

Knowledge of Disease and Treatment Understanding among Patients with Hemophilia: Interim Results among Patients Attending the Gulf States Hemophilia and Thrombophilia Center (GSHTC)



Stephanie Gustafson, Aroub A. Khleif, Nidra Rodriguez, **Miguel A. Escobar**

The University of Texas Health Science Center at Houston, Gulf States Hemophilia & Thrombophilia Center
Houston, TX, USA



OBJECTIVES

- Understanding the dimensions of self-care and benefits of treatment, including adherence to a prescribed regimen is essential in ensuring improved health outcomes among persons with hemophilia.
- The primary objective of this study was to evaluate patients' knowledge of their disease and level of understanding of their hemophilia treatment.

METHODS

- This was a prospective study conducted among patients attending the GSHTC between September 2012 and October 2013.
- Patients were eligible to participate in the study if they were greater than 3 years of age, did not have an inhibitor, and had a clinical diagnosis of hemophilia A or B (any severity).
- Participants were interviewed (if less than 7 years of age, the parent was interviewed), and asked questions that assessed their knowledge of their disease, including type of hemophilia, their current prescribed treatment and factor product, when to infuse, appropriate handling, and ordering refills.

RESULTS

- A total of 66 patients participated in the study.
- The majority of the sample had hemophilia A (77%), were greater than 18 years of age (median 23, IQR 16, 33), and were on prophylaxis (61%).
- While 93% of patients knew their type of hemophilia and severity (99%), approximately 53% of participants did not know their correct factor level.
- 16% of the sample could not identify the factor product they were currently using, and 20% did not know when the appropriate time was to refill their factor prescription.
- 81% of the sample had no knowledge of the length of time they could store their product at room temperature.
- 43% of patients who were on prophylaxis did not know that the best time to infuse factor was in the morning.
- No significant differences were observed between the person interviewed or the severity of the subject and any of the variables that were examined.

Table 1. Selected demographic and clinical characteristics of patients participating in the study.

Characteristics	n	%
<i>All Patients</i>	66	
Age in years		
Median (IQR)	23 (16 - 33)	
Race/Ethnicity		
Caucasian (Non-Hispanic)	37	57.6
Hispanic	17	25.8
African American	6	9.1
Asian Pacific Islander	5	7.5
Insurance status		
Commercial	44	66.7
Medicare/Medicaid	19	28.8
Uninsured	3	4.5
Hemophilia disease		
A	51	77.3
B	15	22.7
Severity		
Mild	10	15.2
Moderate	8	12.1
Severe	48	72.7
Treatment modality		
On-demand	26	39.4
Prophylaxis	40	60.6
Patient knew their current factor product		
Yes	55	83.3
No	11	16.7
Patient knew their correct factor level		
Yes	31	47.0
No	35	53.0
Patient knew the length of time to store factor product at room temperature		
Yes	13	19.7
No	53	80.3

IQR, interquartile range

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CONCLUSIONS

- While this study showed a fairly high degree of knowledge regarding hemophilia, patients did exhibit some deficiencies in key areas of their treatment.
- It is vital that patients and caregivers are continuously educated about their treatment during scheduled clinic visits and through other educational programs.
- Knowledge of hemophilia disease among patients is essential to ensuring positive health outcomes.

