



Symptom assessment
resource included
on page 6



A patient counseling resource to support

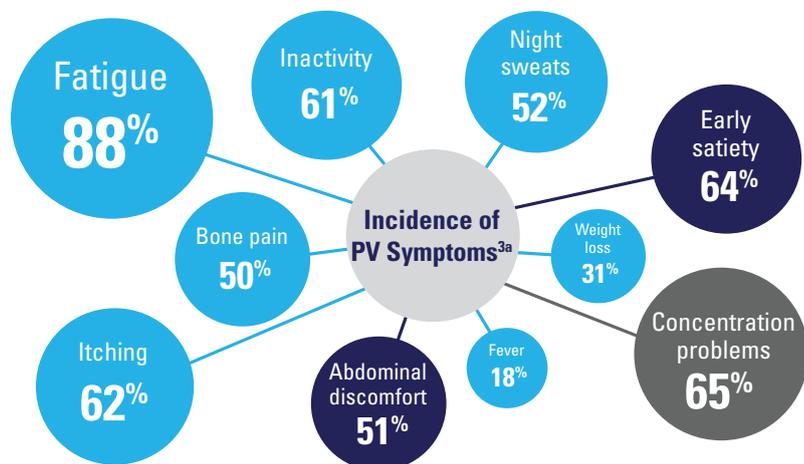
Proactive identification of symptoms associated with polycythemia vera

Polycythemia vera (PV) is a chronic hematologic malignancy that may progress over time, leading to a variety of symptoms that may impact a patient's quality of life.¹⁻⁴

Help your patients understand how symptoms of PV may affect them, so they can take an active role in their care.

A Majority of Patients With PV Reported That Symptoms Impact Quality of Life

PV-related symptoms are prevalent and may impact your patient's quality of life.²⁻⁴



In the MPN Landmark Survey,^b



Type of symptom: ● Cytokine-related ● Hyperviscosity-related ● Splenomegaly-related

^a This prospective study included a total of 1433 patients with MPNs (n=538 with PV), 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 100.³

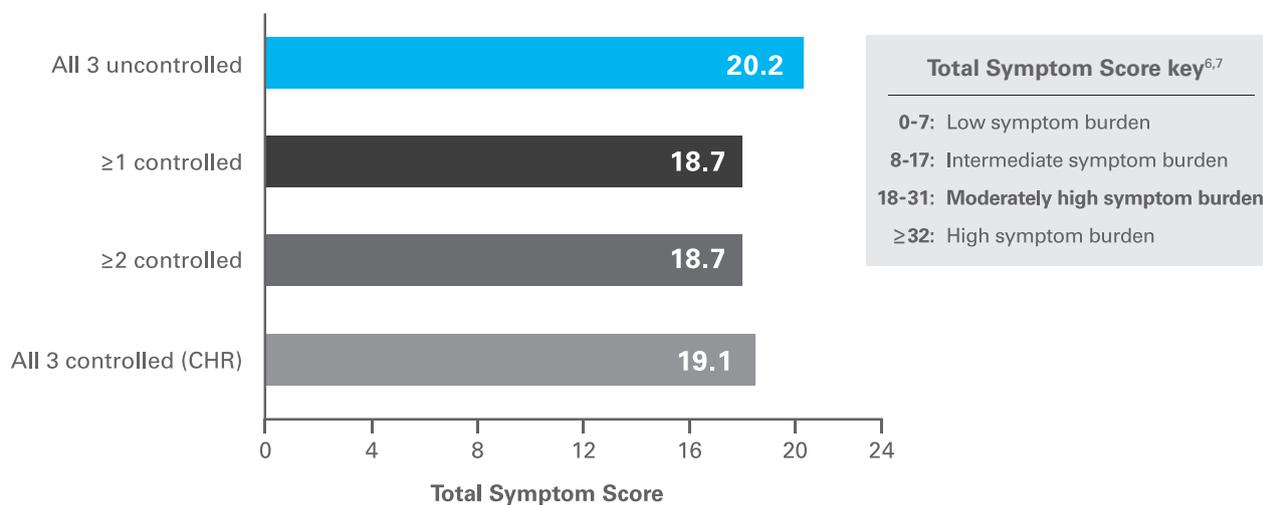
^b The MPN Landmark Survey, funded by Incyte Corporation, was a web-based questionnaire composed of 65 multiple-choice questions intended to help evaluate the patient disease burden in the MPN disease setting. A total of 813 patients in the United States with a previous diagnosis of PV (n=380), myelofibrosis (n=207), or essential thrombocythemia (n=226).⁴

