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I-Wish Publication Summary

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What is I-Wish?

I-WISh: Background

Study design

- 30-minute online cross-sectional survey of patients with ITP and physicians who treated patients with ITP
- **Countries:** Canada, China, Colombia, Egypt, France, Germany, India, Italy, Japan, Spain, Turkey, UK, and US

Patients (N=1507)

- Age ≥ 18 years old
- Diagnosis of ITP
- Not previously completed the I-WISh survey

Physicians (N=472)

- Hematologists or hemato-oncologists with a minimum caseload of 3 patients with ITP
- Responsible for treatment decisions at the time of survey completion

Study aim

- To address the diagnostic burden associated with ITP
- To characterize the patient experience and physician perception of ITP
- To determine any disconnect between patients and physicians regarding disease management, and identify unmet needs

I-WISh: Questionnaire topics

Patient questionnaire

- Demographics and diagnosis (7 questions)
- Symptoms of ITP (4 questions)
- HRQoL and emotion associated with ITP (12 questions)
- Treatment received (17 questions)
- Impact of ITP on work, finances, and support (15 questions)
- Patient and physician relationship (7 questions)

Physician survey

- Demographics (2 questions)
- Diagnosis of ITP and patient caseload (7 questions)
- Symptoms of ITP (5 questions)
- Impact of ITP on aspects of patients' physical, emotional, HRQoL, and social health (11 questions)
- Treatment patterns (13 questions)
- Patient and physician relationship (4 questions)

I-WISh: ITP Life Quality Index

- Patients also completed the ITP Life Quality Index that included 10 questions on the impact of ITP on:
 - Working life or studies, time taken off work or education, ability to concentrate, social life, sex life, energy levels, ability to undertake daily tasks, ability to provide support, hobbies, and capacity to exercise
- Response options were either based on a 4-point scale eg 'never', 'sometimes', 'more than half the time', and 'all of the time', or responses were based on a 7-point Likert scale, eg where 7='a great deal')

I-Wish Publication List

I-WISH 2018 Submissions

Abstract title	Synopsis
EHA 2018 and ECTH 2018 (Encore)	
The Burden of Disease and Impact of Immune Thrombocytopenia (ITP) on Patient Quality of Life and Productivity: Results From the ITP World Impact Survey (I-WISH)	The interim data from patient/HCP survey demonstrated a multifaceted burden of ITP on patients' lives, notably fatigue, affecting emotional well-being and the ability to work
ASH 2018	
Patients With Immune Thrombocytopenia Frequently Experience Severe Fatigue But it is Under-Recognized by Physicians: Results from the ITP World Impact Survey (I-WISH)	Although physicians do not consider fatigue to be as substantial a problem as patients did, patients and physicians are aligned on overall symptom burden in ITP. Results from the I-WISH survey highlight that improved understanding and awareness of the relationships between fatigue, platelet count, and QoL is needed
Results From the ITP World Impact Survey (I-WISH): Patients With Immune Thrombocytopenia Experience Impaired Quality of Life Regarding Daily Activities, Social Interactions, Emotional Well-Being, and Working Lives	Results from the survey indicate that most ITP patients experience substantially impaired QoL, with daily activities, social interactions, emotional well-being, and working lives all affected. Thus, physicians need to consider the impact of ITP disease burden on all aspects of individual patients' lives during ITP management

I-WISH 2019 Submissions

Abstract title	Synopsis
EHA 2019	
Physicians' Perceptions on Causes of Primary and Secondary ITP and Leading Causes of Misdiagnosis: Results from the ITP World Impact Survey (I-WISH)	Results from the I-WISH survey revealed that exclusion of other disorders and misdiagnosis were the leading causes for delay in ITP diagnosis
Patient Perceptions on Splenectomy Outcomes: Results from the ITP World Impact Survey (I-WISH)	Results highlighted the need for improved patient education on the potential adverse effects and complications of splenectomy
Differences in Perceptions on Treatment Approaches Between Physicians and ITP Patients: Results from the ITP World Impact Survey (I-WISH)	Results from the I-WISH survey indicated that physicians estimated treatment success by achieving sustained remission and preferred TPO-RAs over splenectomy, corticosteroids, anti-CD20 or IVIg whereas patients perceived TPO-RAs and anti-CD20s as similarly effective in treating ITP symptoms and expressed less satisfaction with splenectomy
ASH 2019	
Physicians' and Patients' Perspectives on Treatments in ITP – A Multi-Country Perspective: Results from the ITP World Impact Survey (I-WISH)	Results from the I-WISH survey showed that some specific treatment goals were perceived differently by physicians and patients and varied among countries. Physicians ranked reduction in spontaneous bleeds as the most important goal, whereas patients considered healthy blood counts the most important goal.

