Patients' Experiences with Venous Thromboembolism and Their Care Pathway – A Qualitative Study

Objective

To explore patients' experiences with their blood clot [venous thromboembolism, (VTE)] care pathway (diagnosis, treatment, and follow up) and their perspectives on gaps and strategies to improve health care processes.

Practice Points

1. Patients may delay seeking care due to uncertainty about the seriousness of their symptoms. Clear communication about red-flag symptoms associated with VTE through public awareness and clinician-patient discussions may encourage timely care seeking.
2. Patients benefit from structured follow-up, accessible educational resources, and involvement in decisions about VTE treatment and lifestyle changes. Clinicians should encourage patients to ask questions and provide accessible, patient-friendly resources about what to expect in terms of medication therapy and follow-up care.
3. Clinicians supported shared decision-making and prompt access to specialized care following diagnosis can help to alleviate patients' concerns and promote confidence in care.

Methods (PIs: S. Young; T. Lee, G. Carrillo-Balam, T. Rajanderan, K.O. Bonsu, T. Mackenzie)

1. Participants with lived/living experience with VTE were recruited to participate in an individual, semi-structured interview.
2. Participants were asked to discuss their experiences with their VTE care pathway, including diagnosis, treatment, and follow-up.
3. Participants were also asked to share their perspectives about gaps in care and strategies to improve health care processes for VTE care.

Results

- A total of 11 participants were interviewed between August to September 2024.
- Five themes were identified (Table 1).

Table 1. Themes and Illustrative Quotes

Theme 1 - Feeling Uncertain About When to Seek Care
"I was initially ignoring [the symptoms], and I had trouble breathing... walking upstairs and going up a hill where I worked was difficult, and I sort of ignored it until I had maybe a bit of swelling in my calf, and then went into emerge." (50-70 years, man)
Theme 2 - The Emergency Department: From Frustration to Clarity
"Like I said, I was turned away in emerge, which was unbelievable to even think that somebody would tell me that my condition wasn't urgent." (30-50 years, woman)
"I had an ultrasound done, and they said I did have deep vein thrombosis. So, I saw nurse practitioner, I think it was in emerg., and they put me on the medication, and they sent me to a specialist." (70+, woman)
Theme 3 - Prompt Access to a Specialized Thrombosis Service Promotes Better Experiences
"and throughout the day, basically, internal medicine came [to the ER] and introduced themselves and basically described what the CT scan found [...]. They gave me a prescription for blood thinners, and they also gave me a referral to the thrombosis clinic [...], and then shortly after, I was discharged to go back home." (30-50 years, man)
"[staff at the Thrombosis Service] gave me some pamphlets and things like that about what to expect and how to think about moving forward with blood clots and dealing with the blood thinners themselves. And I remember that being useful." (30-50 years, man)

Table 1 continued

Theme 4 - Gaps in Follow-Up Care
“Because I don't have a doctor, I would like [them (specialists)] to follow me a little bit closer. [...] I guess once you're on the medication, you're on it, but you know, you feel like kind of left out in the cold.” (70+, woman)
Theme 5 - The Importance of Shared Decision-Making and Self-Advocacy
“I wasn't given very much information. I felt like I was pulling teeth. I had to insist on seeing a doctor at this clinic [...]. I had to insist on seeing a nurse practitioner that was in the same clinic, just to ask questions: Can I exercise? What is it I can and can't do? What are my options for birth control? I had no idea [...] like, I said it was just more or less you have a DVT.” (30-50 years, woman)

Conclusions

1. The patients surveyed experienced uncertainty about the symptoms of VTE and delayed seeking care until symptoms worsened. They also experienced inconsistency in care and triage at the ER, which affected their overall care experience.

2. The patients surveyed, who were referred to specialized thrombosis services, reported improvements in understanding their condition as well as satisfaction with care.

3. Gaps in follow-up care were reported by many of the patients surveyed, especially those without a regular primary care provider.

4. Shared decision-making, self-advocacy, and prompt access to specialized care following diagnosis could help to alleviate the patients’ surveyed concerns and promoted confidence in care.