Clinical Insights Alliance

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Navigating Complexity in Myelofibrosis: Insights From a Unique Educational Initiative

Executive Summary

The management of myelofibrosis (MF) continues to evolve as clinicians balance disease risk, treatment landscape, symptom burden, quality-of-life considerations, and treatment-related toxicities. To better understand current approaches to MF management among community oncology clinicians, a survey-based needs assessment was conducted. Findings informed the development of Project Journey, a multifaceted educational initiative that included expert-guided online resources, case-based learning, patient perspectives, and a three-part webinar series.

More than 2,000 users engaged with Project Journey resources. Across surveys, educational content, webinar polling, and audience discussion, several recurring themes emerged, including treatment timing, symptom assessment, quality-of-life considerations, management of anemia, and shared decision-making.

Key Findings

- Symptom control and spleen volume reduction were commonly identified treatment goals.
- Clinicians reported varying thresholds for treatment initiation based on splenomegaly.
- Responses were divided between treatment and observation in intermediate-1 risk disease.
- Most clinicians would not delay treatment solely because of anemia, although more complex anemia scenarios produced greater variability in responses.

Background

Although MF is an uncommon hematologic malignancy, it presents significant management challenges for clinicians across practice settings. Patients may experience splenomegaly, constitutional symptoms, progressive cytopenias, impaired quality of life, and risk of disease progression. As treatment options continue to expand, clinical decision-making increasingly extends beyond prognostic risk assessment alone.

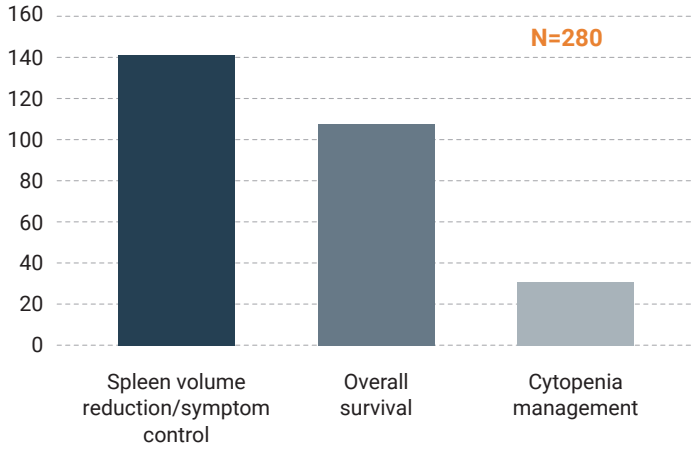
To better understand current approaches to MF management and identify areas where additional education may be valuable, a survey-based needs assessment was conducted among community oncology clinicians.

Day-to-day treatment decisions are often driven by symptom burden and splenomegaly.

Community Oncology Needs Assessment

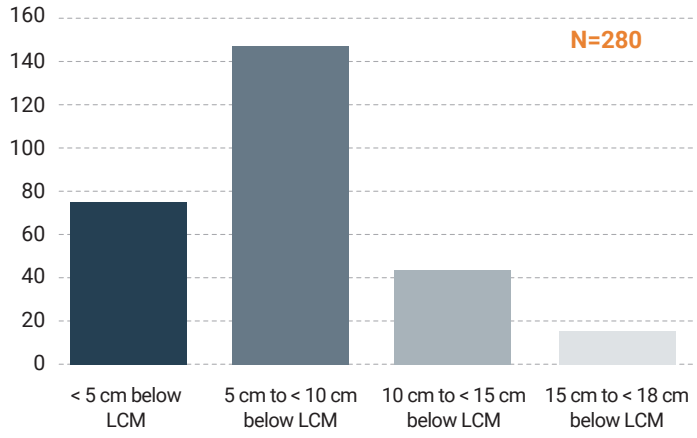
Approximately 280 clinicians participated in the survey. Questions explored treatment goals, treatment initiation thresholds, management of intermediate-1 risk disease, and treatment considerations in the setting of anemia.

What is your primary treatment goal when treating your patients with MF?



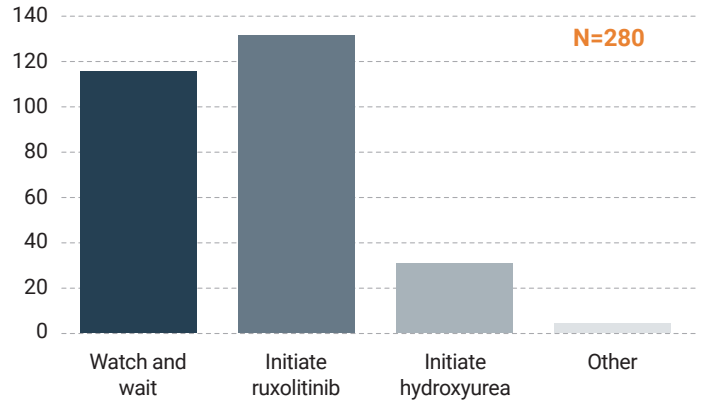
Treatment Goals: Respondents most frequently identified symptom control and spleen volume reduction as primary treatment objectives. Nearly half of survey participants selected this option as their primary treatment goal, suggesting that clinicians remain highly focused on managing the immediate clinical burden of disease. Although overall survival was also frequently selected, the results indicate that day-to-day treatment decisions are often driven by symptom burden and splenomegaly, which represent some of the most tangible and measurable manifestations of MF.

