

Impaired Quality of Life Regarding Daily Activities, Social Interactions, Emotional Well-Being, and Working Lives

Nichola Cooper,¹ Alexandra Kruse,² Caroline Kruse,² Shirley Watson,³ Mervyn Morgan,³ James Bussell,⁴ Waleed Ghanima,⁵ Donald Arnold,⁶ Cristina Santoro,⁷ Ming Hou,⁸ Yoshiaki Tomiyama,⁹ Serge Laborde,¹⁰ Barbara Lovrencic,¹¹ John Waller,¹² Tom Bailey,¹² Gavin Taylor-Stokes,¹² Miona Stankovic¹³ and Drew Provan¹⁴

¹Hammersmith Hospital, Imperial College London, London, UK; ²Platelet Disorder Support Association, Cleveland, OH, USA; ³ITP Support Association, Bolnhurst, UK; ⁴Division of Hematology/Oncology, Weill Cornell Medical College, New York, NY, USA; ⁵Department of Medicine, Ostfold Hospital Trust, Kalnes, Norway; ⁶Department of Medicine, McMaster University, Hamilton, Canada; ⁷Department of Cellular Biotechnologies and Haematology, 'Sapienza' University of Rome, Rome, Italy; ⁸Department of Hematology, Shandong University, Jinan, China; ⁹Osaka University Hospital, Osaka, Japan; ¹⁰O'Cyto, Saint Loubes, France; ¹¹Italian Association of Immune Thrombocytopenic Purpura, Caprino Veronese, Italy; ¹²Bespoke Team, Adelphi Real World, Macclesfield, UK; ¹³Novartis Pharma AG, Basel, Switzerland; ¹⁴Barts and The School of Medicine and Dentistry, London, UK

Introduction

- The impact of immune thrombocytopenia (ITP) on patient quality of life (QoL) is multidimensional, broadly encompassing daily activities, emotional health, and work life.
- Health-related QoL has been shown to be substantially reduced in ITP patients relative to healthy controls,¹ but the full impact of ITP on affected patients is not well-defined.
- The I-WISh survey assessed the burden of ITP and its impact on QoL using a global patient and physician sampling frame.
- The data presented here describe the impact of ITP on QoL, emotional health, and work productivity, and evaluate similarities and differences between patient and physician viewpoints.

