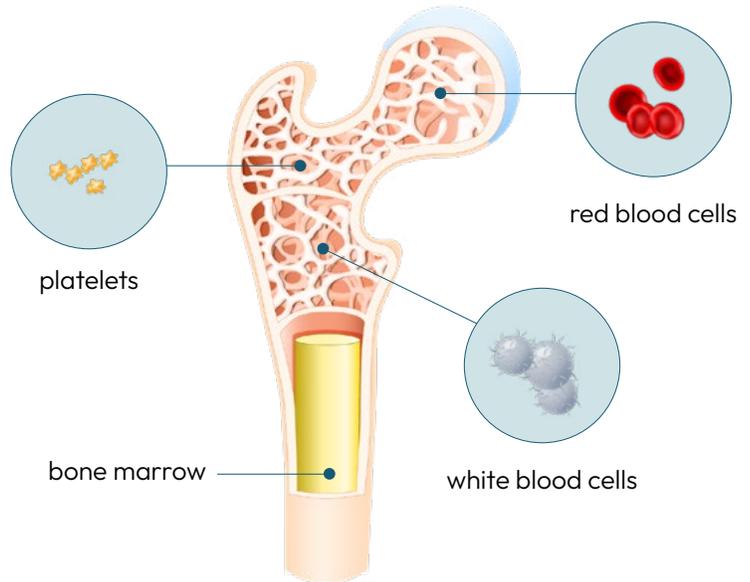


Emerging Therapy Options for Patients with Myelofibrosis



Providing Disease Education to Your Patients with MF

- MF is an MPN, the result of abnormal bone marrow
 - » Result of scar tissue, or fibrosis, and inflammation in the bone marrow
 - » Increase in fibrosis leads to a decrease in healthy blood cells
- Symptoms include fatigue, feeling full, weakness, and itching
- Primary MF is not the result of another bone marrow disease
- Secondary MF is the result of another MPN, such as polycythemia vera (PV) or essential thrombocythemia (ET)
- 10% - 20% of MF cases begin as PV or ET



Providing Nutritional Education to Your Patients with MF

Patients may be concerned about how the following symptoms impact their QOL:



Patient satiety/fullness can lead to weight loss for patients with MF



Chronic inflammation can have an impact on organ function



Anemia leading to deficiencies in vitamins and minerals

The MPN Quality of Life Study Group provides the following recommendations, which you can discuss with your patients:



Avoid over-consuming processed and refined foods such as fast foods, boxed sweets, and sugared soda



Eat small meals frequently throughout the day to combat early satiety and avoid weight loss



Consume foods that support healthy blood (Vitamins A, C, D, E, & B12, and folate, iron, copper)



Consider including healthy foods that may also have anti-inflammatory properties such as fruits, vegetables, whole grains, nuts, oils, fish, etc.

Emerging Therapy Options for Patients with Myelofibrosis



Providing Education and Resources to Your Patients

Foundations and professional societies provide excellent patient education and resource materials, which can include:

- | | | |
|---|--|---|
|  Disease glossary and description of disease |  Conferences and annual events |  Links to hematologic specialists |
|  Caregiver support services |  Financial support services | |
|  Patient and caregiver stories |  Online chats and support groups | |
|  Impact of disease on quality of life |  Podcasts, videos, and suggested readings | |
|  Updates to clinical research |  Nutritional recommendations | |



Strategies for Effective Shared Decision-Making

- Don't make assumptions**
 - Ask the patient about background, practices, religion and culture

- Ask questions**
 - Are you actively listening to your patient?

- Pay attention**
 - Do your office practices welcome everyone? Are you documenting patient feedback?

- Consider cultural differences**
 - Are there cultural practices or individual beliefs that affect the choice of treatment?

- Keep your implicit bias in check**
 - Are you self-reflecting about potential implicit biases?

- Address linguistic barriers**
 - Are interpreter services available, if needed? Do you use Google Translate®?

- Reassure your patients**
 - Are your words and actions showing that you are interested in your patient?

- At the end of the appointment, ask if the patient understands or if there is anything else needed.**

Emerging Therapy Options for Patients with Myelofibrosis



Seek your patient's participation
Help your patient explore and compare treatment options
Assess your patient's values and preferences
Reach a decision with your patient
Evaluate your patient's decision

For Further Information

1. [Practicing Cultural Competence and Cultural Humility in the Care of Diverse Patients](#)
2. [Ending Unequal Treatment: Strategies to Achieve Equitable Health Care and Optimal Health for All](#)
3. [Generalized shared decision making approaches and patient problems. Adapting AHRQ's SHARE Approach for Purposeful SDM](#)