

Evaluation of thrombocytopenia symptoms influence on patients' daily activities using TSIDAV adapted to Ukrainian language

DOI:10.7365/JHPOR.2021.1.1

Authors:

Boretska Olga¹

Szkultecka-Dębek Monika²

Nastyukha Yulia¹

<https://orcid.org/0000-0001-5281-7168>

Kaiser Lidiya³

Drozd Mariola⁴

https://www.jhpor.com/Content/img/logo_orcid.png

1 - Danylo Halytsky Lviv National Medical University, Lviv, Ukraine

2 - Healthcare and Consulting, Warsaw, Poland

3 - Institute of Blood Pathology and Transfusion Medicine of the National Academy of Medical Sciences of Ukraine, Lviv, Ukraine

4 - Medical University of Lublin, Lublin, Poland

Keywords:

Thrombocytopenia, symptoms, vignettes, quality of life

How to cite this article?

Boretska O., Szkulciecka-Dębek M., Nastyukha Y., Kaiser L., Drozd M. Evaluation of thrombocytopenia symptoms influence on patients' daily activities using TSIDAV adapted to Ukrainian language. *J Health Policy Outcomes Res* [Internet]. 2021 [cited YYYY Mon DD];1. Available from: <https://www.jhpor.com/article/2260-evaluation-of-thrombocytopenia-symptoms-influence-on-patients-daily-activities-using-tsidav-adapted-to-ukrainian-language>

contributed: 2020-12-14 final review: 2021-02-17 published: 2021-03-22

Corresponding author: Mariola Drozd mariola@bg.umlub.pl

Abstract

Background: The aim was to study the results of the impact of thrombocytopenia on patients' daily activities using the TSIDAV adapted to Ukrainian language.

Methods: The assessment was performed using the TSIDAV vignette (thrombocytopenia Symptoms and their Impact on patients Daily Activities assessment Vignette), which was translated into Ukrainian language to obtain information on how the daily activities of adult patients with thrombocytopenia are affected by the disease symptoms. Patients (n=49) from one of the Lviv clinics participated in the study. The tool consists of two parts: first part identified the symptoms that cause particular concern to the patients; second part provides a self-assessment regarding the intensity of the specific symptoms influencing patients' daily activities. The quantitative assessment was based on the Likert scale.

Results: 49 patients with thrombocytopenia were interviewed. Bleeding episodes were of particular concern in case of the majority of the patients (22.4%). 30.6% of patients did not indicated any symptoms at all, 18.4% of respondents marked weakness and excessive tiredness. The most significant impact on the performance of daily activities, both for men, and for women, was related to "nose and /or gums bleeding" (40.0% of men and 29.2% of women). None of the respondents indicated "menstrual bleeding" as "significant impact" on their daily activities.

Conclusion: The Ukrainian-language TSIDAV has confirmed its function as an instrument for assessing the impact of the thrombocytopenia symptoms on patients' daily activities, it can be used for individualized support clinical and/or pharmaceutical intervention.

Introduction

Patients with thrombocytopenia which is defined as platelets level lower than $150 \times 10^9/L$ ^[1,2] usually require prompt observation and treatment. Depending on the etiology and the developmental stage of its course, the disease may range from totally asymptomatic to the conditions that demand immediate help and medical intervention.^[1,2] Most often this was related to acute infection, heparin-induced thrombocytopenia, liver disease, thrombotic thrombocytopenic purpura/hemolytic uremic syndrome, disseminated intravascular coagulation or hematologic disorders.^[1] According to the literature the health-related quality of life (HRQoL) especially when patient suffers from primary immune thrombocytopenia, compared with the general population is lower^[3,4] and it decreases at least to the level observed in patients suffering from other chronic diseases.^[4] However, doctors are not always aware of the impact the disease has on their patients' quality of life and how it affects their daily activities when treating their patients.^[4] There is a debate about including HRQoL assessment in clinical practice in case of patients with chronic diseases and in specific into the thrombocytopenia treatment protocols. Such systematic measures will support the analysis of the pathways of quality of life changes.^[4] One of the factors that helps physicians in taking informed decisions when treating their patients with thrombocytopenia is the knowledge not only about the influence of the treatment on the disease but also on patients' HRQoL and on their daily activities.^[3,4] Therefore, the question is how to best understand how thrombocytopenia as a chronic disease affects the patients' daily activities.^[4]

Objective

Our aim was to study the results of the impact of thrombocytopenia on patients' daily activities using the TSIDAV vignette adapted to Ukrainian language.

