A Patient’s Perspective on Impact of Immune Thrombocytopenia on Emotional Wellbeing: ITP World Impact Survey (I-WISh)

Nichola Cooper,1,a Waleed Ghanima,2 Alexandra Kruse,3 Caroline Kruse,3 Yoshiaki Tomiyama,4 Drew Provan,5 Ming Hou,6 Cristina Santoro,7 Serge Laborde,8 Mervyn Morgan,9 Barbara Lovrencic,10 Tom Bailey,11 Jens Haenig,12 James B. Busse13

1Hammersmith Hospital, Imperial College London, London, United Kingdom; 2Department of Medicine, Ostfold Hospital Trust, Klinen, Norway; 3Platelet Disorder Support Association, Cleveland, OH, United States; 4Osaka University Hospital, Osaka, Japan; 5Barts and The London School of Medicine and Dentistry, London, United Kingdom; 6Department of Hematology, Qilu Hospital of Shandong University, Jinan, China; 7Hematology, University Hospital Policlinico Umberto I, Rome, Italy; 8O’Cyto, Saint Louvès, France; 9ITP Support Association, Bolinhurst, United Kingdom; 10Italian Association for Immune Thrombocytopenic Purpura, Caprino Veronese, Italy; 11Adelphi Real World, Bollington, United Kingdom; 12Novartis Pharma AG, Basel, Switzerland; 13Division of Hematology/Oncology, Weill Cornell Medical College, New York, NY, United States

aCorresponding author
Disclosures

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Introduction

ITP impacts patients’ QoL beyond thrombocytopenia and bleeding, and also has a negative emotional impact\(^1,2\)

I-WISh assessed the burden of ITP and its impact on QoL using a global patient and physician sampling frame

Here, we report the impact of ITP on patients’ emotional wellbeing

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ITP, immune thrombocytopenia; I-WISh, ITP World Impact Survey; QoL, quality of life.
Methods

I-WISH was an exploratory, cross-sectional 30-minute survey conducted in 13 countries between December 2017 and May 2018

1507 patients with ITP

472 physicians

• The emotional impact of ITP on patients was assessed via responses to emotional concern statements. Responses were rated on a 7-point Likert scale to indicate the level of agreement or disagreement with a particular statement, eg:

1. “Not at all”
2. “A great deal”

Scores of 1-2 = low emotional burden
Scores of 6-7 = high emotional burden

ITP, immune thrombocytopenia; I-WISH, ITP World Impact Survey.
Results: Overall, 49% of patients felt that ITP had substantially impacted their emotional wellbeing (rating a 5-7 score)

<table>
<thead>
<tr>
<th>Patient perception of emotional impact statements</th>
</tr>
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<tbody>
<tr>
<td>I often feel anxious/nervous about my platelet counts</td>
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<tr>
<td>I feel frustrated by having to put up with symptoms</td>
</tr>
<tr>
<td>I worry that my condition will get worse</td>
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<tr>
<td>I am stressed about my ITP condition</td>
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<tr>
<td>I feel helpless because of my ITP</td>
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<tr>
<td>I worry about dying</td>
</tr>
<tr>
<td>I am worried that I often feel worse than my doctor thinks I feel</td>
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<tr>
<td>I often worry about my physical appearance</td>
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<tr>
<td>I often wear long-sleeved clothing to hide the signs of bleeding</td>
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<tr>
<td>I worry about my disease</td>
</tr>
<tr>
<td>It is important to me that I have a stable and safe platelet count</td>
</tr>
<tr>
<td>I worry that my platelet count fluctuates for no apparent reason</td>
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<tr>
<td>Overall impact on emotional wellbeing</td>
</tr>
</tbody>
</table>

ITP, immune thrombocytopenia.
Results: Patients with high emotional burden experienced ITP symptoms more frequently than those with low emotional burden.

The total percentages of patients across all emotional statements may be >100% because patients could rate any concern that applied.

ITP, immune thrombocytopenia.
**Results:** The relative proportions of current symptoms among greatly worried patients were similar for all 3 groups of emotional concern.

### Anxiety/worry burden in greatly worried patients (male and female) (rating a 6-7 score)

<table>
<thead>
<tr>
<th>Patients who worried greatly about dying</th>
<th>Patients who worried greatly about disease worsening</th>
<th>Patients who worried greatly about platelet count</th>
</tr>
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<tbody>
<tr>
<td>• More females than males (differences of ≥10 percentage points) reported:</td>
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<td>• More females than males (differences of ≥10 percentage points) reported:</td>
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<tr>
<td>– Anxiety surrounding unstable platelet count (45% vs 31%)</td>
<td>– Fatigue (64% vs 54%)</td>
<td>– Fatigue (62% vs 47%)</td>
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<tr>
<td>– An increased number of moderate-to-severe headaches/migraines (29% vs 14%)</td>
<td>– Anxiety surrounding unstable platelet count (48% vs 37%)</td>
<td>– Anxiety surrounding unstable platelet count (46% vs 33%)</td>
</tr>
<tr>
<td>– Dizziness (25% vs 15%)</td>
<td>– Bruising (38% vs 28%)</td>
<td>– An increased number of moderate-to-severe headaches/migraines (26% vs 11%)</td>
</tr>
<tr>
<td>• No substantial difference between sexes was observed for fatigue among those patients who worried greatly about dying (59% in females vs 54% in males)</td>
<td>– An increased number of moderate-to-severe headaches/migraines (25% vs 14%)</td>
<td></td>
</tr>
</tbody>
</table>
Results: Patients who worried greatly were more likely to have platelet counts $<70 \times 10^9/L$
Results: Higher proportions of patients who worried greatly across the 3 anxiety/worry groups were receiving CSs compared with those who did not worry greatly.

Treatment type and patient emotional burden

- CSs (n = 382)
  - Not worried greatly about dying (n = 487)
  - Not worried greatly about disease worsening (n = 193)
  - Not worried greatly about platelet count (n = 181)
- Anti-CD20s (n = 76)
  - Worried greatly about dying (n = 387)
  - Worried greatly about disease worsening (n = 593)
  - Worried greatly about platelet count (n = 633)
- TPO-RAs (n = 245)
  - Patients with high and low emotional burden (scores of ≥6 and ≤2, respectively) are shown in full and shaded colors, respectively.

*The total percentages of patients across all emotional statements may be >100% because patients could rate any concern that applied.
CS, corticosteroid; TPO-RA, thrombopoietin receptor agonist.
Conclusions

The I-WiSh survey data illustrate that many patients with ITP worry a great deal about their platelet counts, that their disease will worsen, and even about the possibility that they could die.

There was also an apparent link with lower platelet counts generally reported in those who worried greatly.

In general, higher proportions of patients who worried greatly across the 3 anxiety/worry groups were receiving CSs compared with those who did not worry greatly; this may reflect in part the emotional instability brought about by CS use.

Patients with high emotional burden experienced ITP symptoms more frequently than those without high emotional burden.

The notably high proportion of patients who worried about dying, constituting almost one half of all patients, reflects the profound emotional impact of ITP, which may be exacerbated by CSs.

Among patients who worried greatly across the 3 anxiety/worry groups (dying, disease worsening, unstable platelet count), females reported higher rates of certain symptoms (eg, moderate-to-severe headaches/migraines) than males.

CS, corticosteroids; ITP, immune thrombocytopenia; I-WiSh, ITP World Impact Survey.
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• This poster is an encore presentation and data were first presented at the 25th Congress of the European Hematology Association (EHA), Virtual Congress, June 11-14, 2020:

• Other I-WISH survey results are reported at ASH 2020 – please see posters 845 and 2668.