Methods

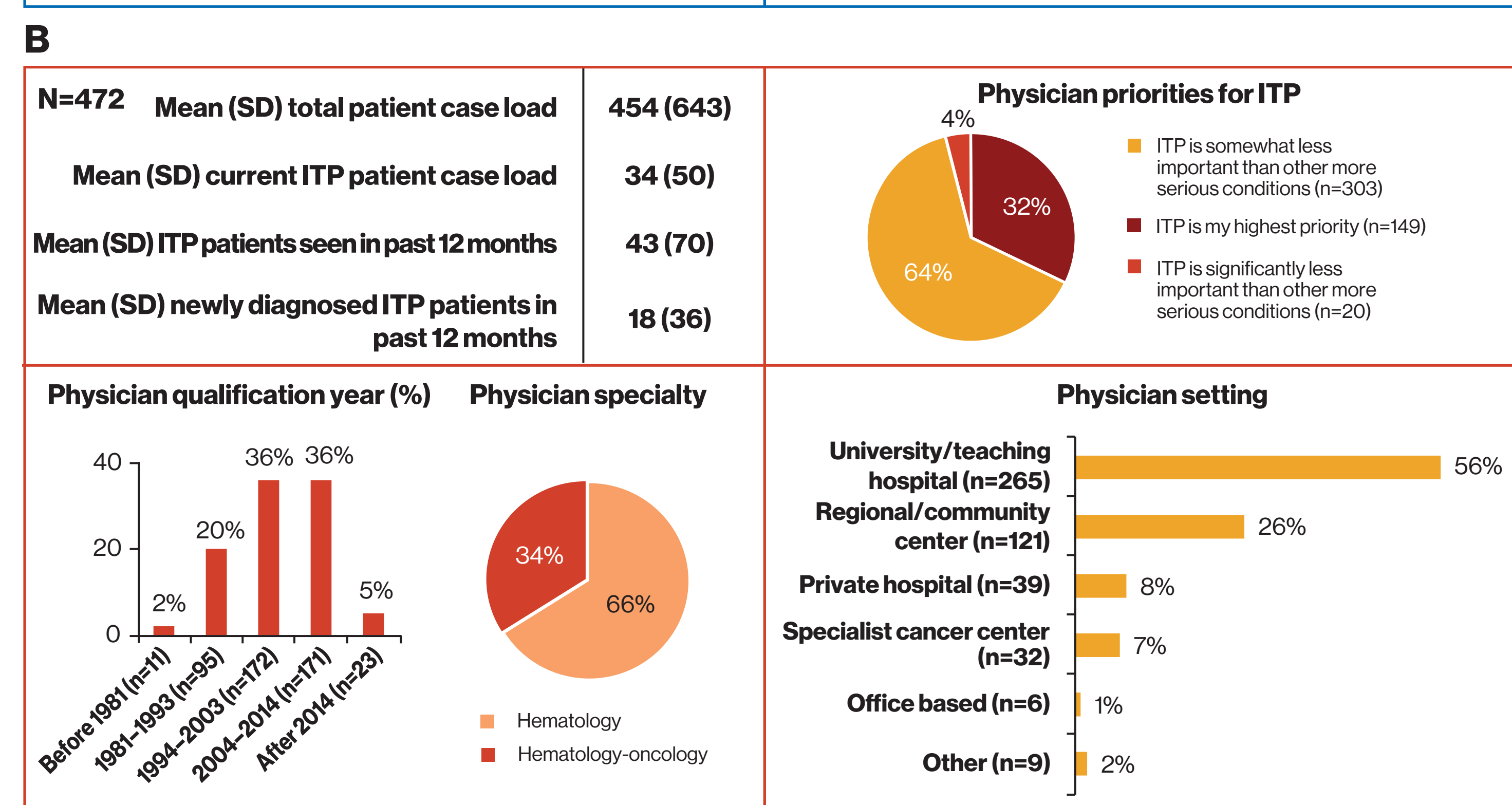
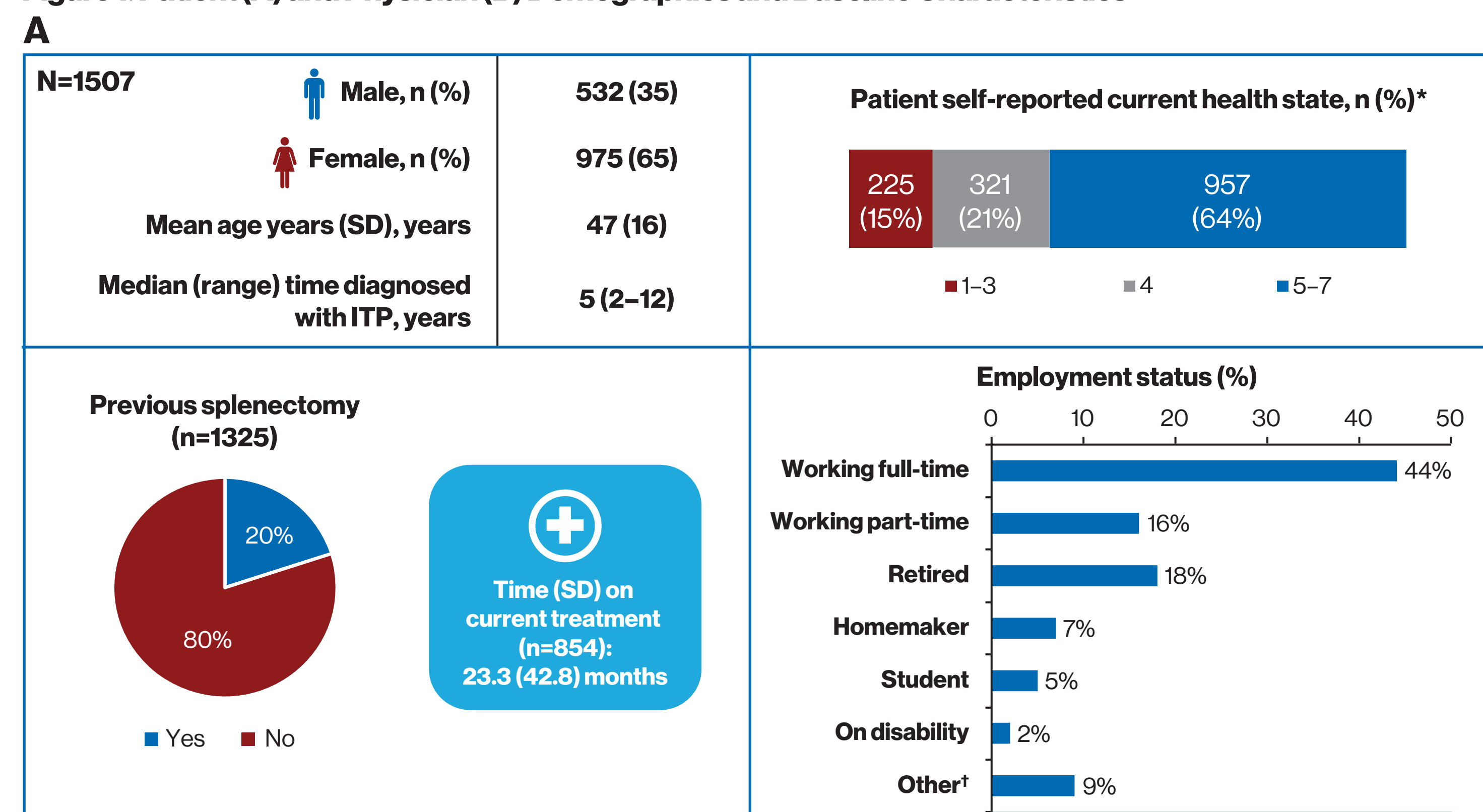
- I-WISh was an international cross-sectional survey of ITP patients ≥18 years, recruited via physicians and patient support groups, and physicians, recruited via local fieldwork agencies.
- Patients and physicians completed a 30-minute online survey that included demographics and the impact of ITP on QoL, emotional health, work productivity, and need for caregivers.
- A steering committee of expert physicians and patient advocacy ITP specialists designed and endorsed the survey materials.