ITP, immune thrombocytopenia; IVIg, intravenous immunoglobulin; I-WISH, ITP World Impact Survey; TPO-RAs, thrombopoietin receptor agonists

I-Wish Publication Short Summaries



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The burden of disease and impact of immune thrombocytopenia (ITP) on patient quality of life and productivity: results from the ITP world impact survey (I-WISh)

Cooper (Abstract # PF654)

Poster

- ITP significantly impacted QoL and daily living, there was high symptom burden, and a negative impact on emotional well-being and patient's ability to work
 - 50% of patients stated ITP had a high impact on their emotional well-being (a score of ≥ 5 on a 7-point Likert scale, where 7 is a great deal)
 - Patients reported a high impact of ITP on their work, with 37% of patients having reduced their hours at work because of ITP
- Fatigue was the most severe symptom and patients indicated a desire to increase their energy levels, suggesting patients are primarily concerned with the impact of ITP on their QoL

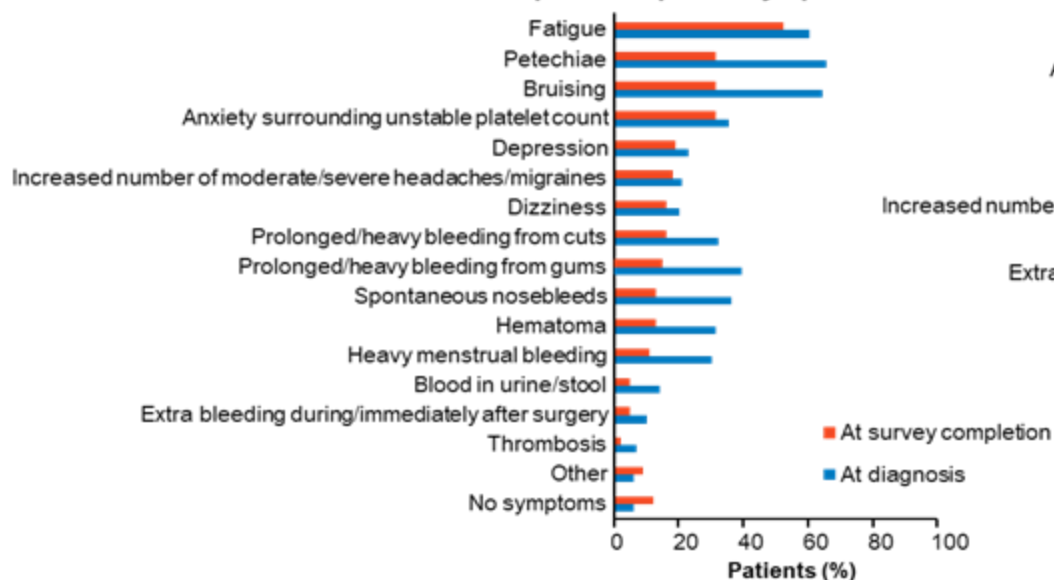
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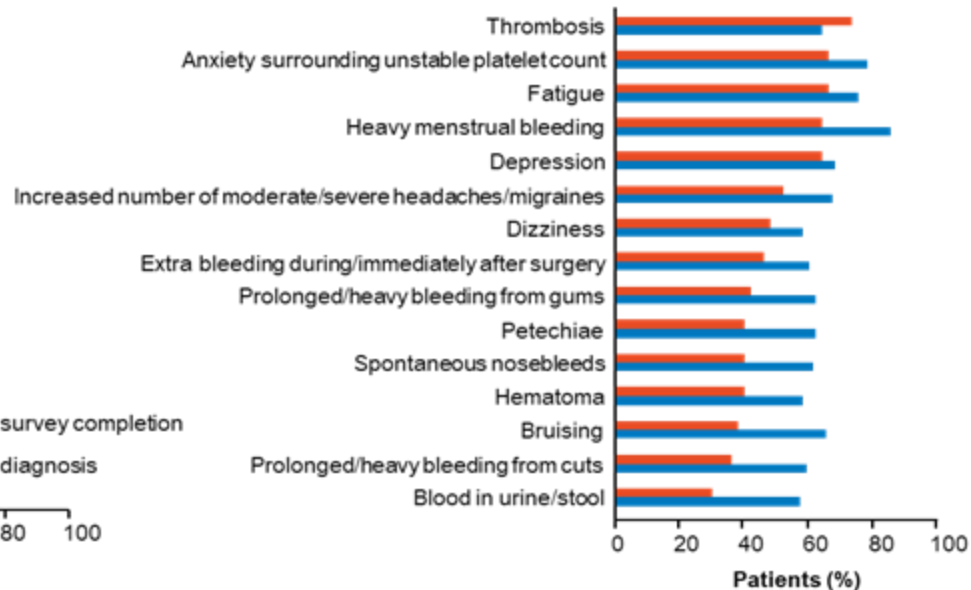
Poster



