In 2015 in the US, several PID patients were treated with approximately 12 million grams of immunoglobulin (Ig). However, increasing use of Ig may not always correlate with decreased or elimination of symptoms. This speaks to the need for more holistic care and treatment options that target the underlying causes of the disease. A major focus of treatment is ensuring that patients have access to necessary IgG treatments and C1q levels to maintain optimal health.

In the study described here, we included 135 participating investigators across the U.S. Patients eligible to participate were those requiring Ig therapy for a variety of conditions, including primary immune deficiencies, autoimmunity, and other inflammatory conditions. The study enrolled 226 patients, with 90% being over the age of 18 and 31% being 65 or older (Fig. 3A).

As part of the registry, we included data on patient outcomes and opinion. The analysis of these data suggests that patients have a clear preference for subcutaneous Ig (SCIg) over intravenous Ig (IVIg) administration. In fact, at the six-month time point, patients reported less pain with SCIg administration (Fig. 7). Additionally, patients rated their current Ig treatment highly, with an average score of 7/10 (Fig. 9).

In terms of physical and mental quality of life, analysis of SF-36 survey data shows that patients treated with Ig show significant improvements in physical and mental health compared to unaffected population norms. Our results support the idea that Ig is a valuable maintenance therapy for PID patients, and that the benefits of Ig therapy outweigh any potential costs or side effects.

Conclusion

In conclusion, the Immunoglobulin Diagnosis, Evaluation, and key Learnings (IDEaL) Patient Registry seeks to offer a solution to these gaps in care. By analyzing the experiences of patients and healthcare providers, we aim to improve the quality of care and outcomes for PID patients. Through our ongoing efforts, we hope to continue to gather valuable insights into the needs and experiences of PID patients, and to help improve the care they receive.

References

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Analysis of Physical and Mental Quality-of-Life Markers in Primary Immune Deficiency Patients on Immunoglobulin Therapy: Results from the Immunoglobulin Diagnosis, Evaluation, and key Learnings (IDEaL) Patient Registry Program

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Materials and Methods

Methods

Results

Gender and Age Breakdown

In the analysis of survey data, 44% of the patients were male, 44% were female, and 3% were not identified. Of these patients, 9% had a primary immunodeficiency and 1% had a secondary immunodeficiency. The average age was 59 years, and 30% were 65 or older (Fig. 3A).

Results

Life Quality Index Markers

The SF-36 survey is a common tool used to assess patient's quality of life. It includes 36 questions that are answered on a 7-point scale, ranging from “not at all” to “very much.” The survey is widely used in clinical trials to gauge patients' physical and mental health pre- and post-treatment. The SF-36 is based on a 7-point scale, with 0 being the lowest score and 100 being the highest score. The scores can be compared to population norms to determine if patients have a significant difference in their health status.

Results (continued)

Ig Administration Route and Dosing

Both intravenous Ig (IVIg) and subcutaneous Ig (SCIg) are approved in the treatment of PID. Of the 206 patients referred to our program, 39% received IV Ig and 22% received SCIg. The average dose for IV Ig patients was 15.5 grams/kg, while the average dose for SCIg patients was 11.2 grams/kg. The average dose for SCIg patients was significantly lower than for IV Ig patients (p < 0.05).

We also looked at patient perception of the different dosing regimens. The average score for IV Ig patients was 8.3/10, and 6.3/10 for SCIg patients. However, the difference was not significant between the two groups.

Conclusions

Among PID patients enrolled in the IDEaL Patient Registry, there are significantly more adult females enrolled than adult males. In the pediatric population, the gender distribution was 45% female and 55% male. This may reflect the distribution of PID cases in the general population, where female patients tend to be more prevalent.

The SF-36 survey suggests that for PID patients, there may be various factors that affect their mental health. This could include the stress of managing a chronic illness, the impact of medication side effects, or the psychological burden of living with a rare disease. Our data suggests that while mental health may be affected, patients generally report a high level of satisfaction with their current treatment regimen.