Results

Patient and Physician Demographics, and Baseline Characteristics

- 1507 patients from 13 countries (Canada, China, Colombia, Egypt, France, Germany, India, Italy, Japan, Spain, Turkey, UK, and USA) completed the survey (Figure 1A).
- 472 physicians from the same 13 countries completed the survey (Figure 1B).

Figure 1. Patient (A) and Physician (B) Demographics and Baseline Characteristics



*7-point Likert scale: 7 is excellent health, 1 is very poor health; †not working, seeking employment, 2%; ‡not working, not seeking employment, 4%; other, 3%. SD, standard deviation

Impact of ITP on Patient QoL in Everyday Life

- Overall, patients rated reduction in energy levels as having the greatest impact on their QoL, as reported in 85% (n=1273/1505) of patients, followed by reduced capacity to exercise and ability to perform daily tasks (Figure 2).
- The proportion of patients reporting an impact of ITP on their QoL increased with symptom burden (Figure 2)
 - 99% of patients (n=305/308) with very high symptom burden reported an impact on energy levels, and ≥90% reported an impact of ITP for 5/10 questions.

- Physicians perceived potential bleeding when playing sports as having the greatest impact on patient QoL (scored ≥5 on a 7-point Likert scale, where 7=great deal), followed by intense exercise, and concerns of bleeding risk during travel (Figure 3).
- Fewer physicians than patients felt that ITP would greatly impact daily activities (52%; n=239 vs 75%, n=1129), family and social life (45%; n=211 vs 70%, n=1048), or exercise (63%; n=297 vs 77%, n=1160) (Figure 3).