^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.⁴

Patients with PV had a moderately high symptom burden regardless of blood count control⁵

- Symptom burden in patients who achieved blood count control versus those who did not was analyzed among 1813 evaluable patients with PV in the prospective, observational REVEAL study^{5a}

Mean Total Symptom Score according to blood count control status (Hct, WBC, PLT)⁵



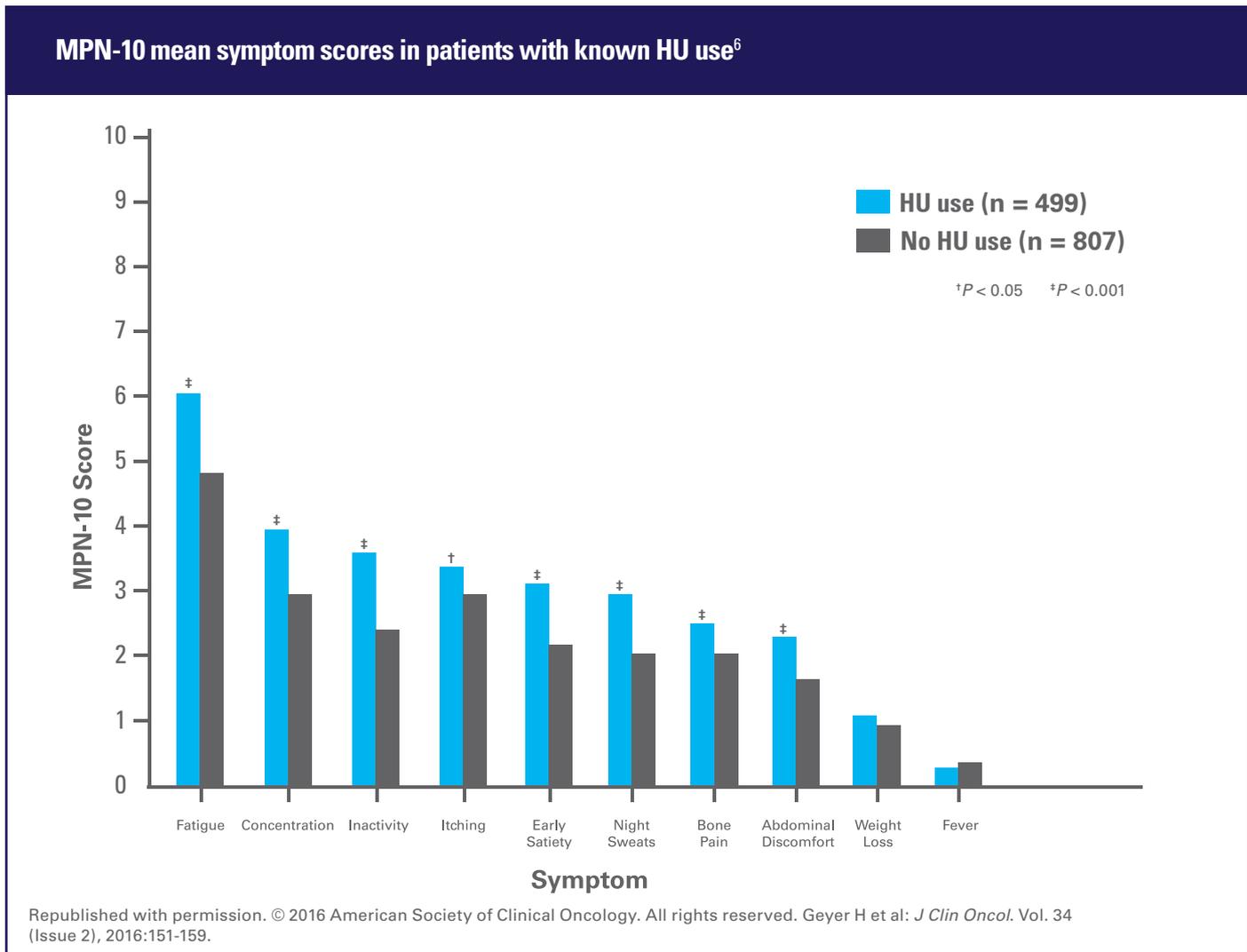
Republished from *Clin Lymphoma Myeloma Leuk*, Vol 19, Issue 9. Grunwald MR et al. Symptom burden and blood counts in patients with polycythemia vera in the United States: An analysis from the REVEAL study. Pages 579-584.e1. Copyright 2019, with permission from Elsevier. <https://www.sciencedirect.com/journal/clinical-lymphoma-myeloma-and-leukemia>.

