

LETTER TO THE EDITOR

Addendum to corticosteroid side effects and risk for bleeding in immune thrombocytopenic purpura: patient perspectives

To the Editor:

We recently published our data from surveys of patients in the Oklahoma immune thrombocytopenic purpura (ITP) Registry and practicing haematologists in the state of Oklahoma which documented a significant difference between ITP patients' and haematologists' perspectives about the severity of side effects of corticosteroid treatment and their concern about the risk for serious bleeding (1). In this publication, we listed multiple potential limitations of our study, principally whether our ITP patients were representative of all ITP patients and therefore whether their responses were generalizable. We were also concerned about the accuracy of the patients' responses, which may have been biased by their recall of past experience, and the heterogeneity of the patient group, which included some patients who's ITP had resolved, some who's ITP remained symptomatic, and some who had persistent thrombocytopenia without

symptoms. We recently had the opportunity to validate our results with a different patient group, patients who attended the Annual Convention of the ITP Support Association in Edinburgh, Scotland on 16 May 2009. Patients attending the Convention, described here as UK patients, were given the same questionnaire as patient participants in Oklahoma, described as US patients. The results are presented in the Table 1.

There was no significant difference between the patient groups regarding their lowest platelet count or the duration they were treated with corticosteroids. In both groups, 80% of patients reported that their lowest platelet count had been less than 10 000/ μ L and approximately one-third of the patients had received corticosteroid treatment for longer than 12 months. The questionnaire asked patients how bothered they were by 18 different side effects of corticosteroid treatment. They graded each side effect according to a four choice scale: 'bothered a lot', 'bothered

Table 1 Comparison of US and UK ITP patients' responses to a questionnaire about corticosteroid side effects and concern for serious bleeding

Survey questions for ITP patients	US patients (n = 64)	UK patients (n = 30)	P*
Lowest platelet count			
<10 000/ μ L	80%	80%	0.87
10 000–30 000 μ L	15%	17%	
>30 000 μ L	5%	3%	
Longest duration of steroid treatment			
Less than 1 month	2%	10%	0.07
1–3 months	22%	17%	
4–6 months	22%	21%	
7–12 months	25%	17%	
>12 months	30%	35%	
Number of steroid complications causing 'a lot of bother'			
Median	4	5	0.39
Range	0–12	0–12	
Concern for bleeding in the patients with platelet count <10 000/ μ L	n = 51	n = 24	
Not at all worried	10%	17%	0.16
Rarely worried	25%	21%	
Sometimes worried	33%	42%	
Very worried	31%	21%	

US patient data have been previously reported(9917). UK patients were surveyed at the Annual Convention of the ITP Support Association in Edinburgh, Scotland on 16 May 2009.

*Comparisons of patients' platelet counts, duration of corticosteroid treatment and concern for bleeding were performed by the Chi-squared test; comparison of steroid side effects was performed by Wilcoxon's Rank Sum test.

sometimes', 'bothered a little', 'no bother'. To compare the US and UK patients, we compared the number of side effects for which patients stated that they were 'bothered a lot'; the median and range of the number of side effects for each patient was not different between the two groups of patients. For 11 of the 18 side effects, the UK and US patients' responses were not different. For six side effects (weight gain, bloating, acne, visual problems, stomach problems and blood pressure problems) more US patients than UK patients responded that they were 'bothered a lot'; for the remaining side effect (insomnia) more UK patients responded that they were 'bothered a lot' ($P < 0.05$ for each of the seven comparisons). Finally, for patients whose lowest platelet count had been less than $10\,000/\mu\text{L}$, there was no statistically significant difference between the UK and US patients on how worried they were about their risk for serious or life-threatening bleeding.

These additional data suggest that the patients' responses in our original report (1) are generalisable and they support our conclusion that ITP patients and their physicians may have significantly different perspectives about the magnitude of corticosteroid side effects and their risk for serious bleeding. These data emphasize the importance of effective communication between ITP patients and their physicians.

Reference

1. Guidry JA, George JN, Vesely SK, Kennison SM, Terrell DR. Corticosteroid side effects and risk for bleeding in immune thrombocytopenic purpura: patient and hematologist perspectives. *Eur J Haematol* 2009; doi:10.1111/j.1600-0609.2009.01265.x.

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