

Title: IgA nephropathy: A real-world comparison between disease severity, symptom burden, and treatment satisfaction reported by patients and nephrologists

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Background: Immunoglobulin A nephropathy (IgAN) is the most common form of primary glomerulonephritis worldwide, with an estimated annual incidence of ~25/1 million. Its clinical manifestations include hematuria, proteinuria, and hypertension. This analysis aims to compare perceptions of symptom burden, disease severity, and treatment (Tx) satisfaction between patients (pts) living with IgAN and their treating nephrologists in Europe, the US, and Asia.

Method: The Adelphi Real World IgAN Disease Specific Programme, a point-in-time survey of IgAN-treating nephrologists and their consulting pts with IgAN, was conducted in the US, Europe (France, Germany, Italy, Spain, and the UK [EU5]), Japan, and China from June-October 2021. Nephrologists completed patient record forms (PRFs) for successive pts presenting with IgAN. Pts voluntarily completed questionnaires that corresponded with the nephrologists' records. Both the nephrologist and patient-reported data included demographics, IgAN signs and symptoms, disease severity, and Tx satisfaction.

Results: Data were collected for 991 pts with IgAN where matched nephrologist and PRFs were completed. Mean (SD) pt age was 42.1 (13.8) years; 57% were male.

Nephrologists and pts reported their perceived severity of the IgAN on a scale of mild, moderate, and severe (n=981). Nephrologists and pts agreed on severity for 77% of pts (US 82%, EU5 77%, Japan 70%, China 78%).

The level of nephrologists' awareness of pt-reported symptoms was analysed. Symptoms like nausea/vomiting (85% cases), appetite loss (80% cases), headache/migraine (69% cases), and aching joints (67% cases) were not recognised by nephrologists.

Pts and nephrologists were asked to score fatigue and pain on a scale from 0 (none) to 10 (worst possible). Overall, nephrologists and pts agreed on the fatigue score in 33% of cases (n=991). Compared with pts, nephrologists under-reported fatigue in 46% of cases (mean (SD) score difference: 2.47 [1.46]) and over-reported in 21% of cases (mean (SD) score difference: 1.95 [1.27]). Pts and nephrologists agreed on the patient's self-reported pain score in 53% of cases (n=988). Compared with pts, nephrologists under-reported pain in 26% of cases (mean (SD) score difference: 2.24 [1.44]) and over-reported in 21% of cases (mean (SD) score difference: 2.06 [1.48]).

Nephrologists and pts reported being satisfied, neither satisfied nor dissatisfied, or dissatisfied (n=982) with current Tx. There was 65% agreement in Tx satisfaction between nephrologists and pts (agreement varied across countries: EU5 76%, US 77%, China 61%, Japan 58%).

Conclusion: Although there seemed to be a good level of agreement between nephrologists and pts on the overall IgAN severity, nephrologists under-reported patient symptoms, notably nausea/vomiting, appetite loss, and fatigue. Although not IgAN specific, these symptoms can decrease quality of life (QoL). Satisfaction with current Tx also differed in around a third of cases. This highlights a communication gap between nephrologists and their pts, especially regarding symptom burden, which could be combated through investment in holistic patient evaluation. Cultural differences may impact symptom perception/reporting, as evidenced by differences between nephrologists and pts in different regions. An improvement in communication may lead to better management and QoL of pts with IgAN.