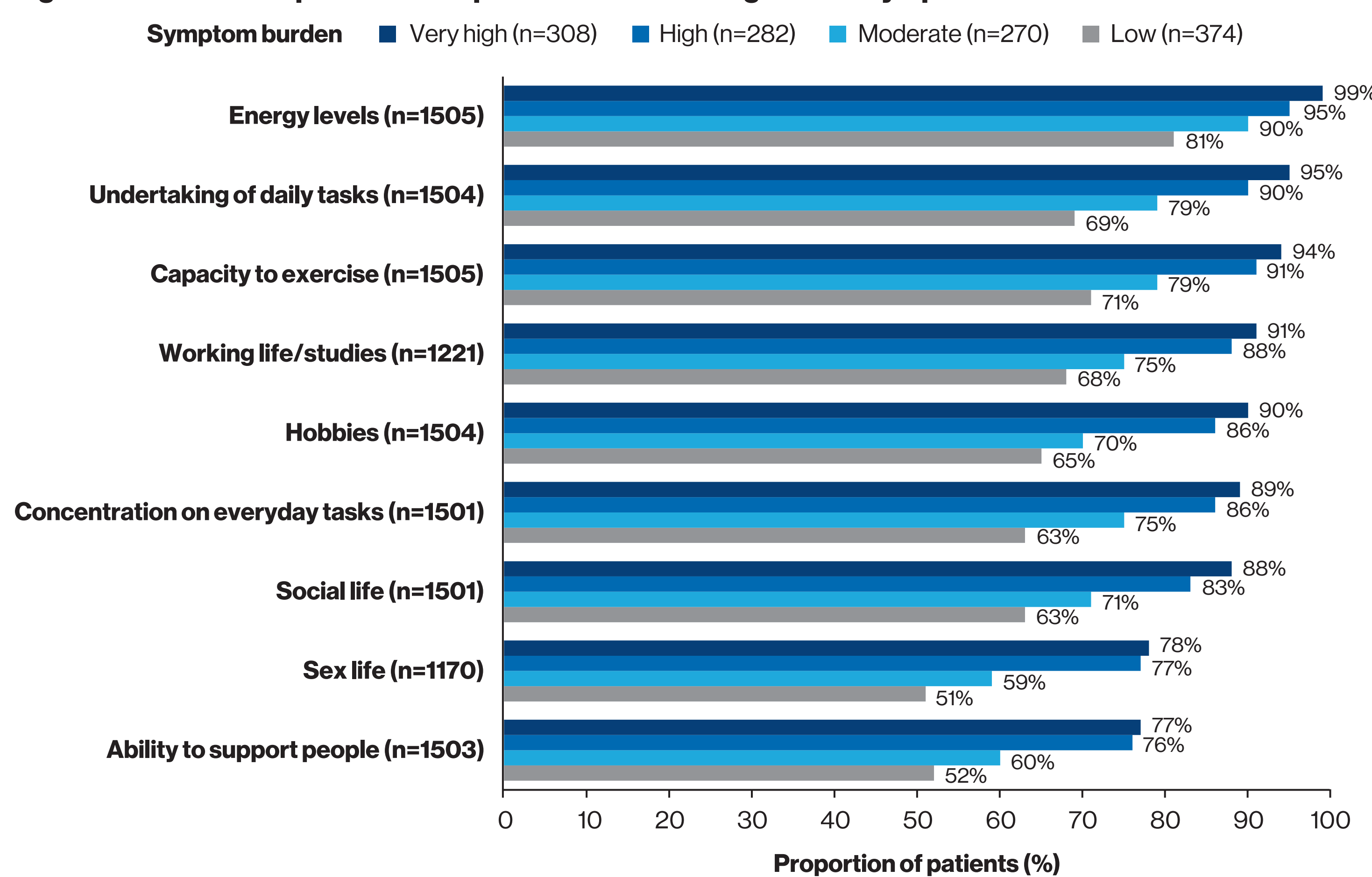
Emotional Impact of ITP

- 49% (n=739) of all patients stated ITP had a high impact on their emotional well-being (score ≥5 on 7-point Likert scale, where 7=great deal)
 - 63% of patients were concerned about their condition worsening (n=954) and their platelet count fluctuating for no apparent reason (n=949).
- Impact on emotional well-being increased with higher symptom burden
 - More patients with very high symptom burden reported high overall emotional impact (76%; n=234/308) and worrying about their condition worsening (85%; n=263/308) (Figure 4).
- Physicians reported similar results to patients for emotional impact, and considered anxiety about platelet counts (84%; n=385/459) to be the most impactful factor, followed by patient's fear about their disease and frustration about having a long-term rare disease (both 75%, n=350/467, n= 346/460, respectively) (Figure 5).

Impact of ITP on Patient Productivity

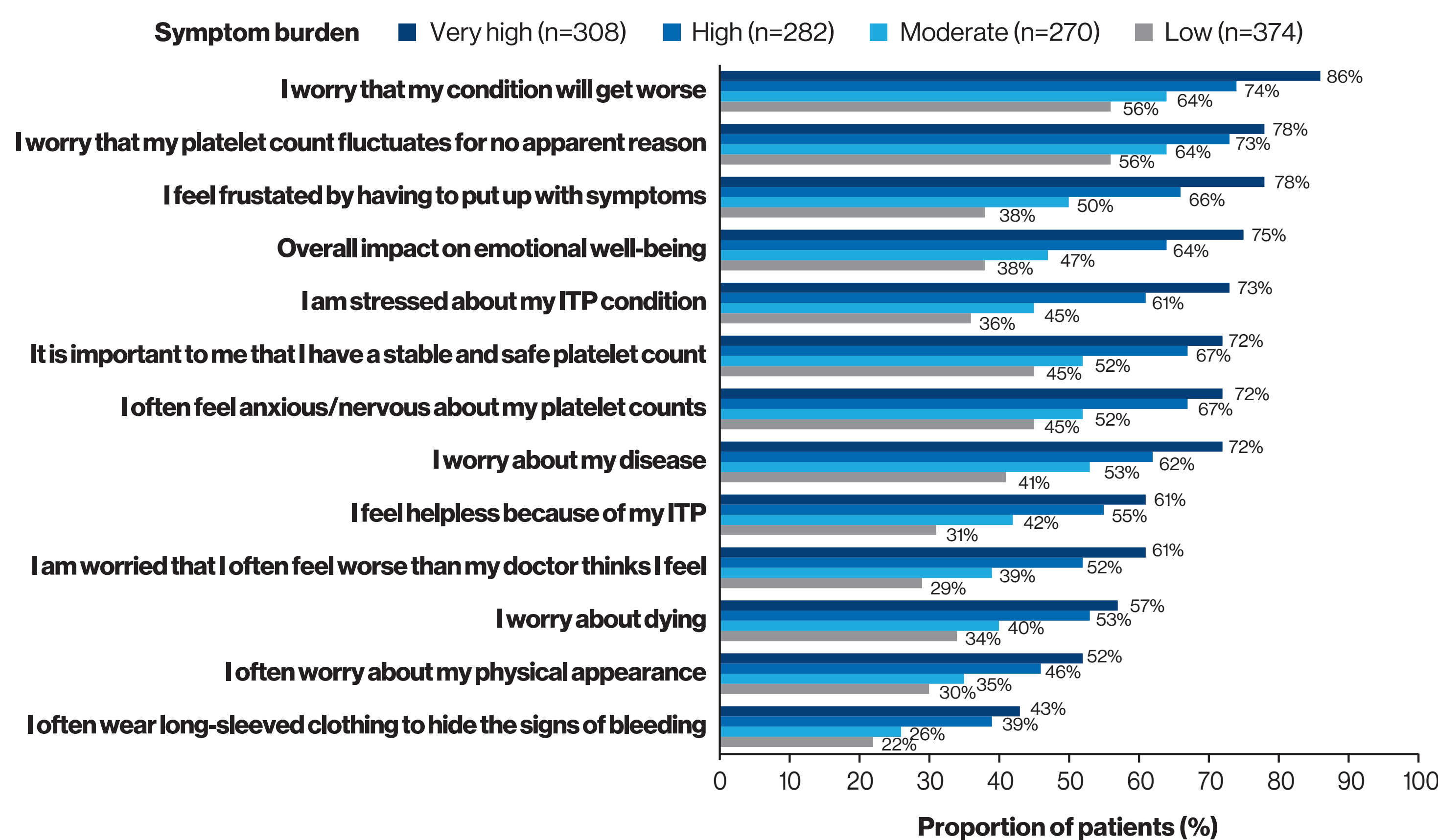
- 43% (n=386/898) of patients reported that ITP affects their work productivity (score ≥4 on a 10-point scale, where 10=completely prevented from working), with 24% (n=215/898) having missed ≥6 hours' work during the week prior to survey completion.
- 49% (n=538/1091) and 45% (n=527/1164) of all patients had seriously considered reducing or had reduced their hours at work, respectively, and 29% (n=307/1070) had considered terminating their employment because of ITP
 - Despite this, 69% (n=615/892) work >30 hours/week.
- The impact on employment increased with higher symptom burden 70% (n=216/308) and 62% (n=191/308) of patients with very high symptom burden reported seriously considering reducing or had reduced their hours, respectively, and 43% (n=132/308) had considered terminating employment (Figure 6).

