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“I feel trapped. It’s lifelong”: Understanding the patient experience of IgAN

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Introduction

- Immunoglobulin A nephropathy (IgAN) is an immune-mediated kidney disease defined by IgA deposition in the glomeruli, leading to chronic inflammation and progressive loss of kidney function (1).
- The clinical presentation of IgAN is heterogenous, and can range from asymptomatic disease detected through routine assessments or screening, to symptomatic presentations marked by urinary changes, pain, fatigue, edema and loss of kidney function (1). There is also a difference on perception of disease burden between patients and doctors. Irrespective of this varied presentation, IgAN is progressive and represents one of the leading causes of chronic kidney disease (CKD). Patients are typically diagnosed at a young age, between 20 and 40 years old. Without treatment, many patients will develop kidney failure (2).
- IgAN can have notable impacts on aspects of patients’ health-related quality of life (HRQoL) (3-5). Primary qualitative research which provides a comprehensive understanding of these experiences is scarce.

Objective

- The objectives of this study were to explore the experience of adults living with IgAN in order to refine a conceptual model of the patient experience and to develop a patient journey map (PJM).

Methods

- Individual 60-minute qualitative interviews were conducted with N=15 participants with IgAN.
- Ethical approval for this study was obtained from the Western Copernicus Group Institutional Review Board (IRB study number: 1389576) prior to interviews taking place.
- Purposive sampling was used to recruit eligible participants from the US aged >18 years with a confirmed diagnosis of biopsy-proven, primary IgAN. Due to the rarity of IgAN, soft sampling quotas were applied to recruit a diverse sample of participants with respect to race/ethnicity, sex, and age.
- All participants were recruited through a specialist recruitment agency and eligible participants completed an IRB approved informed consent form prior to study activities.

Procedure

- Interviews were conducted remotely in English via Microsoft Teams by trained qualitative interviewers.
- An IRB approved semi-structured interview guide was used to conduct the interviews. This encompassed open-ended, concept elicitation questions to allow spontaneous reporting of the signs, symptoms and impacts of IgAN. A timeline task was conducted to explore the patient experience across the IgAN continuum from pre-diagnosis, through to diagnosis and the post diagnosis experience, to facilitate the development of a PJM and refine a conceptual model of the patient experience.

Analysis

- Analysis was conducted using Atlas.ti V9.0 software based on semantic, qualitative, directed content analysis techniques (6, 7) using a combined inductive and deductive approach. The analysis applied an experiential, realist approach, focusing on participants’ individual perspectives and experiences of IgAN. Quantitative demographic data was descriptively summarized.

Results

- Fifteen adults with IgAN participated. Participants mean age was 48 years, and 60% of the sample were female. 47% of the sample were white, and 67% were not Hispanic or Latino. Mean time since diagnosis was 40.5 months (range: 3-85). Most participants had CKD Stage 1 (n=9/15, 60%) and the median GFR value was 88 (range: 29-109). The majority of participants (n=10/15, 67%) were currently receiving treatment for IgAN which most often included lisinopril (n=7/15, 47%), prednisone, or methylprednisolone (both reported by n=4 participants [27%]).

Conceptual model

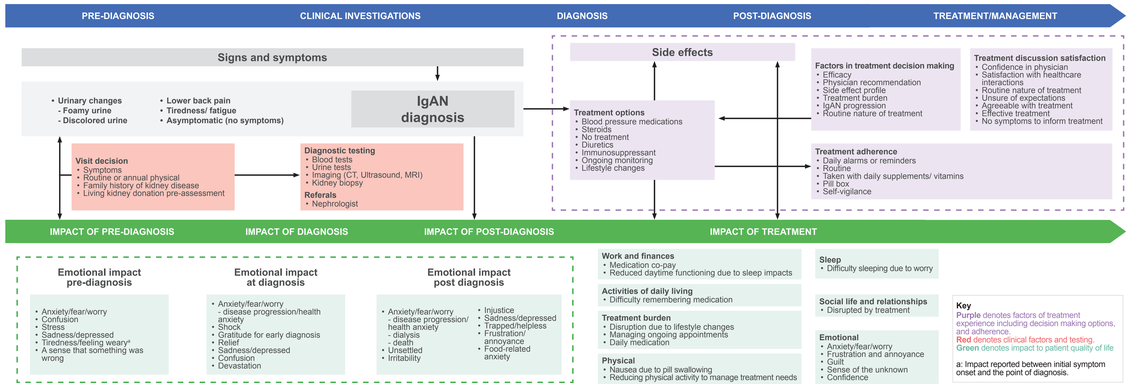
- A conceptual model of the patient experience of IgAN is presented in **Figure 1**. This model represents an update of a conceptual model initially developed from a review of qualitative literature in 2021 (4), and later revised following a targeted literature review of qualitative evidence from between 2021 and 2024 (5). The current study further refined this model to incorporate findings from the primary interviews.
- This model provides a visual representation of the patient experience of IgAN, highlighting signs/symptoms and impacts of the condition. The concepts are delineated by those reported in the literature, and those reported by participants during the interviews, and also identifies concepts that were reported to be associated with treatment.

Patient journey map

- **Figure 2** presents a PJM of the patient experience of IgAN. This provides a chronological representation of participants early symptom experience of IgAN, the diagnosis experience, and a summary of emotional impacts, treatment experiences and treatment impacts.

