



A patient counseling resource to support

Proactive identification of splenomegaly and symptoms associated with **myelofibrosis**

Myelofibrosis (MF) is a serious hematologic malignancy characterized by splenomegaly and a substantial symptom burden that can have a profound impact on patients' lives.¹⁻³

Help your patients with MF understand how splenomegaly and symptoms may affect them, so they can take an active role in their care.

SPLENOMEGALY IS AN IMPORTANT CLINICAL INDICATOR IN MF⁴

Spleen Size Should Be Assessed at Diagnosis in Patients With MF⁵

Prevalence of Splenomegaly at Diagnosis

~90%

of patients with MF had palpable splenomegaly at diagnosis¹

Based on a study of 1054 patients with primary MF; data were available for 768 patients, 681 of whom had palpable splenomegaly¹

Burden of Splenomegaly in MF

- Splenomegaly may be associated with pain, early satiety, abdominal discomfort, and other symptoms^{6,7}

- New or increasing splenomegaly is considered to be a marker of disease progression in MF⁸

A palpable spleen of

≥5 cm

below the left costal margin
constitutes progressive disease^{8a}

^a According to the International Working Group-Myeloproliferative Neoplasms Research and Treatment and European LeukemiaNet response criteria. Progressive disease assignment for splenomegaly requires confirmation by CT or MRI showing a ≥25% increase in spleen volume from baseline. Baseline values for both physical examination and imaging studies refer to pretreatment baseline and not to post-treatment measurements.⁸

Image is for illustrative purposes only

Assessing the Spleen in MF

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Myeloproliferative Neoplasms

recommend palpating the spleen at diagnosis in all patients⁵

“ Since most patients with MF have splenomegaly, if your physical exam does not clearly rule out splenomegaly, consider radiographic imaging to have an accurate assessment. **”**

— **Ruben A. Mesa, MD, FACP**

Mays Cancer Center at UT Health San Antonio MD Anderson

Assess for the Presence and Severity of MF-Related Symptoms

Prevalence of Symptoms at Diagnosis

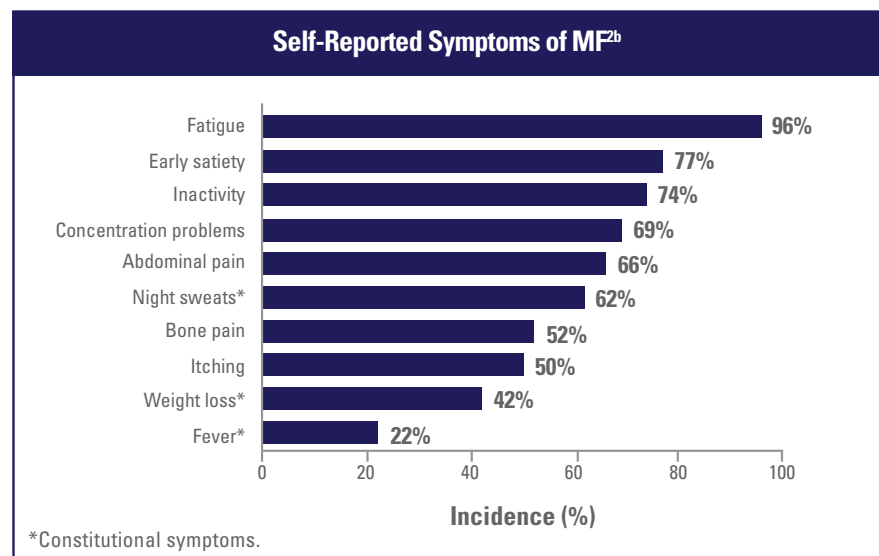
95%

of patients reported **2+** MF-related symptoms at diagnosis
based on a retrospective chart review of 180 patients with MF^{9a}

^a Retrospective observational study of symptom burden and splenomegaly in 180 patients with MF; data were collected at the time of diagnosis of MF in patients without splenomegaly (n=78) or at the time of detection of splenomegaly in patients with splenomegaly (n=102). In patients with splenomegaly, splenomegaly was most often recorded at the time of diagnosis (median time from MF diagnosis to reported splenomegaly was 1 day).⁹

Burden of Symptoms in MF

- In the MPN Landmark survey, many patients with MF (49%) reported experiencing symptoms at least 1 year before diagnosis^{3a}
- Symptoms may be present even in patients with earlier disease^{3,9}



Patient-reported results from the MPN Landmark Survey³:

The majority of patients with MF reported that symptoms impact quality of life



81% reported that their symptoms reduced their quality of life^c



79% reported that MF interfered with family or social life^d

^a The MPN Landmark Survey, funded by Incyte Corporation, was a web-based questionnaire composed of 65 multiple-choice questions intended to help evaluate the patient's perception of disease burden in the MPN disease setting. A total of 813 patients in the United States with a previous diagnosis of polycythemia vera (n = 380), MF (n = 207), or essential thrombocythemia (n = 226) participated.³

^b This prospective study included a total of 1433 patients with MPNs (n = 293 with MF), who were queried on the 10 symptoms from the MPN-SAF TSS/MPN-10. The MPN-SAF TSS is validated for serial tracking of the most pertinent MPN-related symptoms—fatigue, concentration problems, early satiety, inactivity, night sweats, itching, bone pain, abdominal discomfort, weight loss, and fever—scored on a scale of 0 (absent/as good as it can be) to 10 (worst imaginable/as bad as it can be), for a total possible score of 100.²

^c Patients reported whether they strongly agreed, somewhat agreed, somewhat disagreed, or strongly disagreed with the following statement: PV symptoms reduce my quality of life.³

^d Patients reported impact on their activities of daily living on a scale that ranged from 1 (not at all) to 5 (a great deal). The patient was included as having interference with daily activities if they had ever experienced the issue and reported a score >1.³

Assessing Symptoms in MF

NCCN Guidelines[®]

recommend assessing symptoms (in a provider's office) at baseline and monitoring symptom status (stable, improved, or worsening) during the course of treatment.⁵

Changes in symptom status could be a sign of disease progression.

