Examining the relationship between disease treatment and quality of life, especially as treatment relates to efficacy and toxicity could guide shifts in current clinical guidelines. In chronic cases of ITP, an average of three treatments is unsurprising considering many patients receive first-line therapies steroids and IVIG before seeking a second-line therapy for longer-term maintenance. These findings suggest that patients who receive a greater number of different treatments may have found a therapy that best works to raise platelet counts through trial-and-error, due to the range of treatment mechanisms used to manage ITP. In addition, these patients may have also become better acclimated to their condition and consider living with their disease a “new normal,” or they feel better now in comparison to when they were initially diagnosed.

Our analysis does not take into consideration whether a patient received a therapy more than once, is in remission, or the duration of a treatment, thus the data may be in favor of those patients who have undergone multiple treatments for their ITP or found a treatment that works for them. A more longitudinal analysis is required regarding patient quality of life. Constructing a complete view of shifts in medication and treatment with combination therapies would give a better indication of the effects of the number of treatments on quality of life.

The ITP Registry allows patients to see the aggregate results of each survey in real time. From this, patients have the opportunity to be further educated about their disease, treatment options, and compare their ITP journey to the ITP community as a whole; this helps patients feel less alone, alleviating some of the burden of living with ITP.

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