Talking Blood Counts, Treatment Goals, and Health Equity in Myelofibrosis: Findings from a Patient Advocacy Group Consensus Panel

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CONCLUSIONS

- Patients should know and understand **blood counts** to maximize the potential of successfully treating myelofibrosis (MF) through knowledge of progression and treatment options
- **Individualized patient care** in MF is important given variability in symptoms, blood count, and progression scenarios
- Providers should remain up-to-date and inform patients on **available treatment options** so that they feel empowered to discuss every aspect of their management plan, particularly their own signs or symptoms
- Providers should discuss **classes of treatments, options related to genetic mutations, differences in mechanisms of action of different Janus kinase (JAK) inhibitors** to help them understand how each option might affect their overall experience
- Understanding **disparities in access to care** can ensure appropriate resources are available to reach health equity in MF

INTRODUCTION

MF is a myeloproliferative neoplasm (MPN) characterized by **abnormal myeloid cell growth** causing fibrosis in the bone marrow[1]

Primary MF is associated with **a risk of splenomegaly, progression to acute myelogenous leukemia (AML), and shortened survival**[4]

A cross-collaboration of patient advocacy groups established consensus statements to **improve communication between patients, caregivers, and health care providers (HCPs)**

MPN patient advocacy groups (PAGs) have shared experience and a common goal **of empowering patients to improve communication** between patients, caregivers, and HCPs

MF can have a **profound effect on quality of life** with debilitating symptoms[1-3]

Here, we present **key findings** from this consensus meeting

OBJECTIVES

- **Elevate the patient voice** in the evolving understanding of the biology of the disease and treatment
- **Empower patients living with MF and their caregivers** to have an active conversation with their providers about their symptoms, blood counts, changes to their disease (to be aware of progression), and other factors as part of their treatment plan
- **Provide support for PAGs** to work together and bring forth a unified platform for patient support and dialogue

METHODS

Consensus panel formed to establish statements

1. **Eleven representatives** from **5 MPN-focused** patient advocacy groups formed the panel
2. Third-party medical writer drafted consensus statements across **7 domains**
3. **Domains included:** Disease classification, blood counts, treatment goals/ management plans, symptom tracking and progression, patient and provider questions, health equity, patient support
4. Representatives provided feedback on statements via an **online survey**
5. Advisors then attended a **virtual consensus panel meeting** to deliberate and discuss the online survey results
6. With a final vote, meeting attendees reached **consensus on each statement**

RESULTS

Here, we present key priorities that emerged in each domain

HEALTH EQUITY

Patients and health care teams should be aware of how differences in things like race, income, geography, and health care coverage impact disease management. All patients should have access to resources and support.

BLOOD COUNTS

Patients with MF should know their blood counts, why they're important and what they mean. Patients should feel empowered to have conversations with their health care teams about blood counts and health care teams should be willing and prepared for this dialogue.

TREATMENT GOALS AND MANAGEMENT

Patients should feel empowered to talk to their health care team about treatment options and what they want from a treatment. Health care teams should set goals with patients, share treatment options and what they mean, prepare patients for treatment, and set expectations.

TABLE 1: Consensus Statements for the Health Equity Domain

Patient-Facing Statements:

- Patients should be aware that things like race, income, health care coverage, and where they live impact the health care and resources that are available. Many advocacy groups are working to try to make sure that all people have the same resources available to them
- All patients living with MF should know about available resources (such as access to MF experts) being offered by PAGs and other organizations

HCP-Facing Statements:

- Health care teams, advocacy groups, and communities should be aware of how race, ethnicity, income, and other factors may affect a disease, and work together to solve these challenges by guiding patients to PAGs that have resources for patients living with MF
- Consider how patients' lifestyle factors may impact their availability to come to appointments, afford medications, join support groups, and manage their disease. A patient's medical health care team should be provided resources to be able to support patients or direct patients to the most suitable PAG for additional support

TABLE 2: Consensus Statements for the Blood Counts Domain

Patient-Facing Statements:

- People living with MF should feel empowered to talk to their health care team about blood counts, why they matter, how they relate to their disease and/or progression, and what that may mean for them. They may also want to talk to their health care team about any differences in what their blood counts show and how they feel

HCP-Facing Statements:

- It's important to be prepared and willing to have conversations with patients about their blood counts and what they mean, why they matter to them, and how they're associated with the symptoms of MF a patient may be experiencing, as well as progression or necessary treatment changes
- Shared dialogue should occur when a patient has become transfusion-dependent to assess if there are better options available based on treatment goals
- When choosing the best treatment option for each patient, it's important to take blood counts into consideration and if these are being affected by their current treatment, their disease, or other reasons

TABLE 3: Consensus Statements for the Treatment Goals and Management Plan Domain

Patient-Facing Statements:

- MF is different for each patient. Talking to their health care team about what they want from a treatment, their symptoms, their blood counts, and treatment options may help patients find the treatment plan that is best for them
- People living with MF should be offered the necessary tools to understand the differences among Janus kinase (JAK) inhibitors, how they work, and which one may be best for them based on their MF symptoms and the gene mutations driving their disease
- Examples of questions provided to people living with MF may be helpful to support dialogue around medications, such as how long it may take to start working, what side effects it may have, and how to manage side effects or discuss treatment changes

HCP-Facing Statements:

- MF is a different experience for each patient. Ask what is most important for a patient's treatment goals and be prepared to discuss which treatment option is best for them
- Stay updated on the differences among JAK inhibitors, to decide whether they are right for patients based on their patients' symptoms, risk level, treatment goals, and stage of their disease and how it may be progressing
- When appropriate, warranted, and possible for the patient, explain gene mutations to patients with MF disease advancement and test them to determine whether the gene mutation driving their MF disease should be considered in the treatment options discussed
- Be ready to listen and answer any questions a patient may have about their prescribed medication. Be proactive in outlining expectations to patients and encourage them to ask questions
- Better preparation can often help patients manage starting a new treatment by helping them to work through side effects and allowing the proper time to see better outcomes vs stopping therapy before giving it the time needed to obtain possible outcomes

References

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