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APPENDIX B

- Patient Questionnaire
- Physician Questionnaire
INTRODUCTION TO THE MPN LANDMARK SURVEY

MPN LANDMARK SURVEY Background

The LANDMARK SURVEY OF MYELOPROLIFERATIVE NEOPLASMS (MPNs) was developed to provide the first detailed, comprehensive picture of patient and physician experiences related to MPNs, including myelofibrosis (MF), polycythemia vera (PV), and essential thrombocythemia (ET), in the United States.

This large survey was developed to evaluate the patient’s disease burden and patient–physician communication in MPN disease setting. It specifically examines the domains of symptomatology, disease burden, quality of life (QOL), timing to diagnosis, symptom recognition, activities of daily living, productivity, symptom assessment, prognostic assessment, treatment management attitudes, and physician–patient communication. To enhance patient care, it is important to have a current and clear understanding of how MPNs affect the health and daily lives of patients.

Steering Committee

The MPN LANDMARK SURVEY was developed in collaboration with an external steering committee that consisted of diverse MPN experts/thought leaders including MPN specialists, allied health providers, patient advocacy group members, epidemiologists, and survey experts. Serving as members of the Steering Committee were:

- Ruben Mesa, MD—Committee Chairman
- John Boyle, PhD
- Salman Fazal, MD
- Christopher C. Gayer, PhD
- Sara Goldberger, BA, MS
- Xiaomei Ma, PhD
- James Mangan, MD, PhD
- John O. Mascarenhas, MD, MS
- Carole B. Miller, MD
- Maureen Thyne, PA
- Wendy Wilson, RN, MSN, OCN
MPN LANDMARK SURVEY DESIGN

Patient Survey

A national sample of patients diagnosed with MF, PV, or ET was recruited from multiple sources to participate in an online survey conducted from May through July of 2014. Invitations were delivered by direct mail to consumers who opted in to receive health care related information. A digital recruiting campaign for the survey was conducted online during the 6 weeks of survey fielding. To supplement the online campaign, a newspaper campaign was conducted in 5 major markets. As the multichannel recruitment campaign was taking place, 1500 patient recruitment invitations were distributed through specialists treating patients with MPNs. Patient data were collected using a web-based survey tool. The survey was conducted only in English and averaged approximately 22 minutes in length. Patients received no remunerations for their participation. A total of 813 patients participated, including 207 surveys with MF patients, 380 surveys with PV patients, and 226 surveys with ET patients.

<table>
<thead>
<tr>
<th>Population</th>
<th>Interview Dates</th>
<th>Completed Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men and women aged ≥18 y</td>
<td>May 16, 2014–July 13, 2014</td>
<td>207 MF patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>380 PV patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>226 ET patients</td>
</tr>
</tbody>
</table>

Physician Survey

The physician survey was designed as a national probability sample of specialists treating patients with MPNs, using double-blind selection. A series of random samples were drawn from the American Medical Association/American Osteopathic Association listings of physicians in direct patient care with a primary medical specialty of hematology, oncology, or hematology/oncology. Medical residents and interns were excluded. The initial samples were sent advance letters explaining the survey’s purpose, survey length, participation requirements, and remuneration for completing the survey. Subsequent samples were sent e-mail and fax invitations. The physician data were collected online using a web-based survey instrument designed in parallel with the patient questionnaire. The requirement for physician participation was to have at least 2 patients with MF, 5 patients with PV, or 5 patients with ET in the past 12 months. Consequently, 1 national sample of physicians yielded 3 independent subsamples of physicians treating each of the 3 targeted conditions. The physician survey was conducted only in English and averaged approximately 22 minutes in length. Physicians received remuneration of $185 for their participation. A total of 457 physician surveys were completed, including 156 surveys with physicians treating MF patients, 250 surveys with physicians treating PV patients, and 51 surveys with physicians treating ET patients.

<table>
<thead>
<tr>
<th>Population</th>
<th>Interview Dates</th>
<th>Completed Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>May 21, 2014–July 13, 2014</td>
<td>156 MF physicians</td>
</tr>
<tr>
<td>▪ Hematologists</td>
<td></td>
<td>250 PV physicians</td>
</tr>
<tr>
<td>▪ Medical oncologists</td>
<td></td>
<td>51 ET physicians</td>
</tr>
<tr>
<td>▪ Hematologists/Oncologists</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
MF Background

Myelofibrosis (MF) is a specific type of MPN. MF is a disease of the bone marrow and also known as bone marrow cancer or a blood cancer. It causes the bone marrow to make too many or in some cases too few blood cells which can lead to scar tissue or a build up in the bone marrow. This interferes with the production of blood cells and may cause some of the key symptoms associated with MF. MF is considered to be a serious, chronic condition that will likely get worse over time.¹

About 16,000 to 18,500 people in the United States have been diagnosed with MF.² It occurs equally in men and women and while it can occur at any age, it is more common to be diagnosed later in life, around 65 years of age and older.³

Because of the underproduction of blood cells in the bone marrow, the spleen becomes responsible for producing more blood cells, which causes the spleen to enlarge. An enlarged spleen may cause the following symptoms: pain or discomfort in the abdomen or under the left ribs, feeling full even if you haven’t eaten or you have eaten very little, decreased activity or inactivity. Other symptoms of MF not related to the spleen are fatigue, anemia, itching, and night sweats.⁴

It should be noted, this executive summary does not include a full report of the data collected from the MF LANDMARK SURVEY. On request, data can be provided for any question that was not included within the context of this report. Throughout the report, individual values are rounded and may not total 100%.
Key Insights From the MF LANDMARK SURVEY

Most MF patients have significant symptom burden from their disease, and most patients agreed that symptoms reduced their QOL and have had an impact on employment.

- 96% of patients surveyed reported having experienced ≥1 symptom. The most common symptoms reported were fatigue, abdominal discomfort, night sweats, and difficulty sleeping (Figure 1).
- Symptoms rated the most severe were fatigue, problems with sexual desire, inactivity, problems with concentration, and difficulty sleeping (Figure 2).
- 47% of patients experienced symptoms for >2 years before they received a formal diagnosis (Figure 18).
- Nearly two thirds of patients surveyed (65%) reported that MF has caused them at least some physical, emotional, and financial hardship in the past month (Figure 7).
- MF patients said they voluntarily terminated their job (31%), took early retirement (30%), or reduced hours at work (59%) as a result of their condition (Figure 10).
- Most MF patients (81%) strongly agreed or somewhat agreed that MF symptoms reduced their QOL (Figure 15).
- For the MF patients, slowing or delaying disease progression (42%) was the single most important goal for therapy (Figure 30).
- Of those patients who relied on a caregiver (41% of surveyed patients) to help with their condition, most (85%) said that their main caregiver was a spouse or partner (Figure 77).
- All of the MF patients in the survey reported that they had some sort of health insurance to cover their health care costs (Figure 81).

Most patients reported being very satisfied with their communication and relationship with health care providers (HCPs).

- Nearly all patients (91%) and physicians (90%) were satisfied with their current communication about the condition and its treatment (Figures 64-65).
- A Nurse Practitioner or Physician Assistant (42%) were the most commonly reported HCPs aside from the current physician in their care (Figure 76).
- Patients preferred to receive educational materials from the Internet (90%), online email discussions (47%), and their doctor’s office (27%) (Figure 78). Patients most frequently went to MPN Advocacy Group web sites (82%), hospital web sites (68%), and health web sites (47%) on the Internet (Figure 79).

Although most patients reported a very positive relationship with their physician, there were some gaps in the comparisons.

- 83% of physicians said that they utilized a prognostic risk score assessment to classify their MF patients (Figure 57). By contrast, only 54% of MF patients reported that their MF physician provided a risk classification for their condition (Figure 56).
- Almost all physicians (96%) agreed even mild to moderate symptoms can have a significant impact on a patient’s QOL (Figure 40); physicians recommended drug treatment in just over half of patients (53%) with moderate symptoms and rarely (13%) recommended drug treatment to patients with mild symptoms (Figure 39).
- Most patients (51%) stated that physicians proactively asked how they are feeling overall, whereas most physicians’ (55%) stated that they asked about most important, specific symptoms (Figures 46-47).
- Of MF patients, 30% disagreed that their physician had created a treatment plan for them despite 96% of physicians reporting they had created a plan or established goals for their patients (Figures 70-71).
Patient Demographics

MF tended to affect older persons. The mean age of MF patients in the survey was 65 years of age. Most MF patients (55%) in this sample were aged 60-74 years. Nearly a quarter of the patients (23%) were aged 45-59 years. A little less than one fifth of MF patients surveyed (18%) were aged 75 years and older. Only 4% of patients in the sample diagnosed with MF were under the age of 45 years. The patient sample was nearly equally divided between men (46%) and women (54%).

Surveyed patients diagnosed with MF were less likely to be minority, lower income, or lower educational attainment than the general population. Almost all MF patients (98%) reported their race as white. Nearly two thirds (65%) had a college degree or higher. Additionally, 53% of patients had a household income greater than $75,000, and the reported median yearly income was $87,500.

Please note, although the survey respondents were more highly educated and had a higher income than the general population, because there were no data describing income and educational attainment among people with MPNs, we cannot say whether the respondent sample for these domains is representative of all people with MPNs. Responses across the education and income categories were compared, and no differences or trends were seen in either group.

Patient Demographics

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>% of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Range, y</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;18</td>
<td>0</td>
</tr>
<tr>
<td>18–44</td>
<td>4</td>
</tr>
<tr>
<td>45–59</td>
<td>23</td>
</tr>
<tr>
<td>60–74</td>
<td>55</td>
</tr>
<tr>
<td>75–90</td>
<td>18</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>46</td>
</tr>
<tr>
<td>Women</td>
<td>54</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>0</td>
</tr>
<tr>
<td>No high school</td>
<td>1</td>
</tr>
<tr>
<td>High school graduate</td>
<td>8</td>
</tr>
<tr>
<td>Technical post-secondary</td>
<td>3</td>
</tr>
<tr>
<td>Some college</td>
<td>23</td>
</tr>
<tr>
<td>4-year college graduate</td>
<td>32</td>
</tr>
<tr>
<td>Postgraduate degree</td>
<td>32</td>
</tr>
<tr>
<td><strong>Household Income, US $</strong></td>
<td></td>
</tr>
<tr>
<td>$15,000 or less</td>
<td>3</td>
</tr>
<tr>
<td>$15,001–$25,000</td>
<td>4</td>
</tr>
<tr>
<td>$25,001–$35,000</td>
<td>9</td>
</tr>
<tr>
<td>$35,001–$50,000</td>
<td>8</td>
</tr>
<tr>
<td>$50,001–$75,000</td>
<td>16</td>
</tr>
<tr>
<td>$75,001–$100,000</td>
<td>23</td>
</tr>
<tr>
<td>&gt;$100,000</td>
<td>30</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6</td>
</tr>
</tbody>
</table>

*Table 1. Note: Individual values are rounded and may not total 100%*
Physician Demographics

An overwhelming majority of the physicians within this sample identified themselves as hematologists/oncologists (91%) and reported that hematology comprises 26% - 75% of the cases they see in practice.

Most MF-treating physicians (61%) in the sample graduated from medical school in 1999 or later. Only 14% graduated before 1980, and 22% graduated from medical school between 1980 and 1989. Because interns and residents were not eligible for the survey, only 1% graduated in 2010 or later. Overall, the mean length of time since graduation for physicians in this survey was 21 years.

Physicians most often saw their patients in academic hospitals (30%) or single specialty groups (42%). Less commonly, physicians saw their patients in community hospitals (12%). Smaller proportions of MF physicians were in multispecialty groups (9%), solo practice (5%), or another setting (2%).