Incidence of patient-reported symptoms



Proportion of patients reporting symptoms as most severe*



*Symptoms were considered most severe when scored ≥ 5 on a 7-point Likert scale (7=worst imaginable)
ITP, immune thrombocytopenia; QoL, quality of life

Patients with ITP frequently experience severe fatigue but it is under-recognized by physicians: Results from the ITP world impact survey (I-WISh)

Kruse (Abstract # 2273)

Poster

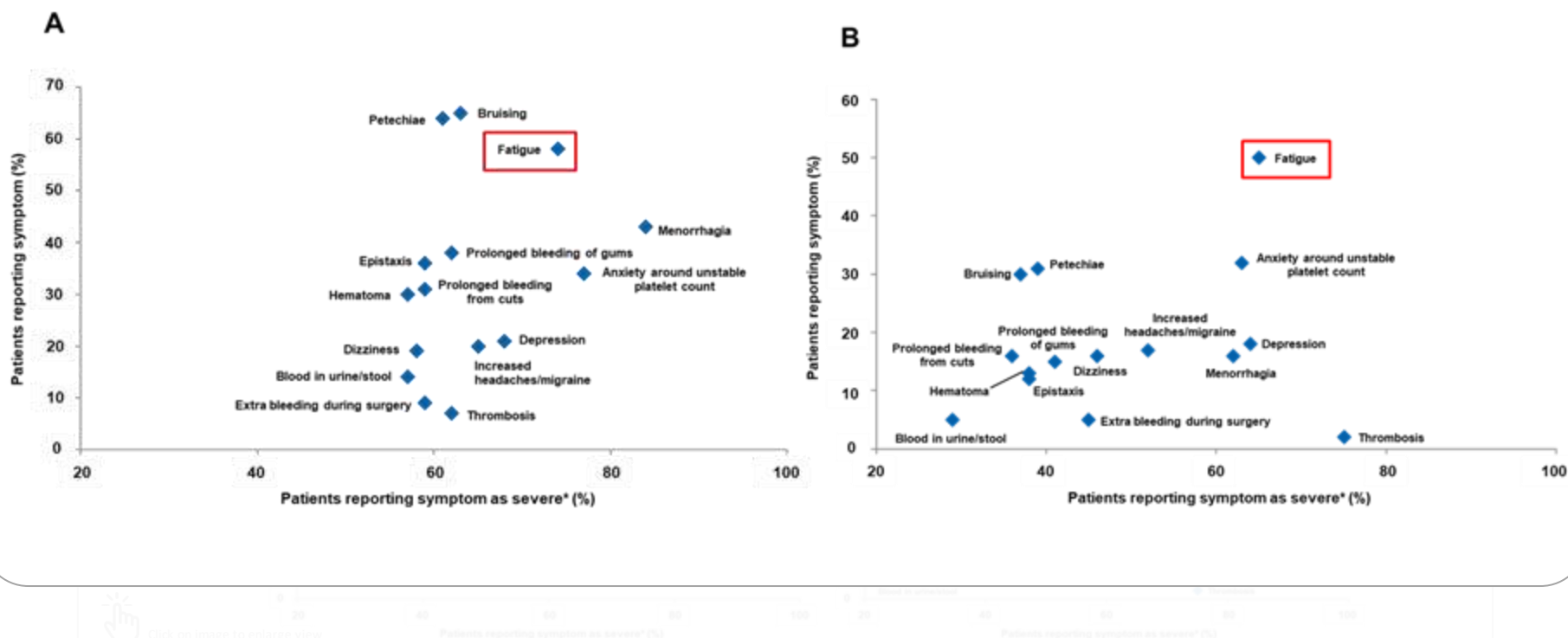
- Fatigue was under-reported by physicians compared with patient-reported data (at diagnosis vs completion)
 - (58% vs 50%) patient-reported whereas physicians reported (31% vs 30%)
- Fatigue being most severe symptom, patients expressed desire to resolve fatigue, menorrhagia and around platelet count and bruising
- Physicians believed fatigue increased as platelet count reduced suggesting fatigue may be intrinsically related to disease activity and could be alleviated by increasing the platelet count
- Overall satisfaction between patients and physicians was high regarding communication (79% vs 89%), disease management (78% vs 87%), and understanding of treatment goals (76% vs 94%)

Patients with ITP frequently experience severe fatigue but it is under-recognized by physicians: Results from the ITP world impact survey (I-WISH)

Kruse (Abstract # 2273)

Poster

Patient Perception of Occurrence and Severity of ITP Signs and Symptoms at Diagnosis (A), and Time of Survey Completion (B)



*Patients reported symptom severity on a 7-point Likert scale where 1=not severe at all and 7=worst imaginable ITP, immune thrombocytopenia