Figure 2. Patient Perception of ITP Impact on QoL According to Their Symptom Burden Level



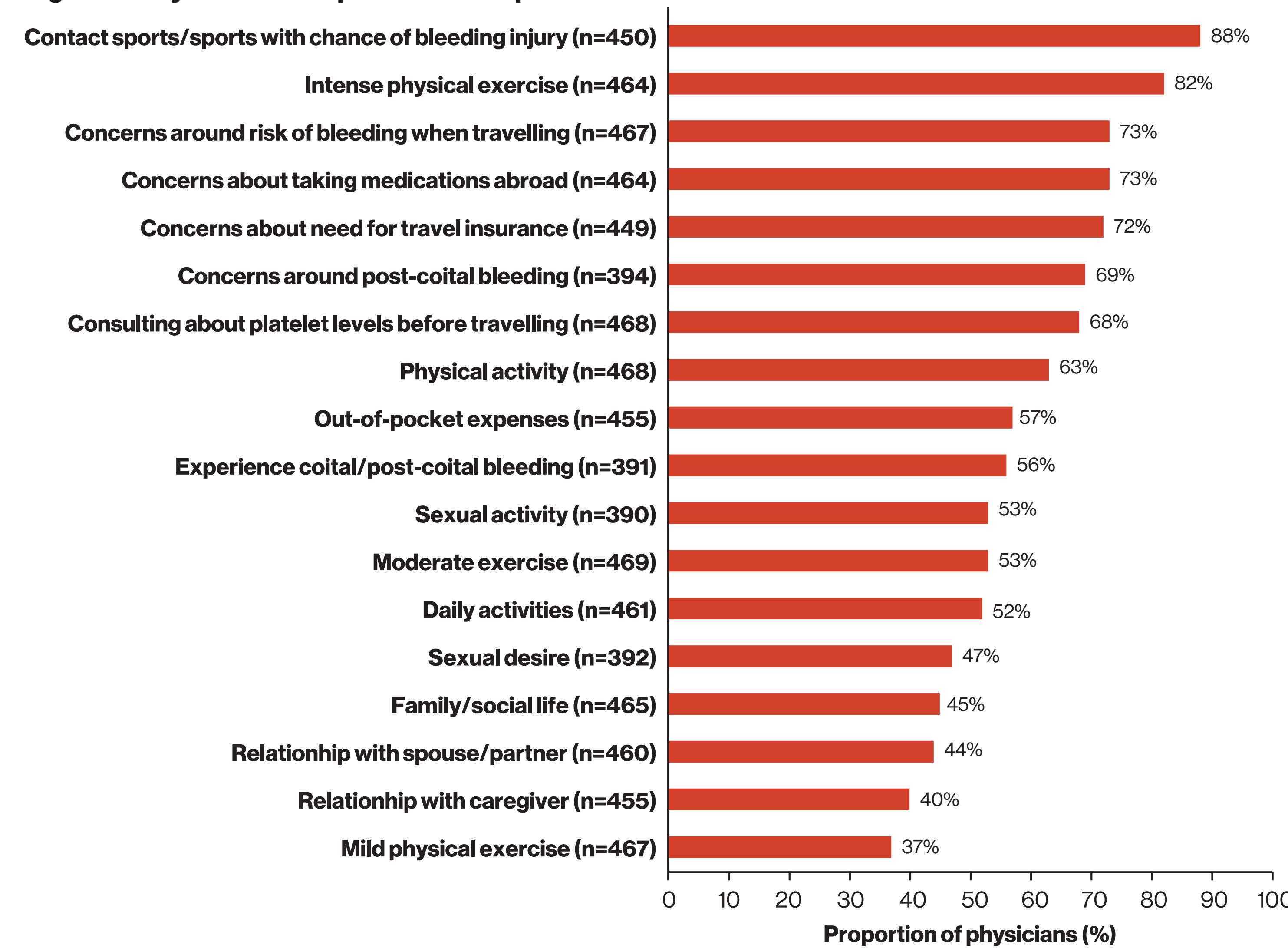
Patients were asked to rate the impact of ITP on different aspects of their life in the last month using the ITP Life Quality Index. Results are shown combined for the proportion of patients who responded 'sometimes', 'more than half the time', and 'all the time'. For each category, patient numbers are shown for all respondents (ie all symptom levels) and percentages are based on n values for the symptom level subgroup for each category. Symptom burden score was calculated by combining individual symptom severity scores for each patient at diagnosis and at survey completion and then assigning patients into quartiles at a global level. Not all patients completing the survey were included in this symptom burden subanalysis as only 1234 patients reported having symptoms. For some patients, the categories 'Working life/studies,' and 'Sex life,' were either not applicable or not answered, so patient numbers are lower

