

The background of the entire page is a microscopic view of blood components. In the upper half, several red blood cells are shown in various orientations, some appearing as bright red discs. In the lower half, there are larger, more detailed views of platelets, which are small, spiky, and purple-colored. The overall lighting is a mix of blue and red, creating a clinical and scientific atmosphere.

# The assessment of the impact of thrombocytopenia symptoms on the patients' daily activities with the use of TSIDAV vignette

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## Authors:

**Monika Szkultecka-Dębek<sup>1</sup>,  
Mariola Drozd<sup>2</sup>,  
Małgorzata Nowakowska<sup>3</sup>,  
Marta Bem<sup>4</sup>, Nina Wiśniewska<sup>1</sup>,  
Joanna Mazur<sup>5</sup>**

- 1- Department of Dermatology, Military Institute of Medicine, Warsaw
- 2- Department of Applied Pharmacy, Medical University of Lublin
- 3- Students Research Society "Social Pharmacy" of Department of Applied Pharmacy, Medical University of Lublin
- 4- Faculty of Social Science, Warsaw University of Life Sciences - SGGW
- 5- Department of Child and Adolescent Health, Institute of Mother and Child Warsaw

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## Abstract

**Objective:** Assessment of the impact of thrombocytopenia symptoms on patients' daily activities using vignettes.

**Methods:** Vignettes were used to collect information from adult patients and children's caregivers in order to assess the impact of thrombocytopenia symptoms on patients' daily activities. Each vignette consisting of two parts aimed at collecting qualitative information about major health problems related to thrombocytopenia symptoms and at measuring the intensity of the symptoms' impact on daily activities in a quantitative way.

Descriptive part collected patients' qualitative information about symptoms influencing their daily functioning or those bothering them the most. Quantitative part using Likert scale assessed the impact of specific symptoms on patients' lives.

**Results:** We collected 61 questionnaires from 31 women, 17 men, 13 children's caregivers. Among men the biggest impact on activities was observed in relation to petechiae and easy bruising (both symptoms were declared as significant by 29% of respondents). 68% women considered skin and mucosa petechiae, 65% indicated easy bruising and 52% bleeding from gums and nose as having significant impact on daily activities. 62% of parents or caregivers believed that petechiae and mucosa had significant impact on the performance of the children's daily activities, same significance was referenced to easy bruising (54%) and bleeding from gums and nose (42%).

**Conclusions:** Thrombocytopenia symptoms influence patients' daily activities and the most frequently mentioned symptoms influencing those across all groups were petechiae and easy bruising. According to the calculated vignettes values the highest impact on daily activity of the symptoms was indicated for children.

## Introduction

As a continuation to our previous research which assessed the potential usage of vignettes in relation to quality of life, we have designed a vignette to capture information about the impact of thrombocytopenia symptoms on patients' lives<sup>[1,2]</sup>. The name of our vignette is TSIDAV - Thrombocytopenia Symptoms and their Impact on patients Daily Activities assessment Vignette.

Thrombocytopenia is a rare disease, but its symptoms can make both the patients' and their care givers' daily life difficult. Immune thrombocytopenic purpura (ITP)

is an autoaggressive disease and is usually diagnosed in children between 1st-7th year. In 80% of the cases it is acute and the remission is observed after 2-4 months. In 20% of the cases it becomes a chronic or recurrent disease<sup>[3]</sup>.

In case of life-threatening consequences such as bleeding into the central nervous system (CNS), in children it occurs rarely, only in 0.2% to 0.9% of ITP, but it worsens the quality of life of the patients and is of great concern to the parents and the physicians mainly due to the need of repeated immunosuppressive treatment.

