

## Prospective Evaluation of the Non-Compliant Severe Hemophilia Patients

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Dear Editor,

The patients' compliance with the determined treatment regimen is a current issue in the treatment of hemophilia, and there are many studies that report compliance issues among patients (1, 2).

In our study, we applied a survey to 40 patients which participated in the adolescent workshop and monitored 16 adolescent patients with severe hemophilia and investigated the changes in the compliance rate during the one-year process. We wanted to share it with the medical public thinking that the results were very valuable.

### Material and Method

The survey that we developed was applied to the volunteers that participated in Hemophilia Federation Workshop in March 2017. The survey was applied with the face-to-face method. The subjects that were found to be non-compliant (the patients that neglect to apply the prophylaxis as recommended by their physician) were monitored for 1 year. These subjects were reached by phone on months 6 and 12. The scope of these telephone calls was as follows: whether the subject was currently on prophylaxis, whether they were complying with the treatment plan and the reasons for non-compliance. This survey is an activity initiated to patients during routine workshop. Therefore, we did not apply to ethics committee approval.

### Results

There were a total of 40 subjects: 39 patients with severe hemophilia and 1 patient with von Willebrand disease (vWD). Among these subjects, 16 were found to be non-compliant: 12 patients with hemophilia A, 3 patients with hemophilia B and 1 patient with vWD. The average age of these 16 subjects was 21.25. 10 patients (62.5%) were receiving prophylaxis. 2 of the patients were middle school, 11 were high school and 3 were university graduates.

There were 10 patients who were receiving prophylaxis at start of study. Also, there were 12 patients in sixth month and 14 patients in first year. The ratio of compliant patients is 43.75% in sixth month and 56.25% in first year.

It was determined that there were three reasons for non-compliance with the treatment: time constraints, being tired of the treatment, and problems with vascular access. The number of patients that reported to experience these problems is presented in Table 1.

### Discussion and Conclusion

The definition of 'acceptable compliance' can greatly differ between studies. Generally, if a patient administers at least 75 to 80% of the recommended doses, they are accepted to have perfect compliance (3). 16 subjects that were found to be non-compliant were monitored for 1 year, and it was determined that the rate of compliance increased only to 56.25% in our prospective cohort study.

The adolescent patients are more resistant to comply with the recommended treatment plans. In this age group, the patients go through several biological, social and emotional changes that influence their approach to the disorder (4). Due to these factors, the non-compliance problem has a complicated nature that cannot be resolved through only recommendations. Treatment incompatibility is a chronic process in life-long chronic disease as hemophilia. As each patient is affected by different factors, it might be useful to conduct individual meetings with each patient, instead of group trainings.

#### References

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**Table 1. The causes of non-compliance to treatment of 16 patients.**

	Time Constraints (n)	Being tired of the treatment (n)	Problems in vascular access (n)
0 month	3	7	6
6 month	3	4	2
12 month	3	4	0