ASSESSMENT OF CURRENT CLINICAL PRACTICES IN INTEGRATING TREATMENT GUIDELINES FOR HEMOPHILIA

Neil Frick, MS, Susan Gitzinger, PharmD, MPA; Haleh Kadhoda, MS, Emily Van Laar, MS; Charlotte Warren, Michelle L. Witkop, DNP, FNP-BC

1 BACKGROUND

- The National Hemophilia Foundation (NHF)-McMaster’s guidelines emphasize the importance of integrated care in hemophilia, particularly in patients who develop inhibitors. Inhibitors develop in approximately 30% of patients with severe hemophilia A, making it critical that clinicians recognize all aspects of inhibitor management.
- This study’s objective was to assess clinicians’ current clinical practices related to hemophilia treatment guidelines to identify knowledge, competency, and practice gaps and barriers to optimal care of patients with inhibitors.

2 METHODS

- To assess current knowledge, the NHF and Medscape Education developed a continuing medical education (CME)-certified clinical practice assessment survey comprising 24 multiple-choice questions.
- The survey assessed knowledge, attitudes, and confidence with regard to newly developed hemophilia treatment guidelines emphasizing integrated care for patients with inhibitors, and the application of these guideline-based recommendations.
- The survey launched on the Medscape Education website on December 5, 2016, and participant responses were collected through January 26, 2017.
- Confidentiality was maintained and responses were de-identified and aggregated prior to analyses.
- Data were collected from the 42 hematologists and 128 pediatricians who answered all questions in the survey during the study period.

Source of Support

This CME-certified activity was supported by an independent educational grant from Biothera.

Notes

For more information, contact Susan Gitzinger, PharmD, MPA, Associate Director of Clinical Strategy, Medscape, LLC, at sightinger@medscape.net.

3 RESULTS

DEMOGRAPHICS

- Pediatrists (n=128) Hematologists (n=42)
- Male: Female 77%: 23%
- Age: 66% 34%
- Race: White: Asian: Other 91%: 7%: 2%
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- Practice type: 43% Academic: 37% Community: 20% Teaching
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SUMMARY OF RESULTS (n=170 physicians)

Case: SL is a 27-year-old black woman who is a known carrier of severe hemophilia A. Her family history includes a grandfather and 2 brothers with severe hemophilia A. Her grandfather died at age 55 years of a head bleed. One brother was diagnosed with an inhibitor and has multiple hemarthropathies, as well as hepatitis C virus and human immunodeficiency virus (HIV) secondary to hemophilia. She delivers a baby boy, AJ, who has severe hemophilia A. Due to concerns from the family, he is not started on prophylaxis. At 9 months he develops a scrotal bleed from bouncing on his heels.

The hemophilia treatment center (HTC) hematologist discusses with the family the SIPPET results as well as the family’s continued concerns over any type of prophylaxis. The mother remains strongly against the use of any treatment guidelines to identify potential inhibitors and the development of inhibitors during prophylaxis. AJ is at risk for a target joint, and during a re-evaluation at the HTC, an inhibitor level is drawn. The inhibitor test comes back at 2 BU/mL. AJ’s parents are still resistant to using factor, and because they have heard that watchful waiting regarding inhibitors is an option, they want to consider this.

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4 CONCLUSIONS

- The need for further education was seen in:
  - best practices in integrated care using evidence-based guidelines and recommendations for PWH
  - current and emerging clinical data guiding acute and prophylactic management
  - risk factors for the development of inhibitors during prophylaxis
  - screening and management of inhibitor formation, including ITI

Further educational efforts tailored to address these gaps are warranted.

At 3 months, AJ develops an ankle bleed, and his parents treat the bleed with rFVIII and make the trip to the distant HTC. One month after their HTC visit, AJ has another bleed in the same ankle. This bleed is worse and takes 4 infusions of rFVIII to resolve.

The family agrees to return in 2 weeks for another inhibitor test, or sooner if there are any signs of bleeding or worsening of symptoms. They agree to review all the information on inhibitor levels and further discussion during the next inhibitor test.

In one week, AJ experiences another ankle bleed that does not respond to rFVIII. He is given rFVIIa with total bleed resolution. The family returns immediately to the HTC. His inhibitor level is reported at 7 BU/mL.

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AJ’s parents agree to start ITI with rFVIII. The HTC agrees to follow AJ weekly via telemedicine through their local primary care provider, and the parents agree to come to the HTC monthly and as needed to resolve any issues.

DATA FROM THIS EDUCATIONAL RESEARCH YIELD IMPORTANT INSIGHTS INTO THE CLINICAL PRACTICE GAPS RELATED TO THE MANAGEMENT OF HEMOPHILIA IN PATIENTS WITH INHIBITORS.

- Only 12% of hematologists and 4% of pediatricians reported being fully confident in managing patients with inhibitors.
- This low self-reported confidence among both hematologists and pediatricians was substantially by responses to specific questions on inhibitors (Figures 2-5) and ITI (Figures 6-9).

- The need for further education was seen in:
  - best practices in integrative care using evidence-based guidelines and recommendations for PWH
  - current and emerging clinical data guiding acute and prophylactic management
  - risk factors for the development of inhibitors during prophylaxis
  - screening and management of inhibitor formation, including ITI

Further educational efforts tailored to address these gaps are warranted.