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BACKGROUND

- IgAN or Berger's disease is a rare autoimmune renal disease characterised by the presence of predominant IgA1 deposits in the glomerular mesangium, ⁽¹⁾ with the peak incidence observed in young adults aged 20–30 years. ^(2,3)
- IgAN 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. ⁽⁴⁾
- There is scarcity of published evidence on the humanistic burden of IgAN. In this new 'digital age', the use of social media and analysis of posts can be an innovative way to capture patients 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 open sources such as Twitter, Blogs/Media, Patient Forums, Facebook and Newswires from February 2017–September 2018.
- A search strategy was developed using Medical Subject Heading (MeSH) terms for IgAN 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 IgAN originating from the US and the UK were included in the analysis.

RESULTS

- A total of 1,336 relevant posts (mix of posts from both patients and caregivers) were included for analysis, of which 87% originated from the US while the remaining posts were from the UK (Figure 1A).
- Twitter was the primary source of information, contributing to 49% of total posts followed by other sources such as Patient Forums (40%), Blogs/Media (6%), News (4%) and Facebook (1%) (Figure 1B).

Figure 1. Percentage Split of Posts by Geographies and Data Sources (N=1,336)

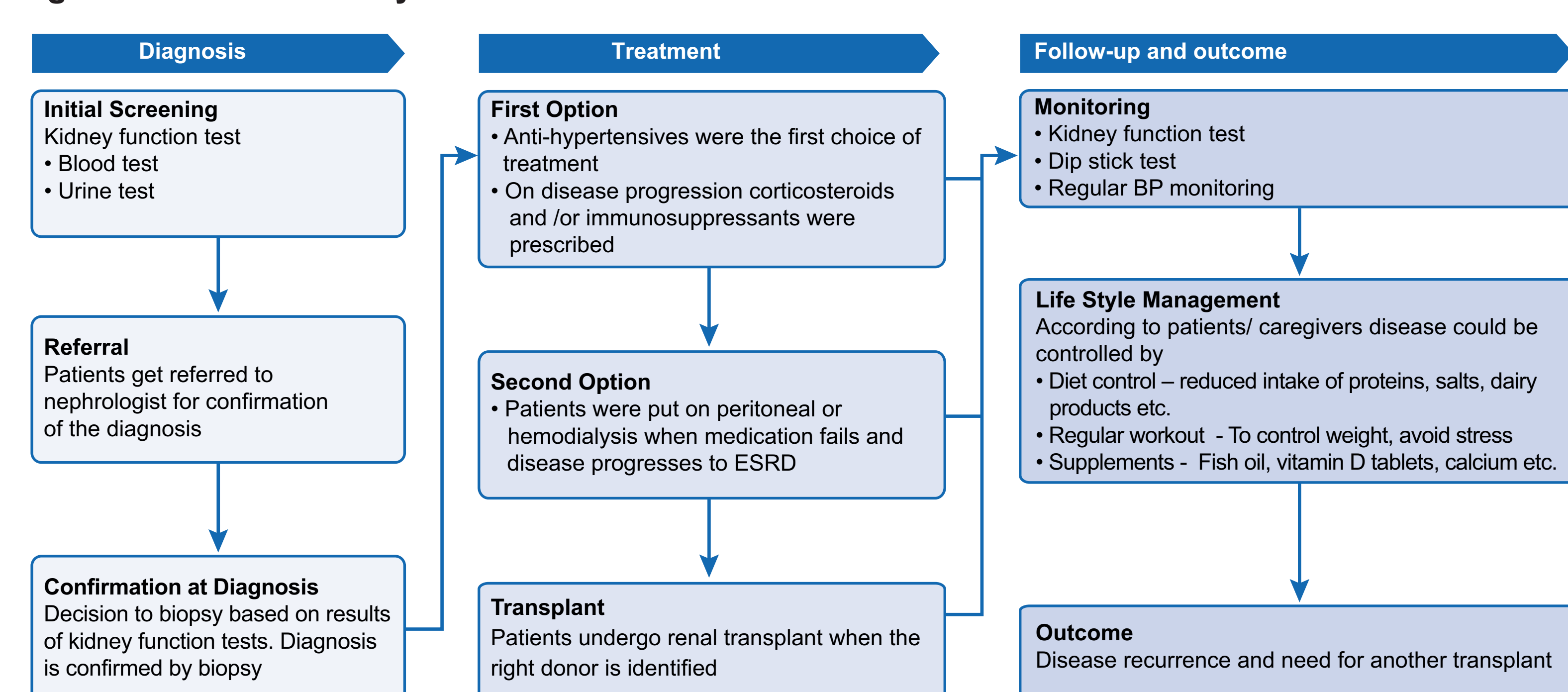


- The key discussions from patients and caregivers were mainly focused on seeking or sharing advice, information, and experiences on IgAN symptoms, diagnosis, treatment options and current disease management

Patient Journey and the Perspectives on IgAN

- 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



ESRD: End-stage renal disease

Symptoms and Comorbidities

- The presence of "cola coloured urine", "blood in the urine" (haematuria) or "foamy urine" (proteinuria) were the major reasons leading to initial physician visits (Figure 3).
