading (MeSH) terms for aHUS and a social media data aggregator tool (SalesForce Social Studio®) was used to download social media posts.
- The downloaded data was anonymized to remove all personal identifiers and categorized for analysis based on channels, stakeholders, sentiments and key themes of discussion.
- Post data anonymization, data curation, analysis and insights generation was carried out using primarily human interventions that was partly supported by machine learning interventions such as Natural Language Processing (NLP) algorithms.
- The search was restricted to the English language for conversations originating from the US and the UK on open channels.

Results

- A total of 3,849 relevant social media posts (mix of posts from patient advocacy groups, news reporters, health care providers, patients and caregivers etc.) were included for analysis, of which 71% originated from the US while the remaining posts were from the UK.
- Twitter was the primary source of information, contributing to 85% of total posts followed by other sources such as Patient Forums (8%), Blogs (4%), Facebook (2%) and News (1%).

- The key discussions were mainly focused on seeking or sharing advice, information, and experiences on aHUS disease awareness, treatment options, diagnosis, symptoms, and quality of life.

Symptoms and comorbidities

- aHUS symptoms appear to vary and a typical patient experienced a wide range of symptoms as the disease progress.
- The patients initially experienced generic symptoms like fatigue, vomiting, yellowness of skin and abdominal pain. This was followed by deterioration of the kidney function, requiring immediate attention.
- Hypertension and pre existing renal conditions were some of the most common comorbidities mentioned by patients.

Patient journey and the perspective on aHUS

- The analysis provided key insights into the patient journey in the healthcare system.

Diagnosis journey

- The first clinical touch point was the emergency care unit/ Intensive Care Unit (ICU) following the onset of symptoms. As the disease progressed to other organs like the kidneys, the patients were referred to specialists.
- Multiple blood investigations and renal biopsy required for diagnosis caused emotional stress in patients/caregivers.
- Approximately 40% of the patients reported kidney dysfunction. High blood pressure, and low level of platelets were other diagnostic findings.
- A key unmet medical need of avoiding delay in establishing a clear diagnosis of aHUS was uncovered from patient journey posts.

Treatment journey and disease management

- The treatment journey illustrated in **Figure 1** was developed based on the discussions retrieved from social media during the study period. Patients expressed challenges at each stage from disease onset till maintenance phase.
- Patients with severe kidney dysfunction were on dialysis or underwent kidney transplants along with receiving supportive therapies.
- Eculizumab, the first approved treatment for aHUS was a preferred treatment option, however some of the unmet needs perceived with eculizumab were:
  - Concerns over the high drug cost
  - Inconvenience in long term management associated with intravenous infusion administration
  - Uncertainty in treatment duration and insurance coverage
  - Limited treatment options other than eculizumab

### Impact of aHUS on patient's quality of life

- Restricted physical activity due to symptoms such as fatigue and lack of energy, limited social interactions because of regular dialysis requirement, inability to resume work combined with emotional aspects such as fear of disease progression, anxiety, depression and financial burden due to the high cost of eculizumab affected the QoL as illustrated in **Figure 2**.

