

Symptoms of Myelofibrosis Affecting Patient Quality of Life

Baseline Health

> Age



> Medical comorbidities



> Psychological



> Medications



> Nutritional status



Vascular Events

> Clots, bleeding



> Elevated blood counts



> Abdominal vein thrombosis



Cytopenias

> Transfusions



> Medication-related as a result of disease



Progression

> Transformation into another blood cancer



> Worsening of the current disease state



Organ Dysfunction

> Spleen enlargement



> Liver issues



> Pulmonary extramedullary hematopoiesis



Inflammation

> Constitutional symptoms



> Cachexia



> Anemia



> Cognitive dysfunction



Assessing Patient Quality of Life

- > Patients living with MF often experience severe symptom burden
- > Patient-reported outcomes (PROs) can be used to assess the range of symptoms that patients with MF experience daily and impact patient quality of life (QOL)
- > It is essential that patient symptom severity is assessed by nursing professionals frequently



Disease-related symptoms result in a **reduced QOL in 81% of patients with MF**



Misalignment between the patient and the clinician is common (perceptions of symptom burden, treatment goals, unmet needs, and expectations)



Conversations that build trust to enhance QOL should include gender differences, patient comorbidities, and the rare and chronic nature of myelofibrosis

QOL ITEMS TO DISCUSS WITH PATIENTS



Physical function



Social function



Limitations due to physical health



Bodily pain



Mental health



Emotional problems



Vitality



Disease symptoms and side effects of treatment



Daily life impact, including ability to work



Examples of Questionnaires to Assess Patient Quality of Life in Clinical Practice

European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30)

Measures the effect health problems on activities in the past week

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Work Productivity and Activity Impairment Questionnaire-Specific Health Problem (WPAI-SHP) Questionnaire

Measures the effect of a target health problem on work productivity and other regular activities

Participant completes via online survey at **Week 4 Baseline** and Months 6, 12, 18, 24, 30, & 36 Follow-up Contacts

The following questions ask about the effect of your PROBLEM on your ability to work and perform regular activities. *Please fill in the blanks or circle a number, as indicated.*

1. Are you currently employed (working for pay)? Yes No
If NO, check "NO" and skip to question 6

The next questions are about the past seven days, not including today.

2. During the past seven days, how many hours did you miss work because of problems associated with your PROBLEM? *Include hours you missed on sick days, times you went in late, left early, etc., because of your PROBLEM. Do not include time you missed to participate in this study.*

_____ HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

_____ HOURS

4. During the past seven days, how many hours did you actually work?

_____ HOURS (If "0", skip to question 6.)

5. During the past seven days, how much did your PROBLEM affect your productivity while you were working?

For Further Information

1. [NCCN Guidelines Version 1.2024. Myelofibrosis](#)
2. [Patient-reported outcomes of patients with myelofibrosis or essential thrombocythemia enrolled in the MOST study](#)
3. [The Myeloproliferative Neoplasm Landscape: A Patient's Eye View](#)
4. [The personal impact of living with a myeloproliferative neoplasm](#)
5. [How myeloproliferative neoplasms patients' experience and expectations differ from physicians': the international MPN Landmark survey](#)

Emerging Therapy Options for Patients with Myelofibrosis



MPN Total Symptom Score (MPN-SAF TSS)

MYELOPROLIFERATIVE NEOPLASM SYMPTOM ASSESSMENT FORM TOTAL SYMPTOM SCORE (MPN-SAF TSS; MPN-10)
 (Recommended for monitoring symptoms during the course of treatment)

Symptom	1 to 10 (0 if absent) ranking 1 is most favorable and 10 least favorable
Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during past 24 hours	(No fatigue) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Circle the one number that describes, during the past week, how much difficulty you have had with each of the following symptoms	
Filling up quickly when you eat (early satiety)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Abdominal discomfort	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Inactivity	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Problems with concentration – compared to prior to my MPD	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Night sweats	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Itching (pruritus)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Bone pain (diffuse not joint pain or arthritis)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Fever (>100 F)	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)
Unintentional weight loss last 6 months	(Absent) 0 1 2 3 4 5 6 7 8 9 10 (Worst Imaginable)