Previous Next

Results from the ITP World Impact Survey (I-WISH): Patients with ITP experience impaired QoL regarding daily activities, social interactions, emotional well-being, and working lives

Cooper (Abstract # 4804)

Poster

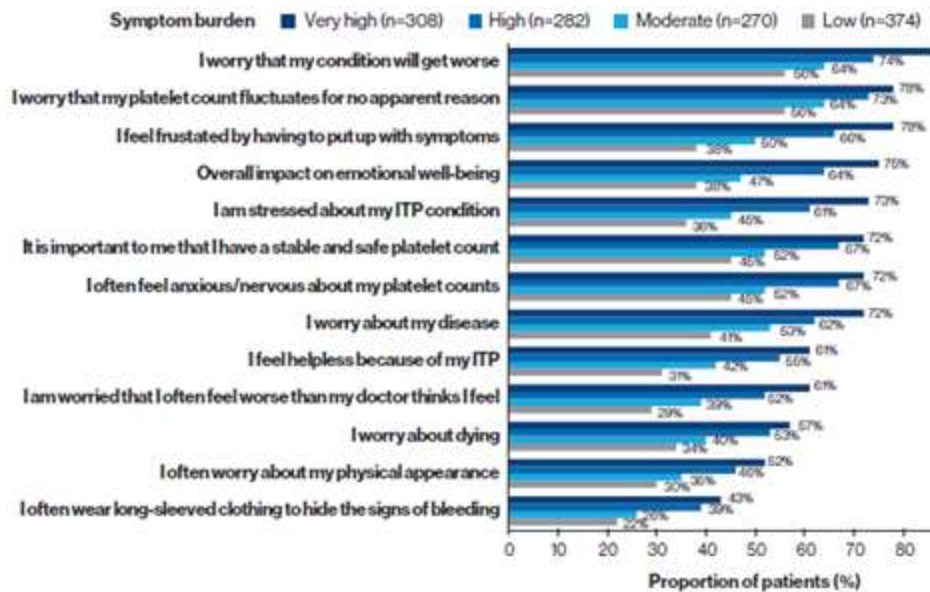
- Overall, 85% of patients reported reduced their energy levels as the greatest impact of ITP on QoL
- 43% (n=386/898) of patients reported negative impact on work productivity; 49% (n=538/1091) and 45% (n=527/1164) of patients had considered reducing or had reduced their hours at work, respectively
- Impact on patient emotional status increased with symptom burden; 63% of patients were concerned about condition worsening and platelet count fluctuation
- With patients expressed desire to increase energy levels, results highlight the need for physicians to consider these findings in effective management of ITP

Results from the ITP World Impact Survey (I-WISh): Patients with ITP experience impaired QoL regarding daily activities, social interactions, emotional well-being, and working lives

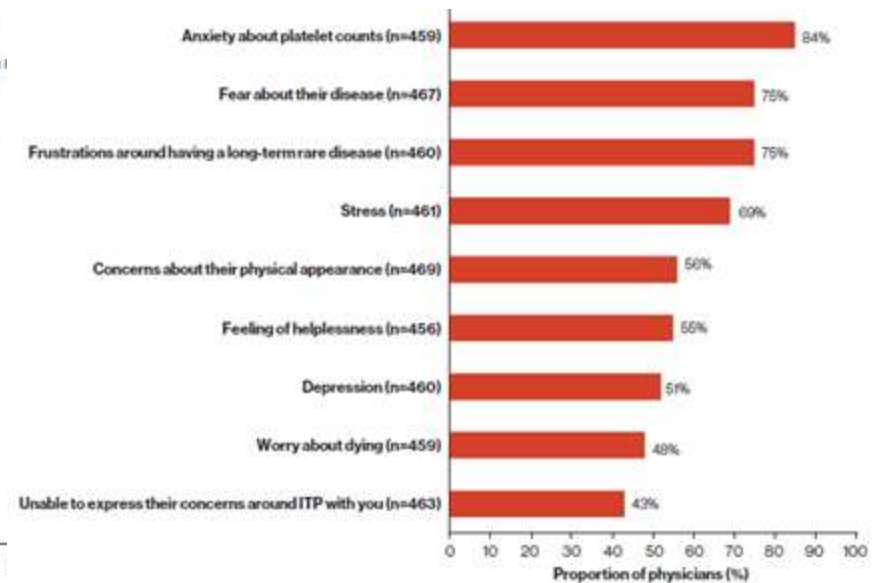
Cooper (Abstract # 4804)

Poster

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



Physician Perceived Factors of ITP Driving an Emotional Impact



Patients and physicians rated their perceptions about the emotional impact of ITP using a 7-point Likert scale where 1=not at all to 7=a great deal. The data presented are for scores ≥ 5
 ITP, immune thrombocytopenia; QoL, quality of life

