"Tiredness…That's the main thing, this is why I work part time.":
A thematic analysis of patient perspectives on care and unmet needs in C3G and primary IC-MPGN

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CONCLUSIONS

- **Patients with mild symptoms of C3 glomerulopathy (C3G) and primary (idiopathic) immune complex membranoproliferative glomerulonephritis (IC-MPGN) frequently experience delays in diagnosis, leading to prolonged suffering.**
- **Symptoms of C3G and primary IC-MPGN significantly impact physical and emotional health, disrupting daily life and work.**
- **This impact is compounded by side effects of treatment for symptom management and fears about the future.**
- **There is an urgent need for faster diagnosis and effective targeted therapies to reduce the burden of disease.**

INTRODUCTION

- C3G and primary IC-MPGN are rare chronic kidney diseases affecting ~5000 people in the United States (US) and ~8000 in Europe [1].
- While studies exist looking at the clinical burden of C3G/primary IC-MPGN, data on the humanistic burden in patients are limited [2].
- To improve patient outcomes and alleviate this burden, an understanding of how C3G/primary IC-MPGN impacts patients, and any current unmet needs patients may have is needed.

OBJECTIVE

- This study aimed to understand perceptions of care and unmet needs in patients with C3G/primary IC-MPGN in the US and Europe using a qualitative interview methodology.

METHODS

- Patients (n=13) aged ≥18 years with biopsy-confirmed C3G/primary IC-MPGN in France (FR), Germany (DE), Italy (IT), Spain (ES), the United Kingdom (UK) and the United States (US) participated in a 1:1 semi-structured telephone or online interview between July 2024 – January 2025.
- Trained interviewers followed a discussion guide covering topics including diagnosis, symptoms, treatment side-effects and how they impact wellbeing, and concerns about the future.
- Interview transcripts were reviewed and inductively coded using ATLAS.ti software (v.25.0).
- Thematic analysis was conducted in which key themes were identified, reviewed and refined until consensus was reached [3].

RESULTS

Theme 1 – The process of receiving a diagnosis is highly variable across patients

- 8/13 patients described a prolonged period between experiencing symptoms and referral to a nephrologist.
- These patients tended to have more milder presenting features, with four of the eight patients reporting delays due to HCPs treating the symptoms rather than the disease, and four reporting delays due to misdiagnoses.

> *"…It took me forever to get an appointment with the nephrologist […] Over many, many years"* – Patient, DE

> *"…If I had been diagnosed with the disease from the beginning, I might not have gone through so many years of suffering. It was an ordeal.'* Patient, ES

- 5/13 patients received a diagnosis quickly, of whom four presented with acute symptoms (e.g. edema, pain)

Theme 2 – Fatigue/exhaustion were frequently cited as a burdensome; impacting multiple domains of patients' lives

- Fatigue/exhaustion was cited as highly burdensome by 8/13 patients, which had both a physical and cognitive impact affecting many domains of patients' lives including the ability to work/study, socialise and exercise.

> *"My brain works less well, I'm much more irritable"* – Patient, FR

> *"I couldn't play football, work…it was a lot of emotions."* – Patient, UK

> *"The feeling that you are completely exhausted and just feel weak, so really drained and low on energy...you no longer have the physical strength, you feel as though you're being drained of energy"*– Patient, DE

> *"Tiredness…That's the main thing this is why I work part time. I just do everything at a much slower pace and don't do some of the things that I used to do."*– Patient, UK

Theme 3 – A significant emotional burden of disease was frequently reported

- 11/13 patients described irritability and frustration, and 8/13 patients expressed anxiety and fears for the future.
- Among patients who were pre-transplant, fears revolved around their condition worsening, decreasing treatment effectiveness, and or potential complications while post-transplant, patients' fears related to their illness returning.

> *"My scare still today is that both kidneys completely give out, they're unresponsive to even dialysis."* – Patient, US

> *"When I ask about my disease, they tell me that it is chronic and that there is no cure. That worries me [...] Sometimes, I don't know if I'm okay today and tomorrow"*– Patient, US

> *"The big thing with this disease is, there's a high degree of chance that disease can return with a transplant."* – Patient, UK

- Visible manifestations of disease or treatment side effects also had an impact, with 4/13 patients noting that weight gain due to corticosteroid use severely impacted their self-image and relationships.

> *"I think it affects my relationship with my partner because it's given me, obviously, very bad self-esteem issues, and I feel like I don't look how I did when we first got together"* – Patient, UK

PATIENT DEMOGRAPHICS

	Overall n=13	EU5 n=11	US n=2
Age, years			
Mean (SD)	41.8 (14.5)	40.9 (15.6)	46.5 (6.4)
Sex: Female, n (%)	11 (85)	9 (82)	2 (100)
Patient ethnicity*, n (%)	**n=12**	**n=10**	**n=2**
White	10 (83)	9 (90)	1 (50)
Other	1 (8)	1 (10)	-
Prefer not to say	1 (8)	-	1 (50)
Patient diagnosis (biopsy confirmed)			
C3G	8 (62)	6 (55)	2 (100)
Primary IC-MPGN	5 (38)	5 (45)	-
Kidney transplant received?, n (%)			
Yes	3 (23)	2 (18)	1 (50)
No	10 (77)	9 (82)	1 (50)
Currently on dialysis?, n (%)			
Yes	3 (23)	2 (18)	1 (50)
No	10 (77)	9 (82)	1 (50)

Abbreviations: Eu5 - European 5 (France, Germany, Italy, Spain, and the United Kingdom, US – United States of America, C3G - C3 glomerulopathy, IC-MPGN - immune complex membranoproliferative glomerulonephritis, IQR – interquartile range, HCP – healthcare provider
*Ethnicity was not collected in France (n=1 patient) due to the French Constitutional Council prohibiting the collection of this information

LIMITATIONS

- Convenience sampling was used, with an attempt to capture a wide range of experiences. As a limited pre-determined sample size was collected, it is possible that concept saturation may not have been achieved, and results should not be taken as representative of the broader C3G/primary IC-MPGN patient population.

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