Patients and Methods

The assessment of the impact of thrombocytopenia symptoms on the daily activities of patients was performed using a new tool developed by Polish team, the TSIDAV vignette (Thrombocytopenia Symptoms and their Impact on patients Daily Activities assessment Vignette). TSIDAV was adapted in Ukraine as a result of Polish-Ukrainian cooperation.^[5] The use of those new vignettes in Ukrainian language allowed to obtain information on how the daily activities of adult patients with thrombocytopenia are affected by the disease symptoms. Patients treated in one of the clinics of the city of Lviv participated in the assessment. The study was performed be-

tween December 2017 and October 2018. Each patient gave their oral consent to participate in the study and as a result 49 correctly completed TSIDAV questionnaires were collected and analyzed.

The instrument we used consists of two parts. The first part of the vignette allowed to identify which from the symptoms of the disease could potentially be limiting the daily activities and which are the symptoms that cause particular concern to the patient. The patients were asked to indicate those symptoms. The second part consisted on a self-assessment of the patient providing information on how intensively the specific symptoms influence patients' daily activities. The authors of the developed vignettes used the Likert scale for the quantitative assessment.^[5, 6]

A simple descriptive statistical analysis was used.

The Ethics Committee approval was granted by the Lviv National Medical University and the collected data were anonymous.

Results

In total, 49 patients with thrombocytopenia were interviewed (25 men and 24 women) and the results of the first part of the estimated vignettes are presented in [table 1](#).

Regardless of the fact that 30.6% of patients did not indicated any symptoms, and 20.4% indicated the absence of symptoms of thrombocytopenia which affect their daily activities a significant part of respondents marked the impact of subjective symptoms. 18.4% of respondents marked weakness and excessive fatigue (12% men; 25% women), 10.2% anxiety and fear associated with the disease (12% men; 8.3% women). Among the objective symptoms patients indicated bleeding (16.3%), petechiae (10.2%), and easy bruising (6,1%). Particular concern in case of the majority of the patients caused bleeding (22.4%).

The results of the second part of the TSIDAV are shown in [tables 2 and 3](#).

Table 1. Results of the assessment of thrombocytopenia symptoms impact with TSIDAV by patients (n=49).

Disease symptoms	Influencing patients' daily activities		Causing special concerns to patients	
	Number of patients	%	Number of patients	%
Weakness and excessive fatigue	9	18.4	7	14.3
Bleeding	8	16.3	11	22.5
Anxiety and fear associated with the disease	5	10.2	5	10.2
Petechiae in the skin and/or mucous membranes of the mouth	5	10.2	5	10.2
Easy bruising	3	6.1	4	8.2
Pain	-	-	1	2.0
No symptoms	10	20.4	5	10.2
No answer	15	30.6	15	30.6

Table 2. Impact of disease symptoms on daily activities among men (n=25)

Symptom	Score (N)				
	Significant impact -2	Medium impact -1	Indifferent 0	Small impact +1	No impact +2
Petechiae	20.0% (5)	24.0% (6)	16.0% (4)	20.0% (5)	20.0% (5)
Easy bruising	16.0% (4)	28.0% (7)	24.0% (6)	12.0% (3)	20.0% (5)
Bleeding from the gums and/or nose	40.0% (10)	16.0% (4)	16.0% (4)	4.0% (1)	24.0% (6)

Table 3. Impact of disease symptoms on daily activities among women (n=24)