Physicians' perceptions on causes of primary and secondary ITP and leading causes of misdiagnosis: Results from the ITP World Impact Survey (I-WISH)

Busse (Abstract # PF712)

Poster

- The high rate of secondary ITP and absence of specific testing for ITP contribute to ITP misdiagnosis
- Additional testing for infections (HIV and Helicobacter pylori) and ultrasonography to detect liver disease and/or portal hypertension would promote an early diagnosis
- Better testing to exclude drug-derived causes is required for distinguishing between types of thrombocytopenia
- Exclusion of other disorders was perceived as the leading cause of delays in making an accurate diagnosis of ITP (68%)
- If physicians were more confident in making a diagnosis of ITP, or if online video consultations were available, this might reduce the delay in diagnosis

HIV, human immunodeficiency virus; ITP, immune thrombocytopenia; I-WISH, ITP World Impact Survey

◀ Previous Next ▶



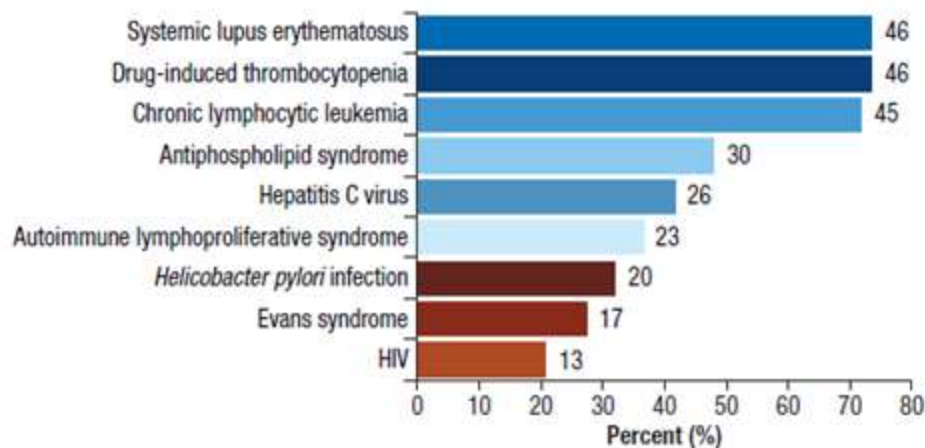
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Bussel (Abstract # PF712)

Poster

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Physicians' Perceptions of the Main Causes of Secondary ITP



Survey question:

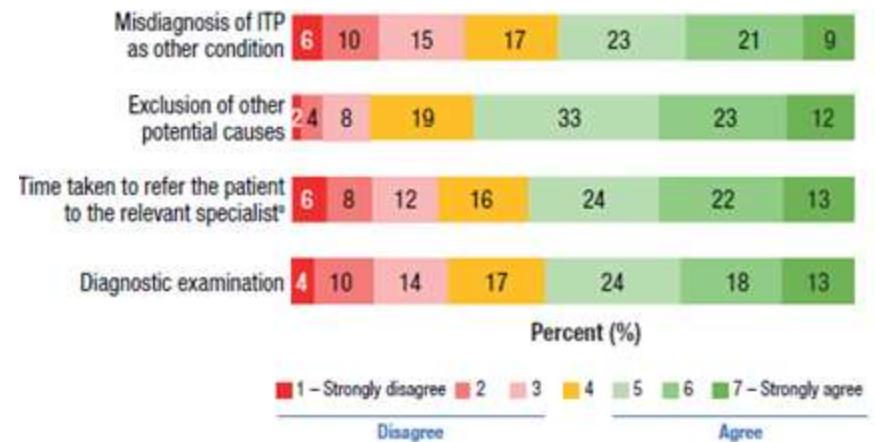
"In your experience, which 3 conditions are the most common cause of secondary ITP?"



Click on image to enlarge view

ITP, immune thrombocytopenia

Physicians' Reasons for Delays in Diagnosis



Survey question:

"Considering your own experience, what impact does the following have on the potential to delay the formal diagnosis of ITP?"