Most physicians surveyed saw more than 200 total outpatients per month, with a mean number of 253 outpatients seen per month. Specific to MF, nearly two thirds of the physicians surveyed reported that as many as 6 MF patients were under their care. The average number of MF patients seen by physicians surveyed represented about 4% of their total reported outpatient visits. Additionally, physicians reported seeing an average of 6 newly diagnosed MF patients.

### Table 2

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>% of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Year of Graduation From Medical School</strong></td>
<td></td>
</tr>
<tr>
<td>2010+</td>
<td>1</td>
</tr>
<tr>
<td>1960–1969</td>
<td>2</td>
</tr>
<tr>
<td>1970–1979</td>
<td>12</td>
</tr>
<tr>
<td>1980–1989</td>
<td>22</td>
</tr>
<tr>
<td>1990–1999</td>
<td>25</td>
</tr>
<tr>
<td>2000–2009</td>
<td>39</td>
</tr>
<tr>
<td><strong>Percentage of Hematology Cases in Practice</strong></td>
<td></td>
</tr>
<tr>
<td>0–25%</td>
<td>12</td>
</tr>
<tr>
<td>26–50%</td>
<td>51</td>
</tr>
<tr>
<td>51–75%</td>
<td>18</td>
</tr>
<tr>
<td>76–100%</td>
<td>19</td>
</tr>
<tr>
<td><strong>Practice Setting Physicians Spend at Patient Care</strong></td>
<td></td>
</tr>
<tr>
<td>Community hospital-inpatient</td>
<td>0</td>
</tr>
<tr>
<td>Academic hospital-inpatient</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>Single specialty group</td>
<td>42</td>
</tr>
<tr>
<td>Academic hospital-outpatient</td>
<td>30</td>
</tr>
<tr>
<td>Community hospital-outpatient</td>
<td>12</td>
</tr>
<tr>
<td>Multispecialty group/HMO</td>
<td>9</td>
</tr>
<tr>
<td>Solo practice</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total No. of MF Patients Under Physician’s Care</strong></td>
<td></td>
</tr>
<tr>
<td>1–3</td>
<td>32</td>
</tr>
<tr>
<td>4–6</td>
<td>33</td>
</tr>
<tr>
<td>7–10</td>
<td>14</td>
</tr>
<tr>
<td>11–20</td>
<td>10</td>
</tr>
<tr>
<td>&gt;20</td>
<td>11</td>
</tr>
</tbody>
</table>

*Table 2. Note: Individual values are rounded and may not total 100%*
Symptom Burden

Survey findings showed that most patients had significant symptom burden from MF disease. Most patients agreed that MF symptoms reduced their QOL.

Patients surveyed were asked whether they had ever experienced any of 18 symptoms associated with MF. This question was based on the MPN Symptom Assessment Form (MPN-SAF), a validated instrument used to assess patient-reported MPN symptoms. On average, patients reported 7 symptoms, with some reporting as many as 18 symptoms. Overall, 96% of patients surveyed reported having experienced ≥1 symptom.

The most common symptoms were fatigue (81%), abdominal discomfort (58%), night sweats (55%), and difficulty sleeping (53%) (Figure 1).

Figure 1. Question 8: Have you ever had any of the following symptoms? (n = 207)
Symptom Severity

Patients were asked to rate the severity on a scale from 0 (absent) to 10 (worst imaginable) of each symptom they had experienced in the past 12 months; this question was also based on the MPN-SAF. An overall mean severity score was calculated for each symptom from the individual patient rankings (Figure 2).

The most severe symptoms reported by patients were fatigue (6.3), problems with sexual desire (6.1), inactivity (5.8), problems concentrating (5.1), and difficulty sleeping (5.0). Although abdominal discomfort and night sweats were among the most common symptoms, they were not among the most severe of symptoms.

### Patient-Reported MPN-SAF Mean Severity Score

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Mean Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (n = 168)</td>
<td>6.3</td>
</tr>
<tr>
<td>Problems with sexual desire (n = 65)</td>
<td>6.1</td>
</tr>
<tr>
<td>Inactivity (n = 69)</td>
<td>5.8</td>
</tr>
<tr>
<td>Problems with concentration (n = 61)</td>
<td>5.1</td>
</tr>
<tr>
<td>Difficulty sleeping (n = 109)</td>
<td>5.0</td>
</tr>
<tr>
<td>Bone pain (n = 87)</td>
<td>4.8</td>
</tr>
<tr>
<td>Filling up quickly when eating (n = 91)</td>
<td>4.6</td>
</tr>
<tr>
<td>Depression or sad mood (n = 73)</td>
<td>4.5</td>
</tr>
<tr>
<td>Abdominal pain (n = 63)</td>
<td>4.4</td>
</tr>
<tr>
<td>Problems with headaches (n = 49)</td>
<td>4.3</td>
</tr>
<tr>
<td>Unintentional weight loss (n = 77)</td>
<td>4.3</td>
</tr>
<tr>
<td>Night sweats (n = 114)</td>
<td>4.1</td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet (n = 84)</td>
<td>4.1</td>
</tr>
<tr>
<td>Abdominal discomfort (n = 120)</td>
<td>4.0</td>
</tr>
<tr>
<td>Itching (pruritus) (n = 94)</td>
<td>3.9</td>
</tr>
<tr>
<td>Dizziness/vertigo/lightheadedness (n = 86)</td>
<td>3.8</td>
</tr>
<tr>
<td>Fever (&gt;100°F) (n = 37)</td>
<td>3.4</td>
</tr>
<tr>
<td>Cough (n = 65)</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Figure 2. Question 13a-dd: How severe is [symptom]?

### Spleen-Related Symptoms

Splenomegaly, or enlarged spleen, is prominent in most patients diagnosed with MF. Spleen-related symptoms include abdominal discomfort, abdominal pain, and filling up quickly when eating. Most patients surveyed had experienced abdominal discomfort (58%); 44% of patients reported experiencing filling up quickly when eating, and nearly a third reported abdominal pain (30%).

MF patients reported filling up quickly when eating as the most severe spleen-related symptom, with a mean severity score of 4.6. The mean severity score reported by patients for abdominal pain was 4.4 and for abdominal discomfort was 4.0.
Symptom Resolution

Patients surveyed were asked to select the symptom they would most like to resolve from the symptoms they were currently experiencing. Nearly half of patients reported fatigue (47%) as the symptom they would most like to resolve, followed by abdominal discomfort (7%) and bone pain (6%) (Figure 3).

**First Symptom MF Patients Would Like to Resolve as Reported by Patients**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>47%</td>
</tr>
<tr>
<td>Abdominal discomfort</td>
<td>7%</td>
</tr>
<tr>
<td>Bone pain</td>
<td>6%</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>6%</td>
</tr>
<tr>
<td>Dizziness/vertigo/lightheadedness</td>
<td>6%</td>
</tr>
<tr>
<td>Itching (pruritus)</td>
<td>6%</td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet</td>
<td>5%</td>
</tr>
<tr>
<td>Depression or sad mood</td>
<td>3%</td>
</tr>
<tr>
<td>Night sweats</td>
<td>3%</td>
</tr>
<tr>
<td>Problems with sexual desire</td>
<td>3%</td>
</tr>
<tr>
<td>Problems with concentration</td>
<td>2%</td>
</tr>
<tr>
<td>Unintentional weight loss</td>
<td>2%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>2%</td>
</tr>
<tr>
<td>Inactivity</td>
<td>2%</td>
</tr>
<tr>
<td>Filling up quickly when eating</td>
<td>1%</td>
</tr>
<tr>
<td>Cough</td>
<td>1%</td>
</tr>
<tr>
<td>Fever (&gt;100° F)</td>
<td>1%</td>
</tr>
<tr>
<td>Problems with headaches</td>
<td>1%</td>
</tr>
</tbody>
</table>

Figure 3. Question 14: Of the symptoms that you are currently experiencing, which one would you most like to resolve? (n = 199)
Symptom Recognition

Fatigue (88%), bone pain (87%), filling up quickly when eating (86%), and unintentional weight loss (84%) were the most recognized symptoms associated with MF by patients who reported experiencing that symptom in a previous question. More than half of all symptoms listed were recognized as being the result of MF by most patients (Figure 4).

Most patients in the survey were able to recognize the most common symptoms associated with MF; however, some of the most severe symptoms reported by patients, such as difficulty sleeping and problems with sexual desire, were not as well recognized among patients experiencing those symptoms.

Symptoms Associated With MF Recognized by Patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage Recognized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue (n = 168)</td>
<td>88%</td>
</tr>
<tr>
<td>Bone pain (n = 87)</td>
<td>87%</td>
</tr>
<tr>
<td>Filling up quickly when eating (n = 91)</td>
<td>86%</td>
</tr>
<tr>
<td>Unintentional weight loss (n = 77)</td>
<td>84%</td>
</tr>
<tr>
<td>Abdominal discomfort (n = 120)</td>
<td>77%</td>
</tr>
<tr>
<td>Night sweats (n = 114)</td>
<td>77%</td>
</tr>
<tr>
<td>Inactivity (n = 69)</td>
<td>73%</td>
</tr>
<tr>
<td>Abdominal pain (n = 63)</td>
<td>70%</td>
</tr>
<tr>
<td>Itching (pruritus) (n = 94)</td>
<td>67%</td>
</tr>
<tr>
<td>Problems with concentration (n = 61)</td>
<td>67%</td>
</tr>
<tr>
<td>Dizziness/vertigo/lightheadedness (n = 86)</td>
<td>61%</td>
</tr>
<tr>
<td>Fever (&gt;100°F) (n = 37)</td>
<td>60%</td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet (n = 84)</td>
<td>57%</td>
</tr>
<tr>
<td>Depression or sad mood (n = 73)</td>
<td>53%</td>
</tr>
<tr>
<td>Difficulty sleeping (n = 109)</td>
<td>51%</td>
</tr>
<tr>
<td>Problems with headaches (n = 49)</td>
<td>47%</td>
</tr>
<tr>
<td>Problems with sexual desire (n = 65)</td>
<td>45%</td>
</tr>
<tr>
<td>Cough (n = 65)</td>
<td>34%</td>
</tr>
</tbody>
</table>

Figure 4. Question 12: Which of these symptoms do you feel are a result of your MF?
Emotional Burden

The survey results showed that MF carries an emotional burden for many patients. Survey participants were asked to rate the extent to which MF has had an impact on them in the past month in a number of emotional or psychosocial areas.

More than 90% of patients reported that their condition had at least some impact on them (a rating between 2 and 5 on a scale of 1-5) in the past month, as it caused them to feel anxious or worried about their condition (Figure 5). Seventy-five percent of patients have felt depressed or discouraged as a result of MF.

Two thirds of patients felt their condition was controlling their life to at least some extent. A smaller proportion of patients reported that they had been irritable or angry or avoided social interactions at least some in the past month (Figure 5).

Emotional Impact of MF Reported by Patients

![Survey Results]

Figure 5. Question 24: Rank the following statements as they have occurred during the past month, as a result of your MF (n = 207)

Note: Labels for data under 5% are not displayed
Physical Burden

In addition to an emotional burden, most MF patients reported that their MF condition had a physical impact on their life in the past month.

Most patients reported that their condition caused their sleeping habits to change (57%), caused trouble focusing (53%), or caused changes in how they looked (52%) to some extent in the past month (Figure 6).

Ten percent or fewer patients indicated that MF had a great deal of impact (score of 5, on a scale of 1-5) in any of these specific areas.

Physical Impact of MF Reported by Patients

<table>
<thead>
<tr>
<th>Statement</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sleeping habits have changed</td>
<td>43%</td>
<td>22%</td>
<td>14%</td>
<td>15%</td>
<td>7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My condition has caused changes in how I look</td>
<td>48%</td>
<td>22%</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have trouble focusing at work/reading/watching TV</td>
<td>47%</td>
<td>21%</td>
<td>17%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have noticed a change in my appetite</td>
<td>53%</td>
<td>15%</td>
<td>18%</td>
<td>8%</td>
<td>7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 6. Question 24: Rank the following statements as they have occurred during the past month, as a result of your MF (n = 207)
Note: Labels for data under 5% are not displayed

Hardship Caused by MF

Nearly two thirds of patients surveyed (65%) reported that MF caused them at least some physical, emotional, and financial hardship in the past month (Figure 7). Seventeen percent of patients reported that their condition caused a great deal of hardship in the past month.

