BACKGROUND
• While immunoglobulin A nephropathy (IgAN) has been shown to be associated with clinical and economic burden, the humanistic burden is less understood.

HONUS: Humanistic Burden of Rare Nephropathy - Understanding the impact of IgAN and FSGS on Patients and Care-partners.

Methods
Adult patients and their care-participants were recruited from two nephrology practices: NephCure Kidney International, King of Prussia, PA, USA; and Kidney Research United, Peterborough, UK. The Patient Care-partner of IgAN and FSGS patients who participated in HONUS before May 2023.

Study Population
• Adult patients (i.e., ≥18 years old) and their paired adult care-partners, and their data were included in this analysis (Table 1).

Objectives
• To quantify the humanistic burden of IgAN and care-partner perspectives.

Sample size
• 116 adult patients with IgAN and their care-partners in the United States (US) who participated in HONUS before May 1, 2023.

Figure 1. GAD-7 and PHQ-9 total scores

Figure 2. Most burdensome symptoms

CONCLUSIONS
• Adult patients with IgAN in the US experience impaired mental and physical health, depression, anxiety, and work productivity compared with the general US population. Care-partners for adult patients with IgAN are also affected in terms of mental and work productivity.

• Both patients with IgAN and their care-partners also report widespread fear and uncertainty for the future due to the disease.

LIMITATIONS
• Selection bias may exist as participants who voluntarily enroll into the survey may differ from those who do not.

• The study relied on self-reported survey responses and could be subject to biases resulting from concerns common to all self-reported measures. Participants self-reported diagnosis and disease history of IgAN may differ from clinicians' diagnosis.

• Lack of a control group and use of historical US general population estimate for reference.

Participant responses may be confounded by the COVID-19 pandemic. This broader circumstance may impact socioeconomic status, availability of care, health outcomes, and health insurance.

REFERENCES


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