

The Immunoglobulin Patient Experience: 2024 Patient 360 Survey

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Abstract

Introduction

Immunoglobulin (Ig) therapy is a lifesaving treatment used in over 70 diagnoses, ranging from immunodeficiency, autoimmune neuromuscular and rheumatologic disorders, as well as hematologic and inflammatory conditions. The Patient 360 is a dedicated education, advocacy and research arm of the Ig National Society (IgNS). To better understand the needs of Ig therapy patients, and to assess their real-life infusion experience, we surveyed Ig patients affiliated with the IgNS Patient 360.

Methods

This exploratory, confidential and deidentified survey of patients receiving Ig was distributed to IgNS patient-subscribers via the Jotform HIPAA-compliant survey tool between May and July 2024. An interim analysis of 308 respondents was conducted.

Results

167 respondents (54%) had primary immunodeficiency (PI), either with or without an autoimmune comorbidity, 49 (16%) had a neuromuscular disorder, 42 (14%) had a rheumatological disorder and 24 reported other conditions for which they are receiving Ig therapy.

Respondents with PI reported that the most frequent symptoms that led to their diagnoses were unspecified chronic infections (71%), frequent rounds of antibiotics (62%), sinus infections (60%), and respiratory infections (59%). Respondents with autoimmune neuromuscular disorders indicated balance issues (73%), decreased energy/stamina (61%), and gastrointestinal issues (31%). Respondents with rheumatological disorders indicated energy/stamina (50%), skin issues (38%), and skin rash (31%). Respondents with "other" diagnoses reported decreased energy/stamina (54%) and chronic infection (38%). PI patients reported the time from first symptoms to diagnosis was a mean of 17.74 years (SD = 17.23), compared to 4.72 (SD= 5.58) years for those with neuromuscular disorders, 2.3 (SD = 4.53) years for those with rheumatological disorders, and 5.31 (SD = 9.2) for those who experience "other" conditions. The difference between the mean delay for a PI diagnosis versus and all others was statistically significant ($p < .01$). When assessing the use of non-specialized medical care, emergency departments, urgent care, and primary care visits were all associated with increased delays in diagnosis. Additional IVIG and SCIG findings are provided in this poster.

Discussion

This analysis demonstrated that patients with PI continue to experience the longest delays in diagnosis, while presenting with the most commonly described signs and symptoms of PI. Patients with neuromuscular and rheumatologic disorders also experienced significant delays in diagnosis, albeit shorter than those with PI. Interestingly, utilizing emergency department services, urgent care and even primary care were associated in increased delays in diagnosis. This finding suggests that education and awareness about PI screening is critical for physicians and other healthcare professionals practicing in these settings. It also suggests that referral to specialists is delayed, and the reason for this delay warrants further investigation.

Conclusion

As one of the most complex clinical specialties, Ig therapy treats patients with a large variety of serious, chronic disorders. Timely diagnosis and access to treatment can be life-saving, and yet, patients continue to experience unacceptably long delays. Lack of awareness and absence of practical screening tools for the non-specialist practitioners, a fragmented healthcare system, and the rare nature of these disorders are all contributing factors. Robust education, awareness, and screening programs and referral pathways are necessary and urgent in the primary care and urgent/emergency sectors.

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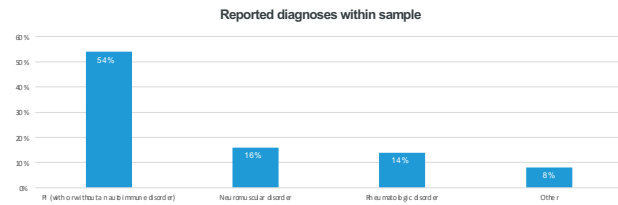
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Results

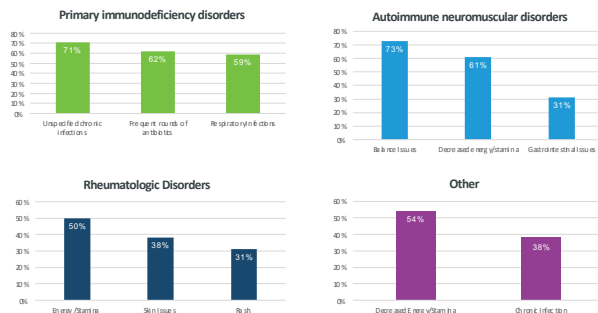
Of those who chose to specify their diagnosis, 167 respondents (54%) had primary immunodeficiency (PI), either with or without an autoimmune comorbidity, 49 (16%) had a neuromuscular disorder, 42 (14%) had a rheumatological disorder and 24 reported other conditions for which they are receiving Ig therapy.

Figure 1.



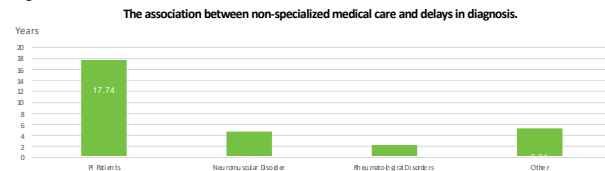
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Figure 2. Main symptoms associated with each diagnostic group



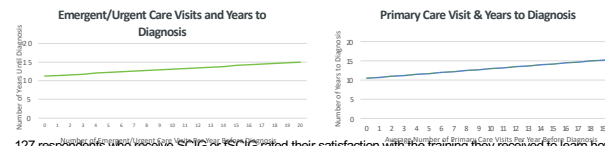
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Figure 3.



