Addressing Clinical Management Challenges in the Treatment of Rare, Non-Malignant Hematologic Disorders through Educational Interventions

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Background: Despite continuous progress, the management of rare, non-malignant hematologic disorders is still fraught with challenges, including delays in diagnosis, a paucity of targeted therapies and treatment guidelines, suboptimal clinical outcomes, limited clinical trials, and access to information and support. To improve competence in navigating some of these challenges and incorporate patient perspectives in treatment selection, educational initiatives focusing on three rare hematologic disorders were designed in collaboration with the National Organization for Rare Disorders (NORD).

Methods: As part of the Second Annual Rare Cancers and Blood Disorders series, three CME activities on AL amyloidosis (60 minutes), paroxysmal nocturnal hemoglobinuria (PNH) (30 minutes), and cold agglutinin disease (CAD) (30 minutes) were broadcast on OMedLive in April 2022 and remain on-demand through April 2023. A 90-minute complementary PNH program was broadcast live-online on OMedLive in May 2022 and remains on-demand through May 2023. All programs were led by expert hematologists in each subject area. Live programs featured an interactive panel of physicians and live Q&A. Additionally, the 90-minute PNH program featured patient vignettes to elevate clinicians' awareness of patient experiences. For each program, knowledge and competence questions were administered pre-, immediate post-, and 2 months post-activity. Provider reported barriers and challenges managing patients with rare blood disorders, and intent to modify treatment plans post-program were also assessed.

Results: As of July 13, 2022, 297 clinicians have participated in these activities, 92% of whom are physicians, advanced practitioners (NP/PA), and nurses. Sixty percent of clinicians see between 1 and 10 patients each week with any of these rare disorders (AL, CAD, or PNH). CME questions administered across all programs revealed low baseline knowledge and competence as shown in Table 1. Following the educational activities,improvements ranging from 19% to 59% were seen for pre/post paired responses across all CME questions. Limited knowledge about clinical presentation and differential diagnoses were noted as the top barriers to diagnosis of all three disorders. The greatest challenges in managing patients were identified as "time to diagnosis" for AL amyloidosis and PNH and "lack of novel therapies" for CAD; and most clinicians (41%) perceived"adhering to treatment schedules" as the greatest treatment related challenge faced by patients. Ninety-four percent of clinicians were motivated to modify treatment plans according to their patients' treatment response. Qualitative and 2-month follow-up data on clinical practice change and impact on patient outcomes will be shared.

Conclusions: Online education on rare, non-malignant hematologic disorders improves clinician knowledge of evidence-based management strategies, uncovers persistent gaps in barriers to care, and stimulates clinical practice change that incorporates patient perspectives, leading to better patient outcomes.

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