Physical, Emotional, and Financial Hardship Caused by MF as Reported by Patients

<table>
<thead>
<tr>
<th>Statement</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>My condition has caused physical/emotional/financial hardship</td>
<td>35%</td>
<td>22%</td>
<td>16%</td>
<td>10%</td>
<td>17%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 7. Question 24: Rank the following statements as they have occurred during the past month, as a result of your MF (n = 207)
MF Interference With Patient Daily Activities

The survey showed that MF causes interference with a patient's daily activities. Most patients reported that their condition caused at least some interference in their family or social life, their sex life, or their daily activities (Figure 8).

Some MF patients reported that their condition caused a great deal of interference in their family or social life (17%), their sex life (9%), or their daily activities (21%) (Figure 8).

Interference With Daily Activities

![Bar chart showing the extent of interference in various daily activities.]

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Family or social life
- 21%
- 25%
- 20%
- 17%
- 17%

Daily activities
- 47%
- 15%
- 12%
- 6%
- 21%

Sex life
- 37%
- 25%
- 15%
- 15%
- 9%

Pain and discomfort are limiting my activities
- 39%
- 24%
- 13%
- 12%
- 12%

Figure 8. Question 25: To what extent does MF interfere with the following...? (n = 207)
Impact on Employment

The survey findings showed that MF had an impact on the employment and productivity of patients when they were in the workforce.

Most patients surveyed were retired (54%). For those patients in the workforce, nearly a fifth were employed full-time (18%), 8% were employed part-time, and 7% were self-employed (Figure 9). The rest of the patients surveyed reported being on disability (11%), unemployed (2%), or stay-at-home moms (1%).

Patients were also asked questions regarding the impact of MF on their employment status. Please note that those patients who reported “not applicable” to question 21 were excluded in the following percentages and chart below (Figure 10). More than half of those who were working after their diagnosis reported that they had to reduce hours at work (59%) as a result of their MF. Additionally, nearly a third of patients said they voluntarily terminated their job (31%), took early retirement (30%), or went on medical disability (28%) as a result of their condition (Figure 10).

Figure 9. Question 22: What is your current employment status? (n = 207)

<table>
<thead>
<tr>
<th>Patient Employment Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>11%</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>8%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>7%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2%</td>
</tr>
<tr>
<td>Stay-at-home mom</td>
<td>1%</td>
</tr>
<tr>
<td>Employed full-time</td>
<td>18%</td>
</tr>
<tr>
<td>Retired</td>
<td>54%</td>
</tr>
</tbody>
</table>

Impact on Employment Status as a Result of MF

- Reduced hours at work (n = 119) 59%
- Voluntarily terminated job (n = 125) 31%
- Early retirement (n = 125) 30%
- Medical disability (n = 134) 28%
- Involuntarily terminated from job (n = 120) 5%

Figure 10. Question 21a-e: As a result of your diagnosis have you ever...?*

*Note: Data excludes “Not applicable” responses.
Impact on Productivity

MF had an impact on productivity for those in the workforce as well as patient’s planned activities outside of work.

To better understand the impact of MF on a patient’s social life, patients were asked how many days of the last 30 days did they have to miss work or cancel any scheduled activities. They were also asked how many days were spent in bed most or all of the day because of MF.

Twenty-nine percent of patients reported taking at least 1 sick day from work as a result of MF (Figure 11). Forty-two percent of patients reported having to cancel at least 1 planned activity (Figure 12). Additionally, 32% of patients reported spending at least 1 day in bed all or most of the day (Figure 13). Of those MF patients who missed at least 1 day in the last 30 days, the average was 3 sick days, 6 days of canceled activities, and 6 days spent in bed.

**MF Impact on Patient Productivity**

**Sick Days From Work**

- 1–7 days, 27%
- 8–14 days, 2%
- None, 71%

**Canceled Activities**

- 1–7 days, 33%
- 8–14 days, 4%
- 15–21 days, 2%
- 22–30 days, 2%
- None, 59%

**Days Spent in Bed**

- 1–7 days, 25%
- 8–14 days, 2%
- 15–21 days, 4%
- 22–30 days, 1%
- None, 68%

*Figure 11. Question 23: In the last 30 days, how many days did you have to call in sick as a result of your diagnosis symptoms? (n = 52)*

*Note: Individual values are rounded and may not total 100%*

*Figure 12. Question 17: In the last 30 days, how many days did you have to cancel planned or scheduled activities as a result of your diagnosis? (n = 207)*

*Note: Individual values are rounded and may not total 100%*

*Figure 13. Question 18: In the last 30 days, how many days did you stay in bed all or most of the day as a result of your diagnosis? (n = 207)*

*Note: Individual values are rounded and may not total 100%*
Current State of Health

Patients surveyed were asked to describe their current state of health at the time of survey administration. Thirty-four percent of patients described their current state of health as “Fair” (Figure 14). A third of patients described their current state of health as “Good” (33%).

Nearly a fifth of patients reported their current state of health as “Very Good,” and another 6% reported their current state of health was “Excellent” (Figure 14).

On the opposite end of the spectrum, 6% of patients reported their current state of health as “Poor,” and 1% reported it as “Very Poor.”

![MF Patients Current State of Health](image)

**Figure 14. Question 7: How would you describe your current state of health? (n = 207)**

Note: Individual values are rounded and may not total 100%

Impact on QOL

An overwhelming majority of patients agreed that MF symptoms reduced their QOL. In fact, 50% of MF patients strongly agreed that MF symptoms reduced their QOL, while another 31% of patients somewhat agreed with this statement (Figure 15).

**MF Symptoms Reduced QOL Reported by Patients**

![Impact on QOL](image)

**Figure 15. Question 35a: Please indicate whether you agree/disagree with the following statement, MF symptoms reduce my quality of life (n = 207)**
Summary of Findings

- The most common symptoms reported by at least half of MF patients were fatigue, abdominal discomfort, night sweats, and difficulty sleeping (Figure 1).
- Overall, 96% of MF patients surveyed reported having experienced ≥1 symptom (Figure 1).
- Nearly half of MF patients reported fatigue as the symptom they would most like to resolve (Figure 3).
- Fatigue, bone pain, filling up quickly when eating, and unintentional weight loss were the most recognized symptoms associated with MF by patients who reported experiencing that symptom (Figure 4).
- Most patients reported that their condition had at least some emotional impact on them in the past month, causing them to feel “anxious or worried” and “depressed or discouraged” about their condition in the past month (Figure 5).
- Most MF patients reported that their condition had a physical impact on their life in the past month (Figure 6).
- Nearly two thirds of patients surveyed (65%) reported that MF has caused them at least some physical, emotional, and financial hardship in the past month (Figure 7).
- More than half of those who were working after their diagnosis reported that they had to reduce hours at work (59%) as a result of their MF. Additionally, nearly a third of patients said they voluntarily terminated their job (31%) or took early retirement (30%) as a result of their condition (Figure 10).
- Forty-two percent of patients reported having to cancel ≥1 planned activity; 32% of patients reported spending ≥1 day in bed, and 29% reported staying home from work for ≥1 day as a result of MF (Figures 11-13).
- Thirty-four percent of MF patients described their current state of health as “Fair” (Figure 14).
- Most MF patients (81%) strongly agreed or somewhat agreed that MF symptoms reduced their QOL (Figure 15).
PATIENT DIAGNOSIS & MEDICAL HISTORY

Timing of Diagnosis

MF patients were asked to recall the age and year in which they were first diagnosed. Most patients had been diagnosed within the last 5 years (64%) (Figure 16), and 42% of patients were diagnosed between the ages of 60-74 years (Figure 17). The median number of years since diagnosis for patients surveyed was 4 years, and the mean age at diagnosis was 59 years of age.

Time From Symptoms to Diagnosis

Patients were asked how long before their MF diagnosis they had experienced each of their reported symptoms. The time from specific symptoms to diagnosis varied by symptom. However, when examining all the symptoms, there was a span of more than a year between onset and diagnosis reported in 63% of MF patients. Furthermore, 47% of patients reported symptoms were experienced for more than 2 years before receiving a formal diagnosis (Figure 18).

Time From Symptoms Overall to MF Diagnosis

Figure 16. Question 2B_YEAR: In what year were you first diagnosed with myelofibrosis? (n = 175)
Note: Individual values are rounded and may not total 100%

Figure 17. Question 2B: At what age were you first diagnosed with myelofibrosis? (n = 182)
Note: Individual values are rounded and may not total 100%

Figure 18. Question 10a-dd: How long before you were diagnosed did you first experience [symptom]? (n = 161)
Note: Individual values are rounded and may not total 100%
Symptoms at Time of Diagnosis

Fatigue was the most common symptom at the time of diagnosis, reported by 58% of MF patients who reported symptoms (Figure 19). Patients also mentioned they experienced night sweats (28%), abdominal discomfort (26%), difficulty sleeping (25%), unintentional weight loss (25%), and filling up quickly when eating (21%). Nearly one fifth of patients reported no symptoms at time of diagnosis (19%).

Regarding spleen-related symptoms experienced by patients at time of diagnosis, 26% reported abdominal discomfort, 21% reported filling up quickly when eating, and 14% reported abdominal pain.

![Figure 19. Question 9: Which of these symptoms were you experiencing at time of diagnosis? (n = 199)](image-url)
Other Diagnosed Conditions

MF patients were asked to select other conditions they were managing in addition to MF, also known as comorbid conditions. Most patients (56%) reported no other conditions (Figure 20).

Forty-four percent of patients reported other conditions that included diabetes (6%), moderate to severe kidney disease (6%), emphysema/chronic obstructive pulmonary disease (COPD)/chronic bronchitis (5%), and leukemia (5%).

Other Conditions Experienced by Patients

Figure 20. Question 19: Do you currently have any of the following conditions? (n = 207)
Previous History of PV or ET Diagnosis

Patients diagnosed with MF could have been diagnosed previously with PV or ET and could have developed secondary MF. Close to a quarter of patients surveyed reported a previous diagnosis of PV (23%), and 28% had been diagnosed previously with ET (Figure 22).

Patient Bleeding History

MF may be characterized by a bleeding history, in addition to other symptoms. Most patients surveyed (73%) reported a history of bleeding before being diagnosed with MF (Figure 23). This percentage included those patients who selected the “other” response option which may have included conditions not related to bleeding. Easy bruising was experienced by most patients (52%) followed by nosebleeds (23%) and heavy menstrual periods (14%).

Patient-Reported Bleeding History Before MF Diagnosis

Figure 23. Question 26: Did you ever suffer from any of the following prior to being diagnosed with MF? (n = 207)
Note: “Other” category may have included conditions not related to bleeding
Diagnosed Bleeding Event History

In addition to a bleeding history, patients were asked if they had ever been diagnosed with a more serious bleeding event before their MF diagnosis. Although individually the bleeding events were relatively uncommon, collectively 36% of MF patients were diagnosed with ≥1 of these conditions (Figure 24). However, most patients reported they had never been diagnosed with a bleeding event (64%).

