PATIENT INSIGHTS FOR COMPLEMENT 3 GLOMERULOPATHY (C3G) USING SOCIAL MEDIA LISTENING

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BACKGROUND

- C3G is a complex and chronic ultra-rare renal disease resulting from excessive activation of the complement alternate pathway (AP) due to autoantibodies or genetic mutations of AP regulatory proteins.(1)
- The disease occurs early in life and patients are heterogeneous as their clinical presentations and rate of progression to end-stage renal disease (ESRD) vary. Some of the common clinical symptoms mentioned in literature are the presence of proteinuria and haematuria.(2,3,4)
- There is a lack of published evidence on the humanistic burden of C3G. The use of social media and analysis of posts can be can be a good way to capture first patient insights and understand the burden associated with this renal disease from a patient's perspective.

OBJECTIVE

- The objective of this study was to explore the patient journey, quality of life (QoL) and unmet needs from the patients' perspective through social media listening (SML).

METHODS

- This retrospective SML study gathered data from Twitter, Blogs/Media, Forums, Facebook and Newswires from September 2015–September 2018.
- A search strategy was developed using Medical Subject Heading (MeSH) terms for C3G 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 NLP (Natural Language Processing) algorithms.
- Discussions in English language specific to C3G originating from the US and the UK were included in the analysis.

RESULTS

- A total of 791 relevant posts (mix of posts from both patients and caregivers) were analysed, of which 73% originated from the US while the remaining 27% of the posts were from the UK **(Figure 1A)**.
- Twitter was the primary source of information, contributing to 67% of total posts followed by other sources such as Patient Forums (14%), Blogs (9%), News (8%), and Facebook (2%) **(Figure 1B)**.

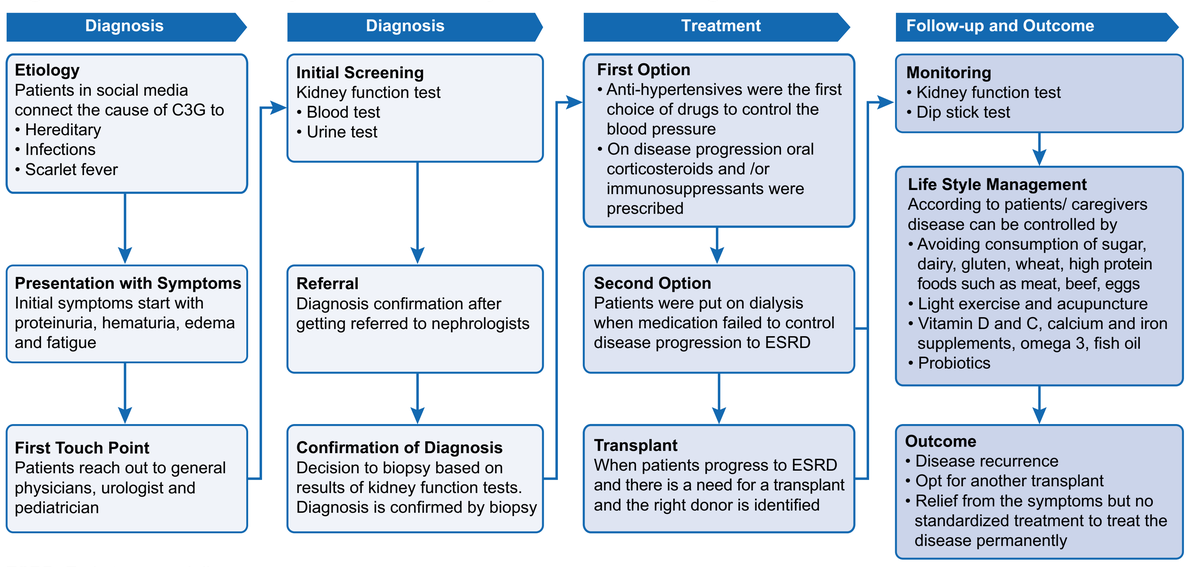
Figure 1. Percentage Split of Posts by Geographies and Data Sources

- The key discussions from patients and caregivers were mainly focused on seeking or sharing advice, information, and experiences on C3G symptoms, diagnosis and treatment options and support groups.