Figure 1: Treatment journey and unmet needs
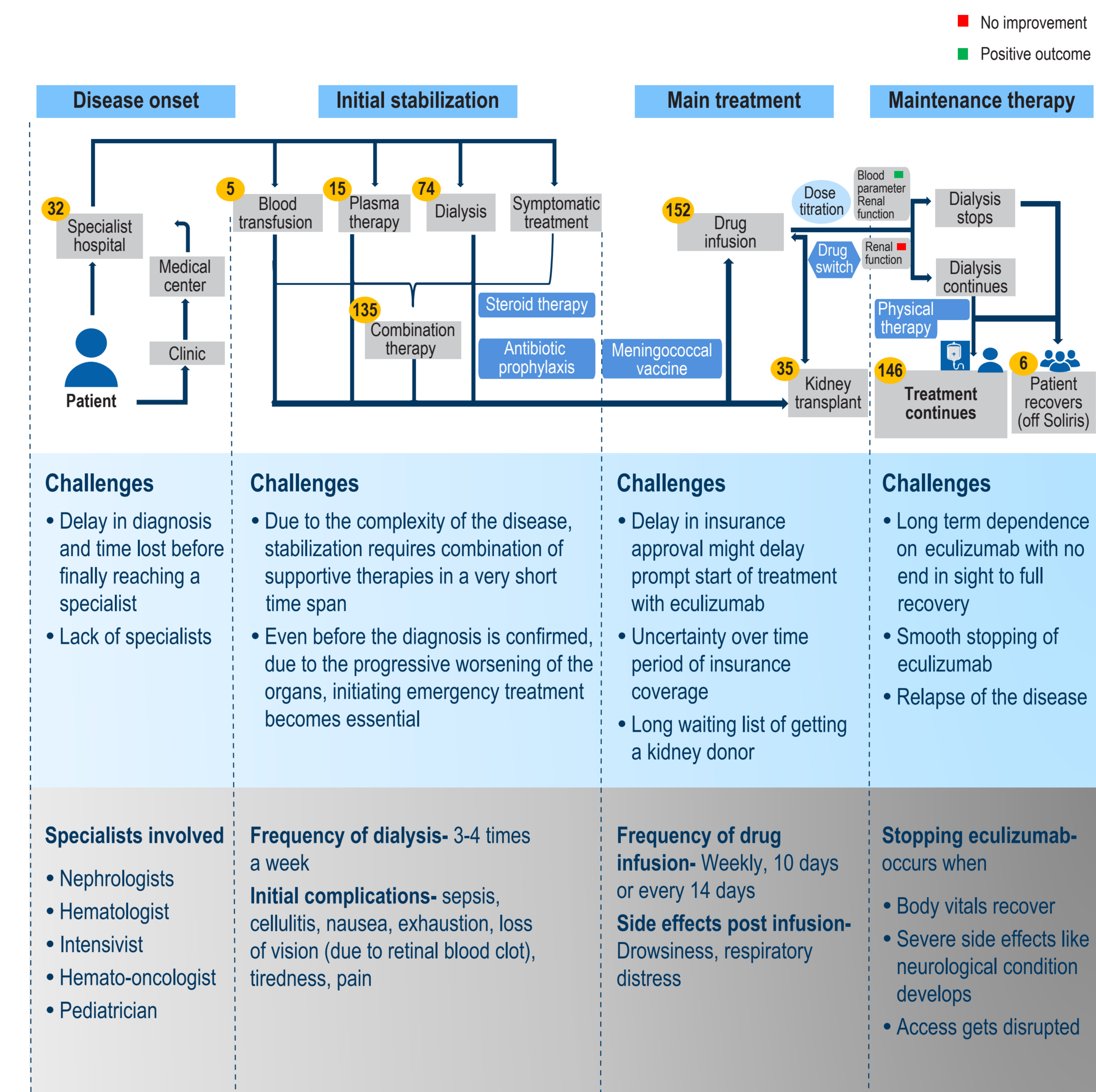
The numbers in yellow circle indicate the number of posts