Among adults in Poland ITP incidence is estimated as 3.5: 100 000 The annual incidence of ITP in the adult population is 2/100 000. The disease can occur at any age and both in male and female population. In adults spontaneous remission of the disease is less likely. Most of the cases are diagnosed at 20-50 years of age

The most characteristic symptoms of thrombocytopenia are petechiae, purpura as well as skin and mucosa bleedings. The most frequent bleedings are from the nose, gums, urinary tract and from the genital tract in women. Intracranial bleeding also happens and is treated as life threatening complication<sup>[4]</sup>. Those symptoms can impact the patients' quality of life and with the specially designed vignettes we aimed to collect data which will allow us to qualify symptoms and have better understanding of such influence.

## Methods

The data were collected at Lublin hospital among hematology clinic adult patients as well as children's caregivers in the period: from 1<sup>st</sup> March to 30<sup>th</sup> April 2016.

The inclusion criterion for the study was diagnosed thrombocytopenia.

The study was a survey using the TSIDAV vignette and it was carried out among patients and caregivers of patients with thrombocytopenia regardless of the cause.

The investigator interviewed the patients or caregivers before or after a visit to the doctor's office. In the course of the conversation he filled out the *researcher survey* which included the TSIDAV vignette.

The Ethics Committee approval was granted and all patients signed informed consent forms. The collected data were anonymous. The vignettes were used to collect information from both adult female and male patients and children's parents or caregivers in order to assess the impact of thrombocytopenia symptoms on the quality of life of the patients.

Each vignette consisting of two parts aimed at collecting qualitative information about the major health problems related to the thrombocytopenia symptoms in each studied group and to measure the intensity of the symptoms' impact the quality of life in a quantitative way.

In the descriptive part of the vignette, the patients were asked to provide qualitative information about the symptoms which either affect most their daily activities or bothering them the most. The second part was quantitative and was using the Likert scale to assess the impact of specific symptoms on patients' lives. The options to be chosen by respondents were as follows: significant impact, medium impact, indifferent, small impact, no impact.

## Results

In total we have collected 61 questionnaires, 31 were from women, 17 from men and 13 from children's caregivers. The study involved 61 people (48 adults and 13 children's caregivers).

The group of adults consisted of 31 women and 17 men. 13 children's caregivers filled the survey with the vignette (of 8 girls and 5 boys).

The average age of adults was 50.8 years (median = 53 years; min = 23 years; max = 86 years). In women, the average age was 47.74 years (median = 51 years; min. = 23 years; max = 85 years), while in men the average age was 56.47 years (median 59 years; min. = 23 years; max = 86 years). In the children group the mean age was 7.1 years (median = 7 years, min = 3 years, max. 16 years). The girls' age ranged from 3 to 16 years (mean = 8.4 years; median 7.5 years) and boys' age was 3 to 8 years (mean = 4.5 years; median = 3.5 years).

The place of residence for 28 patients was a village, and a city for 33. Among female patients 14 were living in the countryside and 17 in the city. In case of male patients, 11 were living in the city and 6 in the countryside. Among children, 8 lived in the countryside, and 5 in the city.

Among men 29% have declared a significant impact of skin and mucosal petechiae on their daily activities and in the opinion of 12 % of men there was no impact at all (table 1).

Score	Number of responses	%
2	2	12%
1	3	18%
0	6	35%
-1	1	6%
-2	5	29%

Table 1. Impact of skin and mucosal petechiae on daily activities among men

Score	Number of responses	%
2	3	18%
1	3	18%
0	4	24%
-1	2	12%
-2	5	29%

Table 2. Impact of easy bruising on daily activities among men

29% men considered easy bruising as significant impact on their daily activities, while 18% did not perceive it as having any impact. (table 2)

Score	Number of responses	%
2	7	41%
1	3	18%
0	2	12%
-1	1	6%
-2	4	24%

Table 3. Impact of bleeding from gums and nose on daily activities among men

In case of 41% of men there was no impact of gums and nose bleeding on their daily activities, while in the opinion of 24% it was significant (table 3).

When asked to provide detailed information on what symptoms are those which most affected their daily activities, 41% of men reported weakness, fatigue and lack of strength.

47% of men expressed no concerns related to thrombocytopenia symptoms.