At what baseline spleen size do you typically consider initiating treatment for a patient with MF who presents with mild to moderate symptoms?



Treatment Initiation: Survey findings demonstrated notable variation in thresholds for initiating therapy based on splenomegaly. Most respondents reported initiating treatment when spleen enlargement reached 5–10 cm below the left costal margin (LCM), while approximately one-quarter indicated they would consider treatment at smaller spleen sizes. These findings suggest that many clinicians consider both symptom burden and spleen size when determining when intervention is appropriate, reflecting an increasingly individualized approach to treatment timing.

You just diagnosed your patient with intermediate-1 primary MF. The patient has a spleen that is palpable 5 cm below the LCM; has mild disease-related symptoms; and has no anemia and no thrombocytopenia. What would you typically do next?



Intermediate-1 Risk Disease: In a clinical vignette involving a patient with intermediate-1 primary MF, mild symptoms, and no cytopenias, respondents were divided between initiating ruxolitinib and continued observation. While a slight majority favored treatment initiation, the substantial proportion selecting watchful waiting highlights ongoing variation in clinical practice. These findings suggest that treatment timing in lower-risk disease remains an area where clinician judgment, patient factors, and institutional practice patterns continue to influence decision-making.

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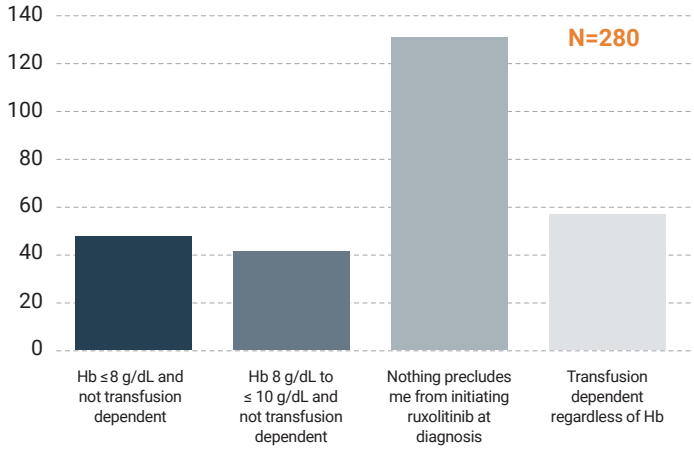
For your appropriate patients with MF and anemia, which of the following would preclude you from initiating ruxolitinib at diagnosis?



Anemia Management: Most clinicians indicated that baseline anemia alone would not necessarily preclude treatment initiation. Nearly half of respondents reported that no degree of baseline anemia would prevent them from initiating ruxolitinib, suggesting comfort with managing cytopenias alongside therapy. However, transfusion dependence remained an important concern for a subset of clinicians, highlighting the complexity of treatment decisions in patients with concurrent anemia.

Transfusion dependence remained an important concern for a subset of clinicians.

From Needs Assessment to Educational Design

Themes identified through the survey informed the development of Project Journey. Areas of practice variation became focal points for educational content, case studies, patient stories, and expert-led discussions.

Examples included:
- Treatment timing → "Watch-and-Wait Dilemma" case study
- Intermediate-1 risk disease → "Early Intervention" case study
- Anemia management → "Anemia Barrier—or Is It?" case study
- Symptom burden and quality of life → Patient-focused educational content and webinar programming

Educational Response: Project Journey

Project Journey was developed as a centralized educational resource designed to support clinicians caring for patients with MF across the continuum of care.

The initiative ultimately included more than 25 educational assets spanning disease biology, diagnosis, treatment selection, symptom assessment, patient management, expert perspectives, patient stories, and case-based learning.

Contributing faculty included recognized experts in MF and myeloproliferative neoplasms. The educational approach emphasized practical guidance applicable to real-world clinical decision-making.

Program Reach:
- Project Journey: 2,023 users, 2,486 sessions, 2,993 page views
- Companion survey-analysis resource: 933 users, 1,041 sessions, 1,341 page views

Extending the Conversation Through Live Education

To complement the online educational platform, a three-part webinar series, Mastering Myelofibrosis: Navigating Complexity Across the Care Continuum, was presented by Abdulraheem Yacoub, MD, of the University of Kansas Medical Center.

Webinar 1: From Observation to Intervention: Clinical Decision-Making in Myelofibrosis (81 attendees)
Webinar 2: Beyond Blood Counts: Addressing Quality of Life in Myelofibrosis (88 attendees)
Webinar 3: Management of Myelofibrosis and the Challenges of Cytopenias (86 attendees)

Audience polling and discussion reinforced many of the themes identified in the original needs assessment.