Symptom	Score (N)					No answer
	significant impact -2	medium impact -1	indifferent 0	small impact +1	no impact +2	
Petechiae	8.3% (2)	33.3% (8)	25.0% (6)	12.5% (3)	20.8% (5)	-
Easy bruising	16.7% (4)	33.3% (8)	12.5% (3)	29.2% (7)	8.3% (2)	-
Bleeding from the gums and/or nose	29.2% (7)	20.8% (5)	20.8% (5)	8.3% (2)	20.8% (5)	-
Heavy menstrual bleeding	-	12.5% (3)	29.2% (7)	4.2% (1)	41.7% (10)	12.5% (3)

Tab. 4. TSIDAV values

	mean	SD	min	max
Women	-0.18	0.95	-2.00	1.20
Men	-0.44	0.69	-1.33	1.17
Total	-0.31	0.83	-	-

According to the results obtained by the second part of TSIDAV the impact of the disease symptoms on daily activities among men was different (Table 2).

The analysis of the results obtained by the second part of TSIDAV among women also demonstrated a different impact of disease symptoms including the heavy menstrual bleeding (table 3).

The results of the final assessment of the impact of thrombocytopenia symptoms on the patients' daily activities confirmed that the strongest measure of the effect on the performance of daily activities, in both men and women, was "nose and/or gums bleeding". 40.0% of men and 29.2% of women assessed the impact of that symptom as significant. Figure 1 presents the overall results in percentage correlation.

The appearance of easy bruises was another symptom assessed by the respondents as a symptom that affects the performance of daily activities. Similar percentage of women and men (16.7% women vs 16.0% men) indicated the impact as significant.

The overall results in percentage correlation are presented in figure 2.

Such symptoms as petechiae were assessed as having a significant impact on patients' daily activities more frequently by men than women (20.0% vs 8.3%). The overall distribution of responses in percentage scale is presented on figure 3.

None of the respondents indicated that "heavy menstrual bleeding" had a significant impact on the performance of daily activities. 41.7% of women assessed this specific symptom as the one which does not affect their daily activities, 29.2% women chose the answer "indifferently", and only 12.5% of the interviewed women described the impact of this symptom as average.

The calculated mean values of TSIDAV scale are in the range <0 to -1.0 which means that the symptoms of the disease have a high impact on patients' daily activities (table 4). It should be stated that the obtained results among men to a greater extent indicate the impact of the disease on their daily activities than in the female group. Particular attention should be paid to the obtained minimum and maximum TSIDAV values. In case of women, the lowest minimum value recorded on the TSIDAV scale was -2.00 and the maximum value was 1.20 . Similar values were noted among men. It confirms that the quality

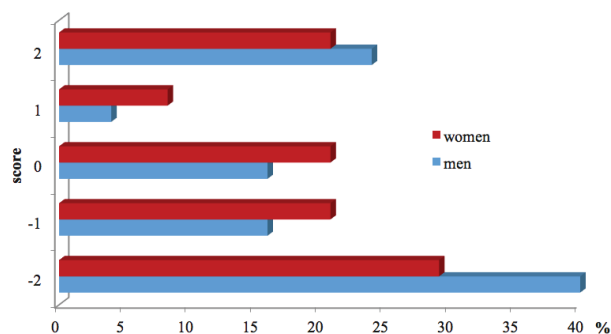


Figure 1. Overall results in percentage correlation with the impact of "gums and / or nose bleeding" on the patients' daily activities

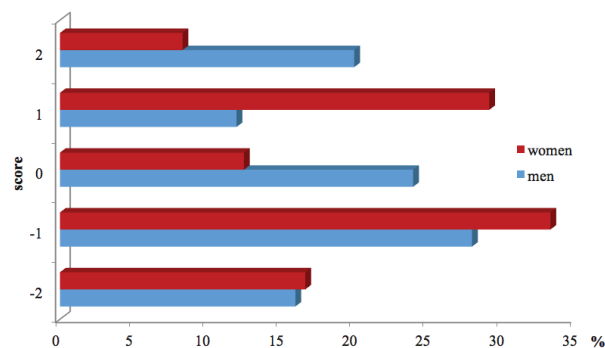


Figure 2. Overall results of the impact of "light bruises" on patients' daily activities in percentage correlation