Within female group the analyzed results have shown that 68% of women considered petechiae on their skin and mucosa as having significant impact on their daily activities and 65% declared as significant impact also easy bruising (table 4, table 5).

Score	Number of responses	%
2	2	6%
1	1	3%
0	4	13%
-1	3	10%
-2	21	68%

Table 4. Impact of skin and mucosal petechiae on daily activities among women

Score	Number of responses	%
2	1	3%
1	2	6%
0	2	6%
-1	6	19%
-2	20	65%

Table 5. Impact of easy bruising on daily activities among women

In relations to bleeding from gums and nose, according to 52% of women, the impact on daily activities was significant. However 23% of them declared that there was no impact at all. (table 6).

Score	Number of responses	%
2	7	23%
1	0	0%
0	1	3%
-1	7	23%
-2	16	52%

Table 6. Impact of bleeding from gums and nose on daily activities among women

We also asked women about prolonged menstrual bleeding. 45% stated no impact on their daily activities, while 35% declared a significant impact (table 7).

Score	Number of responses	%
2	14	45%
1	1	3%
0	3	10%
-1	2	6%
-2	11	35%

Table 7. Impact of prolonged menstrual bleeding on daily activities among women

In the second part of the vignette when we asked about what symptoms are those which affected the daily activities most, 35% of women reported weakness.

Women expressed biggest concern about weakness and bleedings (both abundant menstruation and the risk of bleeding). In total 39% of women were concerned with it. As far as children are concerned, we have asked their parents or the caregivers to provide answers to our vignettes. 62% of parents believed that the petechiae on the child skin and mucosa had a significant impact on the performance of daily activities by their children (table 8).

Score	Number of responses	%
2	0	0%
4	0	0%
0	2	15%
-1	3	23%
-2	8	62%

Table 8. Impact of skin and mucosal petechiae on children daily activities according to caregivers

54% of parents believed that the easy bruising had a significant impact on the activities performed daily by a child. According to 23% it was indifferent (table 9).

Score	Number of responses	%
2	0	0%
1	0	0%
0	3	23%
-1	3	23%
-2	7	54%

Table 9. Impact of easy bruising on children daily activities according to caregivers

2% of parents believed that bleeding from the gums or nose had significant impact on the daily activities of the child (table 10).

Score	Number of responses	%
2	1	8%
1	1	8%
0	3	25%
-1	2	17%
-2	5	42%

Table 10. Impact of bleeding from gums and nose on children daily activities according to caregivers

Having analyzed the second part of the vignette, regarding the symptoms that most affect the daily activities of a child we found that in parents' and/or caregivers' opinion the most frequently mentioned ones were bruising and weaknesses as those which make daily activities difficult to their children. And the main concern was related to bleedings.

## Discussion

Our study aimed to analyze the impact of thrombocytopenia symptoms on daily activities of both adult patients and children. In our research, to the question: "Please describe which of the symptoms associated with the disease hinder activities of daily living, by limiting the activity?" we obtained information that among women there was a wide variation in terms of reported symptoms that influence their daily activities. 35% of them most commonly reported weakness. It was also significant for men since as many as 41% reported weakness, fatigue and lack of strength as mostly affecting their daily routines. Caregivers answered that their children frequently found bruising and weakness hinder their daily activities and only one respondent replied that nothing interrupted the child's activity.

As far as the question related to the symptoms that cause concern women mainly mentioned weakness and bleeding, abundant menstruation and the risk of bleeding.

A total of 39% of women were concerned about it. 47% of men did not have any particular concerns with symptoms of thrombocytopenia. Among children's caregivers the symptoms of particular concern were the current bleedings or those which can occur in the future and they mentioned different types of bleeding.

The second part of the vignettes was based on the Likert scale. Respondents indicated the degree of difficulty in performing daily activities due to the symptoms of the disease. Likert scale included the following answers: *a significant impact, medium impact, indifferent, slight impact and no impact.*

Having analyzed the obtained results it was observed that for 68% of women petechiae had a significant impact on daily activities, while in the men group 35% of them considered it neutral, 29% significant influence, and only 12% indicated no impact. 62% of caregivers / parents thought that petechiae had a significant impact on the performance of daily activities of their children. None of the caregivers indicated that there was no impact or that it was only slight.

