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"The smouldering disease that is slowly eating away the kidneys, those people get missed": A thematic analysis of healthcare provider perspectives on the care pathway and unmet needs in C3G and primary IC-MPGN in the US and Europe

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INTRODUCTION

- C3 glomerulopathy (C3G) and primary (idiopathic) immune complex membranoproliferative glomerulonephritis (IC-MPGN) are rare chronic kidney diseases affecting ~5000 people in the United States (US) and ~8000 in Europe [1].
- Diagnosis is complex due to the heterogeneous nature of the diseases and the need for biopsy confirmation, and, at time of interview, there were no approved treatments that targeted the underlying cause of the disease [2,3].
- To improve diagnosis and treatment, we must understand how healthcare providers (HCPs) perceive current diagnostic and care pathways.

AIM

- The aim of this study was to understand HCP perceptions of current care pathways and unmet needs in patients with C3G and primary IC-MPGN in the US and Europe.

METHOD

- Nephrologists (n=21) managing at least one patient 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 bespoke 1:1 semi-structured telephone or online interview from July – December 2024.
- Trained interviewers followed a discussion guide with topics such as diagnosis, current care pathways, and future treatment prospects.
- Interview transcripts were reviewed and inductively coded using ATLAS.ti software (v.22.2.5).
- Thematic analysis was conducted in which key themes were identified, reviewed and refined until consensus was reached [4].

RESULTS – Key themes

Theme 1 – All HCPs (21/21) perceived timely diagnosis is a key unmet need

- 18/21 HCPs described "milder" or asymptomatic patients at initial presentation were considered at greatest risk of misdiagnosis and delays in referral to specialist care.
- HCPs reported non-specific symptoms (e.g. haematuria and hypertension) were overlooked or not investigated as potential indicators of a rare disease in primary care.
- Patients who presented with specific severe acute symptoms were rapidly referred to a nephrologist, an aspect of care HCPs deemed effective.

"It can be a smouldering burn, but it's not a bonfire. Those people who have a bonfire going on in those kidneys, they get picked up. It's the burn, the smouldering disease, that is slowly eating away the kidneys, those people get missed... They don't have symptoms, and they don't get their urine test done because it's not being suspected. It's a rare disease." – Nephrologist, US

Theme 2 - Biopsies could be challenging to obtain due to systemic factors and/or patient preference

- 6/21 HCPs stated that biopsies, which are needed for a definitive diagnosis, can be difficult or time consuming to obtain.

"The organisational related factors will be the case of arranging a bed because the NHS is under a huge pressure from other problems, so to find a bed for an elective procedure, such as the biopsy, it sometimes takes a bit of a long time." – Nephrologist, UK

"Once the patient is in our system, the biopsy could be the most time-consuming, either because the patient does not want to perform it urgently for personal reasons or because, at a specific moment, there is something else overloading." – Nephrologist, ES

Theme 3 – Healthcare providers perceived a lack of effective treatment options, however, they were optimistic for future treatment options

- 5/21 HCPs reported that care options were limited for patients with C3G / primary IC-MPGN following diagnosis.
- 3/21 HCPs reported that treatments that target the complement cascade were identified as being particularly promising.

"I don't have any drugs that are really approved for it and provide the performance I want." – *Nephrologist, DE*

"I think the most interesting thing at the moment for C3G is the inhibition of C3… the dream... is being able to...characterize specifically where we have to impact the complement cascade." – Nephrologist, ES

"Well, I think that complement inhibitors are going to be a very important change when we have them really available in regular practice." – Nephrologist, ES

Table 1: Healthcare provider caseload and setting

	Overall n=21	Eu5 n=13	US n=8
Primary HCP setting, n (%)			
Teaching hospital	14 (67)	11 (85)	3 (38)
Specialist treatment center	3 (14)	2 (15)	1 (12)
Non-teaching hospital	2 (10)	0 (0)	2 (25)
Ambulatory care	2 (10)	0 (0)	2 (25)
Primary HCP setting location, n (%)			
Urban	16 (76)	12 (92)	4 (50)
Suburban	4 (19)	1 (8)	3 (38)
Rural	1 (5)	0 (0)	1 (12)
Number of C3G / primary IC-MPGN patients treated in the last 12 months, median (IQR)	6.0 (6.0, 14.0)	6.0 (6.0, 12.0)	5.0 (5.0, 42.5)
Number of C3G / primary IC-MPGN newly diagnosed in the last 12 months, median (IQR)	2.0 (2.0, 4.5)	2.0 (2.0, 4.0)	2.5 (2.5, 20.0)

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

CONCLUSIONS

- HCPs highlighted a need for timely diagnosis, access to diagnostic tools, and novel targeted treatments for C3G / primary IC-MPGN to reduce patient burden
- Though HCPs highlighted the lack of treatment currently available, they are optimistic about future treatments such as targeted C3 inhibition.
- To improve care, physician education to recognise ambiguous symptoms as potential rare disease indicators, patient education surrounding the importance of renal biopsies, and updated treatment guidance to include emerging therapies are needed.

Limitations

- Convenience sampling was used, with an attempt to capture a wide range of experiences, however results should not be taken as representative of the broader C3G / primary IC-MPGN treating physician population.
- A limited pre-determined sample size was collected, as such it is possible that concept saturation may not have been achieved.
- For interpretation it is worth noting that sample size in the US is lower than that in the Eu5

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