

Patient Journey, Perceptions, and Burden Associated with Immunoglobulin A Nephropathy (IgAN): A Qualitative Study

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Background

There is a lack of published evidence on patient perspectives in IgAN; a rare condition that can progress to end stage renal disease (ESRD). The objective of this study was to understand the patient journey, disease perceptions and burden of disease from the patients' perspective.

Methods

This qualitative study was conducted after review board approval through a moderated online bulletin board platform and by telephone interviews, to allow comprehensive answering of pre-defined questions. Participants were recruited via physician referral and were screened to ensure eligibility and willingness to participate. Analysis was conducted using a combination of various qualitative analytical tools.

Results

Eight participants with a confirmed diagnosis of IgAN from North America and Europe, aged 29–58 years participated. Diagnosis was often incidental as symptoms were underestimated or unnoticed. Participants were overwhelmed to learn they were diagnosed with a chronic disease and many did not understand the seriousness of the outcomes associated with the same. Post diagnosis, participants were referred to a nutritionist to discuss diet changes and received blood pressure medications. Some participants also received steroids and immunosuppressants. Frequency of monitoring visits varied and created anxiety if the disease progressed, based on new lab values. Speed of disease progression was different amongst patients. Besides symptoms

like fatigue and lack of energy, some participants had to deal with emotional burden of feeling alone and fearful of the future with potential dialysis, transplantation and shortened life expectancy. According to the participants, the lack of standard procedures for early screening and diagnosis along with the absence of adequate information in patient friendly language and counselling were some of their needs. Additionally, participants expressed the need for a support mechanism with similar peers to learn to live with the disease and to counteract the feeling of being alone.

Conclusion

This study provides insights into how differently IgAN patients perceive and live with their disease. The insights obtained can be used to inform drug development and include what matters most to patients. Finally, this study highlights that a comprehensive education program for patients and caregivers is needed.

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