

The American Perspective

Communicating about the impact of ITP on everyday quality of life

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When I meet with patients and families affected by ITP, my most important questions are focused on how ITP impacts their everyday life. For newly diagnosed patients, I want to know about activities they participated in previously that they are currently avoiding and how much they worry about their low platelet count and risk of bleeding. I ask patients about how this impacts their daily routine and well-being. For patients who are on a medication treatment, I also want to know if their current treatment approach is improving their daily well-being and low platelet symptoms and, also, how their daily quality of life is being affected by how the treatment is given, tolerated, and monitored as well as its financial impact. I find that the answers to these questions are key in understanding how best to support the patient and their family and in guiding decision-making about treatment.

Although reviewing bleeding symptoms is critical at all hematology appointments, discussing the other impacts of ITP and its treatment on everyday life should not be underestimated. This includes discussions about activity restrictions, work or school related impacts, fatigue, worry, among other effects. Guidelines for the management of ITP in children direct clinicians to treat ITP based on both bleeding symptoms and the impact of ITP on health-related quality of life. Using impairment of quality of life to guide the ITP treatment approach in children is particularly important, as close observation without a medication is a common treatment approach in the absence of bleeding symptoms. Even in the absence of bleeding, observation may not be the best treatment for an individual child or adolescent depending on the impact of ITP on their daily life. In adults with ITP, the platelet count and bleeding symptoms are often the focus of the decision for treatment, but consensus guidelines also recommend consideration of quality of life and fatigue in management decisions.

In research trials, to learn about the effect of ITP and its treatment on daily quality of life, we ask patients to complete standard questionnaires that have been shown to be accurate

in measuring quality of life in individuals with ITP. For children, the questionnaires are aimed at the quality of life of the child and vary by age. Questionnaires are also completed by parents/guardians, both in terms of the impact of ITP on their child and on their own everyday well-being. The questionnaire most often used in children is called the Kids ITP Tool (KIT). In this tool, examples of questions children are asked include: how often they feel anxious or tired, how often they are bothered that they could not do things with their friends or activities that they like, or how bothered they are by their medication or having their blood taken. Other ways of evaluating the impact of ITP in children include surveys measuring fatigue. These questionnaires have shown that fatigue in children with ITP is common, similar to fatigue in adults with ITP, and may improve with ITP-directed treatments.

In research studies of adults with ITP, questionnaires are also used to evaluate the impact of ITP on everyday quality of life, including the ITP-Patient Assessment Questionnaire (ITP-PAQ). This questionnaire asks about bother from the effects of ITP and its treatment on physical health, work, social activities and exercise as well as the impact on psychological health, fatigue, and bleeding symptoms. One of the largest research studies of the impact of ITP on everyday quality of life was the ITP World Impact Survey (I-WISh) which included over 1500 adults with ITP and almost 500 physicians from across the globe. A comprehensive questionnaire about quality of life was developed specifically for this survey study. The findings from the I-WISh study describe the extensive impact ITP has on an individual's energy and capacity to exercise as well as the limitations it causes on daily tasks. In this adult population, nearly half were considering or had already reduced their working hours and reported that ITP significantly reduced their work productivity. The physicians who also completed the survey were experienced in the treatment of ITP and reported an awareness that ITP significantly reduced patient everyday quality of life. Improving quality of life was ranked by these physicians as the second most important goal of treatment, right after reducing spontaneous bleeding symptoms. This report has helped to raise awareness more broadly in the hematology community about the importance of asking patients about the impact of ITP on their well-being beyond bleeding symptoms and platelet counts.

Currently, outside of research studies, in most hematology practices, standard questionnaires are not used for evaluating the impact of ITP and its treatment on everyday life. Clinicians who are less familiar with ITP may be unaware of the broad impact of ITP on an individual and maintain focus on bleeding and the platelet count during medical visits. As work is conducted to continue to raise awareness among clinicians, you should feel empowered to tell your physician how ITP and its treatment impacts your everyday life and find out what support is available to you and how individual treatments can be initiated or modified to help improve your quality of life. We all have the tendency to say we are “fine” or “well” when asked how we are, but you should use your appointments to talk about how your everyday life has changed since being diagnosed with ITP. You should use each visit as an opportunity to report the impact of ITP to your clinician. The UK Support Toolkit for ITP Shared Decision Making (<https://itpsupport.org.uk/index.php/en/home/shared-decision-making>), which emphasizes the impact ITP can have on daily quality of life, can help you and your clinician decide how to integrate your report of the impact of ITP into your management approach and treatment plan.