



The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

901.HEALTH SERVICES AND QUALITY IMPROVEMENT - NON-MALIGNANT CONDITIONS

Surveying Patients' Experiences and Perspectives on Venous Thromboembolism Care: An International Study to Identify Gaps and Opportunities in Health Care Delivery

Rushad Patell, MBBS¹, Laura Dodge, ScD², Ang Li, MDMS³, Anna L Parks, MD⁴, Jordan K Schaefer, MD⁵, Alejandra Gutierrez Bernal, MD⁶, Shruti Chaturvedi, MBBS⁷, Anjee Mahajan, MD⁸, Jori E. May, MD⁹, William Robertson¹⁰, Leslie Lake¹¹, Dana E. Angelini, MD¹²

¹ Division of Hematology/Oncology, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA

² Department of Epidemiology, Harvard T.H. Chan School of Public Health, Boston, MA

³ Section of Hematology-Oncology, Department of Medicine, Baylor College of Medicine, Houston, TX

⁴ Department of Medicine, Division of Hematology & Hematologic Malignancies, University of Utah, Salt Lake City, UT

⁵ Division of Hematology/Oncology, Department of Internal Medicine, University of Michigan, Ann Arbor, MI

⁶ University of Minnesota, Minneapolis

⁷ Division of Hematology, Johns Hopkins School of Medicine, Baltimore, MD, BALTIMORE, MD

⁸ University of California, Davis, CA

⁹ Department of Medicine, Division of Hematology/Oncology, University of Alabama at Birmingham, Birmingham, AL

¹⁰ Weber State University, Ogden, UT

¹¹ National Blood Clot Alliance, Philadelphia, PA

¹² Taussig Cancer Institute, Department of Hematology and Medical Oncology, Cleveland Clinic, Cleveland, OH

Background

Patient experience is a well-recognized, independent dimension of health care delivery. Although considerable progress has been made in the diagnosis and management of venous thromboembolism (VTE), data on the patient experience are lacking. We aimed to capture patients' experiences with VTE and anticoagulation in order to prioritize efforts to improve VTE health care delivery.

Methods

An IRB-approved survey was developed with a multidisciplinary team of clinicians and patient advocates. The survey domains included patient demographics, health care experiences, perspectives, and potential gaps in healthcare received for VTE. The survey was pilot tested and subsequently distributed electronically from May-July 2023 through an international patient advocacy group targeting individuals with personal history of VTE. Data are described as counts and proportions. We used log binomial regression to calculate the risk ratios (RR) and 95% confidence intervals (CI) of outcomes associated with seeing a hematologist during or after hospital admission.

Results

Of a total of 1,050 participants, the majority were from the US (81%), including 49 states and the District of Columbia. A response rate could not be calculated given that the web-based survey was openly distributed. The majority of respondents were women (81%), 88% identified as white, and 71% were age 40-69 years. Most patients (68%) experienced their first VTE event >12 months prior to the study, 36% had >1 VTE events and the majority (62%) were diagnosed in the emergency department.

Over one-third (35%) of respondents reported not receiving the correct diagnosis the first time they presented to medical care and 50% of these participants had at least 3 health care visits before reaching the correct diagnosis. The majority (93%) recall information regarding their VTE diagnosis was provided by physicians or advanced practitioners, 65% reported this conversation was <10 minutes, and only 55% felt the diagnosis was explained to their satisfaction. (Table) A minority (16%) of patients received printed or electronic information at the time of diagnosis. Almost all (97%) participants were treated with anticoagulation, but only 48% recalled being provided specific information about the medication including risks and benefits. Only 24% of 563 respondents who menstruate recall discussing the impact of anticoagulation on menstruation with providers, and all recalled discussing this only after they developed anemia or changes in their menstrual flow. Of the 105 participants who were offered the opportunity to speak with a health care advocate, most (73%) accepted it; of those not offered an advocate,

88% reported that they would have accepted the opportunity. Only 53% of respondents reported access to providers for questions regarding their VTE diagnosis. Of 702 patients who were admitted to the hospital for VTE, 32% reported returning to health care, as their symptoms did not improve or worsened, and 30% of these patients were readmitted. Most admitted patients (89%) reported receiving some information about VTE at discharge, but the information received did not match the topics patients wanted. For example, patients most frequently wanted information about support groups (65%), mental health (65%), recurrence risk (55%) and prevention strategies (49%), but few received this information (2%, 2%, 17%, and 33%, respectively (Figure). Most patients were seen by hematologists following discharge (59%) or during hospitalization (35%). Among admitted patients, those who saw a hematologist either during or after admission were significantly more likely to receive information about their VTE (RR: 1.15, 95% CI: 1.06-1.24) and about anticoagulation (RR: 1.23, 95% CI: 1.04-1.45) at discharge compared to patients who did not see a hematologist.

Conclusion

In this first large-scale international survey to capture patient experiences and gaps in VTE care delivery, we identified several potential areas for improvement. Efforts to enhance patient education could improve the patient experience. Further research could explore if better education translates to improved medication adherence, management of bleeding, avoiding polypharmacy, and ultimately clinical outcomes. Professional societies and patient advocacy groups can partner to build resources to improve the quality of care and patient satisfaction for people with VTE.

Disclosures Chaturvedi: Sobi: Honoraria; Sanofi: Other: Advisory board participation; Takeda: Other: Advisory board participation; Sanofi Genzyme: Consultancy; Alexion: Consultancy, Other: Advisory board participation.

Figure: Desired and received domains of information for VTE patients at hospital discharge.

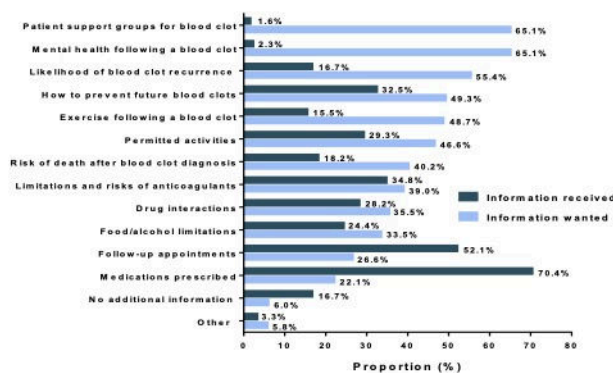


Table: Provider interactions regarding the venous thromboembolism diagnosis

Characteristic	All participants N=1,050
Source of information regarding first blood clot diagnosis*	
Doctor, physician assistant or nurse practitioner	976 (93.0)
Nurse	132 (12.6)
Friend or family member	63 (6.0)
Patient advocate	7 (0.7)
Social worker	3 (0.3)
Other	66 (6.3)
Time spent with provider when told about first blood clot diagnosis	
<5 minutes	252 (27.6)
5–<10 minutes	337 (37.0)
10–<20 minutes	159 (17.4)
20–<30 minutes	88 (9.6)
30–<60 minutes	32 (3.5)
≥60 minutes	44 (4.8)
Diagnosis of first blood clot explained to satisfaction	569 (55.1)
Offered printed or electronic information at time of first diagnosis	
Yes	164 (15.8)
No	683 (65.7)
Do not recall	193 (18.6)
Ability to access provider to ask questions regarding VTE	
Via phone call or electronic message	547 (52.8)
Only with an appointment	354 (34.2)
Not sure	81 (7.8)
Have not tried	54 (5.2)

Data are shown as n (%). *Respondents could select more than one response option, and thus totals may sum to more than 100%

Figure 1

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