

Advancing Care for Patients with Myeloproliferative Neoplasms

Authors: Andrew Kuykendall, MD¹; Mary Stanley, LMSW, PMP²; Laura D’Onofrio²; Kimberly Demirhan MBA, BSN, RN²; Molly Kisiel, MSN, FNP-BC²; and Elana Plotkin, CMP-HC²

¹Moffit Cancer Center, Tampa, FL; ²Association of Cancer Care Centers, Rockville, MD



BACKGROUND

Myeloproliferative neoplasms (MPNs) are rare blood cancers that carry a significant symptom burden. Providing whole-person care for individuals diagnosed with MPNs is critical due to the challenges in diagnosing the disease and its impact on both physical and emotional well-being. Current standard-of-care pharmacological treatments may not fully relieve symptom burden, and approximately 84% of patients with MPNs report a reduced quality of life (QOL).

OBJECTIVES

The Association of Cancer Care Centers (ACCC) collaborated with an expert steering committee of multidisciplinary roles representing diverse cancer care centers to evaluate the current landscape of MPN care delivery and develop a 3-site quality improvement (QI) program.

METHODS

ACCC led 3 cancer centers—varying in sizes and geographic location—through a structured workshop guided by expert faculty. The workshop included pre- and post-assessments and facilitated the development of actionable QI plans tailored to their institutional needs. The workshop featured a facilitated discussion on current MPN symptom care practices, including use of the MPN Symptom Assessment Form Total Symptom Score (MPN-SAF TSS). The program also included the development of a robust repository of nationally available articles, tools, and checklists for patients and providers. These tools provide insights on best practices, treatment options, and symptom management strategies to optimize care for patients with MPNs.

Who participated?

24 health care professionals across 3 cancer programs
Site 1 (NY) treats (annual cases): <ul style="list-style-type: none">~30 patients with polycythemia vera (PV),20 patients with essential thrombocythemia (ET)15 patients with primary myelofibrosis (PMF) cases annually
Site 2 (WV) treats (annual cases): <ul style="list-style-type: none">~80 PV, 110 ET, and 50 PMF cases annually
Site 3 (RI) treats (annual cases): <ul style="list-style-type: none">~260 MPN cases annually (combined PV, ET, PMF)

CONCLUSIONS

The study identified several key opportunities for improving multidisciplinary MPN care:

- Implement Validated Symptom Assessment Tools:** Consider use of structured symptom assessment tools (eg, Fatigue Severity Scale, MPN-SAF TSS), incorporate them into electronic health record systems, and use scores to trigger referrals or other appropriate action.
- Leverage Supportive Resources:** Consider digital tools such as apps to help patients track their symptoms and levels of fatigue, external training resources for clinicians, patient referrals (eg, to fatigue clinics, speech or physical therapy), and patient support groups.
- Address the MPN Disease Continuum:** Recognize the interconnected nature of PV, ET, and PMF. Consider both genomic and clinical risk factors for each condition.
- Strengthen Research Collaboration:** Get to know key players locally and become familiar with what clinical trials are happening at other organizations. Consider strategic alignment of research agendas to avoid overlap in recruitment of patient populations and to encourage patient referrals to each other’s trials.
- Adopt a Team-Based Care Model:** Consider designating staff to conduct in-depth, regular symptom assessments while facilitating collaborative conversations (eg, at tumor boards) for management.

Addressing care gaps requires targeted strategies by clinicians, patients, and patient advocacy groups. This research will be used to inform future educational programming and the development of interventions to improve MPN care.



AUTHOR CONTACT INFORMATION

Laura D’Onofrio
Program Manager, Education Programs
Association of Cancer Care Centers (ACCC)
ldonofrio@accc-cancer.org

Learn more information about this education program and access additional resources on MPNs by scanning the quick response (QR) code or visiting accc-cancer.org/MPN.

RESULTS

Key program achievements included:	Sites achieved this by:
<ul style="list-style-type: none">Integrated validated tools for symptom monitoringEstablished streamlined workflows for diagnostic and therapeutic protocolsEnhanced patient-centered education.	<ul style="list-style-type: none">Hosting regular multidisciplinary meetings to review MPN casesActively listening to and validating patients’ experiences with fatigue and other symptomsUsing validated tools to assess MPN symptom burden and financial hardshipImplementing multidisciplinary education programs to stay current on MPN clinical trials and research.

Aggregate Post-QI Workshop Evaluation Results

Out of the 24 workshop participants, 19 completed the post-workshop evaluation. Respondents included administrators, medical oncologists/hematologists, advanced practice providers, nurses, dietitian/nutritionists, social workers, and fellows.

Item	Agreed
I gained new, practical knowledge about the MPN care continuum.	100.0%
I gained new, practical knowledge about multidisciplinary care practices.	89.4%
I gained confidence in my ability to care for patients with MPNs.	95.0%
I am committed to implementing new, multidisciplinary care strategies to improve outcomes for patients with MPNs.	100.0%
I intend to change something about my practice to improve outcomes for patients with MPNs.	89.4%
Our team has identified and prioritized an important barrier or challenge related to caring for patients with MPNs that we will work on over the next 6 months.	84.2%
I believe our team is committed to improving multidisciplinary care to improve outcomes for patients with MPNs.	100.0%

QI Site Specific Action Plans and Achievements

Site 1		
Aim: Over the next 6 months, create protocols for diagnosis of MPNs and quality of life assessment.		
Activity	Measure of Success for Activity	Achievements
Create protocols for standardized assessment of new patients suspected to have MPNs.	<ul style="list-style-type: none">Develop workflow processPilot new processAmend/adjust as determined by our working group.	Patients now routinely have molecular testing sent out, including bone marrow biopsies being done more commonly, as part of the MPN work up. Further, patients are more commonly being presented in molecular tumor boards to review diagnosis.
Create optional surveys to assess quality of life using standard assessment tools.	<ul style="list-style-type: none">Determine which quality of life tool to implementReview with institutional administration for approval for clinical use.	Site is using distress tools routinely for patients and working to develop a tool specific for nutrition and issues related to MPNs.

Site 2		
Aim: Over the next 6 months, improve patient care and physician awareness related to MPN symptoms through the implementation of a validated tool.		
Activity	Measure of Success for Activity	Achievements
Obtain and implement MPN validated tool.	<ul style="list-style-type: none">Tool obtainedGain physicians buy-inEducate physicians on how to use score as part of decision-making/conversations with patients.	<ul style="list-style-type: none">At the 6-month check-in, the team achieved an 85% physician adoption rate of the tool.Site developed an EHR dot phrase for physicians to support use and upload of the completed MPN-SAF TSS tool to a patient’s chart.

Site 3		
Aim: Over the next 6 months, increase MPN patient-education opportunities delivered by provider during clinic visit.		
Activity	Measure of Success for Activity	Achievements
Provide patient education specifically about the MPN disease trajectory during clinic visits.	<ul style="list-style-type: none">Number of patients educated about MPNsLessons learned/provider observations to improve patient education.	At the end of 6 months, the site facilitated one-on-one education sessions to approximately 60 patients and supplied supporting educational materials.

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