History of Diagnosed Bleeding Event Before MF Diagnosis

![Figure 24. Question 27: Were you ever diagnosed with any of the following prior to being diagnosed with MF? (n = 207)](image)

Note: “Other” category may have included conditions not related to bleeding

Summary of Findings

- The median number of years since diagnosis for patients surveyed was 4 years, and the mean age at diagnosis was 59 years (Figure 17).
- There was a span of more than a year between onset and diagnosis in 63% of MF patients. Furthermore, 47% of patients experienced symptoms for more than 2 years before they received a formal diagnosis (Figure 18).
- Fatigue was the most common symptom at the time of diagnosis, reported by 58% of MF patients in the survey (Figure 19).
- Slightly more than half (56%) of patients reported they had no other diagnosed conditions in addition to MF; of the 44% that did report a concomitant condition, it was either diabetes or kidney disease (Figure 20).
- Close to a quarter of patients (23%) reported a previous diagnosis of PV (Figure 21), and 28% had been diagnosed previously with ET (Figure 22).
- Most patients (73%) reported having a bleeding history before being diagnosed with MF (Figure 23).
- Most patients (64%) reported they had never been diagnosed with a serious bleeding event, whereas 36% had been (Figure 24).
Changing Physicians

MF patients were asked whether they had ever changed their MF physician and if so, why they had made that change. The survey results found that nearly half of MF patients (47%) had changed their MF physician (Figure 25). The most common reason for making the change was that the patient was unhappy with the care received from the physician (40%) (Figure 26). A smaller proportion of patients (17%) said they changed physicians because their physician had retired. Although nearly half of MF patients have switched physicians, most patients reported they were highly satisfied with their current physician.

**Figure 25. Question 39: Have you ever changed your MF doctor? (n = 207)**
Note: Individual values are rounded and may not total 100%

**Reasons for Changing MF Physician**

<table>
<thead>
<tr>
<th>Reason</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was unhappy with the care received</td>
<td>40%</td>
</tr>
<tr>
<td>My doctor retired</td>
<td>17%</td>
</tr>
<tr>
<td>I relocated to a different city or state</td>
<td>13%</td>
</tr>
<tr>
<td>Wanted a second opinion or specialist (someone with more knowledge)</td>
<td>12%</td>
</tr>
<tr>
<td>Referred to another doctor/assigned new doctor in same practice</td>
<td>8%</td>
</tr>
<tr>
<td>My insurance coverage changed</td>
<td>4%</td>
</tr>
<tr>
<td>Doctor moved/leaved practice/otherwise no longer available</td>
<td>3%</td>
</tr>
<tr>
<td>Wanted a more convenient location, closer to home</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
</tbody>
</table>

**Figure 26. Question 39A: Why did you make a change? (n = 97)**
Note: Individual values are rounded and may not total 100%
Number of MF Physician Visits Per Year

On average, MF patients saw their physician 11 times in the last year. However, there was a broad variation among MF patients as shown in Figure 27. More than half of MF patients reported 6 or fewer physician visits in the past year (56%), and the remainder reported 7 or more visits in the past year.

Number of MF Physician Visits in the Past 12 Months

![Bar chart showing the distribution of visits per patient category with percentages for each range: 0 (1%), 1–2 (11%), 3–4 (26%), 5–6 (18%), 7–10 (12%), 11–15 (15%), 16–20 (6%), 21–25 (4%), 26–30 (2%), >30 (5%).]

Figure 27. Question 38: How many times have you seen your doctor in the last 12 months? (n = 207)

Note: Individual values are rounded and may not total 100%
Treatment Management Ever Received Reported by Patients

Patients were asked to select the treatments that they had ever received to help manage their MF. It should be noted that patients may not have been receiving reported treatment(s) at time of survey completion.

The most common treatment patients had ever taken to manage their condition was antiplatelet therapy (62%). Nearly half of all patients reported taking targeted therapy (48%), and 42% of patients reported taking chemotherapy at some point in their disease (Figure 28).

Treatments unrelated to drugs were also included in the list. Over a third of MF patients (36%) reported having received a procedure.

Treatment Management Ever Received Reported by MF Patients

Figure 28. Question 28: Select any of the following treatments that you have ever received to help manage your diagnosis. (n = 207)
Burden of Treatment Side Effects

Patients surveyed who reported ever receiving specific treatments (bone marrow transplant, removal of spleen, transfusion, and radiation therapy) were asked to report the extent to which side effects from those specific treatments negatively affected their QOL.

Most patients (89%) who had ever received a bone marrow transplant (n = 9), reported side effects had at least some negative impact on their QOL (Figure 29). Twenty-two percent of those patients reported the side effects from bone marrow transplant had “a great deal” of negative impact on their QOL.

Seventy-one percent of patients who had their spleen removed (n = 7) reported at least some negative impact on their QOL from side effects related to the treatment.

A little more than a third of patients (35%) who had received a transfusion (n = 66), reported the side effects had at least some negative impact on their QOL.

Of the 6 patients who received radiation therapy, 67% reported that side effects from radiation had at least some negative impact on their QOL.

Burden of Treatment Side Effects as Reported by MF Patients

![Bar chart showing the burden of treatment side effects as reported by MF patients.](image)

Figure 29. Question 28cc-rr: On a scale from 1 (not at all) to 5 (a great deal), to what extent do side effects from [treatment] have a negative impact on your quality of life?
Treatment Management Goal Attitudes Reported by Patients

Patients were asked, aside from a cure for MF, what was their most important goal for therapy. Among the MF patients in the survey sample, slowing or delaying disease progression was the most important goal for therapy reported by 42% of patients (Figure 30).

Better QOL reported by 21% of patients surveyed and healthy blood counts (11% of patients surveyed) were also mentioned within the top 3 most important goals for therapy.

**Most Important Goal for Therapy Reported by Patients**

![Figure 30](image)

- **Slow/delay progression**: 42%
- **Better QOL**: 21%
- **Healthy blood counts**: 11%
- **Symptom improvement**: 7%
- **Reduction in spleen size**: 6%
- **Reduce blood transfusions**: 6%
- **Anemia treatment**: 4%
- **Prevention of vascular/thrombotic events**: 3%
- **Other (specify)**: 1%

Figure 30. Question 32: Other than a cure for diagnosis, what is your most important treatment goal for therapy? (n = 207)

Other Therapies Beyond Prescription Drugs and Treatments

Patients surveyed were asked to report any other therapies, beyond prescription drugs and treatments, they used to manage MF symptoms. Most patients (60%) reported they exercised to help manage MF symptoms (Figure 31). Additionally, nearly half of patients surveyed (48%) reported taking nonprescription supplements to manage symptoms. A quarter of patients (25%) mentioned a change in their diet to help manage symptoms.

**Managing MF Symptoms Beyond Prescription Drugs and Treatments**

![Figure 31](image)

- **Exercise**: 60%
- **Nonprescription supplements**: 48%
- **Change in diet to combat specific nutrient deficiencies**: 25%
- **Meditation**: 14%
- **Massage**: 13%
- **Nutritional supplements**: 12%
- **Yoga**: 10%
- **Acupuncture**: 5%
- **Don’t know**: 12%

Figure 31. Question 31: Aside from prescription drugs and treatments, select any of the following things you do to manage your myelofibrosis symptoms? (n = 207)
Patient Measures of Treatment Success

In addition to their goals for treatment, patients were asked what measures they used to determine whether an MF treatment was successful or not. Most commonly, MF patients (84%) selected lab results or blood counts as one of the measures they used to evaluate their treatment (Figure 32).

Measures of Treatment Success Reported by Patients

<table>
<thead>
<tr>
<th>Measure</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lab results/blood count levels</td>
<td>84%</td>
</tr>
<tr>
<td>Feedback from doctor</td>
<td>71%</td>
</tr>
<tr>
<td>Reduction in spleen size</td>
<td>46%</td>
</tr>
<tr>
<td>Overall symptom relief</td>
<td>42%</td>
</tr>
<tr>
<td>Enhances QOL</td>
<td>40%</td>
</tr>
<tr>
<td>Fewer symptoms</td>
<td>40%</td>
</tr>
<tr>
<td>Reduce blood transfusions</td>
<td>21%</td>
</tr>
<tr>
<td>Prevent or reduce thrombotic events</td>
<td>9%</td>
</tr>
<tr>
<td>None</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
</tbody>
</table>

Figure 32. Question 30: What measures do you use to determine whether a treatment is successful or not successful? (n = 207)

Summary of Findings

- Nearly half of MF patients (47%) had changed their MF physician, and the most common reason for making the change was unhappiness with the care received from the physician (40%) (Figures 25-26).
- MF patients saw their physician an average of 11 times in the last year (Figure 27).
- The most common treatment patients had ever received to manage their condition was antiplatelet therapy (62%). Nearly half of all patients (48%) reported ever taking targeted therapy, and 42% of patients reported taking chemotherapy at some point in their disease (Figure 28).
- A little more than a third of patients (35%) who had received a transfusion (n = 66) reported the side effects had at least some negative impact on their QOL (Figure 29).
- Among the MF patients in the survey sample, slowing or delaying disease progression was the most important goal for therapy reported by 42% of patients (Figure 30).
- Most patients (60%) reported they exercised to help manage MF symptoms (Figure 31).
- Most MF patients (84%) selected lab results or blood counts as one of the measures they used to evaluate their treatment (Figure 32).
Utilization of Prognostic Risk Score Assessments

Physicians were asked a series of questions about their utilization of prognostic risk score assessments. Most physicians reported they used a prognostic risk score assessment (83%) for the management of their patients’ MF (Figure 33).

Subsequently, those physicians who answered “yes” were asked to select the prognostic risk score assessment tool they used most often. Forty-five percent of physicians who used a prognostic risk score assessment tool selected the International Prognostic Scoring System (IPSS) as their most commonly utilized tool (Figure 34).

Close to one fifth of physicians (17%) reported they did not use a prognostic risk score assessment tool for the management of their patients’ MF. When asked to select from a list of reasons why not, most reported they were familiar with the assessment tools; however, they did not find them very useful (63%). Other reasons included “not familiar with any available prognostic risk assessments” (19%) and “assessments are useful but I do not have enough time to incorporate them into my practice” (19%).

Utilization of Prognostic Risk Score Assessments Reported by Physicians

Yes, 83%

No, 17%

Figure 33. Question 26A: Do you classify your MF patients according to prognostic risk category? (n = 156)

Most Commonly Utilized Prognostic Risk Score Assessment

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Utilization</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Prognostic Scoring System (IPSS)</td>
<td>45%</td>
</tr>
<tr>
<td>International Prognostic Scoring System Plus (IPSS+)</td>
<td>18%</td>
</tr>
<tr>
<td>Dynamic International Prognostic Scoring System (DIPSS)</td>
<td>19%</td>
</tr>
<tr>
<td>Dynamic International Prognostic Scoring System Plus (DIPSS+)</td>
<td>17%</td>
</tr>
<tr>
<td>Lille Scoring System</td>
<td>2%</td>
</tr>
<tr>
<td>IPSET Thrombosis</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
</tr>
</tbody>
</table>

Figure 34. Question 26B: Select the prognostic assessment you utilize the most. (n = 129)
Current Treatment Management Reported by Physicians

Physicians were provided with the same list of treatments as the patient survey and were asked to select the treatments they had ever recommended to their MF patients. An overwhelming majority of physicians (92%) reported they had recommended targeted therapy to their MF patients. Also, among the other commonly ever recommended treatments were procedures (94%), antiplatelet therapy (85%), and chemotherapy (72%).

Treatments Ever Recommended by Physicians to Manage Diagnosis

- Procedures: 94%
- Targeted therapy: 92%
- Antiplatelet therapy: 72%
- Chemotherapy: 65%
- Erythropoetin stimulating agents (ESA): 48%
- Immunomodulatory: 43%
- Corticosteroids: 42%
- Anticoagulant: 35%
- Antihistamine: 35%
- Antidepressants: 35%
- Other: 35%

Figure 36. Question 34: Have you ever recommended any of the following treatments to your MF patients? (n = 156)
Decision to Observe Patient or Recommend Drug Treatment at Time of Diagnosis

Physicians surveyed were asked to estimate the proportion of patients they decided to observe at time of diagnosis (Figure 37). They were next asked to estimate the proportion of patients to whom they decided to recommend drug treatment at diagnosis (Figure 38).

