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Treatment Goals from the Perspective of Immunoglobulin A Nephropathy Patients - Results from a Real-World Study

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CONCLUSIONS

- Relief of overall IgAN symptoms as a treatment goal was reported by the majority of patients with nearly half of patients being open to trying new treatment options.
- More than two thirds of patients were concerned about the progression of their disease to kidney failure and the potential need for dialysis in the future, despite current treatment.
- The study findings highlight the unmet need with the available therapeutic options in achieving desired treatment goals, and thus, emphasising the need for better treatment options.
- Partnering with patient groups to support their expressed needs around education and understanding of the future treatment landscape for IgAN will be very important.

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INTRODUCTION

- Immunoglobulin A Nephropathy (IgAN) is a rare disease with an estimated annual incidence of 25 cases per million worldwide¹.
- Approximately 50% of IgAN patients with proteinuria ≥ 1 g/day progress to kidney failure in 15 years, despite current therapies like renin angiotensin system inhibitors, corticosteroids and other immunosuppressive agents².
- Limited data are available on treatment goals for IgAN from the patient perspective in the real-world setting.

OBJECTIVE

- The aim of this analysis was to assess the treatment goals of IgAN patients and their perceptions on currently available treatment options.

METHODS

- Data were drawn from the Adelphi IgAN Disease Specific Programme (DSP™), a cross-sectional survey with retrospective data collection of IgAN-treating nephrologists and their consecutively consulting patients, across the United States (US), Europe (France, Germany, Italy, Spain and the United Kingdom), China, and Japan conducted between June and October 2021.
- The methodology has been previously described,^{3,4} validated,⁵ and demonstrated to be representative and consistent over time⁶.
- Ethics exemption was obtained where required from the Pearl Institutional Review Board and Hospital Clínic de Barcelona.
- Nephrologists completed structured online records for their next 10 patients presenting with IgAN, including data on patient demographics, consultation and treatment history.
- Patients for whom a nephrologist completed a form, voluntarily filled self-completion forms regarding their treatment goals and their perception of currently available treatment options.
- All analyses were descriptive.

RESULTS

- Out of a total of 1,792 patients, 886 (49%) filled self-completion forms; their mean (standard deviation; SD) age was 41.2 (13.6) years and 57% (n=508) were male (Table 1).
- The median (interquartile range; IQR) duration since current treatment initiation to the time of survey was 0.9 (0.4 – 1.7) years.

Table 1. Demographics of IgAN patients

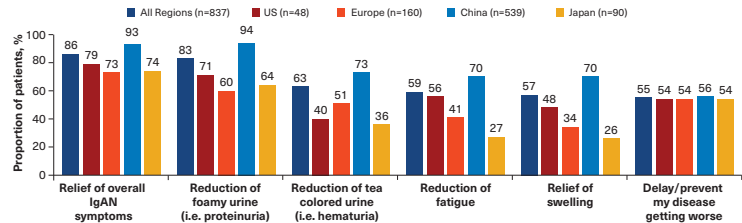
	All Regions	US	Europe	China	Japan
n	886	61	182	539	104
Age (years), mean (SD)	41.2 (13.6)	43.8 (12.7)	43.8 (13.0)	38.7 (13.1)	48.3 (14.2)
Male patients, n (%)	508 (57%)	29 (48%)	125 (69%)	301 (56%)	53 (51%)
n	802	59	171	480	92
Duration since current treatment initiation to the time of survey (years), median (IQR)	0.9 (0.4 – 1.7)	0.9 (0.4 – 1.5)	1.4 (0.5 – 3.6)	0.7 (0.4 – 1.2)	1.3 (0.5 – 4.6)

Europe: France, Germany, Italy, Spain and the United Kingdom; IgAN: Immunoglobulin A Nephropathy; IQR: Interquartile Range; SD: Standard Deviation; US: United States

Treatment goals of IgAN patients at the time of survey

- Of 886 patients, 837 (94%) reported their treatment goals with the most common one being a relief from the overall IgAN symptoms (n=720, 86%; Figure 1). Other treatment goals reported by patients were:
 - Reduction of foamy urine (i.e. proteinuria): (n=696, 83%)
 - Reduction of tea colored urine (i.e. hematuria): (n=526, 63%)
 - Reduction of fatigue: (n=496, 59%)
 - Relief of swelling: (n=478, 57%)
 - Delay/prevention of progression of disease to a worse condition (n=461, 55%).

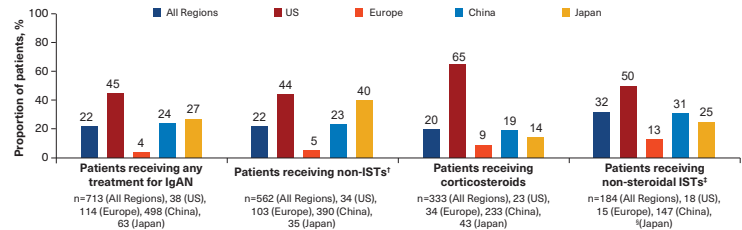
Figure 1. Patient-reported top six treatment goals at the time of survey



Treatments received and perceptions among IgAN patients at the time of survey

- Treatments received:** A total of 701 (79%) patients received non-immunosuppressants (non-ISTs; including angiotensin-converting enzyme inhibitors and angiotensin receptor blockers), 404 (46%) received corticosteroids and 208 (23%) received non-steroidal ISTs.
 - Patients also received alternative (Chinese traditional) medicines (n=193, 22%), other treatments (n=134, 15%), including non-steroidal anti-inflammatory drugs and anti-depressants and biologic immunosuppressants (n=16, 2%) such as rituximab.
 - Many patients were receiving more than one treatment, a total of 621 (70.1%) of patients were prescribed at least two treatments (within the same drug class [e.g. non-ISTs] or across different classes).
- Overall 158 (22%) patients reported that treatments they were receiving at time of survey did not help in their symptom relief. This ranged up to 32%, among patients receiving non-steroidal ISTs (n=58; Figure 2).