Figure 1. Updated conceptual model

Figure 2. Patient Journey Map (PJM)



Symptoms and diagnosis experience

- The majority of participants (n=11/15, 73%) reported experiencing no symptoms prior to their diagnosis. Of the asymptomatic participants, most (n=9/11, 82%) reported their diagnosis to have been an incidental finding after an annual physical or a routine medical appointment.

> ***I had zero symptoms that I was aware of. Basically, it was a routine physical, to make sure that I was healthy.*** (12-M-39)

- Symptomatic participants (n=4/15, 27%) described experiencing urinary changes before diagnosis such as foamy (n=3/4, 75%) or discolored (n=1/4, 25%) urine, lower back pain (n=2/4, 50%) and tiredness and fatigue (n=1/4, 25%). Two symptomatic participants subsequently developed additional symptoms of lower back pain (n=2/4, 50%) and tiredness (n=1/4, 25%) at the point of diagnosis or post diagnosis.
- One initially asymptomatic participant (n=1/11, 9%) also later developed symptoms of foamy, discolored urine and tiredness following their diagnosis.

> ***my urine, I noticed that it was very – it looked different. It was very foamy, like when you pour a beer, it’s very foamy.*** (07-F-48)

Impacts

- IgAN impacted participants in a multitude of ways, as shown in the conceptual model (Figure 1). However, the experience of these impacts differed across the disease continuum.
- Due to the largely asymptomatic presentation of IgAN, participants most frequently described emotional impacts. Just two participants (n=2/15, 13%) described other HRQoL impacts of IgAN prior to diagnosis, while further impacts to HRQoL were reported as their journey progressed. As shown in the PJM, emotional impacts (Figure 2), namely a sense of fear, anxiety and worry were experienced across the disease continuum. For symptomatic participants, this primarily manifested as fear around the symptoms experienced before diagnosis.

Pre-diagnosis

- Before diagnosis, participants reported impacts on cognition (n=1), physical functioning due to fatigue (n=1) and social activities (n=1).

> ***I just became much less active because I was so fatigued.*** (14-F-55)

After diagnosis

- After diagnosis, all fifteen participants described emotional impacts in terms of fears and worries about the uncertain nature of the future and the potential progression their IgAN. For some participants, these fears were described in relation to the potential requirement for dialysis (n=6/15, 40%), or their condition causing death (n=3/15, 20%).

> ***The future could be very different, and my life ultimately could end up controlled by dialysis or complete kidney failure. So it – I’m in good shape now, but I could be in – I could do a complete 180 and go backwards.*** (01-F-41)

- For one participant (n=1/15, 7%), these emotional impacts had wider consequences in relation to considerations around family planning.

> ***Quite frankly, I’m fearful of the uncertainty of – about that. Not sure that we want to bring children into the world, if this is passed on or, or what have you.*** (12-M-39)

- Following diagnosis, almost three quarters of the sample (n=11/15, 73%) described other HRQoL impacts associated with their IgAN, including disruptions to social activities (n=7/11, 64%) work (n=6/11, 55%), physical functioning (n=5/11, 45%), activities of daily living (n=5/11, 45%), and for a small number of participants, sleep (n=2/11, 18%) and cognition (n=1/11, 9%).

> ***It’s just because you feel it, it’s constant, and distracts you, and you want to deal with it. […] I mean, it’s just distracting to my job and ability to focus and push through sometimes.*** (05-F-49)

Treatment and ongoing management

- Most participants were receiving treatment for their IgAN (n=10/15, 67%). Eight participants described their experiences of treatment-related decisions; most often treatment-related decisions were influenced by perceived efficacy (n=4/8, 50%), physician recommendations, and potential side effects and burden of treatment (all n=3/8, 38%).
- Seven participants (n=7/15, 47%) described strategies to support treatment adherence, which most often included alarms or reminders (n=3/7, 43%), or incorporating the medication into daily routines (n=2/7, 28%) such as pairing medication with existing vitamins or supplements (n=2/7, 28%).
- Of the ten participants who were receiving treatment (n=10/15, 67%), impacts to physical functioning, sleep, social life and relationships, and work and finances associated with treatment were reported by just three participants (n=3/10, 30%).
- However, emotional burden was more notable (n=6/10, 60%), particularly in relation to fear, worry, and frustration surrounding the need for ongoing disease management. Some participants described the responsibility of daily medication as burdensome (n=4/10, 40%), despite it becoming integrated into their routine.
- Across the full sample, the demands of attending and scheduling ongoing clinical appointments and medical monitoring were also reported as burdensome (n=7/15, 47%).

Conclusion

- While many participants were asymptomatic or experienced relatively few symptoms, the findings illustrate that the HRQoL impacts of IgAN are disproportionate to the symptom experience. Notable emotional impacts were reported in relation to the lifelong nature of IgAN, the requirement for long-term treatment and management, uncertainty, and fear regarding its progressive nature and the implications of this for participants and their families.
- This work highlights from the patient perspective, that the lived experience of IgAN extends beyond just physical symptoms, with significant impacts to emotional well-being representing a central component of the disease burden.
- These findings are supported by recent literature which encompassed patient and clinician perspectives on the emotional impact of future uncertainty following an IgAN diagnosis (3, 8), and of CKD more generally (9).

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