Physician-Reported Estimated Proportion of Patients Physicians Decided to Observe at Diagnosis

![Bar chart showing the proportion of patients physicians chose to observe instead of recommending drug treatment.](chart)

Figure 37. Question 11: What proportion of patients do you choose to observe instead of recommending drug treatment? (n = 156)

Physician-Reported Estimated Proportion of Patients for Whom Drug Treatment Was Recommended at Diagnosis

![Bar chart showing the proportion of patients for whom drug treatment was recommended at diagnosis.](chart)

Figure 38. Question 12: What proportion of your newly diagnosed patients do you ever recommend drug treatment at time of diagnosis? (n = 156)
**Recommendation for Drug Treatment by Symptom Severity**

Physicians were asked about their likelihood to recommend drug treatment for MF patients based on the severity of their symptoms. Physicians reported they would recommend treatment for an average of only 13% of patients with mild symptoms, 53% of patients with moderate symptoms, and 84% of patients with severe symptoms (Figure 39).

**Physician-Reported Recommendation for Drug Treatment Based on Symptom Severity**

![Bar chart showing recommendation rates by symptom severity](image)

Figure 39. Question 33a-c: What proportion of those MF patients who are experiencing [mild, moderate or severe] symptoms alone, do you ever recommend drug treatment? (n = 156)

**Physician Perception of the Impact Symptom Severity Had on Patient QOL and Drug Treatment**

In another part of the survey, almost all physicians (96%) agreed even mild to moderate symptoms can have a significant impact on a patient’s QOL (Figure 40). Despite the significant impact to QOL, physicians surveyed recommended drug treatment in just over half of patients (53%) with moderate symptoms and rarely recommended drug treatment to patients with mild symptoms (13%) (Figure 39).

**Symptom Impact on QOL**

![Bar chart showing percentage of agreement](image)

Figure 40. Question 22: Agree or disagree with the following statements: Even mild to moderate symptoms can have a significant impact on the quality of life. (n = 156)

Note: Labels for data under 5% are not displayed
Recommendation for Drug Treatment by Presence of Specific Symptoms

Physicians were asked about their likelihood to recommend drug treatment for MF patients based on the presence of specific symptoms. Physicians were most likely to recommend drug treatment for MF patients who were experiencing symptomatic splenomegaly (82%) (Figure 41). Additionally, physicians reported recommending drug treatment for patients experiencing drenching night sweats (65%), fever (59%), unintentional weight loss (59%), and marked leukocytosis (51%). Physicians were slightly less likely to recommend drug treatment in patients experiencing anemia (49%).

Recommendation for Drug Treatment Based on Presence of Specific Symptoms Reported by Physicians

![Graph showing the proportion of MF patients experiencing specific symptoms and likelihood of drug treatment recommendations.]

Figure 41. Question 33d-i: What proportion of those MF patients who are experiencing [specific symptom], do you ever recommend drug treatment? (n = 156)

Treatment Management Goal Attitudes Reported by Physicians

Like patients, physicians were asked to report, aside from a cure for MF, their most important goal for therapy. Most physicians (53%) reported symptom improvement as their most important goal for MF therapy (Figure 42). The second most important goal for therapy reported by physicians was better QOL (26%). The third most important goal for therapy was to slow or delay progression of MF (12%).

Most Important Goal for Therapy Reported by Physicians

![Graph showing the percentage of physicians prioritizing different treatment goals.]

Figure 42. Question 36: Other than a cure for this diagnosis, what is your most important treatment goal for therapy? (n = 156)
Reasons to Change Treatment Reported by Physicians

Physicians reported disease progression (92%) as the top reason to change drug treatment in their MF patients (Figure 43). Side effects (89%) and lack of efficacy (87%) were also reported by the vast majority of physicians.

Overall, most of the reasons listed were selected by most physicians surveyed, with the exception of change in blood counts, which was selected by less than half of physicians (45%).

Physician Reported Reasons to Change Drug Therapy

Unmet Needs in Current Treatments as Reported by Physicians

Physicians were asked in an open-ended question what they considered to be the most important unmet need in MF treatment. Data showed a substantial amount of overlap that occurred in physician responses; therefore, all answers were coded and grouped into broad categories for the purposes of this report. These categories were selected based on a qualitative analysis of the total responses recorded.

More than half of all physicians surveyed (61%) mentioned more effective drugs or therapies for MF as their most important unmet need (Figure 44). A smaller group of physicians mentioned a need for greater symptom improvement (22%), and 19% said that a cure for MF is their most important unmet need.

Most Important Unmet Need in Current Treatments as Reported by Physicians

Unmet Needs in Current Treatments as Reported by Physicians

Physicians were asked in an open-ended question what they considered to be the most important unmet need in MF treatment. Data showed a substantial amount of overlap that occurred in physician responses; therefore, all answers were coded and grouped into broad categories for the purposes of this report. These categories were selected based on a qualitative analysis of the total responses recorded.

More than half of all physicians surveyed (61%) mentioned more effective drugs or therapies for MF as their most important unmet need (Figure 44). A smaller group of physicians mentioned a need for greater symptom improvement (22%), and 19% said that a cure for MF is their most important unmet need.
MF Patients in Comparison With All Other Patients in Clinic/Practice

Physicians were asked to rank their MF patients (1 = least and 5 = most) in terms of priority of time spent on medical care in comparison with all the patients they see in their clinic/practice. The reported mean rank calculated from all responses was 3.5 of 5 (Figure 45).

Additionally, physicians were asked to rank their MF patients in terms of their disease burden compared with all other patients in their clinic/practice. Similar to the previous question, the reported mean rank calculated from all responses was 3.4 of 5.

MF Patients Compared With All Other Patients in Physician’s Clinic/Practice

When thinking about all the patients you currently see in your clinic/practice, where do you rank your MF patients in terms of priority for time spent on medical care?

When thinking about all the patients you currently see in your clinic/practice, where do you rank your MF patients in terms of their disease burden?

Figure 45. Question 52: When thinking about all the patients you currently see in your clinic/practice, where do you rank your MF patients in terms of priority for time spent on medical care? (n = 156) Question 53: When thinking about all the patients you currently see in your clinic/practice, where do you rank your MF patients in terms of their disease burden? (n = 156)

Note: Labels for data under 5% are not displayed

Summary of Findings

- Most physicians (83%) reported using a prognostic risk score assessment tool to manage their patients’ MF, and the most commonly used tool was the International Prognostic Scoring System (IPSS) (Figures 33 and 34).
- Physicians recommended drug therapy to an average of 13% of MF patients with mild symptoms, 53% of patients with moderate symptoms, and 84% of patients with severe symptoms.
- Physicians were most likely to recommend drug treatment for MF patients who were experiencing symptomatic splenomegaly (82%) (Figure 41).
- Most physicians reported symptom improvement (53%) as their most important goal for MF therapy, followed by better QOL (26%), and slowing/delaying the progression of disease (12%) (Figure 42).
- Physicians reported disease progression (92%) as the top reason to change drug treatment in their MF patients (Figure 43).
- More than half of all physicians surveyed (61%) mentioned more effective drugs or therapies for MF as their most important unmet need (Figure 44).
COMPARISON OF PATIENT & PHYSICIAN PERCEPTIONS

Patient-Reported vs Physician-Reported Symptom Assessment

The following section is a comparison of a set of questions that were asked of both patients and physicians in their respective surveys. The purpose of the comparison is to note any areas within the reported data where concordance or discordance may exist in the perception of physicians and their patients. These areas demonstrate that although a conversation is occurring between patients and their physicians, there is room for improvement on both ends that may lead to improved patient outcomes.

The survey provided an opportunity to compare patient and physician perspectives on how MF symptoms are assessed during physician visits. Patients were asked how the physician they see most often assesses MF symptoms they might be experiencing. Physicians were asked how they assess patient symptoms during an average patient visit. There was a significant gap in how patients reported that their physicians assess their symptoms and how physicians described their symptom assessment methods.

Most MF patients (51%) stated that physicians just proactively asked how they were feeling overall, whereas most physicians (55%) reported that they specifically asked about most important symptoms (Figure 46).

In addition to assessment methods, physicians were also asked what tools they used to assess the severity of symptoms experienced by their patients. Most physicians reported that they took into consideration the impact on activities of daily living (72%) and/or their own rating (56%). Only 15% of physicians reported that they used assessment forms.

Patient-Reported Symptom Assessment

Physician-Reported Symptom Assessment

Figure 46. Question 41: How does the doctor you see most often for your diagnosis, assess any symptoms you may be experiencing? (n = 207)

Figure 47. Question 27: During an average patient visit, how do you assess patient’s symptoms? (n = 156)
### Patient-Reported Symptoms vs Symptoms Heard by Physicians

MF patients were asked to report all the symptoms they had ever experienced from having MF, and for comparison, physicians were asked for the 5 symptoms they heard the most from their MF patients. Findings showed that there was similar agreement between patients and physicians on the top symptoms. For instance, fatigue was the most commonly experienced symptom by patients (81%) (Figure 48) and the symptom most commonly heard by physicians from MF patients (96%) (Figure 49). Abdominal discomfort was the second most commonly reported symptom by patients (58%) and the second most commonly heard symptom among physicians (75%). Additionally, night sweats were the third most common symptom among patients (55%) and the fourth most commonly heard symptom among physicians (47%).

However, gaps existed beyond the top symptoms experienced by patients and heard by physicians. Fifty-three percent of patients experienced difficulty sleeping, the fourth most common symptom reported, whereas physicians rarely (8%) reported it in the top 5 symptoms they heard from patients. Additionally, 42% and 41% of MF patients experienced dizziness/vertigo and numbness/tingling in hands and feet, but physicians rarely reported (8% and 4%) these symptoms (Figure 49).

### Symptoms Ever Experienced by MF Patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Patient-reported</th>
<th>Physician-reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>81%</td>
<td></td>
</tr>
<tr>
<td>Abdominal discomfort</td>
<td>58%</td>
<td></td>
</tr>
<tr>
<td>Night sweats</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>53%</td>
<td></td>
</tr>
<tr>
<td>Itching (pruritus)</td>
<td>45%</td>
<td></td>
</tr>
<tr>
<td>Filling up quickly when eating</td>
<td>44%</td>
<td></td>
</tr>
<tr>
<td>Bone pain</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Dizziness/vertigo/lightheadedness</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>Unintentional weight loss</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>Depression or sad mood</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Inactivity</td>
<td>33%</td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td>31%</td>
<td></td>
</tr>
<tr>
<td>Problems with sexual desire</td>
<td>31%</td>
<td></td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Problems with concentration</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Problems with headaches</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>Fever (&gt;100°F)</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>

Figure 48. Question 8: Have you ever had any of the following symptoms? (n = 207)
Symptoms Most Heard by MF Physicians

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>96%</td>
</tr>
<tr>
<td>Abdominal discomfort</td>
<td>75%</td>
</tr>
<tr>
<td>Filling up quickly when eating</td>
<td>62%</td>
</tr>
<tr>
<td>Night sweats</td>
<td>47%</td>
</tr>
<tr>
<td>Unintentional weight loss</td>
<td>42%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>35%</td>
</tr>
<tr>
<td>Itching (pruritus)</td>
<td>30%</td>
</tr>
<tr>
<td>Bone pain</td>
<td>30%</td>
</tr>
<tr>
<td>Inactivity</td>
<td>26%</td>
</tr>
<tr>
<td>Fever (&gt;100°F)</td>
<td>15%</td>
</tr>
<tr>
<td>Depression or sad mood</td>
<td>9%</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>8%</td>
</tr>
<tr>
<td>Dizziness/vertigo/lightheadedness</td>
<td>8%</td>
</tr>
<tr>
<td>Problems with headaches</td>
<td>8%</td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet</td>
<td>4%</td>
</tr>
<tr>
<td>Problems with concentration</td>
<td>3%</td>
</tr>
<tr>
<td>Cough</td>
<td>2%</td>
</tr>
<tr>
<td>Problems with sexual desire</td>
<td>1%</td>
</tr>
</tbody>
</table>

Figure 49. Question 15: What are the five symptoms of MF you most often hear about from your patients? (n = 156)

Patient-Reported Symptoms at Diagnosis vs Physician-Reported

Overall 81% of patients reported symptoms at time of diagnosis. In comparison, physicians were asked to estimate the proportion of patients who presented with symptoms at time of diagnosis. Physicians estimated a mean of 82% of patients who presented with symptoms ranging from mild to moderate severity at time of diagnosis. The physician estimate was very closely aligned with patient-reported data. (Figure 50).