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Patient perceptions on splenectomy outcomes: Results from the ITP World Impact Survey (I-WISh)

Cooper (Abstract # PF714)

Poster

- Overall, 36% of patients perceived splenectomy as being effective in treating their ITP symptoms and 38% of patients were very satisfied with their splenectomy outcomes
- 60% of patients were worried about the immunosuppressive effect of splenectomy, with 30% of patients being worried about the need for regular immunizations
- Only 54% of patients felt they were made aware of the long-term complications of splenectomy before surgery, and 56% of patients were worried about long-term side effects
- The I-WISh survey demonstrated the need for patient awareness on the likelihood of the desired outcomes of splenectomy versus its lifelong risks to help guide their personal preference of treatment

ITP, immune thrombocytopenia; I-WISh, ITP World Impact Survey

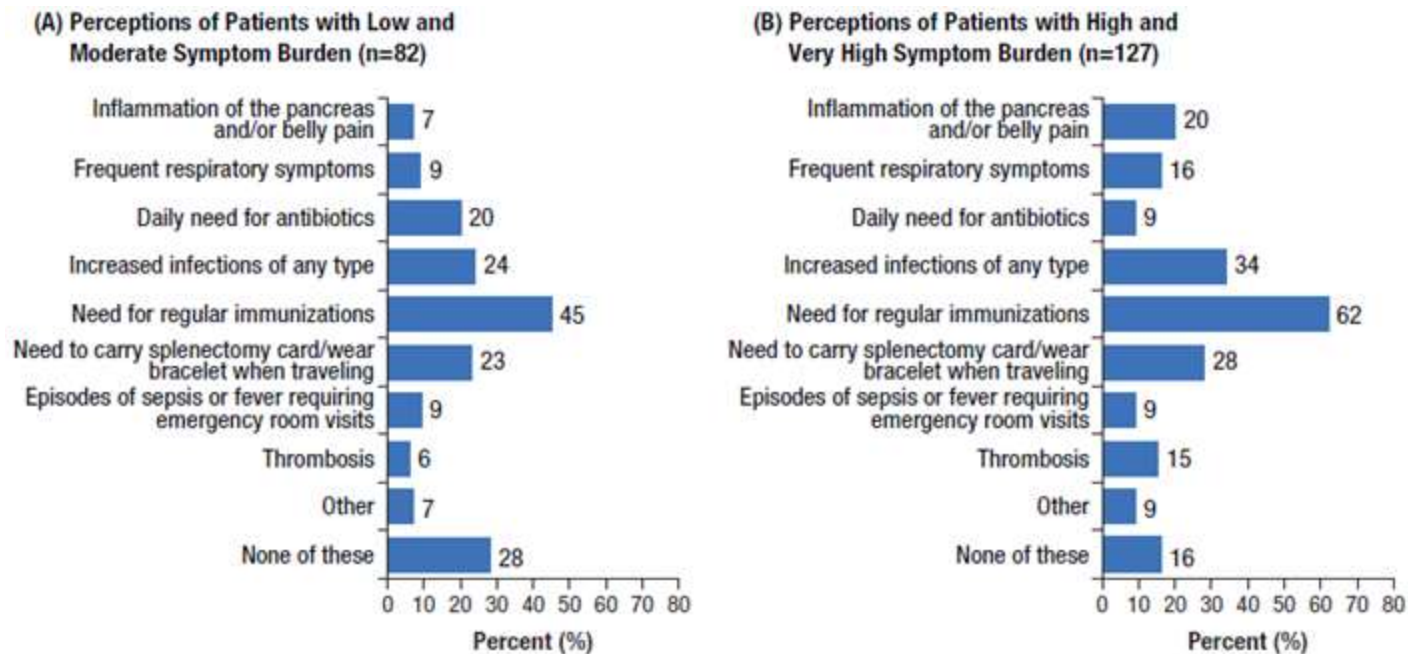
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Cooper (Abstract # PF714)

Poster

- Overall, 36% of patients perceived splenectomy as being effective in treating their ITP symptoms and 38% of patients were very satisfied with their splenectomy outcomes

Patient Perceptions on Consequences of Splenectomy



Survey question:

"Did you experience any of the following as a consequence of undergoing a splenectomy?"

ITP, immune thrombocytopenia

Differences in perceptions on treatment approaches between physicians and ITP patients: Results from the ITP World Impact Survey (I-WISH)

Kruse (Abstract # PF711)

Poster

- Corticosteroids continue to be the most common treatment prescribed following diagnosis of ITP (79%)
 - Physicians were more likely to prescribe corticosteroids over TPO-RAs for patients with platelet levels in the range of $<10-100 \times 10^9/L$ and after first and second relapses
- Among patients with ITP and physicians, achieving sustain remission was the main driver of treatment choice/selection; physicians preferred TPO-RAs over other treatments
- Patients perceived that TPO-RAs were most effective at preventing bleeding and that TPO-RAs and anti-CD20s were similarly effective at treating ITP symptoms
- Patients treated with TPO-RAs (76%) and anti-CD20s (78%) experienced high overall satisfaction with their treatment for control of their ITP, compared with splenectomy