Figure 4. Patient Perceived Factors of ITP Driving an Emotional Impact as According to Their Symptom Burden Level



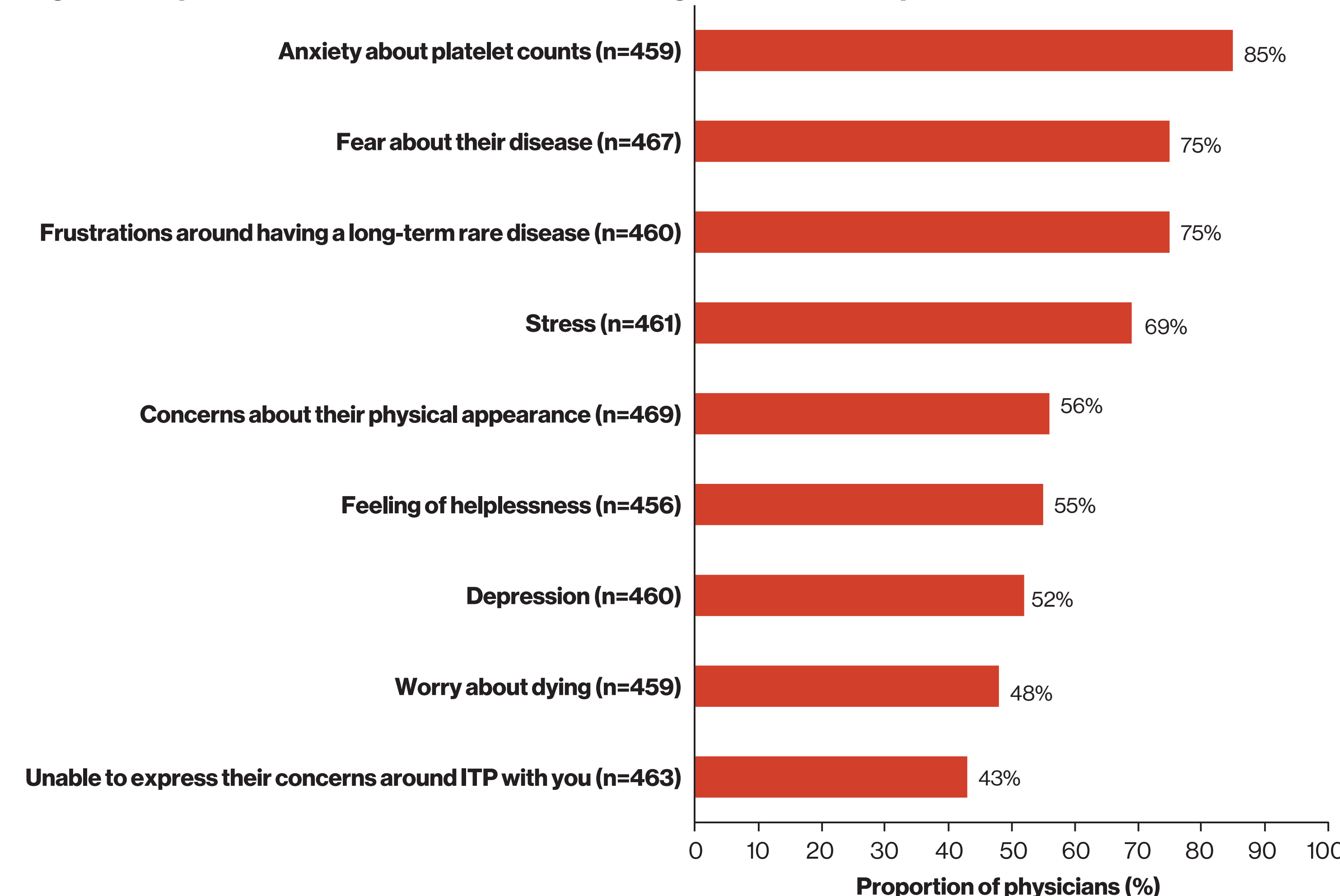
Patients rated their perceptions about the emotional impact of ITP using a 7-point Likert scale where 1=not at all to 7=great deal. The data presented are for scores ≥5. Symptom burden score was calculated by combining individual symptom severity scores for each patient at diagnosis and at survey completion and then assigning patients into quartiles at a global level. Not all patients completing the survey were included in this symptom burden subanalysis as only 1234 patients reported having symptoms