Percentage of Patients With Symptoms at Time of Diagnosis as Reported by Patients vs Physicians-Reported Estimate

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-reported</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>81%</td>
</tr>
<tr>
<td>Physician-reported</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>82%</td>
</tr>
</tbody>
</table>

Figure 50. Question 9: Which of these symptoms were you experiencing at time of diagnosis? (n = 199) Question 10a-d: Out of 100%, what proportion of all newly diagnosed MF patients do you estimate have [no, mild, moderate or severe] symptoms? (n = 156)
Patient-Reported Symptom Resolution vs Physician-Reported Perception

Identical to the patient survey, physicians were asked to select the 1 symptom patients would most like to resolve. Almost two thirds of physicians selected fatigue (65%) as the top symptom to resolve (Figure 51). Fatigue was selected by almost half of MF patients (47%).

Patient-Reported First Symptom They Would Like to Resolve vs Physician-Reported Perception

Figure 51. Question 14: Of the symptoms that you are currently experiencing, which one would you most like to resolve? (n = 199)

Question 17: Out of all the symptoms patients experience, which single symptom do you perceive they would most want to resolve? (n = 156)

Note: Labels for data under 5% are not displayed
Patient-Reported Symptom Recognition vs Physician-Reported Perception

As previously reported in Figure 4, most MF patients in this survey recognized the most common symptoms associated with MF. For comparison, physicians were asked to report the proportion of their MF patients they felt were able to recognize the symptoms associated with MF.

Most physicians (53%) reported that all or almost all of their patients were able to recognize the symptoms associated with MF (Figure 52). Less than half of physicians (47%) reported that some or a few of their patients could recognize the symptoms associated with MF.

**Physician’s Perception of Patients’ Ability to Recognize Symptoms**

![Pie chart showing the distribution of physicians' perceptions of patients' symptom recognition.](image)

- Almost all, 49%
- Some, 42%
- Few, 6%
- None, 0%
- All, 3%

Figure 52. Question 31: What proportion of your MF patients recognize their symptoms as being related to MF? (n = 156)

Note: Individual values are rounded and may not total 100%
Patient-Reported Symptom Severity vs Physician Perception

There was less agreement between patients and physicians when it came to the severity of symptoms. Patients reported fatigue, problems with sexual desire, and inactivity as the most severe symptoms (Figure 53). However, when physicians were asked about the symptoms that had the most negative impact on a patient’s QOL, fatigue, filling up quickly when eating, and abdominal pain were among their top selections.

Patient-Reported MPN-SAF Mean Severity Score by MF Symptom

* Symptoms with most negative impact on QOL as reported by physicians.

Figure 53. Question 13a-dd: How severe is [symptom]?
Patient-Reported History of Diagnosed Bleeding Event vs Physician-Reported

Seventy-three percent of patients reported some type of bleeding history such as easy bruising and nosebleeds before their MF diagnosis, and slightly more than a third of MF patients reported that, before their MF diagnosis, they had been diagnosed with a serious bleeding event (36%) before receiving their MF diagnosis. These percentages included those patients who selected the “other” response option which may have included conditions not related to bleeding. When physicians were asked what proportion of their patients had a previous history of a serious thrombotic/bleeding event, they reported a mean of 18% of patients, which is about half that reported by patients.

Patient-Reported Goals for Therapy vs Physician-Reported

There was significant discordance when patients and physicians were asked, aside from a cure for MF, what was their most important goal for therapy. Among the MF patients in the survey sample, slowing or delaying disease progression (42%) was the single most important goal for therapy, whereas only 12% of physicians selected this response (Figure 54). Among physicians, most reported symptom improvement (53%) as their most important goal for MF therapy, whereas only 7% of patients selected this as their most important goal.

Patient-Reported Most Important Goal for Therapy vs Physician-Reported

<table>
<thead>
<tr>
<th>Goal</th>
<th>Patient-reported</th>
<th>Physician-reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slow/delay progression</td>
<td>42%</td>
<td>12%</td>
</tr>
<tr>
<td>Better quality of life</td>
<td>26%</td>
<td>21%</td>
</tr>
<tr>
<td>Healthy blood counts</td>
<td>0%</td>
<td>11%</td>
</tr>
<tr>
<td>Symptom improvement</td>
<td>53%</td>
<td>7%</td>
</tr>
<tr>
<td>Reduction in spleen size</td>
<td>6%</td>
<td>3%</td>
</tr>
<tr>
<td>Reduce blood transfusions</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Anemia treatment</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Prevention of vascular/thrombotic events</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Figure 54. Question 32: Other than a cure for diagnosis, what is your most important treatment goal for therapy? (n = 207)
Question 36: Other than a cure for this diagnosis, what is your most important treatment goal for therapy? (n = 156)
Patient-Reported Involvement in Treatment Decisions vs Physician-Reported

There was alignment between patients and physicians when it came to the extent of patient involvement in treatment decisions. Patients were asked about their desired involvement in treatment decisions, and conversely physicians were asked to rank the extent to which patients want to be involved in treatment decisions (1 = not at all to 5 = a great deal). Most patients surveyed reported a preference to have at least 50% involvement in treatment decisions (Figure 55). When looking at physician’s preference, most physicians reported that their patients want to be involved with a ranking of either a “4” (44%) or a “5” (26%).

Physicians were subsequently asked about patient compliance with their primary treatment recommendations. Interestingly, 77% of physicians reported that their patients sometimes (65%) or often (12%) did not wish to comply with their recommendation.

Preference for Decision Maker Regarding MF Treatments: Patient-Reported vs Physician-Reported

![Preference for Decision Maker Regarding MF Treatments Chart]

Figure 55. Question 45A: Now select the percentage that best represents your preference for who the main decision maker should be when it comes to decisions regarding your MF treatment. (n = 155) Question 40: To what extent do your patients want to be involved in decisions regarding their treatment? (n = 156)

Note: Labels for data under 5% are not displayed
Patient-Reported vs Physician-Reported Prognostic Risk Score Assessment

There are validated prognostic risk assessment tools available for calculating an MF patient’s prognosis. The survey found that 83% of physicians said that they classified their MF patients according to prognostic risk (Figure 57). By contrast, only 54% of MF patients reported that their MF physician had provided a risk classification for their condition. Of those patients who received a prognostic risk score, 35% were classified as high-risk, 49% were classified as intermediate-risk, and 16% were classified as low-risk (patient-reported).

Figure 56. Question 40: Did your diagnosis doctor classify your current condition with a particular risk score? (n = 207)
Note: Individual values are rounded and may not total 100%

Figure 57. Question 26A: Do you classify your MF patients according to prognostic risk category? (n = 156)
Note: Individual values are rounded and may not total 100%
Patient-Reported Emotional Impact of MF vs Physician Perception

Most physicians ranked all of the items between a “3” to “5,” suggesting moderate to a great deal of emotional impact to patients (Figure 59). Physicians seemed to overestimate the emotional impact of MF on their patients. Most patients and physicians agreed that patients reported feeling anxious or worried and discouraged or depressed about their condition.

### Patient-Reported Emotional Impact of MF

<table>
<thead>
<tr>
<th>Statement</th>
<th>1%</th>
<th>2%</th>
<th>3%</th>
<th>4%</th>
<th>5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have felt anxious or worried about their condition</td>
<td>9%</td>
<td>27%</td>
<td>27%</td>
<td>19%</td>
<td>18%</td>
</tr>
<tr>
<td>I have felt depressed or discouraged</td>
<td>25%</td>
<td>33%</td>
<td>25%</td>
<td>10%</td>
<td>8%</td>
</tr>
<tr>
<td>I have been irritable/angry</td>
<td>22%</td>
<td>22%</td>
<td>12%</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>I have had trouble coping with the stress</td>
<td>50%</td>
<td>25%</td>
<td>19%</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>My condition is controlling my life</td>
<td>33%</td>
<td>25%</td>
<td>19%</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>I have avoided social interactions</td>
<td>75%</td>
<td>12%</td>
<td>7%</td>
<td>5%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Figure 58. Question 24a-k: Rank the following statements as they have occurred during the past month, as a result of your MF (n = 207)

Note: Labels for data under 10% are not displayed

### Physician-Reported Perceptions of Emotional Impact of MF

<table>
<thead>
<tr>
<th>Statement</th>
<th>1%</th>
<th>2%</th>
<th>3%</th>
<th>4%</th>
<th>5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have felt anxious or worried about their condition</td>
<td>14%</td>
<td>51%</td>
<td>32%</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>Have felt depressed or discouraged</td>
<td>8%</td>
<td>24%</td>
<td>49%</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>Have been irritable/angry</td>
<td>5%</td>
<td>22%</td>
<td>37%</td>
<td>26%</td>
<td>15%</td>
</tr>
<tr>
<td>Have had trouble coping with the stress</td>
<td>13%</td>
<td>31%</td>
<td>39%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>Their condition is controlling their life</td>
<td>6%</td>
<td>32%</td>
<td>35%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>Have avoided social interactions</td>
<td>8%</td>
<td>21%</td>
<td>39%</td>
<td>26%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Figure 59. Question 20a-k: As a result of their condition, do you think patients with MF may feel/experience...? (n = 156)

Note: Labels for data under 5% are not displayed
Patient-Reported Physical Impact of MF vs Physician Perception

Most physicians ranked all items between a “3” to “5” on a scale from 1 (not at all) to 5 (a great deal), reporting moderate to a great deal of physical impact (Figure 61). However, most patients ranked the items between a “1” to “2,” suggesting no impact or very little physical impact.

### Patient-Reported Perceptions of Physical Impact of MF

<table>
<thead>
<tr>
<th>Statement</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sleeping habits have changed</td>
<td>43%</td>
<td>22%</td>
<td>14%</td>
<td>15%</td>
<td>7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have noticed a change in my appetite</td>
<td>53%</td>
<td>15%</td>
<td>18%</td>
<td>8%</td>
<td>7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have trouble focusing at work/reading/watching TV</td>
<td>47%</td>
<td>21%</td>
<td>17%</td>
<td>10%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My condition has caused changes in how I look</td>
<td>48%</td>
<td>22%</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 60. Question 24a-k: Rank the following statements as they have occurred during the past month, as a result of your MF. (n = 207)
Note: Labels for data under 5% are not displayed

### Physician-Reported Perceptions of Physical Impact of MF

<table>
<thead>
<tr>
<th>Statement</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleeping habits have changed</td>
<td>15%</td>
<td>39%</td>
<td>35%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noticed a change in appetite</td>
<td>30%</td>
<td>44%</td>
<td>22%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble focusing at work/reading/watching TV</td>
<td>12%</td>
<td>35%</td>
<td>39%</td>
<td>11%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition has caused changes in how the patient looks</td>
<td>7%</td>
<td>24%</td>
<td>39%</td>
<td>22%</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 61. Question 20a-k: As a result of their condition, do you think patients with MF may feel/experience...? (n = 156)
Note: Labels for data under 5% are not displayed

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Patient-Reported Attitudes Towards MF vs Physician-Reported

Patients and physicians were asked a series of questions regarding their attitudes towards MF. There was alignment on all of the questions. Most patients (81%) and physicians (97%) agreed or strongly agreed that symptoms reduced a patient’s QOL (Figures 62-63). Additionally, 98% of patients agreed or strongly agreed that MF is a serious condition. Most physicians agreed or strongly agreed (88%) that MF is a blood cancer. Lastly, most patients (98%) and physicians (99%) agreed or strongly agreed that MF may progress to more serious conditions.