Figure 2. Proportion of patients with no relief or worsening of overall IgAN symptoms with medication(s) at the time of survey*



*Data for this question was obtained by adding "Much Worse", "Somewhat worse" and "No change" responses provided by patients. ¹represents patient numbers <5.

Europe: France, Germany, Italy, Spain and the United Kingdom; IgAN: Immunoglobulin A Nephropathy; ISTs: Immunosuppressants; US: United States; ¹Non-ISTs included angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, statins, diuretics, antiplatelet agents, sodium-glucose cotransporter-2 inhibitors, other non-immunosuppressants, other; ²non-steroidal ISTs included cyclophosphamide, hydroxychloroquine, mycophenolate mofetil, tacrolimus, azathioprine, leflunomide, cyclosporin and other non-steroidal immunosuppressants

LIMITATIONS

- Participating patients may not reflect the general IgAN population since the DSP only includes patients who are consulting with their physician. This means that patients who consult more frequently have a higher likelihood of being included. The large cohort size for China may have impacted interpretation of the overall (all region) data.
- Patients completed the survey on a voluntary basis and this may have contributed for a selection bias.
- Recall bias (not being able to recollect accurate and complete information), a common limitation of surveys, might also have affected responses of both physicians and patients. However, physicians did have the ability to refer to the patients' records while completing the patient record forms, thus minimizing the possibility of recall bias.

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Disclosures

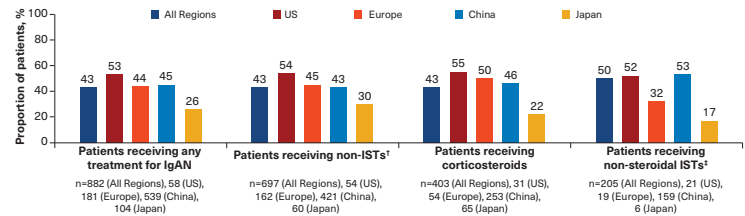
- Data collection for the DSP was undertaken by Adelphi Real World as part of an independent survey and data is owned by Adelphi. Novartis is one of multiple subscribers to the DSP and supported this analysis.
- Richard Lafayette received consulting fees from Alsbund, Alexion, Beigene, BioCryt, Chinook, Chemocentryx, Hillo, Omeros, Otsuka, Novartis, Travere.
- Sydney Tang received speakers' honoraria from AstraZeneca, Bayer, Boehringer Ingelheim, GSK and Novartis.
- Serge Smeets and Carolina Aldworth are shareholders of Novartis Pharma AG.
- Raymond Przybysz and Carolina Aldworth are shareholders of Novartis Pharmaceuticals Corporation.
- Emma Chatterton is a paid employee of Adelphi Real World.

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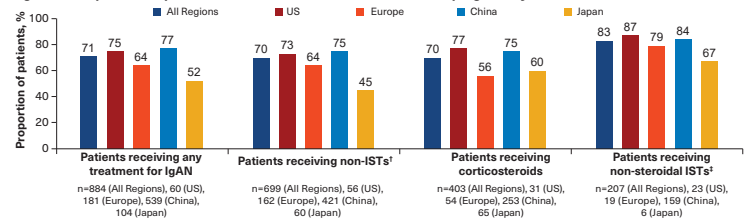
- Overall 383 (43%) patients were very keen to try the next new treatment. This ranged up to half of all patients receiving non-steroidal ISTs (n=103; Figure 3).

Figure 3. Proportion of patients who were very keen to try the next new treatment at the time of survey



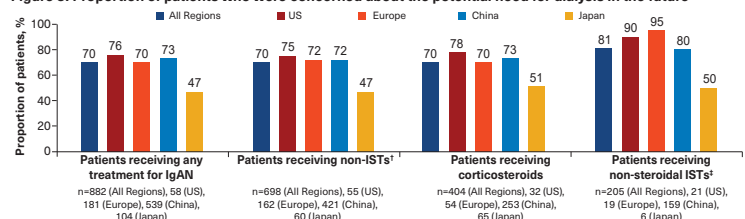
- Overall 631 (71%) patients were concerned about progression to kidney failure in the future. This ranged up to 83%, among patients receiving non-steroidal ISTs (n=172; Figure 4).

Figure 4. Proportion of patients who were concerned about developing kidney failure in the future



- Overall 616 (70%) patients were concerned about potential need for dialysis in the future. This ranged up to 81%, in patients receiving non-steroidal ISTs (n=167; Figure 5).

Figure 5. Proportion of patients who were concerned about the potential need for dialysis in the future



- Overall 164 (19%) patients were not happy with the currently available treatment options. This ranged up to 23%, in patients receiving non-steroidal ISTs (n=46; Figure 6).

Figure 6. Proportion of patients who were not happy with the available treatment options at the time of survey