^a REVEAL was a prospective, observational study that collected contemporary data regarding burden of disease, clinical management, patient-reported outcomes, and healthcare resource utilization from adult patients with PV in the United States, and was sponsored by Incyte. A total of 2510 patients were enrolled over an approximate 2-year period (July 2014 to August 2016), with 2307 patients having completed the MPN-SAF TSS at enrollment. Of these, 1813 (72.2%) had a complete blood count within 30 days before completion of the at-enrollment MPN-SAF TSS and were evaluable. At the time of enrollment, most patients (n=1714; 94.5%) were being managed with cytoreductive therapy; 1581 patients (87.2%) were managed with phlebotomy, HU, or a combination thereof. Complete hematologic remission (CHR) was defined as Hct <45%, WBC count <10 × 10⁹/L, and PLT count ≤400 × 10⁹/L; these same criteria were used to determine if Hct, WBC, and PLT were controlled.⁵

Symptom Burden in Patients With PV Is Substantial and May Not Be Adequately Controlled With Hydroxyurea (HU)

On average, patients with known HU use had a moderately high symptom burden (TSS = 29.2)⁶

- A prospective study of 1334 patients with PV where a subset of patients received HU (n=499)^{6a}



^aA prospective study of 1334 patients with PV was conducted to assess baseline symptoms with certain disease features: known HU use (n = 499), known phlebotomy (n = 646), palpable splenomegaly (n = 369), or all 3 features (n = 148), and compared to a control group of patients that lacked the specified feature. Assessment of MPN symptoms was performed by using the MPN-Symptom Assessment Form Total Symptom Score (MPN-SAF TSS; MPN-10). All items were evaluated on a 0 (absent) to 10 (worst imaginable) scale. The MPN-10 TSS has a possible range of 0 to 100 with 100 representing the highest level of symptom severity. The TSS for each patient was analyzed to place the patient into the quartiles of low symptom burden (TSS, 0 to 7), intermediate symptom burden (TSS, 8 to 17), moderately high symptom burden (TSS, 18 to 31), or high symptom burden (TSS ≥32).⁶

NCCN Clinical Practice Guidelines in Oncology (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.⁸

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

Proactive symptom assessment is an important component of patient care.

Actively Monitor Symptom Status in Your Patients With PV

Enhance your conversations about symptoms with contextual questions

- Patients with PV may not recognize that their symptoms may be related to their cancer.⁹ Open-ended questions can encourage your patients to express their symptom burden and severity based on what they experience in daily life.

