

# Discerning Insights and Perspectives on Treatment for Myelodysplastic Syndrome: Impact of Aligned Patient and Provider Education



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**Background:** Current therapies for myelodysplastic syndrome (MDS), such as allogeneic bone-marrow transplantation, erythropoiesis stimulating agents, lenalidomide, and hypomethylating agents, are not adequate for many patients. Recently approved and emerging investigational therapies with different mechanisms of action are providing additional treatment options for patients with low-, intermediate-, or high-risk MDS. Clinical trials offer treatment options for those patients with newly diagnosed or untreated MDS, which remains an unmet need in the treatment paradigm. The substantial accumulation of new data has created knowledge and practice gaps among clinicians that can impact management. To meet these needs, a patient-provider education initiative was developed to bring awareness to new therapies, including diversifying clinical trials, and assist clinicians in integrating advances in the field.

**Methods:** In collaboration with The Aplastic Anemia & MDS International Foundation (AAMDS) two, 1-hour online video-based programs were hosted on CancerCoachLive.com and OMedLive.com in 2021 for patients/families and HCPs, respectively. In 2022, an HCP activity which included the 'patient voice' was hosted on OMedLive.com and remains on-demand through June 2023. The programs were interactive featuring an expert physician panel, patient interviews, polling, and question/answer sessions. Knowledge and competence questions were administered pre-, immediate post-, and 2 months post-activity. Repeated knowledge and competence questions were tested for statistical significance using Chi-Square.

**Results:** As of August 2, the 1,758 HCPs attended the HCP activities with 15,309 patients/caregivers engaging in the patient/caregiver activity. Of the HCPs in attendance, 75% sought CME certificates for participation, and 83% practiced in the community setting. Of the patients/caregivers participating, 59% were female, 89% were older than 55 years of age, and 91% identified as White, non-Hispanic. Behavioral impact was assessed at 2 months following the

program with write-in responses (>90) from patients and HCPs of what behaviors changed or were implemented as a result of participation in the education. Thematic analyses of these responses reveal greatest impact on treatment practices for HCPs and engagement in shared decision-making for patients/caregivers. Clinician gaps in care were also revealed, including 67% of participants being unable to identify which classification system categorized MDS with greater weights on cytogenetic abnormalities and severity of cytopenias. Analyzing the baseline practice pattern data showed that 42% of HCPs would offer allogeneic stem cell transplant for patients with low-risk MDS; 73% were unaware of novel agents and clinical trials results for intermediate-, high-, and very-high-risk MDS; and 60% of HCPs unable to discern which patient profiles would benefit the most with newer therapies. Initial outcomes from the 2022 program highlight barriers to patient enrollment and HCP recommendation of clinical trials for newly diagnosed MDS.

**Conclusions:** The multi-year initiative provided insights into both HCP and patient persistent questions and behavioral changes regarding MDS management. Patients/caregivers reported behavioral improvements in engagement with their treatment teams while providers reported an impact on clinical practice. Additional gaps revealed provide an opportunity for continued education across the risk stratification of MDS.

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