Figure 3. Physician Perception of ITP Impact on QoL



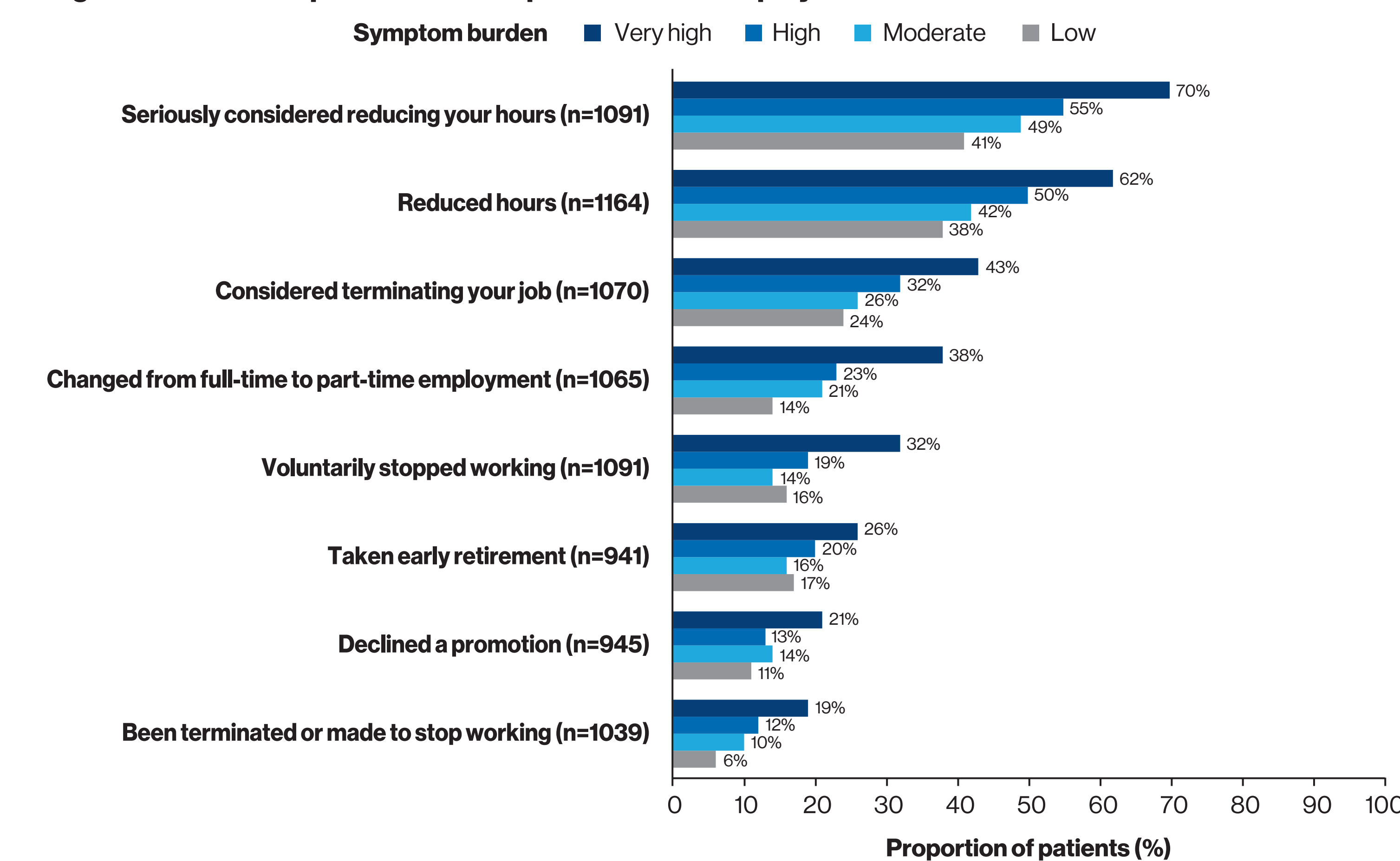
Physicians rated their perceptions about what would impact patient QoL using a 7-point Likert scale where 1=not at all to 7=great deal. The data presented are for scores ≥5

Figure 5. Physician Perceived Factors of ITP Driving an Emotional Impact



Physicians rated their perceptions about the emotional impact of ITP using a 7-point Likert scale where 1=not at all to 7=great deal. The data presented are for scores ≥5.