- IgAN symptoms appear to be heterogeneous from patient to patient and patients might experience a range of symptoms as the disease progresses.
- In the sample of social media posts studied, it was observed that routine medical examination also led to a chance diagnosis of IgAN in few patients, who were otherwise asymptomatic.
- Patients often complained of symptoms such as pain and fatigue which are seldom reported in the literature.
 - For some patients, "pain in the kidney area", "pelvic pain", "back pain" and/or body aches were mentioned as a symptom.
 - Fatigue was the main symptom that had an impact on the patient's QoL. Patients experienced spells of tiredness and loss of energy resulting in limited physical activity, exhaustion, and low stamina.
- Many patients/caregivers discussed being affected by respiratory and urinary infections, before being diagnosed by IgAN. Hypertension was a widely reported comorbidity.

Figure 3. IgAN associated symptoms: Social Media Quotes from Patients and Caregivers



Diagnosis of IgAN

- Diagnosis usually happened at 21–30 years of age, mainly through biopsy. Patients and caregivers have shared their experiences with diagnosis process on social media.
 - One of the unmet needs at the time of diagnosis was the absence of detailed disease-related information and counselling post-diagnosis, causing emotional stress on patients/caregivers.

Disease Management

- Patients/caregivers mentioned on social media that initial treatments were with anti-hypertensives followed by oral corticosteroids and/or immunosuppressants.
 - Patients/caregivers often used social media to find from other patients if the current standard of care could lower urine protein content, reduce hypertension and prevent progression of disease.
 - 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 IgAN progression as they felt that not much information was obtained from their healthcare providers on this topic.

