Title:

Immunoglobulin A Nephropathy: Patient-Reported Symptoms Prior to First Consultation and Diagnosis - Results from a Real-World Survey

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Background and Aims: Immunoglobulin A nephropathy (IgAN) is the most common form of primary glomerulonephritis worldwide, with an estimated annual incidence of 25 cases per million people. Hematuria (tea coloured urine) and proteinuria (foamy urine) are among the most common clinical manifestations of IgAN, however the burden of such symptoms on diagnosis and disease severity is not fully understood. The aim of this analysis was to better understand patient reported symptoms prior to the first nephrologist consultation and diagnosis of patients with IgAN, in the United States, Europe, Japan, and China.

Method: Data were drawn from the Adelphi IgAN Disease Specific Programme (DSP), a point-in-time survey of IgAN-treating nephrologists and their consulting patients, conducted in the United States (US), Europe (EU5: France, Germany, Italy, Spain, United Kingdom [UK]), Japan, and China, between June and October 2021. Nephrologists completed structured online patient record forms for successive patients presenting with IgAN. Patients voluntarily completed questionnaires that corresponded with the nephrologist records, with questions about their IgAN on that day regarding demographics, clinical data, and signs and symptoms.

Results: A total of 991 patients with a nephrologist confirmed IgAN diagnosis completed a self-reported questionnaire. Mean (standard deviation [SD]) patient age was 42.1 (13.8) years, and 57% were male. Patients first noticed their IgAN symptoms at a mean (SD) age of 37.1 (13.1) years.

Proteinuria (58%), hematuria (56%), and fatigue (36%) were the top patient-reported symptoms that prompted patients to see a doctor (n=979). In the EU5, 64% of patients, and in the US 55% of patients, also reported high blood pressure as a sign that prompted them to see a doctor.

Patients reported a median (interquartile range [IQR]) time of 12.9 (4.3-25.7) weeks from first experiencing IgAN symptoms to consulting with a doctor, ranging from 8.6 (4.3-25.7) weeks in Europe to 21.4 (4.3-52.1) weeks in Japan. Of those patients who reported a delay between experiencing symptoms and when they visited a doctor, 52% said that they were waiting to see if their symptoms would go away on their own (US: 64%, EU5: 68%, Japan:

34%, China: 49%) and 35% assumed they were just feeling tired or run down (US: 36%, EU5: 22%, Japan 39%, China 39%).

Most patients reported first visiting either a family doctor/GP (49%) or a nephrologist (34%) for their IgAN symptoms. In China, 20% of patients reported seeing a urologist for their IgAN symptoms (US 0%, EU5 1%, Japan 6%).

Median (IQR) patient-reported time from first doctor visit to IgAN diagnosis was 8.0 (4.0-16.0) weeks. This finding was consistent across geographical regions except in Japan, where median (IQR) duration was 12.0 (4.0-24.0) weeks. Waiting for test results (US: 31%, EU5: 35%, Japan: 34%, China: 68%), waiting to be tested (US: 52%, EU5: 59%, Japan: 37%, China: 54%), and waiting for a referral (US: 48%, EU5: 32%, Japan: 8%, China: 32%) were the top patient-reported reasons for a delay in the patient's IgAN diagnosis.

At time of diagnosis, 47% of patients reported 'mild', 43% 'moderate', and 10% described 'severe' IgAN severity (n=983). 23% of patients in the US reported severe IgAN severity at diagnosis (EU5 14%, Japan 11%, China 7%).

Conclusion: Despite experiencing symptoms, patients with IgAN waited several weeks before consulting a physician. Of those with a delayed diagnosis, over half described their IgAN as moderate or severe. Greater awareness of symptoms of kidney disease may lead to patients seeking help for their symptoms and getting a confirmed diagnosis more quickly. Improvement of the IgAN patient journey pathway in a health care system is important to expedite timely diagnosis of IgAN and subsequent management of the disease.