Figure 6. Patient-Reported Direct Impact of ITP on Employment



For each category, patient numbers are shown for all respondents (ie all symptom levels) and percentages are based on n values for the symptom level subgroup for each category. Symptom burden score was calculated by combining individual symptom severity scores for each patient at diagnosis and at survey completion and then assigning patients into quartiles at a global level

Caregiver Needs for ITP Patients

- 52% (n=784/1505) of patients reported needing care assistance, with their spouse being the main caregiver (60%; n=463/775), requiring an average of 16.3 hours of support in a week.
- Caregivers provided companionship (69%; n=540/784), transportation (49%; n=388/784), and helped with household chores (55%; n=430/784).

Physician Perspective on QoL Tools

- Only 13% (n=60) of physicians reported they currently use a patient self-completed questionnaire to assess QoL
 - 69% (n=325) reported not using a QoL questionnaire but would like to use one
 - 18% (n=87) stated they would not use such a questionnaire.
- For those physicians that reported they currently use or would like to use a QoL questionnaire, 35% (n=135), 49% (n=188), and 13% (n=49) stated they would use it at every consultation, every 6 months, and once a year, respectively.

Conclusions

- I-WISh demonstrates that most ITP patients experience substantially impaired QoL, with daily activities, social interactions, emotional well-being, and working lives all affected.
- Patients frequently report severe fatigue and patients with high ITP symptom burden were particularly affected, with nearly all reporting substantially reduced energy levels.
- Patients also worried about their condition worsening and had reduced work capacity.
- These results highlight the need for physicians to consider the impact of ITP disease burden on all aspects of individual patients' lives during management of ITP.

Reference

1. McMillan R et al. *Am J Hematol* 2008;83:150-154.

Acknowledgments

The study was funded by Novartis Pharma AG. We thank Catherine Risebro of Mudskipper Business Ltd for medical editorial assistance, funded by Novartis Pharmaceuticals Corporation.

Disclosure Statement

N Cooper received honoraria for speaking engagements and advisory boards from Amgen and Novartis. **CKruse** received honoraria for speaking engagements and consultancy fees paid to PDSA from Amgen, Novartis, and Rigol Pharmaceuticals. **SWatson** reports advisory work for Novartis. **JBussell** reports honoraria, membership on a Board of Directors or advisory board, and research funding for Amgen, Novartis, and GSK; research funding from Boehringer Ingelheim, Prophylax Pharma, Protalex, and Rigol Pharmaceuticals; membership on a Board of Directors or advisory board for Momenta Pharmaceuticals, Prophylax Pharma, Protalex, and Rigol Pharmaceuticals; patents and royalties from UpToDate; participating in a speakers' bureau for Physician Education Resource. **W Ghanima** received research grants from Bayer, Bristol-Myers Squibb, and Novartis and honoraria for participation in advisory boards for Amgen and Novartis. **DArnold** received research grants from Novartis, Amgen, and Bristol-Myers Squibb and worked as a consultant for Amgen, Novartis, Rigol, Grifols, Principia, and UCB. **CSantoro** reports participating in speakers' bureau for Glaxo and Amgen, advisory boards for Grifols and Gilead, and speakers' bureau and advisory boards for Shire, Novo Nordisk, Bayer, Pfizer, CSL, and Sobi. **Y Tomiyama** reports honoraria and membership of an advisory committee for Novartis and honoraria from Chugai and Kyowa-Kirin. **D Provan** received research grants and honoraria from Novartis and Amgen, and consultancy fees from UCB, MedImmune, and ONO Pharmaceutical. **M Stankovic** is a full-time employee of Novartis. **AG J Waller**, **T Bailey** and **G Taylor-Stokes** are employees of Adelphi Real World, which has received consultancy fees from Novartis. **A Kruse**, **M Morgan**, **M Hou**, **S Laborde** and **B Lovrencic** have nothing to disclose.

Poster presented at ASH Annual Meeting, San Diego, California, USA, December 1-4, 2018

Text: Q00fd5
To: 8NOVA (86682) US Only
+18324604729 North, Central and South America, Caribbean; China
+447860024038 UK, Europe & Russia
+46737494608 Sweden, Europe
Visit the web at:
http://novartis.medicalcongressposters.com/Default.aspx?doc=00fd5

Scan this QR code



Copies of this poster obtained through Quick Response (QR) code are for personal use only and may not be reproduced without written permission of the authors