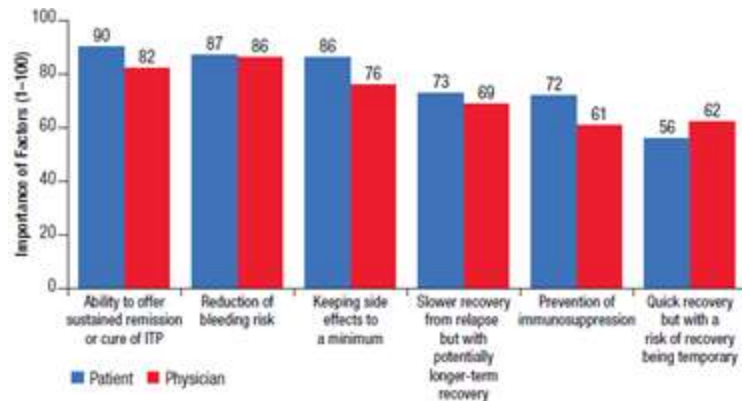
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Kruse (Abstract # PF711)

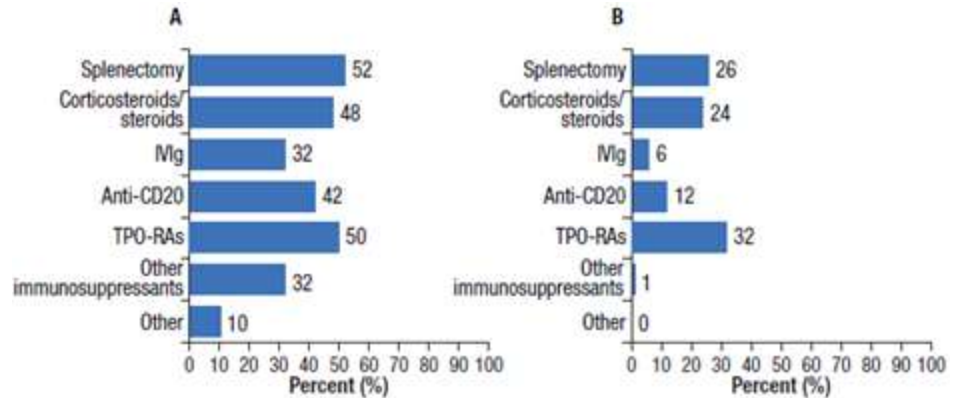
Poster

- Corticosteroids continue to be the most common treatment prescribed following diagnosis of ITP (79%)
 - Physicians were more likely to prescribe corticosteroids over TPO-RAs for patients with platelet levels in the range of $<10-100 \times 10^9/L$ and after first and second relapses
- Among patients with ITP and physicians, achieving sustain remission was the main driver of treatment

Importance of Factors When Making Treatment Decisions



Proportion of Patients Experiencing Lasting Remission Following Successful Treatment (A), and Preferred Class of Treatment for ITP if Sustained Remission Is the Goal (B)



Physician survey question: "Of the statements listed, which is more important to you when making decisions for your ITP patients?"

Patient survey question: "How important do you consider the following aspects when making treatment decisions to manage your ITP condition?"

Physician survey questions:

- 1) "In your opinion, what proportion of patients experience a lasting remission following successful treatment with (or discontinuation of) the following?"
- 2) "What is your preferred class of treatment for ITP if sustained remission is your goal?"

ITP, immune thrombocytopenia; IVIg, intravenous immunoglobulin; TPO-RAs, thrombopoietin receptor agonists

Physicians' and Patients' Perspectives on Treatments in ITP – A Multi-Country Perspective: Results from the ITP World Impact Survey (I-WISH)

Bussel (Abstract # 1097)

Poster

- Results from survey showed that certain specific treatment goals are perceived differently by physicians and patients
- Corticosteroids were the most prevalent ITP treatments prior to (79%) and at time of survey (26%).
- TPO-RAs and anti-CD20 have changed the landscape of second-line ITP therapies, but their utilization varies greatly among countries
- An overall agreement was generally observed, which may have been facilitated by increased physician and patient access to information through the internet and other sources, eg, medical education activities

Physicians' and Patients' Perspectives on Treatments in ITP – A Multi-Country Perspective: Results from the ITP World Impact Survey (I-WISH)

Russell (Abstract # 1097)

Poster

Top 3 ITP treatment goals ranking by patients



Percentages of pts, %



Top 3 ITP treatment goals ranking by physicians



Percentages of MDs, %

Physicians and patients were asked: "Other than a cure for ITP, what are your 3 most important treatment goals?"