Patient Journey and Perspectives on C3G

- The analysis provided key insights into the patient journey as described by the patients. The patient journey illustrated below was developed based on the patient/caregiver discussions on social media during the study period **(Figure 2)**

Figure 2. Patient Journey as Described by the Patients/caregivers



ESRD: End-stage renal disease

Symptoms and Comorbidities

- C3G patients experienced a range of symptoms **(Figure 3)** and these symptoms varied from patient to patient.
- Fatigue emerged as the most bothersome symptom for C3G patients.
  - Patients complained that "being low on energy" or "feeling exhausted/tired" impacted their day to day activities and caused them to sleep excessively.
  - According to caregivers, fatigue impacted paediatric patients' concentration and performance in schools.
- According to various posts, swelling/oedema caused pain and restricted physical activity. Patients also mentioned that the severity of oedema increased towards evening.
- Along with fatigue and oedema the presence of "urine protein spillage" (proteinuria) and/or "blood in the urine" (haematuria) and hypertension lead to initial physician visits**.**
- Many patients/caregivers discussed being affected by chronic infections before appearance of renal symptoms and C3G diagnosis.

Figure 3. Social Media Quotes from Patients on Symptoms Associated with C3G

Diagnosis of C3G

- Diagnosis usually happened at 11–20 years of age through biopsy and patients and caregivers often shared their experiences with the diagnosis process on social media.
  - The perception of patients and caregivers was that there was a delay in diagnosis. After experiencing symptoms patients consulted general practitioners where they had to undergo a battery of tests (which involved multiple visits), followed by referral to a nephrologist who then confirmed the condition through biopsy.
  - Patients and caregivers mentioned that there was a lack of detailed disease-related information and counselling, causing emotional stress on patients/caregivers.

Disease Management

- Many of the posts were related to queries on managing the condition. Nearly 50% of the posts mentioned initial treatment with anti-hypertensives followed by oral corticosteroids and/or immunosuppressants.
  - Patients/caregivers often used social media to enquire if the current standard of care could prevent disease progression and also posted information on any new/ongoing clinical trials for C3G.
  - The need for a curative and safe treatment was highlighted in patient conversations given the lack of efficacious therapies and the side-effects of corticosteroids.
  - Additionally, patients/caregivers were of the opinion that diet management could control disease progression and enquired on social media if there was any particular diet that could manage C3G progression as they felt that not much information was obtained from their healthcare providers on this topic.

