

Strategies to Improve Care in Myelofibrosis

CHECKLIST TOOL

Risk stratification in myelofibrosis patients helps determine treatment trajectory and predicts long-term survival. This helps providers decide if a stem cell transplant is necessary and if so, when.

The recommended scoring system is the Mutation-Enhanced International Prognostic Score System (MIPSS70+ V2.0), which takes into consideration and expands upon not only the factors in the Dynamic International Prognostic Scoring System (DIPSS), but also high-risk mutations and karyotype. The integration of data (ie, clinical, cytogenetic, and mutation) improves risk stratification for patients with myelofibrosis. With these results, the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) can be utilized to assist in making treatment decisions.



An online calculator for MIPSS70+ V2.0 can be found at: mipss70score.it

MPN-10: Symptom Scoring

As practitioners know, most patients with myelofibrosis present symptoms at diagnosis. MPN-10 is a tool that is designed to help assess myelofibrosis patients and track the severity of their symptoms. This can be a helpful tool to track from one visit to the next. The tool provides a visual indication of worsening or improving symptoms, assisting providers as they continue to treat the patient with the current therapy or pursue alternative treatment.



An online MPN10 calculator can be found at: acc-cancer.org/MPN-Assessment

Myeloproliferative Neoplasm Symptom Assessment Form (MPN-SAF)

Circle the number that describes, during the past week, how much difficulty you have had with each of the following symptoms:

Filling up quickly when you eat (Early Satiety)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Abdominal pain	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Abdominal discomfort	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Inactivity	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Problems with headaches	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Problems with concentration	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Dizziness/Vertigo/Lightheadedness	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Numbness/Tingling (in my hands and feet)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Difficulty sleeping	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Problems with sexual desire or Function	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
What is your overall quality of life?	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)

Figure 1. MPN10 Symptom Tracker. Track the severity of your myelofibrosis symptoms.

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are recognized as the standard for clinical direction and policy in cancer care. They are formulated using evidence-based recommendations with the guidance of a panel of physicians, nurses, pharmacists, and scientists.

They provide up-to-date and easy to follow diagrams on what treatments are recommended based on diagnosis and risk stratification.

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Register for a free account to access the NCCN Guidelines® for Myeloproliferative Neoplasms.

www.nccn.org

FINANCIAL AND PSYCHOSOCIAL CONSIDERATIONS

Finances

Prescribing through EHRs, known as e-prescribing, reduces prescribing errors, increases efficiency, and helps to reduce costs. But it is what occurs after that determines whether a patient will be able to receive appropriate treatment. Often medications require prior authorization approval and may require an appeal, depending on the insurance policy. Even if the medication is approved, it can be out of reach for patients who may not be able to afford co-pays. There are a variety of financial assistance programs available. The

programs may include aid from pharmaceutical companies with co-pay cards, drug assistance programs when patients are uninsured or underinsured, or through local or national non-profit charitable organizations.

Being knowledgeable about which pharmaceutical companies have assistance programs as well as available foundations for patients, can make a world of difference in the initiation and continuation of therapy.

Psychosocial Considerations

Myelofibrosis is a progressive and chronic disease that can result in worsening symptoms, affect quality of life, and cause mental distress. Utilizing a screening tool at each visit to assess financial and social burdens can help providers place consultations as needed, whether that is to the financial department, social worker, psychiatrists/psychologists, or supportive care (eg, physical therapy, occupational therapy, pain management, fatigue clinic, etc.) due to deteriorating symptoms. Given that this disease primarily affects the elderly, it may be beneficial to consider including a family member or friend when discussing diagnosis, treatment, etc., if the patient is willing. This allows for an integrative conversation that can help the patient feel more at ease with a strong support system.

Aside from treatment of the disease, some patients struggle with transportation to office appointments and treatments. Below are some resources that can support cancer care teams as they assist patients with their needs.

ACCC Patient Assistance and Reimbursement Guide:

- [Patient Assistance & Reimbursement Guide](#): Provides up-to-date information about anti-cancer medication assistance and reimbursement programs.

Foundations/Organizations:

- [Good Days Foundation](#): Provides resources for life-extending treatments.
- [CancerCare](#): Offers counseling, support groups, and financial assistance.

- [Patient Access Network Foundation \(PANF\)](#): Assists patients with out-of-pocket costs associated with medication and treatment.
- [Leukemia/Lymphoma Society \(LLS\) Co-Pay Assistance Program](#): Helps patients cover co-pays for medical expenses and insurance premiums.
- [Mercy Medical Angels](#): Provides free transportation nationwide to/from medical care for qualifying individuals and their families.
- [Patient Airlift Services \(PALS\)](#): Nonprofit that arranges free flights for patients requiring medical diagnosis, treatment, or follow-up and cannot afford or are unable to fly commercially.
- [MPN Research Foundation](#): A nonprofit research foundation in pursuit of original myeloproliferative neoplasms (MPN) treatments.
- [MPN Advocacy & Education International](#): Provides care teams with educational materials on myeloproliferative neoplasms (MPN).
- [Patient Empowerment Network](#): Offers patients and care teams free educational resources

References

1. Scherber R, Dueck AC, Johansson P, et al. The Myeloproliferative Neoplasm Symptom Assessment Form (MPN-SAF): International prospective validation and reliability trial in 402 patients. *Blood* (2011) 118 (2): 401–408. Accessed August 25, 2023. <https://ashpublications.org/blood/article/118/2/401/28465/The-Myeloproliferative-Neoplasm-Symptom-Assessment>.

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The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. For more information, visit acc-cancer.org.

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