For 65% of women easy bruising had a significant impact on activities of daily living, 29% of men believed that there was a significant impact of easy bruising to their daily routines, and 18% of men believed that easy bruising had no impact on their daily activities. 54% of parents believed that the easy bruising had a significant impact on the daily activities performed by their children. According to 23% of caregivers it was indifferent, but no one thought that the effect was only slight or that there was no impact at all.

52% of women believed that bleeding from the gums or nose had a significant impact on the activities performed by them daily, while 23% believed that they had no influence. 41% of men believed that there was no impact of bleeding from the gums or nose on their daily activities, while 24% believed that the impact was significant. 42% of parents believed that bleeding from the gums or nose had a significant impact on the daily activities of their children.

For 45% of women prolonged menstruation did not impact the performance of daily activities, but 35% declared that it had a significant impact.

According to literature data on Health-Related Quality of Life (HRQoL) of children with chronic ITP remain rare. However researchers in China have assessed QoL in children with chronic immune thrombocytopenia and they confirmed that ITP affects HRQoL of both children and parents. Parents were much more concerned with the disease than their children<sup>[5]</sup>.

In relation to newly diagnosed thrombocytopenia patients in Netherlands researchers analyzed 107 children aged 6 months-16 years using the Pediatric Quality of Life Inventory™ and Kids' ITP Tools questionnaires at diagnosis and during standardized follow-up comparing results with healthy children. In children who recovered significantly higher health-related quality of life scores than in children with persistent immune thrombocytopenia were obtained<sup>[6]</sup>.

Other research focused on the impact of therapy on the reported HRQoL in children with primary immune thrombocytopenia using the Kids ITP tool. The observation was that treatment of ITP did not improve, and could worsen, the HRQoL of children with ITP<sup>[7]</sup>.

Among adult patients with persistent primary ITP there was a HRQoL study performed using as the primary QOL outcome measure the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36). The questionnaire consisted of 36 items covering following domains: physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health. The authors concluded that persistent primary ITP patients were those who were experiencing the most important limitations in both physical and mental HRQOL domains in comparison to the general population<sup>[8]</sup>.

An interesting research was performed in China where authors used the KIT with children diagnosed with ITP and their parents to assess HRQoL among children and also the QoL of the parents. The study included 43 children with newly diagnosed ITP and their parents. The children's version of the KIT consisted of 26 items divided into 5 domains: treatment side effects, intervention-related, disease-related, activity-related, and family-related concerns. The KIT used to assess parents QoL consisted of 26 items divided into 6 domains: diagnosis-related, monitoring-related, child's restricted activity-related, daily life-related, disease outcome, and emotional impact. The authors, similarly to our research, used the Likert scale. It was a 6 points scale, from 1 (not at all) to 6 (a great deal) and the high score represented a high concern level. Parent KIT scores were significantly higher than the child KIT scores, and it suggested that QoL of parents was significantly lower than children's.

Among the children KIT, the highest mean score was noted in the "intervention-related" and "activity related" while among the parents the highest score was noted in the "emotional impact" and "disease outcome". The older the children were, they cared for more and were more worried about the disease. Interestingly, the parents' scores were no different in different age groups. That was

interpreted by researchers that whatever the children are old or young, Chinese parents worried about ITP disease in the same degree<sup>[9]</sup>.

In the published literature we have not found a similar vignette to our TSIDAV assessing the QoL of patients with thrombocytopenia in relation to specific symptoms caused by the disease.

## Conclusions

Thrombocytopenia symptoms influenced patients' daily activities both in adults and children. The most frequently mentioned symptoms influencing daily activities in all groups was petechiae and easy bruising. According to the calculated vignettes values the highest impact on daily activity of the symptoms were declared for children as declared by parents or caregivers.

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