Evaluate Symptoms at Diagnosis and on a Regular Basis in Your Patients With MF

Enhance your conversations about symptoms with contextual questions

- Patients with MF may not recognize that their symptoms may be related to their cancer. Open-ended questions may be able to encourage your patients to express their symptom burden and severity based on what they experience in daily life

SPLENOMEGALY-RELATED SYMPTOMS

Early Satiety



- Do you feel full quickly after meals?
- Have you lost weight in the past 6 months, without intentionally trying to?

Abdominal Discomfort



- Do you have abdominal discomfort, particularly after eating?
- Do you experience any dull or sharp pains in your abdomen?
- Do you experience abdominal discomfort at any other time?
- Do you find it difficult to get into a comfortable position for sleeping?

Caregivers can be a valuable source of information. They often see the impact of MF-related symptoms on a patient's quality of life or daily activity.

CYTOKINE-RELATED AND OTHER SYMPTOMS^a

Fatigue and Inactivity



- Do you feel tired even after getting enough sleep, or do you tire quickly during the day?
- How many normal waking hours each day do you spend in a bed or chair?
- Are there activities that you were able to do 3 months ago that you struggle with now?

Concentration Problems



- How often have you felt a “brain fog”—memory lapses (such as problems remembering words or dates), inability to pay attention for long periods of time, or generally having problems concentrating that interfere with your ability to work (or other relevant activity)?
- How has this impacted your life? Have you had to change school plans, work, or how you function at home?

Day or Night Sweats



- Do you experience sweating, particularly at night or in the evenings?
- Does this require you to change your sheets or clothing?
- Does this wake you up or impact your sleep? How often has it occurred in the past month?

Bone Pain



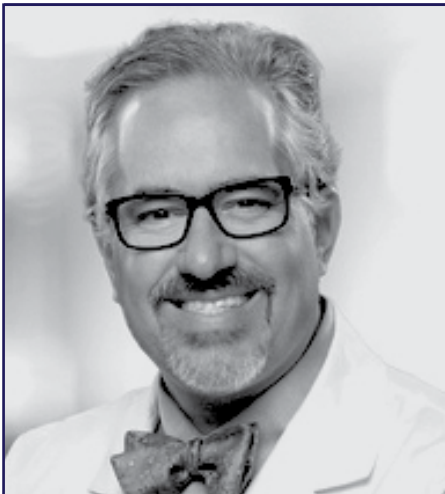
- Have you felt a dull achiness throughout your body (not just focused in one area or joint)?
- Do you feel achiness at night in bed or when sitting idle during the day?
- Does bone pain ever cause you to change or limit your activities?

Itching



- Have you experienced an increase in itchiness?
- When you shower, do you ever feel itchy afterwards? How often?
- Have you found yourself taking shorter/fewer/cooler showers to try to avoid itchiness?

^a Weight loss and fever are cytokine-related symptoms that have also been observed in patients with MF and should be considered in a comprehensive symptom evaluation.



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“ Early identification of splenomegaly in patients with MF is critical, as it is an important clinical sign. An enlarged spleen can directly cause symptoms (pain, discomfort, early satiety). Since most patients with MF have splenomegaly, if your physical exam does not clearly rule out splenomegaly, consider radiographic imaging to have an accurate assessment.

In MF, symptoms can develop gradually over time and thus may not be fully appreciated by patients as they have sometimes compensated for them. Some symptoms, such as reduced energy levels, night sweats, and bone pain, may be dismissed by patients as not related to their disease. Educating patients on MF-related symptoms will empower patients to take an active role in managing their disease. ”

The following page is intended to help your patients identify MF-related symptoms. You may use this symptom assessment resource as a tool to prompt discussion during clinic visits or provide your patient with a copy to take home for reference.

CI, confidence interval; CT, computed tomography; HR, hazard ratio; MF, myelofibrosis; MPN, myeloproliferative neoplasm; MPN-SAF, Myeloproliferative Neoplasm Symptom Assessment Form; MPN-SAF-TSS, MPN-SAF Total Symptom Score (MPN-10); MRI, magnetic resonance imaging; NCCN, National Comprehensive Cancer Network.

References:

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5. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Myeloproliferative Neoplasms V.1.2020. © National Comprehensive Cancer Network, Inc 2020. All rights reserved. Accessed May 21, 2020. To view the most recent and complete version of the guideline, go online to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.
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Take an Active Role in Your Care: Communicate Your Symptoms to Your Healthcare Team

Myelofibrosis (MF) can cause a variety of symptoms, some of which you may have experienced even before being diagnosed. Many people with MF don't realize that their symptoms may be caused by their disease.

These symptoms can have a very real impact on your life. Symptoms can also provide valuable information about your disease, so it's important to discuss them with your healthcare team.

Get to know these MF-related symptoms:



Pain or discomfort in your abdomen or under your left ribs



Feeling full when you haven't eaten or have eaten very little



Fatigue (weariness, tiredness)



Inactivity or not being able to do the activities you like to do



Trouble concentrating or "brain fog"



Sweating at night or during the day



Bone pain (widespread, not joint pain or arthritis)



Itching, especially after a warm shower



Weight loss in the past 6 months, without intentionally trying to lose weight



Fever >100°F

Talk to your healthcare professional about any new or changing symptoms you may be experiencing, even if you think they are not related to your MF