**Patient-Reported Attitudes Towards MF**

![Bar chart showing patient responses](Figure 62)

- Symptoms reduce my quality of life: 12% strongly disagree, 7% somewhat disagree, 31% somewhat agree, 50% strongly agree.
- MF is a serious health condition: 7% strongly disagree, 90% strongly agree.
- MF may progress to more serious conditions: 10% strongly disagree, 88% strongly agree.

**Physician-Reported Attitudes Towards MF**

![Bar chart showing physician responses](Figure 63)

- Symptoms reduce a patient’s quality of life: 21% strongly disagree, 76% strongly agree.
- MF is a blood cancer: 9% strongly disagree, 35% somewhat disagree, 53% strongly agree.
- MF may progress to more serious conditions: 17% strongly disagree, 81% strongly agree.

*Note: Labels for data under 5% are not displayed*
Summary of Findings

- Most MF patients (51%) stated physicians just proactively asked how they were feeling overall, whereas most physicians (55%) stated that they asked about most important, specific symptoms (Figure 46).

- Findings showed that there was similar agreement between what patients reported as top symptoms experienced versus what top symptoms physicians heard (fatigue, abdominal discomfort, and night sweats). However, gaps existed. For example, 53% of MF patients experienced difficulty sleeping, the fourth most common symptom reported; however, physicians rarely (8%) reported it (Figures 48-49).

- Overall 81% of patients reported symptoms at time of diagnosis. In comparison, physicians estimated a mean of 82% of patients who presented with symptoms ranging from mild to moderate severity at time of diagnosis (Figure 50).

- Both patients (47%) and physicians (65%) selected fatigue as the 1 symptom patients wanted to resolve (Figure 51).

- Physicians reported that all (3%), almost all (49%), some (42%), and few (6%) of their patients were able to recognize the symptoms associated with MF (Figure 52).

- There was less agreement between patients and physicians when it came to the severity of symptoms. Patients reported fatigue, problems with sexual desire, and inactivity as the most severe symptoms (Figure 53). However, when physicians were asked about the symptoms that had the most negative impact on a patient’s QOL, they reported fatigue, filling up quickly when eating, and abdominal pain as the top 3.

- Among MF patients in the survey sample, slowing or delaying disease progression (42%) was the single most important goal for therapy, whereas most physicians reported symptom improvement (53%) as the most important goal (Figure 54).

- Most patients (72%) surveyed reported a preference to have at least 50% involvement in treatment decisions. However, most physicians reported that their patients wanted to be involved, with 77% selecting a ranking of 4 or 5 on a scale of 1-5 (Figure 55).

- The survey findings showed that 83% of physicians said that they classified their MF patients according to prognostic risk (Figure 56). By contrast, only 54% of MF patients reported that their MF physician had provided a risk classification for their condition (Figure 57).

- Most patients and physicians agreed that patients reported feeling anxious or worried and discouraged or depressed about their condition (Figure 58). Physicians tended to overestimate the emotional impact, as they ranked the items between a 3 to 5 suggesting moderate to a great deal of emotional impact to patients (Figure 59).

- Most physicians ranked all items between a 3 to 5 on a scale from 1 (not at all) to 5 (a great deal), reporting moderate to a great deal of physical impact (Figure 61). However, most patients ranked the items between a 1 to 2 suggesting no impact or very little physical impact (Figure 60).

- Most patients (81%) and physicians (97%) agreed or strongly agreed that symptoms reduced a patient’s QOL (Figures 62 and 63).
Satisfaction With Communication About Condition

The survey findings showed that nearly all patients (91%) were satisfied with their current physician’s communication about their condition and its treatment. Similarly, nearly all physicians (90%) were satisfied with their communication to patients about their condition (Figure 65).

Satisfaction With Management of Condition

The vast majority of MF patients (92%) were satisfied with their current physician’s treatment and management of their condition. Physicians, however, were more likely to underestimate their patients’ satisfaction with how they managed their condition, as 30% of physicians reported their patients were dissatisfied with their treatment and management of their condition (Figure 67).

Figure 64. Question 42: How satisfied are you with your doctor’s communication about your condition and its treatment? (n = 207)
Note: Individual values are rounded and may not total 100%

Figure 65. Question 48: How satisfied are you with your communications with MF patients about their condition and its treatment? (n = 156)
Note: Individual values are rounded and may not total 100%

Figure 66. Question 43: How satisfied are you with your doctor’s management and treatment of your diagnosis? (n = 207)
Note: Individual values are rounded and may not total 100%

Figure 67. Question 43: In general, how satisfied are your patients with the overall treatment and management of their condition? (n = 156)
Note: Individual values are rounded and may not total 100%
Attitudes Towards Communication Regarding Symptoms

Both patients and physicians were asked a series of questions to describe their attitude towards communication with regard to symptoms. Patients disagreed with statements that implied any difficulty or issues in their communication with their physician about their symptoms. In comparison, although physicians disagreed with all statements implying any difficulty or issues in their communication with patients, they were not as likely as patients to strongly disagree.

Patients reported they felt comfortable discussing their symptoms with their physician (87%), and most patients (85%) were certain on how to describe their symptoms to their physician (Figure 68).

Patient-Reported Attitudes Towards Communication Regarding Symptoms

Physician-Reported Attitudes Towards Communication Regarding Symptoms

Figure 68. Question 47h-n: How much do you agree with the following statements? (n = 207)
Note: Labels for data under 5% are not displayed

Figure 69. Question 51i-n: How much do you agree with the following statement? (n = 156)
Note: Labels for data under 5% are not displayed
Attitudes Towards Communication Regarding Treatment

Although most patients reported a very positive relationship with their physician, there was some discordance worth mentioning. Among MF patients, 29% disagreed that their physician kept them informed about new treatment options; however, 97% of physicians reported that they kept their patients informed (Figure 71). Another 30% of MF patients disagreed that their physician had created a treatment plan for them, despite 96% of physicians reporting they had created a plan or established goals for their patients.

Patient-Reported Attitudes Towards Communication Regarding Treatment

Physician-Reported Attitudes Towards Communication Regarding Treatment

Figure 70. Question 47: How much do you agree with the following statements? (n = 207)
Note: Labels for data under 5% are not displayed

Figure 71. Question 51: How much do you agree with the following statements? (n = 156)
Note: Labels for data under 5% are not displayed
Attitudes Towards Communication Regarding Treatment Goals

There seems to be some discordance between patients and physicians regarding the understanding of treatment goals. Patients feel their physicians completely understand and support their treatment goals however physicians don’t feel as certain that patients understand their goals.

Most patients (69%) reported they felt their physician completely understood and supported their MF treatment goals. On the other hand, only 17% of physicians felt their patients completely understood their treatment goals (Figure 73).

Figure 72. Question 44: How satisfied are you with your MF doctor’s understanding and support of your goals for treatment? (n = 207)
Note: Individual values are rounded and may not total 100%

Figure 73. Question 46: How much do you feel that your MF patients understand your treatment goals? (n = 156)
Note: Individual values are rounded and may not total 100%
Attitudes Towards Communication Regarding MF’s Impact on Patient’s Life

Almost all patients surveyed (96%) agreed that their physician was genuinely concerned about helping them, and 99% of physicians agreed that their MF patients felt that they were genuinely concerned about them. Eighty-four percent of patients reported they felt their physician understood how much MF had an impact on their life, and 94% of physicians reported they did understand. Nearly one fifth of patients disagreed that their physician understood how much MF had an impact on their life (16%) (Figure 74).

**Patient-Reported Attitudes Regarding MFs Impact on Patient’s Life**

![Patient-Reported Attitudes](image)

**Physician-Reported Attitudes Regarding MFs Impact on Patient’s Life**

![Physician-Reported Attitudes](image)
Summary of Findings

- Nearly all patients (91%) were satisfied with their current physician’s communication about their condition and its treatment (Figure 64). Similarly, nearly all physicians (90%) were satisfied with their communication to patients about their condition (Figure 65).

- The vast majority of MF patients (92%) were satisfied with their current physician’s treatment and management of their condition (Figure 66).

- Patients reported they felt comfortable discussing their symptoms with their physician (87%), and most patients (85%) were certain on how to describe their symptoms to their physician (Figure 68).

- Among MF patients, 29% disagreed that their physician kept them informed about new treatment options; however, 97% of physicians reported they kept their patients informed (Figures 70-71).

- There was some minor but meaningful discordance between patients and physicians when it came to treatment plans and establishing goals for therapy in that 96% of physicians reported they created a plan for their patients, but 30% of patients disagreed that their physician created a treatment plan for them (Figures 70-71).

- Most patients (69%) reported they felt their physician completely understood and supported their MF treatment goals. On the other hand, only 17% of physicians felt their patients completely understood their treatment goals. (Figure 72).

- Most patients (84%) and physicians (94%) reported that they understood how much MF had an impact on the patient’s life; however, some patients (16%) disagreed. (Figures 74 and 75).
**ALLIED HEALTH ASPECTS**

**Types of Allied Health Involved in Patient Care**

Patients were asked whether they had seen any other health care professionals (HCPs) within their current MF physician’s office for their condition in the past 12 months. A Nurse Practitioner (NP) or Physician Assistant (PA) (42%) were the most commonly reported HCPs aside from the current physician. Another 33% of patients reported they had not seen any other HCP aside from their main physician in the past 12 months (Figure 76).

As a follow up question, patients were asked to report the extent to which the HCPs were involved in the counseling regarding MF treatment and management on a scale from 1 (not at all) to 5 (a great deal). For those patients who reported interacting with an NP or PA, 34% said they were involved a great deal in their counseling regarding the treatment and management of MF.

**Other HCPs Seen Aside From MF Physician During Office Visit**

![Bar chart showing the percentage of patients who had seen other HCPs during their office visit.](chart)

**Figure 76. Question 48: Within your current MF doctor’s office, have you seen any other health care professionals aside from your MF doctor about your condition in the last 12 months? (n = 207)**
Reliance on Caregivers

MF patients were asked whether they relied on a caregiver to help them with their condition. Most MF patients (59%) reported that they never relied on a caregiver, and another 14% said that they rarely relied on a caregiver (Figure 77). Among those patients who relied on a caregiver (41%) to help with their condition, the overwhelming majority (85%) said that their main caregiver was a spouse or partner.

In a subsequent question, most MF patients reported that MF did not affect their relationship with their caregiver (72%); however, the vast majority of physicians (96%) thought MF interfered with the relationship between caregiver and patient.

**Patient-Reported Reliance on Caregiver**

![Pie chart showing patient-reported reliance on caregivers](image)

*Figure 77. Question 20: Do you rely on a caregiver to help you with your condition? (n = 207) Question 20B: Who is your main caregiver who helps you with your condition? (n = 85)*

Note: Individual values are rounded and may not total 100%
PATIENT UTILIZATION & SATISFACTION WITH MF INFORMATION

Most Helpful Sources of MF Information

MF patients who have done research to learn more about MF were asked where they found the most helpful information about their diagnosis. The Internet was identified by almost all of the MF patients (90%) as one of the most helpful sources. Close to half of all patients (47%) also identified online discussion groups as a source for the most helpful information. Twenty-seven percent of information-seeking patients reported physicians’ offices as one of the most helpful sources of information (Figure 78).