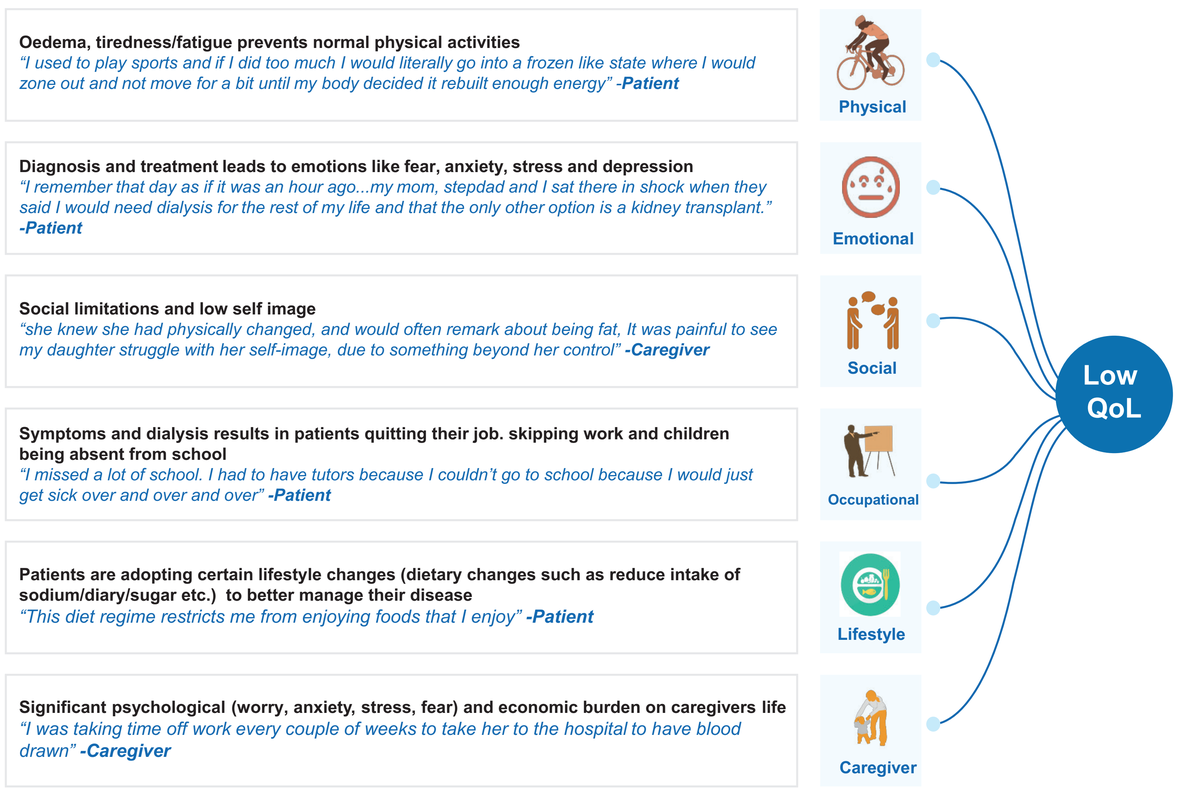
Disease Progression

- According to various posts, failure to respond to medications caused patients to progress to ESRD, requiring them to undergo dialysis/transplant, adding to the disease burden.
- Patients/caregivers mentioned dialysis as difficult, time consuming and causing side-effects.
- Patients/caregivers perceived that once the disease has progressed to ESRD, there is a difficulty in getting the right donor and patients understood that there is a risk of disease recurrence, post-transplant
- Some patients and caregivers were also concerned about the financial burden because of the costs involved in managing the condition (including dialysis and transplant).

Impact of C3G on Patients' QoL

- Restricted physical activity due to symptoms such as fatigue, and oedema combined with emotional aspects such as fear of disease progression, uncertainty of future caused anxiety and stress affecting the QoL, which are illustrated by the patient/caregiver verbatim (**Figure 4)**.
- As a sizeable proportion of the C3G population represented in the posts are in the paediatric age groups. The condition caused them to miss school, affected their academic performances, caused low self-esteem and had significant impact on their as well as their caregivers' QoL.

Figure 4. Impact of C3G on Patients' QoL



LIMITATION

- The SML study had limited data as it only analysed English language posts originating from the US and the UK available on open forums/community pages. Nevertheless, it provides insights on the humanistic burden associated with C3G, which rarely finds a mention in the literature.
- Findings are based only on the patient discussions that appeared in social media during study period.
- It remains unclear if symptoms mentioned are related to the disease or the adverse events of any medication(s). Moreover, it is also difficult to describe the type of patients that use social media to seek information/share experiences (e.g. sicker patients, patients more involved with C3G advocacy groups, patients who are more computer savvy etc.).

CONCLUSIONS

- The insights generated from analysing social media posts are the views of the patients/caregivers and reflects their view points on how they perceive or live with their disease.
- Symptoms such as fatigue, minimally mentioned previously in the literature, contributed to the reduction in the QoL, which needs further exploration in future studies.
- These insights can help in better understanding the patients' perspective which can be taken into account during drug development.

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Conflict of Interest

Nishith Tyagi, Sathyaraj Aasaithambi, Jyoti Chauhan, Aneesh Thomas George and Nancy Zaour are all permanent employees of Novartis.

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