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POSTER ABSTRACTS

906. OUTCOMES RESEARCH-MYELOID MALIGNANCIES

Patient, Caregiver, and Physician Perspectives on Communication in Diagnosing and Treating Higher-Risk Myelodysplastic Syndromes: A Qualitative Study

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Background: Although novel disease-modifying treatments for higher-risk myelodysplastic syndromes (HR-MDS) are emerging, current treatment options for patients with HR-MDS are limited. This study sought to explore patients', caregivers', and hematology and oncology providers' perspectives on and experiences with patient-provider communication and its role in the diagnostic and treatment process in patients with HR-MDS.

Methods: Qualitative, semi-structured interviews with patients with HR-MDS, caregivers to patients with HR-MDS, and board-certified oncologists and/or hematologists managing patients with HR-MDS in the United States. Participants were recruited through the MDS Foundation constituency and through a survey vendor partner. Thematic analysis was used to identify key factors associated with the role and impact of communication between patients, caregivers, and providers.

Results: Eight patients (mean age = 68.1 years, 50% male, 88% White, 88% suburban), 6 caregivers (mean age = 64.3 years, 83% female, 100% White, 83% suburban), and 18 providers (mean age = 52.6 years, 78% male, 67% >10 years of clinical practice, 50% urban, 61% treated >10 patients with HR-MDS in past year) participated in the study. During the diagnostic workup phase, patients and caregivers described communication as limited and stated that they had not been provided with adequate information or educational resources about HR-MDS that could inform decision-making. They reported a significant lack of knowledge about the condition, their prognosis, and available treatment options. Lack of provider communication and inadequate education about HR-MDS was also viewed as a treatment barrier itself, in addition to treatment access, logistical barriers, and lack of support by a caregiver. Some patients and caregivers felt that without adequate knowledge about HR-MDS, they could not ask appropriate questions, while others reported being content with "not knowing" and relying solely on provider recommendations. Having additional education around HR-MDS was viewed as allowing patients to better articulate their preferences during treatment decision-making.

Conversely, providers in the study reported consistently accounting for patient preferences when making treatment recommendations. Providers reported tailoring their communication approach to each patient and seeking equipoise when needing to adequately explain the seriousness of the condition without instilling panic or diminishing hope. However, they also noted variability in willingness to engage in decision-making among their patients with HR-MDS, attributing active participation mediated by patient age, education and health literacy level, and cultural background. Providers described struggling with making treatment recommendations (due to a current lack of effective treatment options) for their patients with HR-MDS as the most significant treatment barrier, further compounded by challenges in explaining the nuances of HR-MDS treatment to patients.

Strong and continuous communication between the patient, caregiver, and clinical care team, along with the availability of resources to facilitate timely communication and education, such as telehealth options and patient portals, were viewed as facilitators by patients and caregivers. Providers noted that nurse navigators, social workers, patient assistance programs, patient advocates, and educational materials were key facilitators in improving patient-provider decision-making and patient outcomes.

Conclusion: While strong patient-provider communication is desired by patients, caregivers, and providers, and can be a catalyst for educated treatment preferences, uncertainty exists around how to best involve patients in HR-MDS treatment decisions. When patients present with lower health literacy, lack of desire to be involved in decision-making, or a preference for a provider-guided decision, providers struggle to find the right balance of education and information provision. As novel therapies emerge and treatment options expand for patients with HR-MDS, it is imperative to further develop and evaluate

educational materials for patients with HR-MDS delivered via novel technological methods, facilitate the use of telehealth and patient portals, and ensure patient navigation of resources to support patient-provider communication.

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