In examining the potential relationship between time from first symptom to diagnosis and number of medical care visits per year prior to diagnosis, we found a positive relationship between number of emergent/urgent care visits reported per year and years to diagnosis, such that for every additional emergency/urgent care visit reported by a respondent there was an average increase of time to diagnosis of .19 years ($\beta = .19, t = 2.26, p < .05$). Similarly, for every visit to a primary care provider reported by a respondent there was an average increase of time to diagnosis of .03 years ($\beta = .03, t = 3.25, p < .01$).

Figure 4



127 respondents who receive SCIG or tSCIG rated their satisfaction with the training they received to learn how to self-administer. 44 (35%) reported being very satisfied with their training, 54 (43%) reported being satisfied, 15 (12%) reported being neither satisfied nor dissatisfied, 10 (8%) reported being dissatisfied, and 4 (2%) reported being very dissatisfied.

Figure 5.

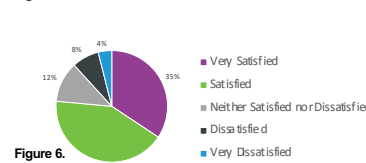
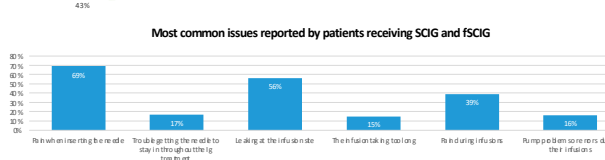


Figure 6.



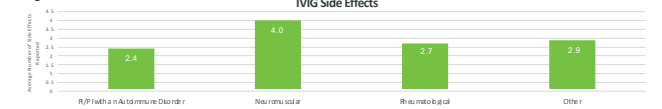
In examining the relationship between satisfaction with SCIG and tSCIG self-administration training and infusion related issues, only the relationship between satisfaction with training and 1) pain when inserting the needle and 2) pump problems/errors were significant. For every one unit increase in reported patient satisfaction with training received, the likelihood of that patient reporting pain when inserting the needle dropped 41%, while the likelihood of that patient reporting pump problems or errors dropped 51%. Interestingly, there was no statistical significance between satisfaction and other infusion-related issues.

Table 1.

	Odds Ratio	Z-value	P-value	Per 1 Unit Increase in Satisfaction
Pain when inserting the needle	.59	-2.34	<.05	41% Less Likely
Needle comes out/does not stay in	1.09	.36	ns	No Significant Change
Leaking at infusion site	.83	-.99	ns	No Significant Change
Infusions take too long (infusion rate slowing down)	.75	-1.18	ns	No Significant Change
Pain during infusions	.77	-1.43	ns	No Significant Change
Pump problems/Errors	.49	-3.05	<.01	51% Less Likely

Respondents who receive IVIG were asked if they took premedication. Of the 149 IVIG respondents, 136 (91.2%) indicated that they take premedication before receiving IVIG. However, among these respondents, taking premedication was not significantly related to a diminishing of any of their IVIG side effects. Overall, patients with neuromuscular diagnoses reported significantly more side effects than patients with PI ($p < .01$). Premedication did not significantly impact side effect incidence or severity.

Figure 7.



Discussion

This analysis demonstrated that patients with PI continue to experience the longest delays in diagnosis, while presenting with the most commonly described signs and symptoms of PI. Patients with neuromuscular and rheumatologic disorders also experienced significant delays in diagnosis, albeit shorter than those with PI. Interestingly, utilizing emergency department services, urgent care and even primary care were associated in increased delays in diagnosis. This finding suggests that education and awareness about PI screening is critical for physicians and other healthcare professionals practicing in these settings. It also suggests that referral to specialists is delayed, and the reason for this delay warrants further investigation. As with our previous data analyses of immunoglobulin patients, premedication was not associated with a reduction in the severity of side effects, underscoring the importance of highly-specialized clinical skillset and training. The lack of relationship between SCIG and tSCIG satisfaction with initial training and highly mitigable infusion related issues is concerning. Mitigable issues such as leaking, pain during infusion, infusion rate slowing down, and the needle coming out, suggests that optimal initial patient education and training, which normally occurs over 3-4 nursing visits, is not sufficient; regular follow up to assess for specific, infusion-related issues after initial training is an essential component of the ongoing plan of care. These findings support the new IgNS standards requiring monthly telephonic or telemedicine assessments of these patients. Other important findings regarding IVIG and SCIG practices and training provide greater insight into best practices for Ig treatment within this unique population.

Conclusion

As one of the most complex clinical specialties, Ig therapy treats patients with a large variety of serious, chronic disorders. Timely diagnosis and access to treatment can be life-saving, and yet, patients continue to experience unacceptably long delays. Lack of awareness and absence of practical screening tools for the non-specialist practitioners, a fragmented healthcare system, and the rare nature of these disorders are all contributing factors. Robust education, awareness, and screening programs and referral pathways are necessary and urgent in the primary care and urgent/emergency sectors. Additionally, monthly assessments with SCIG and tSCIG patients after initial training are necessary to proactively monitor for preventable infusion-related issues during self-administration.