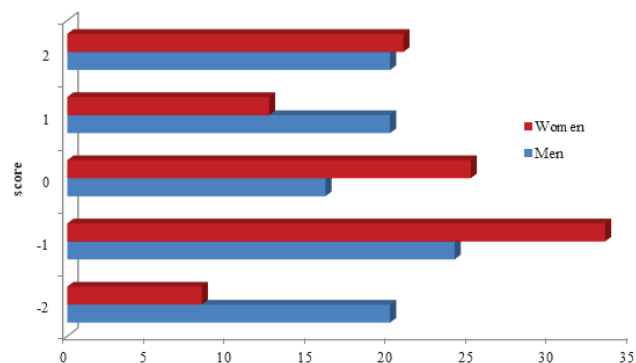


Figure 3. Overall results in percentage correlation with the impact of "petechiae" on patients' daily activities

of life is a subjective feeling of the individual, because the effect of thrombocytopenia symptoms on daily activity ranges from very low impact on daily activity to very high impact on daily activity.

The results we have obtained indicate that in comparison to other symptoms, the symptoms affecting daily activities of patients with thrombocytopenia most significantly are the nose and / or gum bleedings. Special concern was reported by patients in relation to bleeding and almost a quarter of the patients included in the study pointed towards that symptom (22.4%).

Discussion

The influence of the nose and / or gum bleedings symptom ranked as very high was observed more often among men (40.0%) than women (29.2%). The results of studies with the use of TSIDAV vignettes carried out in Poland have also demonstrated the importance of this symptom, but its significant impact on patients' daily activities was reported more frequently by women (52.0%) than by men (24.0%).^[7]

According to the results of our study, the percentage of patients who assessed the effect of easy bruising on their daily activities as very significant is rather small and almost equal among men (16.0%) and women (16.7%). As many as 8.2% of patients are particularly worried by those symptoms. More patients reported the significant impact of easy bruising in a study conducted in Poland, where women (65.0%) considerably outnumbered men (29.0%).^[7, 8]

Concerns due to petechiae in our study was reported by 10.2% of patients. Similar results were obtained in the Polish study among men.^[7, 8]

The questions related to heavy menstrual bleeding shown that none of the patients in the study conducted indicated the influence of this symptom on their daily activities as very significant.

The critical issue that is a component of the patients' quality of life and which impact the quality of life by lowering it is fatigue.^[4] This symptom is one of the most significant concerns, in particular, in the case of patients with primary thrombocytopenia.^[3] Physicians tend to categorize and refer to thrombocytopenia as a "mild" chronic disease. However, the results of the use of SF-36 questionnaire indicate that the reduction of HRQoL in these patients is comparable to other known chronic diseases.^[4] According to the results of our study, weakness or excessive fatigue limited the activity of 18.4% of patients (men 12.0%, women 25.0%). Fatigue is affecting patients' everyday life and experienced clinicians can observe it frequently however still the answer to this question remains open.^[4]

Another factor that affected Ukrainian patients' daily activities was anxiety and the fear associated with thrombocytopenia. 10.2% of patients involved in the performed study (12.0% men; 8.3% women) reported those as symptoms of special significance.

Limitations

A larger studied group could have an impact on the probability of a different distribution of the answers and the obtained results, and thus the conclusions drawn from the study. However, due to the fact that thrombocytopenia is a rare disease, the results of the study can be considered as adequate.

Conclusions

1. The Ukrainian-language TSIDAV has confirmed its function as an instrument for assessing the impact of the thrombocytopenia symptoms on patients' daily activities and their HRQoL, therefore, it can be used for individualized support clinical and/or pharmaceutical interventions.
2. Based on the results of the assessment of the impact of the thrombocytopenia symptoms on patients' daily activities using the Ukrainian-language TSIDAV, it was found that the substantial share of men (40.0%) and women (29.2%) involved in the study confirm significant impact of "gums and / or nose bleeding", although, the "heavy menstrual bleeding" did not have a significant impact on female participants.
3. In addition to the objective symptoms of thrombocytopenia, patients pointed out that "weakness and excessive fatigue" (18.4%) and "anxiety and fear associated with the disease" (10.2%) affect significantly their daily activities. Therefore, subjective characteristics have no less impact on the quality of life of patients with thrombocytopenia compared to the objective symptoms of the disease.
4. The use of the TSIDAV vignette to assess the impact of the disease symptoms on patient's daily activities can indicate to the physician the important factors from the patient perspective. These factors might influence the decision on the patient's treatment related decisions.

