AN ASSESSMENT OF KNOWLEDGE, ATTITUDES, AND ACCESS TO GENETIC TESTING AND COUNSELING SERVICES IN U.S. HEMOPHILIA TREATMENT CENTERS

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Hemophilia is a hereditary bleeding disorder which requires lifelong specialized care. A network of Hemophilia Treatment Centers (HTCs) exists to meet the medical needs of patients affected by hemophilia. Genetic counseling services are an integral part of the HTC model of care; however, many HTCs do not have genetic counselors on staff. As a result, the duty to provide these services must fall to other healthcare providers within the HTC. To assess the knowledge and attitudes of these providers we developed a 49 question survey that was distributed electronically to hematologists and nurses at U.S. HTCs. The survey consisted of three sections: demographic information, knowledge of hemophilia genetics, and attitudes towards genetic services. A total of 111 complete responses were received and analyzed. The average knowledge score among all participants was 74.8% with a total of 81 participants receiving a passing score of 70% or above. Thirty participants scored below 70% in the knowledge section. In general, attitude scores were high indicating that the majority of hematologists and nurses in HTCs feel confident in their ability to provide genetic counseling services. Over 90% of participants reported that they have some form of access to genetic counseling services at their center.

Hematologists and nurses practicing in U.S. HTCs demonstrate sufficient knowledge of the genetics of hemophilia, and they generally feel confident in their ability to provide genetic counseling services to their patients. While their knowledge is sufficient, the average knowledge score was lower than 75%. Certain questions covering new genetic technologies and testing practices were more commonly missed than questions asking about more basic aspects of hemophilia genetics, such as inheritance and carrier testing. Finally, many clinics report having access to a counselor, but it is oftentimes a hematologist or nurse who is providing genetic counseling services to patients. Given the inconsistency in knowledge among providers coupled with the high confidence in one’s ability to counsel patients, it leaves room to question whether information about
the genetics of hemophilia is being communicated to patients in the most appropriate and accurate manner.

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