CYTOKINE-RELATED SYMPTOMS^a

Fatigue and Inactivity



- Are there activities that you were able to do 3 months ago that you struggle with now?
- How much does your fatigue or inactivity influence your day-to-day activities? Your work around the home? Your time spent with friends or loved ones? The things you do for fun? Your enjoyment of life?
- How many normal waking hours each day do you spend in a bed or chair?

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 did this happen in the past month?

Itching



- Have you noticed changes in your skin, particularly itching?
- 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?
- What are other instances where you tend to feel itchy?

Bone Pain



- Have you felt any deep achiness throughout your body?
- Does bone pain ever cause you to change or limit your activities?

HYPERVISCOSITY-RELATED SYMPTOMS

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, 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?

SPLENOMEGALY-RELATED SYMPTOMS

Abdominal Discomfort



- Do you have abdominal discomfort, particularly after eating?
- Do you experience abdominal discomfort at any other time, for example, when lying down flat on your back?

Early Satiety



- Do you feel full quickly after meals?
- Are you losing weight, and if so, how much weight have you lost over the last 6 months?

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

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



“ Establishing an open dialogue about symptoms is one of the most important things you can do for a patient. This is especially true for a chronic cancer like PV, where symptoms can evolve subtly over time and often without overt clinical or laboratory signs. Some patients may not know which symptoms to watch out for, or how general symptoms, such as fatigue or itching after a hot shower, may be directly related to their PV. Clinicians need to be proactive with their patients with PV to help educate them and uncover symptoms before they take their toll on quality of life. In PV, there is a real opportunity to make a difference in patients’ daily lives by assessing, monitoring, and intervening on problematic symptoms. ”

—Robyn M. Scherber, MD, MPH, Asst. Prof. of Medicine at the University of Texas Health Science Center at San Antonio

The following page is intended to help your patients identify PV-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.

CHR, complete hematologic remission; Hct, hematocrit; HU, hydroxyurea; MPN, myeloproliferative neoplasm; MPN-SAF, Myeloproliferative Neoplasm Symptom Assessment Form; MPN-SAF-TSS, MPN-SAF Total Symptom Score (MPN-10); NCCN, National Comprehensive Cancer Network; PLT, platelet; WBC, white blood cell.

References: 1. Mascarenhas J. *Clin Lymphoma Myeloma Leuk.* 2016;16 suppl:S124-S129. 2. Scherber R, Dueck AC, Johansson P, et al. *Blood.* 2011;118(2):401-408. 3. Emanuel RM, Dueck AC, Geyer HL, et al. *J Clin Oncol.* 2012;30(33):4098-4103. 4. Mesa R, Miller CB, Thyne M, et al. *BMC Cancer.* 2016;16:167. 5. Grunwald MR, Burke JM, Kuter DJ, et al. *Clin Lymphoma Myeloma Leuk.* 2019;19(9):579-584.e1. 6. Geyer H, Scherber R, Kosiorek H, et al. *J Clin Oncol.* 2016;34(2):151-159. 7. Emanuel RM, Dueck AC, Geyer HL, et al. *Blood.* 2013;122:4067. 8. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Myeloproliferative Neoplasms V.3.2019. ©National Comprehensive Cancer Network, Inc 2019. All rights reserved. Accessed September 4, 2019. 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. 9. Mesa RA, Miller CB, Thyne M, et al. *Cancer.* 2017;123(3):449-458.



Take an Active Role in Your Care:

Communicate Your Symptoms to Your Healthcare Team

Keeping your blood counts under control is one important goal of managing polycythemia vera (PV). Recognizing and discussing symptoms with your healthcare team is another important goal.

Whether your blood counts are under control or not, PV can still cause burdensome symptoms that can have a very real impact on your life.

Many people with PV don't realize that their symptoms may be caused by their disease. Get to know these PV-related symptoms:



Fatigue (weariness, tiredness)



Pain or discomfort in your abdomen or under your left ribs



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



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



Sweating at night or during the day



Bone pain (widespread, not joint pain or arthritis)



Itching, especially after a warm shower



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



Trouble concentrating or "brain fog"



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 PV.