ITP, immune thrombocytopenia; QoL, quality of life; TPO-RAs, thrombopoietin receptor agonists



I-Wish - Iran : Study Design

- This was a local I-Wish study conducted in Iran after completion of Global I-Wish
- research contract between the Clinical Trial Center of Tehran University of Medical Sciences and Novartis in Iran
- **Participants:**
 - Pediatric and adult patients with ITP
 - Pediatric and adult hematologists who treat patients with ITP

I-Wish - Iran : Study Design

- **Patients and physician selection for survey:**
 - Hematologists in ITP with >3 patients as an active caseload, responsible for treatment decision for ITP patients
 - Patients – diagnosed with ITP, age >6 years; caretakers must respond for patients <18 years, not completed I-wish survey earlier
- **Survey questionnaires** used in Global I-Wish study were contextualized and translated into local language with the guidance of Novartis consultants
- **Duration of surveys:** 30 min (similar to Global I-Wish surveys) for most patients;

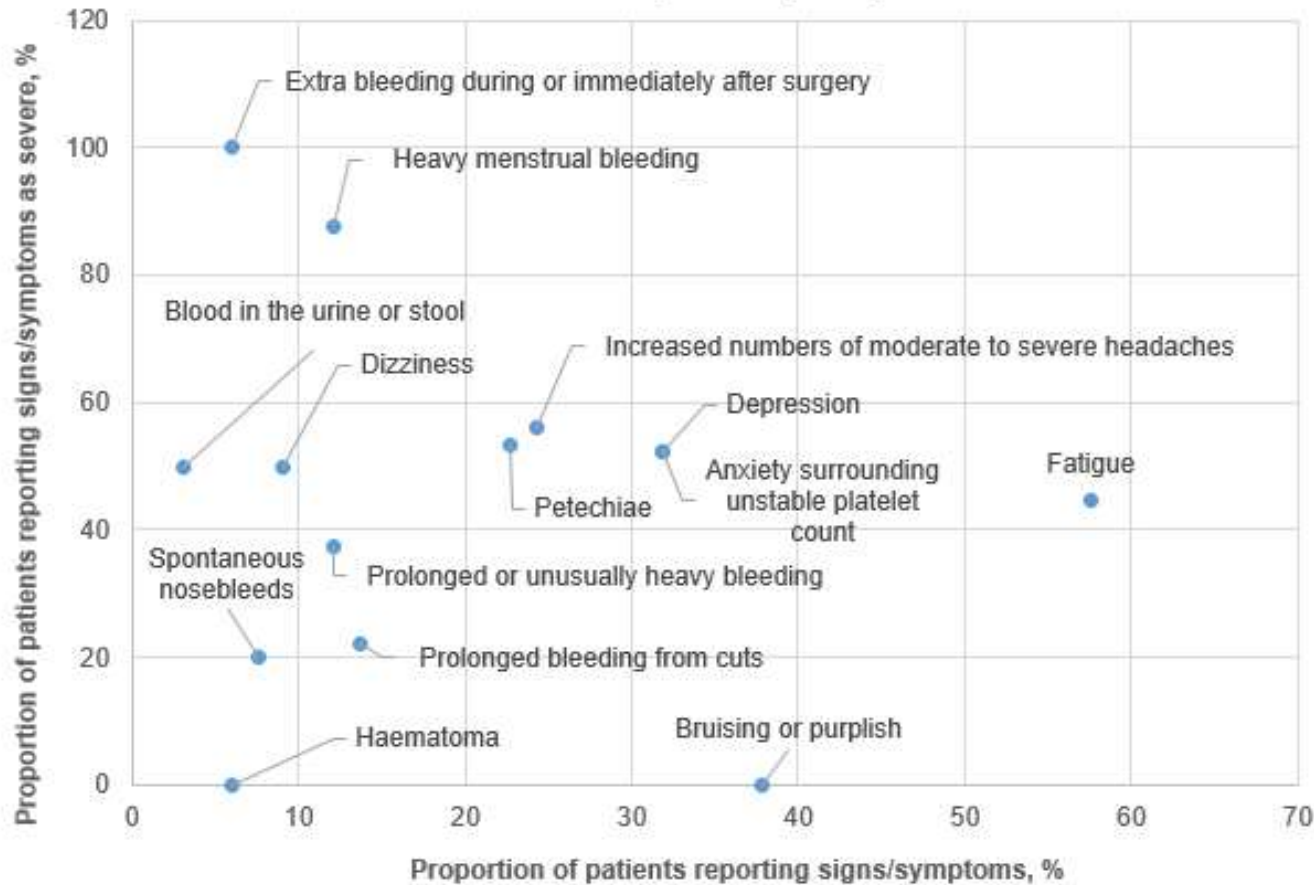
I-Wish - Iran

Table I. Participant demographics and baseline characteristics

	Patients N=114	Adult patients n=87	Pediatric patients n=17
Mean (SD) age, years	38.2 (17.9)	43.0 (15.44)	13.8 (3.92)
Female, n (%)	77 (67.5)	60 (69.0)	11 (64.7)
Male, n (%)	33 (28.9)	26 (29.9)	5 (29.4)

I-Wish - Iran

Most common signs/symptoms at the time of survey by severity in adult patients (N=66)



Thank you