Figure 2: Impact of aHUS on patients' and caregiver's QoL
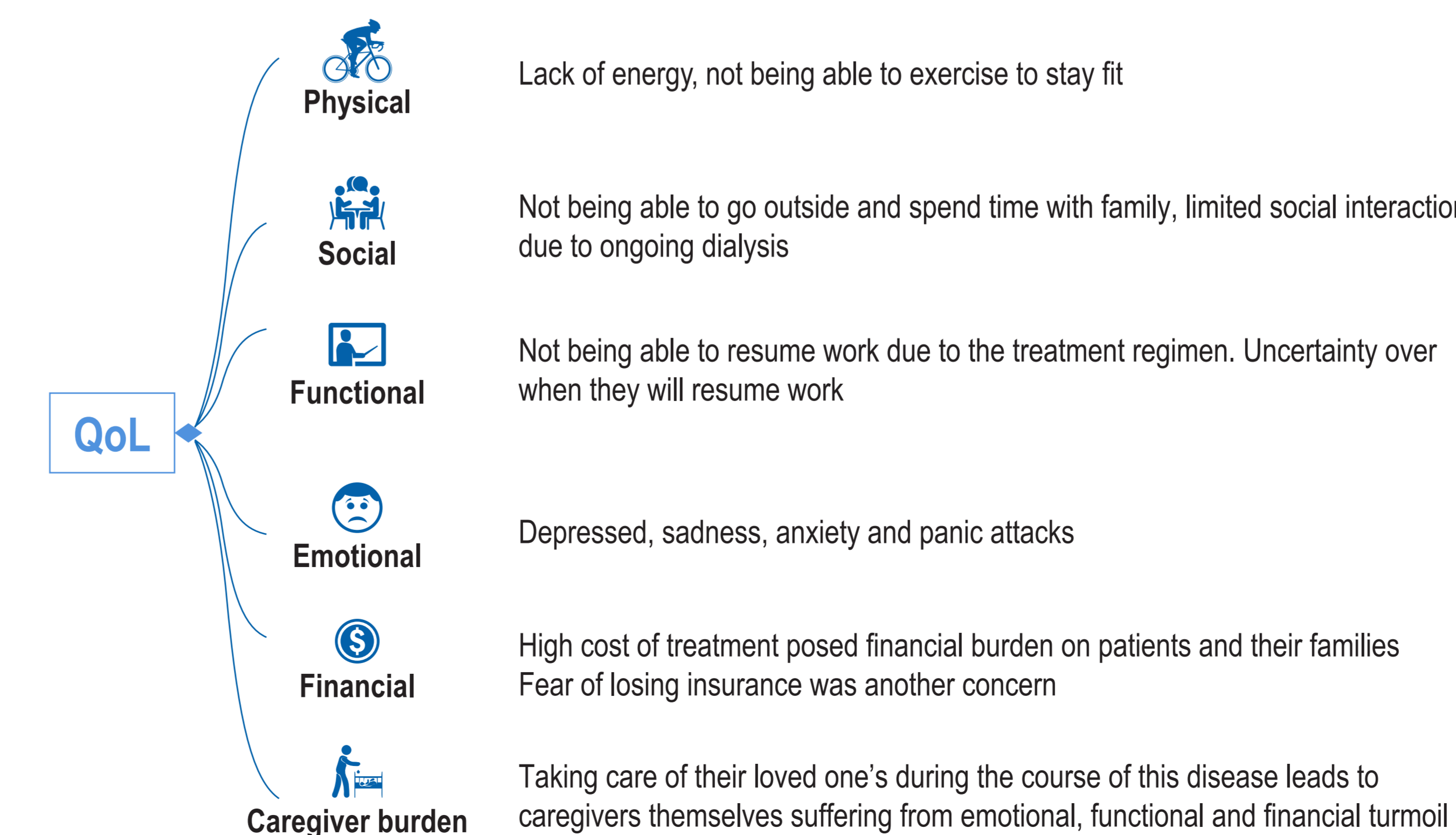
Limitation

- The SML study had limited data as it analysed only English language posts from the US and the UK available on open forums/community pages. Nevertheless, it provides insights on the burden and unmet needs associated with aHUS.
- We were unable to describe the type of patients/caregivers that use social media to seek information/ share experiences (e.g. sicker patients, patients/ caregivers who are more computer savvy etc.)
- It is possible that disproportionate share of posts come from few sources (patients/caregivers), which would limit the results to a few patients only.

Conclusions

- The results of the SML study provide insights generated by analysing social media posts from patients and caregivers and reflects their viewpoints on how they perceive and live with a rare disease like aHUS.
- These insights can improve the understanding of patients' perspectives and unmet needs that can inform the development of new treatment interventions as well as patient support programs for this debilitating disease.

References

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Conflict of interest

Abhinav Maurya, Garima Dixit, Aneesh Thomas George, Sathyaraj Aasaithambi, Rajeshri G Karki, Himanshu Verma and Jim Doherty are all permanent employees of Novartis.

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