Patients who indicated that they used the Internet as a source of information were also asked about which web sites they went to most often for this type of information. They reported that they most frequently went to MPN Advocacy Group web sites (82%), hospital web sites (68%), and health web sites (47%). It should be noted that, because these types of web sites were used in recruiting the sample, the use of these web sites in the general population of MF patients may be overstated in this survey.

Most Helpful Sources of Information

![Bar chart showing the percentage of patients who found the most helpful information in various sources. The top sources are: Internet (90%), Online email discussions (47%), Doctor's office (27%), Other patients (17%), Local patient support groups (13%), Library (4%), Pharmacy (3%), MPN Research Foundation (1%), and Other (3%).]

Figure 78. Question 51A: Where did you find the most helpful information about diagnosis? (n = 201)

Most Often Visited Web Sites for MF Information

![Bar chart showing the percentage of patients who visited various web sites most often for information. The top sites are: MPN Advocacy Group web sites (82%), Hospital web sites (68%), Health web sites (47%), Pharmaceutical company web sites (17%), Facebook (1%), Search engines (1%), Don't know (4%), and Other (2%).]

Figure 79. Question 51B: What sites do you go to most often for information about diagnosis? (n = 180)
Patient Satisfaction With MF Information

An overwhelming majority of patients (91%) said they are satisfied with how informed they were about MF. The very small minority (9%) of patients reported that they were somewhat or very dissatisfied with how informed they were about their condition.

Physicians were also asked how satisfied they perceived their patients to be with how informed on MF they were, and 85% of physicians thought their patients were satisfied.

Patient-Reported Attitudes Towards Search for MF Information

MF patients were asked a series of questions regarding their attitudes towards their search for MF information. Overall, results showed that patients did not feel like it took a lot of effort to get the information needed (72%) and they did not feel frustrated during their search (73%) (Figure 80). Additionally, patients were not concerned with the credibility of the information (65%) and they did not find the information confusing (66%). Patients also reported they found a lot of good information during their search (83%).

Patients were asked about how or where they prefer to receive their information, and 76% preferred to receive these materials directly from their physician, 72% of patients preferred to learn about MF on the internet, and 51% preferred to receive educational materials in the mail.

Patient-Reported Attitudes Towards Search for MF Information

<table>
<thead>
<tr>
<th>Preference</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>It took a lot of effort to get the info needed</td>
<td>36%</td>
<td>44%</td>
<td>39%</td>
<td>37%</td>
</tr>
<tr>
<td>I felt frustrated during my search for info</td>
<td>6%</td>
<td>11%</td>
<td>47%</td>
<td>36%</td>
</tr>
<tr>
<td>I was concerned about the credibility of info</td>
<td>4%</td>
<td>24%</td>
<td>49%</td>
<td>23%</td>
</tr>
<tr>
<td>The info I found was confusing</td>
<td>19%</td>
<td>16%</td>
<td>30%</td>
<td>36%</td>
</tr>
<tr>
<td>I prefer to learn about it on the internet</td>
<td>19%</td>
<td>16%</td>
<td>45%</td>
<td>31%</td>
</tr>
<tr>
<td>I prefer to receive educational materials in the mail</td>
<td>8%</td>
<td>16%</td>
<td>45%</td>
<td>31%</td>
</tr>
<tr>
<td>I prefer to receive educational material from my doctor</td>
<td>6%</td>
<td>19%</td>
<td>41%</td>
<td>34%</td>
</tr>
</tbody>
</table>

Figure 80. Question 55a-i: How much do you agree or disagree with each of the following? (n = 207)
Type of Health Care Coverage Reported by Patients

All of the MF patients in the survey reported that they had some sort of health insurance or health plan to cover their health care costs. Nearly half (45%) said that their primary source of health coverage was Medicare. Another 39% reported they had commercial group insurance through an employer or union (Figure 81).

Monthly Out-of-Pocket Prescription Drug Costs

Half of MF patients (53%) reported that they paid out-of-pocket costs of $25 or less per month for prescription drug costs related to the treatment and management of their MF condition. Few patients (23%) paid more than $100 per month in out-of-pocket prescription drug costs related to their condition.
Summary of Findings

- A Nurse Practitioner or Physician Assistant (42%) was the most commonly reported HCP aside from the current physician. Another 33% of patients reported they had not seen any other HCP aside from their main physician in the past 12 months (Figure 76).
- Most MF patients (59%) reported that they never relied on a caregiver. Of the 41% who relied on a caregiver, 85% relied on a spouse or partner (Figure 77).
- The Internet was identified by almost all of the MF patients (90%) as one of the most helpful sources. Close to half of all patients (47%) also identified online discussion groups as a source for the most helpful information (Figure 78).
- All of the MF patients in the survey reported that they had some sort of health insurance or health plan to cover their health care costs. Nearly half (45%) said that their primary source of health coverage was Medicare. Another 39% reported they had commercial group insurance through an employer or union (Figure 81).
REFERENCES


2. Data on File. Incyte Corporation


Additional Patient Data

Most Important Treatment Goal for MF Patients

Q32: Other than a cure for diagnosis, what is your most important treatment goal for therapy? (n=207)
Note: Labels for data under 5% are not displayed

2nd Most Important Treatment Goal for MF Patients

Q33: What is your next (2nd) most important treatment goal for therapy? (n=207)
Note: Labels for data under 5% are not displayed

3rd Most Important Treatment Goal for MF Patients

Q34: What is your next (3rd) most important treatment goal for therapy? (n=207)
Note: Labels for data under 5% are not displayed
Physician Specialty and Setting

Q36: What is the medical specialty of the doctor that you see most often for your diagnosis? (n=207)
Note: Labels for data under 5% are not displayed

Q37: How would you describe the setting where you see this doctor most often for your diagnosis? (n=207)
Note: Labels for data under 5% are not displayed

Frequency of Physician Visits in the Last 12 Months

Q38: How many times have you seen your doctor in the last 12 months? (n=207)
Note: Labels for data under 5% are not displayed
Learning More About MF Diagnosis

Q50: Did your doctor give you any information to learn more about your diagnosis? (n=207)

Note: Labels for data under 5% are not displayed

Patient Satisfaction With How Informed They Are About MF

Q52: How satisfied are you currently with how informed you are about MF? (n=207)

Note: Labels for data under 5% are not displayed
Difficulty and Frequency of Research

Q53: How difficult was it to find good information about diagnosis? (n=207)
Note: Labels for data under 5% are not displayed

Q54: When was the most recent time you looked for information about diagnosis or its treatment? (n=207)
Note: Labels for data under 5% are not displayed

Race and Ethnicity

Q59: Are you of Hispanic, Latino or Spanish origin? (n=207)
Note: Labels for data under 5% are not displayed

Q60: Select your race from the following (n=207)
Note: Labels for data under 5% are not displayed
Family History of an MPN Diagnosis

Q64a-c: Has anyone else in your family ever been diagnosed with: essential thrombocythemia, myelofibrosis, and polycythemia vera? (n=207)

Note: Labels for data under 5% are not displayed
Additional Physician Data

Stem Cell Transplant Program and MPN Clinical Trial Experience

Q6: Does your center have a stem cell transplant program? (n=156)

- Yes, 41%
- No, 59%

Q7: Has your clinic/practice ever participated as a study site for MPN clinical trials? (n=156)

- Yes, 32%
- No, 67%
- Don’t know, 1%

Q8: How many MPN clinical trials has your clinic/practice been involved in the last 2 years? (n=50)

- 0 to 5: 82%
- 6 to 10: 16%
- Over 10: 

Labels for data under 5% are not displayed.
Symptom Severity in All MF Patients Currently Under Physician Care

<table>
<thead>
<tr>
<th>Symptom Severity</th>
<th>Proportion (%)</th>
<th>Mean</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe Symptoms</td>
<td>80%</td>
<td>17%</td>
<td>15%</td>
</tr>
<tr>
<td>Moderate Symptoms</td>
<td>40%</td>
<td>32%</td>
<td>30%</td>
</tr>
<tr>
<td>Mild Symptoms</td>
<td>45%</td>
<td>32%</td>
<td>30%</td>
</tr>
<tr>
<td>No Symptoms</td>
<td>77%</td>
<td>18%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Q14a-d: Out of 100%, what proportion of all MF patients that you currently follow have [no, mild, moderate or severe] symptoms? (n = 156)

Note: Labels for data under 5% are not displayed

Physician-Reported Symptoms Impacting Patients QOL

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Proportion (%)</th>
<th>Mean</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal discomfort</td>
<td>7%</td>
<td>3.67</td>
<td>4</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>6%</td>
<td>3.91</td>
<td>4</td>
</tr>
<tr>
<td>Bone pain (diffuse not joint pain or arthritis)</td>
<td>11%</td>
<td>3.53</td>
<td>4</td>
</tr>
<tr>
<td>Cough</td>
<td>10%</td>
<td>2.63</td>
<td>3</td>
</tr>
<tr>
<td>Depression or Sad mood</td>
<td>20%</td>
<td>2.33</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>16%</td>
<td>3.26</td>
<td>3</td>
</tr>
<tr>
<td>Dizziness/Vertigo/Lightheadness</td>
<td>5%</td>
<td>3.17</td>
<td>3</td>
</tr>
<tr>
<td>Fatigue</td>
<td>10%</td>
<td>4.40</td>
<td>5</td>
</tr>
<tr>
<td>Fever (&gt;100°F)</td>
<td>15%</td>
<td>3.47</td>
<td>4</td>
</tr>
</tbody>
</table>

Q16a-dd: On a scale from 1 (not at all) to 5 (a great deal), which of the following symptoms have a major negative effect on an MF patient's quality of life. (n=156)

Note: Labels for data under 5% are not displayed
Symptom and Splenomegaly Impact on QOL

Q23: Agree or disagree with the following statements: Patient’s quality of life is not significantly affected unless splenomegaly is severe (n=156)

Comfort Assessing Symptoms and Approaches Most Utilized by Physicians

Q24: Agree or disagree with the following statements: I am comfortable assessing my patients’ symptoms (n=156)
Note: Labels for data under 5% are not displayed

Q30: What tool(s) or approaches do you use to assess symptom severity in your patients? (n=156)
Note: Labels for data under 5% are not displayed
### Interference With Activities of Daily Living

<table>
<thead>
<tr>
<th>Activity</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily activities</td>
<td>17%</td>
<td>55%</td>
<td>25%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean: 4.02; Median: 4.00</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family or social life</td>
<td>14%</td>
<td>26%</td>
<td>45%</td>
<td>14%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean: 3.56; Median: 4.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex life</td>
<td>12%</td>
<td>29%</td>
<td>41%</td>
<td>16%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean: 3.57; Median: 4.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain and discomfort are limiting patient’s activities</td>
<td>16%</td>
<td>55%</td>
<td>26%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean: 4.05; Median: 4.00</td>
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<td></td>
</tr>
<tr>
<td>Relationship with patient’s caregiver</td>
<td>5%</td>
<td>13%</td>
<td>29%</td>
<td>39%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Mean: 3.32; Median: 3.00</td>
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</tr>
</tbody>
</table>

Q25a-e: To what extent do you feel that MF interferes with the following activities in a patient’s life? (n=156)

Note: Labels for data under 5% are not displayed.

### Explanation of Symptoms and MF Disease Progression

<table>
<thead>
<tr>
<th>Activity</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Run through a full and comprehensive list of symptoms</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>52%</td>
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<tr>
<td>Outline the symptoms they are most likely to experience</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>28%</td>
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<tr>
<td>Mention the top, most bothersome symptoms</td>
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<td></td>
<td>19%</td>
</tr>
<tr>
<td>Other</td>
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</tr>
</tbody>
</table>

Q28: During an average patient visit, how do you discuss the symptoms that the MF patient might experience? Do you... (n=156)

Note: Labels for data under 5% are not displayed.
Q41: How often does an MF patient not wish to comply with your primary treatment recommendation? (n=156)

- Sometimes: 65%
- Often: 12%
- Never: 23%