What Clinicians Told Us: Overall Themes

While the survey provided an initial snapshot of clinician perspectives on MF management, additional insights emerged through educational engagement, webinar polling, audience discussion, and participant questions. Collectively, these activities offered a broader view of the challenges clinicians encounter in routine practice and the areas where they continue to seek practical guidance.

Notably, many of the themes identified in the original needs assessment resurfaced throughout the educational initiative. Questions regarding treatment timing, symptom burden, quality-of-life considerations, and management of anemia and cytopenias appeared consistently across survey responses, webinar discussions, and audience interactions. The recurrence of these themes suggests that clinicians continue to navigate complex treatment decisions throughout the MF care continuum and value opportunities for expert guidance and peer learning.

Differences in treatment decisions may begin with differences in risk assessment itself.

Theme 1: Treatment Timing Remains a Challenge

Survey findings, webinar polling, and discussion highlighted ongoing variability in treatment initiation decisions, particularly among patients with lower-risk disease. Webinar polling reinforced this variability. Although most participants expressed support for earlier intervention in selected patients, a minority continued to favor observation for intermediate-1 disease. Polling also revealed substantial variation in the prognostic scoring systems clinicians use in routine practice, suggesting that differences in treatment decisions may begin with differences in risk assessment itself.

Symptom severity often serves as a stronger trigger for treatment initiation than spleen size alone.

Theme 2: Symptoms Matter

Symptom burden emerged repeatedly as a central factor influencing treatment decisions. Survey respondents frequently identified symptom control as a primary treatment goal, and webinar polling suggested that symptom severity often serves as a stronger trigger for treatment initiation than spleen size alone. Polling also revealed variability in the use of formal symptom assessment tools, indicating opportunities for more consistent symptom evaluation in routine practice. Together, these findings reinforce the importance of systematically assessing symptom burden throughout the disease course.

These discussions reinforced the importance of incorporating quality-of-life considerations into routine assessment and ongoing management.

Theme 3: Quality of Life Extends Beyond Blood Counts

Clinicians demonstrated strong interest in understanding the broader impact of MF on patient functioning and well-being.

Discussions throughout the educational initiative emphasized that symptom burden extends beyond measurable clinical parameters and can significantly affect daily activities, employment, social engagement, and overall quality of life. Webinar participants frequently explored how symptoms such as fatigue, early satiety, and constitutional symptoms influence patient experiences and treatment decisions. These discussions reinforced the importance of incorporating quality-of-life considerations into routine assessment and ongoing management.

Anemia management remains an area where clinicians continue to navigate multiple reasonable treatment options.

Theme 4: Anemia Remains a Persistent Concern

Questions regarding anemia management appeared consistently across survey findings, educational content, and webinar discussions. While clinicians generally expressed confidence initiating therapy in the setting of baseline anemia, webinar polling demonstrated greater variability in approaches to treatment-emergent anemia. Participants reported multiple management strategies—including erythropoiesis-stimulating agents, luspatercept, and dose modification—with no single approach clearly preferred. These findings suggest that anemia management remains an area where clinicians continue to navigate multiple reasonable treatment options.

Educational discussions highlighted the importance of aligning treatment decisions with patient goals and preferences through shared decision-making.

Theme 5: Patients and Clinicians May Prioritize Different Outcomes

Educational discussions highlighted the importance of aligning treatment decisions with patient goals and preferences through shared decision-making. While clinicians often focus on clinical measures such as spleen reduction, symptom improvement, and disease control, patients may place equal or greater emphasis on maintaining daily function, preserving independence, minimizing treatment burden, and achieving long-term outcomes. The inclusion of patient perspectives throughout the initiative reinforced the value of understanding how individual patients define treatment success and underscored the importance of ongoing communication between patients and their care teams.

Future Directions

The consistency of themes observed throughout this initiative suggests continued opportunities for education in treatment timing, symptom assessment, quality-of-life evaluation, and management of cytopenias. Future educational efforts may further explore patient perspectives, emerging therapies, and evolving approaches to individualized care.

Conclusion

Although MF remains an uncommon malignancy, the complexity of treatment decision-making continues to present challenges for clinicians across practice settings. Findings from this educational initiative suggest that questions surrounding treatment timing, symptom burden, quality of life, and management

The complexity of treatment decision-making continues to present challenges for clinicians across practice settings.

of anemia remain highly relevant in practice. The variability observed across survey responses and webinar polling further suggests that clinicians often face multiple reasonable management pathways when caring for patients with MF, particularly in areas where evidence continues to evolve.

By combining needs assessment, expert-guided education, case-based learning, patient perspectives, and live discussion, Project Journey provided multiple opportunities for clinicians to engage with these challenges and explore practical approaches to patient care. The consistency of themes observed across survey responses, educational engagement, webinar participation, and audience discussion underscores the ongoing value of educational initiatives focused on real-world clinical decision-making in myelofibrosis. ■

Scan to explore the complete MF resource

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