What is new?

The symptoms of the disease hinder the daily life and quality of life of the patient suffering from thrombocyto-

penia. The authors adapted the Polish version of the TSIDAV vignette for Ukraine and tested the tool in Lviv. This innovative tool used aimed to support clinical and/or pharmaceutical intervention decisions. The study confirmed that the tool can be used in Ukrainian language version and the results are clinically relevant.

Authorship Contributions

OB and MSzD contributed equally to this study. BO, MSzD and MD developed the project. OB, YN and LK conducted the experiments and collected data. OB, MSzD and MD analyzed the results. OB and YN prepared the data. OB, YN and MSzD wrote the manuscript. OB, MSzD, YN, LK, and MD have reduced the manuscript. LK provided patients with questionnaires.

Conflicts of Interest: Authors declare none potential conflicts of interest.

Funding Information: This research did not receive any specific grant from founding agencies in the public, commercial, or not for profit sectors.

Availability of data and material (data transparency) is at Olga Boretska

Ethical approval: Authors declare: "All procedures performed in studies involving human participants were in accordance with the ethical standards and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards."

The Ethics Committee approval was granted (protocol №4 20th April 2015 p. Danylo Halytsky Lviv National Medical University, Lviv, Ukraine). The collected data were anonymous.

References

1. Gauer, R.L., Braun, M.M.; Thrombocytopenia. *A Fam Physician*. 2012;85(6): 612-622.
2. Izaak M., Bussel, J.B.; Management of thrombocytopenia. *F1000Prime Reports*. 2014;6: 45-55.
3. Efficace, .F, Mandelli, F., Fazi, P., Santoro, C., Gaidano, G., Cottone, F., Borchiellini, A., Carpenedo, M., Simula, M.P., Di Giacomo, V., Bergamaschi, M., Vincelli, I.D., Rodeghiero, F., Ruggeri, M., Scaramucci, L., Rambaldi, A., Cascavilla, N., Forghieri, F., Petrungaro, A., Ditunno, P., Caocci, G., Cirrincione, S., Mazzucconi, M.G.; Health-related quality of life and burden of fatigue in patients with primary immune thrombocytopenia by phase of disease. *Am J Hematol*. 2016 Oct;91(10):995-1001. doi: 10.1002/ajh.24463.
4. Sestøl, H.G., Trangbæk, S.M., Bussel, J.B., Frederiksen, H.; Health related quality of life in adult primary immune thrombocytopenia. *Expert Review of Hematology*, 2018. doi: 10.1080/17474086.2018.1548930
5. Boretska, O., Nastyukha, Y., Szkulciecka-Dębek, M., Drozd, M.; The adaptation of new methodology of quality of life assessment in patients with thrombocytopenia in Ukraine as a result of Polish-Ukrainian collaboration. *JHPOR*, 2016;2:41-47.
6. Szkulciecka-Dębek, M., Drozd, M., Bem, M., Kiepuska, N., Mazur, J.; Assessment of thrombocytopenia symptoms using vignettes. Preliminary report on the development and implementation of a new instrument. *JHPOR*, 2015;2: 95-99
7. Szkulciecka-Dębek, M., Drozd, M., Nowakowska, M., Bem, M., Wiśniewska, N., Mazur, J.; The assessment of the impact of thrombocytopenia symptoms on the patients' daily activities with the use of TSIDAV vignette. *JHPOR*, 2016;1: 37-42.
8. Szkulciecka-Dębek, M., Drozd, M., Bem, M.; The quality of life perception by gender and place of residence during assessment of thrombocytopenia impact on patients' daily activities using TSIDAV vignette. *Pol J Public Health*. 2017;127(1): 24-27.