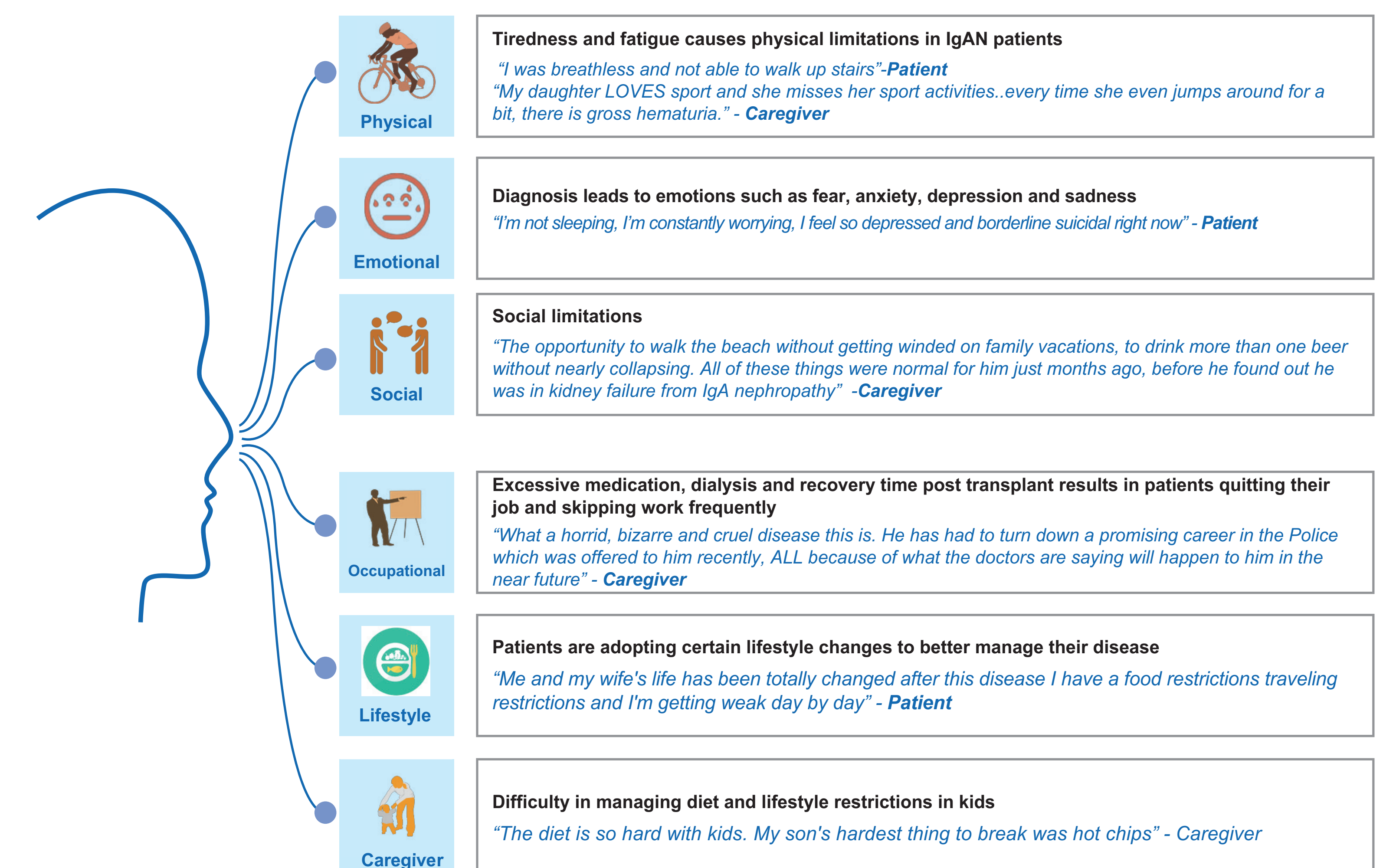
Disease Progression

- Approximately 30% of patients discussed progressing to ESRD within 7–12 years, requiring dialysis and few patients also mentioned need for renal transplant, adding to the disease burden.
- Patients perceived that once the disease has progressed to ESRD, there was difficulty in getting the right donor for renal transplant and they also understood that there was a risk of disease recurrence post-transplant.

Impact of IgAN on Patients' QoL

- Restricted physical activity due to symptoms such as fatigue and pain combined with emotional aspects such as fear of disease progression, anxiety, depression and regular dialysis requirement affected the QoL which are illustrated by the patient/caregiver verbatim (Figure 5).
- Additionally, female patients were fearful that their condition could result in "preeclampsia" in pregnancy

Figure 5. Impact of IgAN on Patients' QoL



LIMITATION

- The SML study had limited data as it only analysed English language posts from the US and the UK available on open forums/community pages. Nevertheless, it provides insights on the humanistic burden associated with IgAN, which is rarely found 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 were related to the disease or due to co-morbidities or are adverse events of any medication(s).
- Moreover, it was 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 IgAN advocacy groups, patients who are more computer savvy etc.)

CONCLUSIONS

- The results of the SML study provides insights generated by analysing social media posts from patients and caregivers and reflects their view points on how they perceive or live with their disease.
- The insights generated from analysing social media posts are the views of the patients/ caregivers
- The symptoms of fatigue and pain, minimally mentioned previously in the literature, have an impact on QoL, which needs further exploration in future studies.
- Furthermore, 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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